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Invigorating The Public Body : A Case Study Of HIV/AIDS Activist Confrontations Against Big Pharma For Access To Medicines

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Invigorating The Public Body: A Case Study Of HIV/AIDS Activist Confrontations Against Big Pharma For Access To Medicines

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"Invigorating The Public Body: A Case Study Of HIV/AIDS Activist Confrontations Against Big Pharma For Access To Medicines"

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Abstract

Using "illness as metaphor," critical communications theory, citizenship studies and critical political economy, this thesis presents a case study of the confrontation between "Big Pharma" and HIV/AIDS activists concerning access to HIV/AIDS medicines; a confrontation that spilled over into the World Trade Organization (WTO) causing worldwide public outrage. The timeline starts in the 1980s, but focuses on confrontations between these actors during the 1990s and early 2000s.

By making HIV/AIDS 'public' and 'political,' activists: battled stigmatization; revealed the politics of medicine; made Big Pharma more socially responsible; influenced the WTO's and global health agenda; and stirred dissent against a neoliberal globalization, exposing power relations between the global rich and global poor.

This is about a powerful *antiBody* (HIV/AIDS activists) targeting a dangerous *site of infection* (Big Pharma) and combating the spread of two *illnesses* (HIV/AIDS and neoliberalism) which invigorated the 'public body' both in terms of public health and debate.

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Table of Contents

Introduction: An Examination of an Infected Public Body

A Diagnosis of Infection: Understanding the Problematic

Thesis Objective

The objective of this thesis is to present a case study of the confrontation between "Big Pharma" (the world's top multinational pharmaceutical corporations) and HIV/AIDS activists with respect to access to HIV/AIDS medicines; a confrontation which spilled over into the realms of the World Trade Organization (WTO) and which caused public outrage around the world. The timeline for this thesis' case study will start in the 1980s in order to establish the context within which the confrontation between these two actors develops, however, the aim of this thesis' case study is mainly focused on highlighting the significance of the events and outcomes of the confrontation between these actors in the 1990s and early 2000s. The analysis in this case study will demonstrate how Big Pharma's indifference to larger social responsibility was thwarted by HIV/AIDS activists and as a result, Big Pharma decided to change its course and become more responsive to public demands. In this fight for their lives, HIV/AIDS activists not only awakened the world to the realities of the HIV/AIDS crisis and the politics of medicine, but also stirred dissent against the market-driven mentality inherent to the neoliberal ideology that was predominant at the time. Therefore, in trying to put an end to HIV/AIDS, these activists also revealed the hazardous underpinnings of a neoliberal globalization to the public, exposing the stark power relations that had been established between the global rich and global poor.

To phrase it another way and to establish the conceptual structuring of this thesis, essentially the objective of this thesis' case study is to tell the story of how a powerful *antiBody* (HIV/AIDS activists) was able to target a dangerous *site of infection* (Big Pharma) and combat

the spread of two *illnesses* (HIV/AIDS and neoliberalism) which invigorated the 'public body' both in terms of public health and public debate.

Introducing the Two 'Illnesses'

During the 1980s and 1990s when HIV/AIDS was discovered as an epidemiological illness, rapidly infecting bodies throughout the globe and attacking individuals' immune systems, so too was a *social illness* surging through the public bodies of nation-states, weakening public support systems. This social illness was neoliberalism; an ideology of economic liberalism which promotes a proliferation of free market ideology, the minimization of the role of the state, and the expansion of the market to become arbiter of as many social relations and objects as possible. Initially introduced in the 1980s, this ideology gained momentum during the 1990s as it was aggressively advanced by international institutions, corporations and the governments of prominent developed countries. These global elite crafted a neoliberal political economic globalization which stressed the primacy of the market. As a result, there was a paradigm shift in global thought and neoliberalism came to be the signature political economic ideology that dominated the idea climate of the times.

Colleen O'Manique, a Women's Studies professor at Trent University, focuses her academic research on the global political economy of health with a specific concentration on gender issues taking into account global health policy, economic restructuring and human rights. Although the epidemiological illness of HIV/AIDS and neoliberalism as a metaphoric social illness are not often traced and conceptualized together, in 2004, O'Manique wrote *Neoliberalism and the AIDS Crisis in Sub-Saharan Africa: Globalization's Pandemic*. It was this book which inspired the use of these parallel narratives to fulfill the aforementioned analytical objective of this thesis.

Parallel Narratives of the Two 'Illnesses'

As neoliberalism was implemented in different nation-states to connect local economies with the global economy during this time period, it simultaneously increased the disparity between the "haves" and "have-nots" of the world—privileging private interests over the needs of the poor. Similarly, the epidemic of HIV/AIDS travelled across international borders connecting people through contagion and also exacerbating the conditions of the poor as more men and women got infected and were unable to work and more children were orphaned. This is why world-renowned economist, Jeffrey Sachs, refers to the devastating impact of HIV/AIDS on a poor population as a type of "poverty trap" (Sachs, "End of Poverty," 195). He sums up the interrelationship quite succinctly when he says: "Poor health causes poverty and poverty causes poor health" (Sachs, "End of Poverty," 204). By the same token, the parallels in the narratives are further exemplified when considering how the spread of neoliberalism eroded the public support systems needed to mitigate HIV/AIDS, meaning that individuals in impoverished communities only became even more destitute. As much as both of these illnesses created these collective problems, the traditional understanding of both ironically stems from an individualistic perspective.

Neoliberalism sees the 'body politic' or 'public body' as divided into self-interested individuals within a completely depoliticized market, separate from the political domain and the public domain. "A key goal of the 1980s and 1990s' 'neo-liberal revolution' has been the increased separation in society of the political sphere from the economic sphere" (Andreasson, 16). Neoliberal ideology compartmentalizes issues of the market into a 'private' sphere with its own 'natural' rules of supply and demand that are exempt from public contestation. The goal of neoliberalism is to extend the allegedly 'private' sphere of the market to as many areas of life as

possible. Paralleling this mode of thought is the conventional biomedical paradigm of understanding medicine and health.

The biomedical paradigm sees the sick individual body as separate from the larger public body and surrounding political economic factors; illness is understood as a 'private' matter solely addressed by the sick individual and the biomedical community. Just as the operations in the market are deemed neutral within a neoliberal paradigm, so too is the production and practice of medicine considered to be neutral within the biomedical paradigm: "It is usually believed that medicine, because it is 'scientific', can produce an unchallengeable and autonomous body of knowledge which is not tainted by wider social and economic considerations" (Doyal, 12). Moreover, within these paradigms medicine and the market are viewed as entities which will inevitably produce the most positive results for the common good; medicine should keep individuals healthy and theoretically, the actions of individuals within the market should keep the economy healthy for everyone's benefit. In this case study, HIV/AIDS activists would expose the fallacy of the neutrality of both medicine and the market by making HIV/AIDS 'public' and by challenging Big Pharma.

A Common 'Site of Infection'

For the purposes of this analysis, Big Pharma represents an analytical *site of infection* for both epidemiological illness and social illness alike since during the 1990s its business practices facilitated the spread of both HIV/AIDS and neoliberal ideology.

Big Pharma is comprised of multinational pharmaceutical corporations, and as the standard corporate prerogative dictates, their main purpose as social institutions is to make money by producing, marketing and distributing medicines. During the 1990s, Big Pharma's pursuit of profit shaped a pattern of reckless actions and socially irresponsible corporate excess.

For the sake of profit, Big Pharma's business practices prioritized the market over the public interest, which not only perpetuated neoliberal ideology, facilitating the spread of this social illness, but also implemented measures that would restrict access to HIV/AIDS medicines, facilitating the spread of this illness as well.

As Salih *Booker* & William *Minter* wrote in an article for *The Nation* in 2001, Big Pharma had helped lay the groundwork for an "international political economy—in which undemocratic institutions systematically generate economic inequality—[*and which*] should be described as 'global apartheid'"; a "global apartheid" whereby there are those that can afford antiretroviral drugs and those that cannot, essentially, those who can afford to live and those who cannot (Booker and Minter, 11). Big Pharma was part of the neoliberal economic globalization of the 1990s orchestrated by the influential 'powers-that-be' which carried out a global commodification of health. As a result, Big Pharma would also become a prime target for the anti-globalization backlash, of which HIV/AIDS activists were a part.

The Rise of an Activist 'AntiBody'

Throughout this thesis, these HIV/AIDS activists will be referred to as an *antiBody* which works to block the spread of the epidemiological illness of HIV/AIDS and inoculate the public against the market-driven social illness of neoliberalism. I have chosen to capitalize the "*B*" in the antiBody to stress that together these activists form a counteractive (anti) body of people (Body) within the larger 'public body' or 'body politic.'

When the HIV/AIDS activist antiBody initially formed during the 1980s in the United States, people living with HIV/AIDS mobilized to contest widespread stigma and discrimination. However, as the narrative of HIV/AIDS unfolded, these activists also started fighting to insert their voices into the 'private' biomedical sphere of discourse. They became mediators between

the public and the biomedical community, making the production and practice of medicine a public issue and exposing the perceived 'neutrality' of medicine as a fallacy. Moreover, HIV/AIDS activists would then challenge Big Pharma corporations, fighting for better access to HIV/AIDS treatment and exposing the fallacy of a 'neutral,' 'private' market. This fight spread into the realm of international politics as HIV/AIDS activists would have to contest the governments of developed countries and the World Trade Organization (WTO). People living with HIV/AIDS around the world began taking up the fight within their own local communities, making HIV/AIDS treatment activism a global movement.

In their confrontations with Big Pharma, the governments of prominent developed countries (primarily the United States) and the WTO, HIV/AIDS activists exposed the cracks in the neoliberal ideology's promotion of the primacy of the market. As more people learned about HIV/AIDS activists' claims for social justice, the public became more attuned to the failure of the market-driven approach that had been used to craft a neoliberal economic globalization.

> At the broadest level, the issue of access to ARVs underscores the struggle at the global level between two competing political projects. On the one hand, there is the neoliberal project, concerned first with disembedding the market from political influence and second with expanding its reach across social institutions. On the other hand, there is a social-democratic project concerned with the delivery of welfare provisions on a more egalitarian basis rooted in conceptions of social justice (Thomas, 262).

The 1990s became a time period characterized by these dialectical tensions in the struggles between the 'top-down' power of the global elite to the 'bottom-up' power of activists like those of the HIV/AIDS movement. In fighting for their lives, the HIV/AIDS activist antiBody not only made it clear that they should have a voice at the table, but brought the human right to health to the forefront, framing medicines as 'public goods' and advocating for better access to medicines.

Things to Consider

It is important to note that this case study is time-bound and is also narrowly focused on Big Pharma's role in inhibiting access to HIV/AIDS medicines during the 1990s and early 2000s. As the HIV/AIDS crisis in developing countries has evolved over the years, it has become more apparent as to how multifaceted the problems related to the prevention and treatment of HIV/AIDS really are. These problems include (but are not limited to): corrupt governments, gender inequality, a lack of infrastructure, distribution issues, sexual practice, dissemination of HIV/AIDS education, and residual cultural stigmatizations against those living with HIV/AIDS. To effectively mitigate HIV/AIDS, both prevention and treatment should be stressed through ad hoc initiatives [such as those run by non-governmental organizations (NGOs)] as well as through large-scale, comprehensive responses in which the role of the state cannot be underestimated. Venturing forward into this thesis, it is imperative for one to keep in mind the complexity of the HIV/AIDS crisis and to recognize that corporations only bear part of the responsibility to work towards a solution; a responsibility for which HIV/AIDS activists made sure corporations would be held accountable.

Throughout the course of this thesis, there are also many questions to consider. What is the role of corporate social responsibility? What are the implications of drawing lines between 'private' and 'public' domains with regards to medicine and the market? What was the result of citizen activism during this time period? How did activists affect the epidemiological illness of HIV/AIDS and the social illness of neoliberal ideology? To provide a roadmap for these various directions of questioning stemming from this case study, the following theoretical methodologies will be utilized.

A Prescription for Theoretical Inquiry

The theoretical framework of this thesis will apply critical political economy, citizenship discourse, critical communications theory, and will also explore "illness as metaphor" as a conceptual tool for analysis. This theoretical framework is fitting for the examination of this subject because each area of theory touches on different and very important aspects of this topic.

Illness as Metaphor

Understanding the intersections of metaphors and illness as conceptual tools is an idea that Susan Sontag discusses at length in her book *Illness as Metaphor and AIDS and its Metaphors*. Sontag quotes from Aristotle's piece *Poetics* to cite one of the earliest definitions of metaphor. Aristotle wrote: "Metaphor ... consists in giving the thing a name that belongs to something else" (qtd. in Sontag, 93). In her book, Sontag is particularly interested in deconstructing the metaphors employed to conceptualize illness. For example, she discusses how there is a tendency to use military metaphors to describe medical situations such as: a disease's "invasion" of the body, the body's immunological "defences," and describing treatments as "aggressive" (Sontag, 97). Sontag investigates the history behind and the use of such metaphors in order to examine the impact that these implicitly or explicitly have on the people who live with the illness in question.

This form of analysis is useful because it breaks one out of the biomedical paradigm's understanding of illness as a 'private' matter isolated for debate within the biomedical community and instead, moves a conceptualization of illness within a social and political context. Sontag's call to examine the metaphors used to conceive illness is significant to the case study in this thesis because, as Sontag recognized herself since she dedicated the second edition of her book specifically to an examination of AIDS, from the beginning, conceptualizations of

HIV/AIDS as an illness has been fraught with metaphors that have caused much stigmatization and grief for people living with it. This thesis will deconstruct the metaphors affiliated with HIV/AIDS but will also discuss how activists created new metaphors which would serve as conceptual tools to disseminate their message and serve as a source of empowerment for those living with HIV/AIDS.

This thesis also draws from Sontag's investigation of the relationship between illness and metaphor in terms of using the body and illnesses themselves as metaphors to explain people or events outside of the medical field. Sontag explains how applying metaphors as explanatory tools is an age-old practice:

> Saying a thing is or is like something-it-is-not is a mental operation as old as philosophy and poetry, and the spawning ground of most kinds of understanding, including scientific understanding, and expressiveness (Sontag, 93).

More specifically, Sontag delves into a deep discussion of how illness is used as metaphor to explain and discuss politics and society. She writes, "Illnesses have always been used as metaphors to enliven charges that a society was corrupt or unjust. Traditional disease metaphors are principally a way of being vehement" (Sontag, 72). Sontag discusses how Plato and Thomas Hobbes likened civil disorder within a society as a type of illness and Niccolo Machiavelli compared statecraft as a "therapeutic art" that could use foresight to prevent social crises which he likened to serious disease (Sontag, 76-77). This thesis utilizes illness as metaphor to provide a mental construct for understanding the different intersecting parts of the case study in question; applying the aforementioned medical concepts of "illness," "antibody," and "site of infection."

The focus of the case study is based on access to HIV/AIDS medicines, thus the story itself is rooted in HIV/AIDS as an epidemiological illness which develops into a global pandemic during the 1990s, the time period of this case study. HIV/AIDS is a primary social

phenomenon which drives the actors and events in this case study. Another driving social phenomenon in this story is neoliberalism which, in following the tradition of the political thinkers already mentioned, I have likened to a *social illness*.

Using illness as metaphor to explain neoliberalism is useful because neoliberal ideology took the world by storm during this time period much like an infectious pandemic. Applying this metaphor is also conceptually useful because in comparing this ideology to an illness, there is a clear communication that the effects of this social phenomenon have been negative on the overall. The negative connotation is attached to the ideological shift towards neoliberalism because the market-driven mentality stemming from it led to a prioritization of private interests above that of humanity and health which is evident within this thesis' case study of access to medicines.

Comparing Big Pharma as a *site of infection* and HIV/AIDS activists as an *antiBody* is also beneficial as these terms identify the role of these actors in the problematic of this case study. Big Pharma's business practices during this time period facilitated the spread of HIV/AIDS and propagated neoliberal ideology, thus in both cases acting as a *site of infection*—an entity from which illness stems. HIV/AIDS activists, on the other hand, worked to block the proliferation of both thus acting as an antiBody—an entity which forms to fight illness. Therefore, this thesis uses illness as metaphor to enhance the analytical composition and flow of the case study at hand.

A Critical Political Economic Framework

Using a critical political economic framework implies an analytical investigation that takes into account the historical, economic, political and social context of the object of inquiry

examining the power relations and vested interests of actors. To carry out this query, this thesis draws from select works of political economists for different purposes.

Karl Polanyi (1957) is referred to for his conceptualizations of the social construction of the market economy and the commodity which contributes to a discussion of the implications of an increasing commodification of health; calling attention to the agency behind market relations. Ulrich Beck's (1995) sociological notions of "industrial fatalism" and "organized irresponsibility" are used to characterize the 1990s. These concepts are utilized to evaluate the legislation of the larger public hazards in the Trade Related Aspects of Intellectual Property Rights (TRIPS) Agreement. This thesis also pulls from theorists whose thoughts are derived from Marxist theory. One is Justin Rosenberg (2000, 2005) whose deliberations on revisiting globalization theory and instead examining globalization within a Marxist framework are valuable when analyzing the spread of neoliberalism as a social phenomenon. Georg Lukacs' (1971) work is also based in Marxist theory. His discussion about how the 'ruling class' produces any legal system's rules to suit their own interests, is significant as it provides theoretical context to how corporations and developed countries framed the rules of TRIPS in their favour to the disadvantage of developed countries.

The political economic framework used throughout this thesis incorporates both an examination of structure as well as an examination of the different levels of agency that actors have within the structures of power. This political economy can be considered "critical"

> in the sense that instead of describing the prevailing order of the world it seeks to reveal how that order is created and sustained (Cox, 1981: 129). Thus, it is ultimately an analysis of social change, an attempt to re-embed the social in the political economy with the possibility of identifying alternate power-sharing arrangements (Payne, 2005)"(Banerjee, 127).

Therefore, through this case study's analysis of how HIV/AIDS activists were able to challenge the 'powers-that-be' and successfully make their demands come to fruition, this analysis can hopefully act as a tool for devising what social change might be possible for the future.

Citizenship Studies

Traditionally, citizenship studies focused on the rights and duties of the citizen solely in reference to the nation-state as the arbiter of what rights and duties citizens should bear. However, the processes of globalization, such as an increase in communications and travel, the increase of Diasporas, and the integration of national economies, have called into question the conventional "state-based" approach to citizenship.

> National boundaries have traditionally demarcated the basis on which individuals are included or excluded from participation in decisions affecting their lives; but if many socioeconomic processes, and the outcomes of decisions about them, stretch beyond national frontiers, then the implications of this are serious (Held, 22).

The theoretical attempts that have emerged to grapple with the implications of this new global climate and the role of the citizen have revitalized new discourses examining what citizenship means in the modern-day globalized world.

One can look to Engin F. Isin and Bryan S. Turner (2002), Jonathon Fox (2005) and Janet Conway (2004) to appreciate a new conceptualization of citizenship which goes beyond the nation-state, and instead, shows citizenship to be "postnational" or "transnational" in nature. A main theme throughout the literature of these citizenship theorists is that: "rather than merely focusing on citizenship as legal rights, there is now agreement that citizenship must also be defined as a social process through which individuals and social groups engage in claiming, expanding or losing rights" (Isin and Turner, 4). Jonathon Fox calls this conceptualization of citizenship as a "social process," the "society-based approach."

This "society-based" approach is telling because in moving beyond the traditional notion of citizenship that conventionally taught us to believe that only matters of the state are 'political,' this discourse addresses other processes of inclusion and exclusion from social, cultural and economic communities such as the experience of people living with HIV/AIDS. Sontag (although not a citizenship theorist) quite justifiably relates illness to citizenship when she divides the 'well' and the 'sick' metaphorically into separate kingdoms:

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place (Sontag, 3).

Because of their illness, people living with HIV/AIDS were forced to the cultural margins of society, an exiled "kingdom," and consequently experienced harsh societal exclusion through discrimination and stigma. To fight their way from the margins, people living with HIV/AIDS constructed illness and access to medicines as a 'public' and 'political' matter.

Like other newer claims for citizenship, HIV/AIDS activism came to the forefront to state [the feminist mantra] that "the personal is political." They established that they should have a legitimate right to be heard by the biomedical community, corporations, governments and international institutions alike. Unlike any mobilization surrounding an illness prior to that point, which had mainly focused on fundraising for research and support for those living with an illness, HIV/AIDS activists demanded that they have a place at the table for debate. They demanded that they have a say in how their society perceived them as individuals living with illness, that they have a say in the medicine to which they have access, and that they have they a voice in determining the initiative taken by their governments. Essentially, part of this new understanding of citizenship is working towards having a legitimate voice at the table (Conway, 374).

Another reason why the new citizenship discourse is invaluable to this case study is because like many of the new claims for citizenship, HIV/AIDS activists framed their discourse within human rights—since people from different locations around the world were unified in fighting for their lives. These struggles for human rights are not only being fought through the conventional legal mechanisms of nation-states but also on a global scale using a network of global media and international communications platforms. Thus, the "social process" conceptualization of citizenship serves better than the "state-based" approach of citizenship when considering how social movements now challenge different actors, such as corporations and multilateral institutions, as opposed to just their own national governments.

> The politics of human rights is now 'beyond the violating state' not because states are no longer accountable ... but because in a global economy accountability is increasingly shared by corporations, international economic actors and—in some cases—rich donor governments (Nelson and Dorsey, 203).

From this standpoint, using the new citizenship discourse is actually invaluable to framing the story of HIV/AIDS activism and how its global network of activists from different local communities demanded access to medicines by challenging Big Pharma and the neoliberal policies of the WTO. Through fighting for better public health initiatives and better access to medicines, these activists advocated for a global human right to health. In this way, HIV/AIDS treatment activism is part of the new surge of social movements that have put social and economic rights back on the global political agenda by inserting their claims into the global public sphere (Isin and Turner, 7). As Isin and Turner put it:

> Citizenship studies is ultimately ... about addressing injustices suffered by many peoples around the world, making these injustices appear in the public sphere, enabling these groups to articulate these injustices as claims for recognition and enacting them in national as well as transnational laws and practices, and thus bringing about fundamental changes (Isin and Turner, 2-3).

This thesis' examination of the success of HIV/AIDS activists in firstly, bringing HIV/AIDS into the domestic public sphere and secondly, bringing a fight for access to HIV/AIDS medicines into the global public sphere perfectly personifies the subject matter of this new citizenship discourse.

The HIV/AIDS activist antiBody's efforts in making public health issues 'public' and 'political' has a lot to do with reclaiming medicine and health from the 'private' domain of the aforementioned 'private' realm of biomedical discourse as well as reclaiming it from the 'private' market domain. This is exactly why a dialogue of critical communications theory analyzing the implications of what is 'private' or 'public' is also necessary to this topic's exploration.

Critical Communications Theory

Critical communications theory is essential to questions of 'private' and 'public' when theorizing where the boundaries between a private good or a public good are; that is, whether something is considered part of the public domain or 'the Commons' (which can be accessed by anyone and is outside the property rights system), or whether something is commodified within the private market domain (which is owned by a private body and inside the property rights system). Communications scholars such as Jurgen Habermas, Michael Hardt and Antonio Negri (2000) and Daniel Drache (2001, 2008) have theorized about the significance of the public domain and the Commons and their theories will be drawn upon for discussion in this thesis.

> The universe of the public is divided from the world of the private by shifting, permeable, and sharply contested boundaries of private property rights. We have to pay special attention to the highly contested boundary disputes that occur where the public overlaps with the private (Drache, "Defiant Publics," 56-57).

Throughout globalization there has been an increase in the private enclosure of the Commons, such as in terms of the privatization of water and education. The issue of access to HIV/AIDS medicines specifically pertains to the problematic of the commodification of information through

the expansion of intellectual property rights, and also an increase in the commodification of health.

In recent years, neoliberal agendas from multilateral institutions, the governments of some key developed countries as well as Big Pharma corporations, have been exerting top-down pressure to prioritize global capital over human interests. They have done this through creating a monopolization of lifesaving knowledge by establishing the international patenting of pharmaceutical processes and products through the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement, as well as through encouraging developing countries to privatize healthcare programs. In addition, due to Big Pharma's business practices, medicines are treated as commodities which are researched for the higher-paying consumers (the developed world), produced for the least costs (meaning less innovation), and distributed based on what will attain the most profits (blocking price controls). Health and medicine have been forced to dance the line between 'public' and 'private' goods; with the aforementioned actors attempting to push them further into the market domain and other actors, those of the HIV/AIDS activist antiBody, attempting to reclaim them for the public domain.

Therefore, to draw on Habermas' theorizations, health and medicine are governed by two competing logics in two different worlds—what Habermas (1981; translated in 1987) refers to as the "system" and the "lifeworld." The "system" is the area of social life that runs on instrumental reason and is purely based on concerns of efficiency and calculation; it includes the realm of the market domain and thus Big Pharma. The "lifeworld" operates through "communicative action" whereby people discuss what is in the interests of everyone concerned; this logic is exerted by HIV/AIDS activists. The "lifeworld" logic is that which exists in what Habermas coined as the "public sphere" where the vocalization of public struggles and concerns takes place.

The "public sphere" is the sphere in which citizens address common affairs and/or problems. Habermas (1989) believed this sphere to be all-encompassing of the entire public body but Nancy Fraser (1992) revisits this concept and posits that there are multiple publics. She theorizes that there are "weaker publics" (who have less influence in decision-making), "stronger publics" (who have more influence in decision-making), "counterpublics" (who present alternative, counterdiscourses for understanding their identities and demands). Using Fraser's conceptualization of Habermas' "public sphere" with multiple publics is valuable to this thesis' discussion because each actor addressed in the discussion exhibits different levels of power: Big Pharma, governments of developed countries and multilateral institutions are the "stronger publics," people disadvantaged by the restriction of access to HIV/AIDS medicines are the "weaker publics" and the HIV/AIDS activists represent the "counterpublic" which in advocating for a right to health and access to medicines would challenge the neoliberal ideology of the "stronger publics."

By making HIV/AIDS 'public' they were not only challenging the notion of illness being a 'private' personal matter but also challenging the notion that matters of health belong in the 'private' market domain. As Fraser argues,

> Critical theory needs to take a harder, more critical look at the terms 'private' and 'public.' These terms, after all, are not simply straightforward designations of societal spheres; they are cultural classifications and rhetorical labels. In political discourse they are powerful terms frequently deployed to legitimate some interests, views, and topics and to valorize others (Fraser, 131).

The analysis throughout this thesis hopes to take up this call in critical theory by examining the implications of addressing access to medicines and health as 'private' or 'public.'

Having explained the different theoretical underpinnings of this thesis, it is important to note at this point that I carry out this theoretical examination as an 'outsider,' not from within the

key affected groups that I analyze. Therefore, I admit to the selectivity and subjectivity involved in my methodology and analysis, but I still hope that it might be useful to those who are in the crux of the problematic that I discuss. This thesis is categorized in four chapters that are outlined below.

Moving into Analytical Dissection: An Outline of Chapters

Chapter 1: A Tale of Two Illnesses—Setting the Context for HIV/AIDS and Neoliberalism

The first chapter outlines the political and economic context of neoliberalism as a social illness and HIV/AIDS as an epidemiological illness, from their onset in the 1980s to their rapid proliferation during the globalization of the 1990s. In tracing the course of neoliberalism, this chapter demonstrates how the spread of this ideology caused a dangerous global commodification of health whereby health was moved further into the 'private' market domain, weakening public health systems and making the mitigation of the HIV/AIDS epidemic in developing countries that much more difficult. In tracing the course of HIV/AIDS, this chapter also illustrates how the sick individual body cannot be viewed as separate from the public body, since, as the controversial history of HIV/AIDS demonstrates, illness is always culturally constructed.

Chapter 2: The Rise of the HIV/AIDS Activist AntiBody—A Mighty "Counterpublic"

The second chapter discusses the formation of the HIV/AIDS activist "counterpublic" and antiBody which would bring HIV/AIDS into the "public sphere" of debate and would transform the understanding of HIV/AIDS from being a 'private,' personal issue, into a 'political' and 'public' issue. This chapter describes activist efforts to counteract the stigmatization and discrimination of people living with HIV/AIDS; to protest the lack of initiative taken by the government; to create alternative flows of information to reframe

HIV/AIDS; and to insert the activist's voice into the biomedical debate, transforming the person's living with HIV/AIDS' role from being viewed as passive objects of research to be recognized as an active subject with a legitimate voice.

Chapter 3: Big Pharma as a Site of Infection

The third chapter uses a case study to explore Big Pharma as an epidemiological and ideological *site of infection* during the 1990s as its business practices facilitated the spread of both HIV/AIDS and neoliberal ideology. The case study will firstly investigate Big Pharma's irresponsible business practice whereby these corporations treated health as a profitable industry and medicine as any other commodity on the market. This portion will discuss Big Pharma's business model including: its skewing of academic research, its manipulation of clinical trials, its manipulation of doctors, its profit-driven research and development agenda, and its pricing of drugs which all worked to privilege profits over people's health. Secondly, the chapter's case study will examine how HIV/AIDS activists started holding Big Pharma accountable for how its commodification of health affected the research and pricing of treatments for HIV/AIDS. Finally, the chapter will conclude with a discussion of how activists used "lifeworld" logic to challenge Big Pharma's "system" logic on a global scale, simultaneously fighting HIV/AIDS and the spread of neoliberal ideology.

Chapter 4: A Global HIV/AIDS Activist AntiBody Challenges Big Pharma as a Site of Infection

This chapter presents the focal point of this thesis' case study as it specifically concentrates on the prominent battles between Big Pharma and HIV/AIDS activists in the 1990s and early 2000s. The chapter will highlight how TRIPS and the confrontations between these actors pointed to socially unjust power relations between the private interests of Big Pharma's intellectual property rights (IPRs) protection and the interests of those living with HIV/AIDS in

developing countries which led to a vigorous engagement of the Global South. The events to be discussed will include: the legal action the U.S. and Big Pharma launched against the South African government for its introduction of the Medicines and Related Substances Control Amendment Act (1997); Brazilian activists' struggle to construct universal access to health as a human right, its Industrial Properties Law (1996), and its threat to use compulsory licenses to challenge Big Pharma; as well as activists' mobilization at the 'Battle of Seattle' against the WTO.

Conclusion: "Am I Part of the Cure? Or Am I Part of the Disease?" (Coldplay, "Clocks")

The concluding chapter shows how through the previously discussed confrontations, HIV/AIDS activists were able to successfully transform the landscape of access to HIV/AIDS medicines in terms of the WTO's agenda, the global health agenda and in terms of Big Pharma's business practice. It will demonstrate how the HIV/AIDS activist antiBody was successful in combating the illness of HIV/AIDS as well as the social illness of neoliberal ideology. The chapter also addresses what issues were left unresolved which have room for improvement. Finally, this chapter proposes recommendations for the future as to how these issues might be resolved through international and national policy as well as Big Pharma's business operations. Theoretically, if implemented these recommendations should increase the level of access to medicines in developing countries, create an industry research and development agenda to better address the needs of people living in developing countries, and strengthen public health systems in developing countries.

Chapter 1: A Tale of Two *Illnesses*: Setting the Context for HIV/AIDS and Neoliberalism

Introduction: A Surge of Two Pandemics

The 1980s and 1990s marked the rise of two pandemics: HIV/AIDS and neoliberalism. While HIV/AIDS was infecting people around the globe, neoliberal ideology spread like an infection as well becoming predominant in the minds of scholars and the public alike. The following chapter will be broken down into two parts to examine the historical and political economic context of each illness respectively.

The first illness examined will be neoliberalism. The tenets of neoliberal ideology and the expansion and implementation of its principles throughout the 1980s and 1990s will be thoroughly discussed. The examination of the neoliberal economic globalization during this time period will include a consideration of its effects on economic restructuring, international development, and the global health agenda. The analysis will conclude with a discussion of the theoretical implications of how neoliberalism's global commodification of health increasingly moves issues of health into the 'private,' 'apolitical' domain of the market.

The second portion of the chapter will examine the development of HIV/AIDS as an illness. Firstly, a condensed historical outline of the medical discoveries related to HIV/AIDS during the 1980s and 1990s will be established. It will then proceed into an analysis of the social and political context of the initial onset of HIV/AIDS during the 1980s discussing the misinformation, stigmatization and silence surrounding this illness in the United States where HIV/AIDS was first discovered.

Initially, neither neoliberalism nor HIV/AIDS were treated as reason for public contestation or crisis as will be demonstrated in this chapter. Neoliberal ideology was widely

preached, promoting a free and expansive market that would act as a solution to all societal ills. As a result, neoliberal policy was widely implemented to 'cure' economic governance issues and there was little dissent to this market-driven logic at the time. HIV/AIDS was spreading throughout the U.S. population and around the globe as a severe pandemic and yet, it was generally considered to be a disease solely of the gay community. It was not acknowledged as a public health crisis but rather a crisis of a marginalized community. The onset of both neoliberalism and HIV/AIDS had misleading beginnings which would have serious public health implications. Therefore, although one is an epidemiological illness and the other a social illness, both would prove to weaken health systems on an individual, local, and global level.

PART I: Neoliberal Era of the 1980s/1990s and a Global Commodification of Health

The Story of Globalization

Understanding the neoliberal agenda's calculated vision of globalization during the 1980s and 1990s is important to a discussion of access to HIV/AIDS medicines because it was this ideological proliferation that shaped a global market economy which privileges the interests of the developed world over developing countries, the rights of corporations over the rights of individuals, and the health of the market over people's health. With neoliberal policies being increasingly implemented during these two decades, there was a steady narrative of profits over health. A clear message was written in the dominant geopolitical climate of the times; health is a commodity like any other. The tale of the neoliberal ideological illness examines the crafting of this political economic globalization.

The Political Economic Context: 'Globalization' in a Marxist Framework

Typically, when analyzing a given historical time period, social theorists try to critically dissect it in order to uncover the agents or causes involved. However, in terms of 'globalization,' which became the signature concept characterizing the 1990s, Justin Rosenberg, a professor of Historical Sociology and International Relations at the University of Sussex, explains in his book, *The Follies of Globalization Theory*, that theorists have often taken the processes' attributes and not only describe them as the *effects* but also as the *causes* of this time period. This has been a trend of globalization theory. For example, if one were to ask why a production plant moved from Canada to China causing major unemployment in a given area, the obvious explanation would be—globalization. 'Globalization' became perceived as the justification for all of the processes occurring during this time period. Thus, when observing prevalent trends in the global market economy such as the rise of the corporation's influence on a global scale, the new evidence of an increased disparity of wealth between the rich and poor, and the spread of consumer brands and products around the world, the global market seemed like a driving force for nation-states and citizens, creating a perception that the "global inevitably drives the local."

To better deconstruct the reason behind the trends taking place during globalization, Rosenberg suggests analyzing globalization as a historical conjuncture: not only looking "inwards" at the events within this time period but also looking "outwards" at the larger historical process within a Marxist framework. Examining globalization within the historical process and a Marxist framework means committing to an "analysis of the wider historical process of capitalist world development" (Rosenberg, "Follies of Globalization," 10). Applying this historical approach leads to the crucial discovery that despite what was predominantly advocated in globalization theory, the media, and the everyday discourse, 'globalization' was not

some new social phenomenon, but rather it was actually the speeding up and intensification of capitalism as the dominant political, economic and social order expanding around the globe.

Karl Marx anticipated the expansionary organic tendencies of capitalist society long before 'globalization' had appeared. He theorized that "capitalist competition…would drive a tendency to indefinite geographical expansion of its social relations" which was to create: (1) "the universalizing tendency of capital", meaning the expansion of the sphere of consumption; (2) "an acceleration process of technological development and change"; and (3) "the ongoing combination of this would tend to accelerate the means of communicating and transport, leading to periodic bouts of time-space compression—the annihilation of space by time," meaning that space appears less restrictive and there is an increasing sense of immediacy in terms of the cultural perception of time (Rosenberg, "Globalization Theory: A Post Mortem," 21). Noting how all these trends have been prominent characteristics of globalization demonstrates that the events that occurred in this time period were actually part of the ongoing capitalistic process of expansion. This is not to say that capitalism's expansion of the market domain is an uncontrollable force. When Marx addresses the aforementioned *tendencies* of capitalism he indicates that, like any tendency, it can be avoided or encouraged accordingly by the ideological leaning of a given time period.

In Karl Polanyi's *The Great Transformation* he states that "man's economy, as a rule, is submerged in his social relationships"; *people* are in control of the ideologies that shape the market economy—not the other way around (Polanyi, 48). Thus, in terms of "the universalizing tendency of capital" or what could also be referred to as "commodification," an "extension of the commodity form to goods and services previously existing outside the market" (Mansvelt, 8), there are always people behind the decisions as to which social relations, goods and/or services

should be distributed through the market domain and how they should be distributed. Things bought and sold in the market domain are commodities because people have imagined them as such—there is always the creation of a "commodity fiction."

> Polanyi argued that the rendering of things not originally produced for sale as commodities required their reconceptualization, and thus their fictionalization, as "property" … A story needed to be told about these resources which was not necessarily linked to their existence or social production but rather narrated as a propensity to be organized through market relations (May, 124).

Whether they may be governmental regulators, faceless corporations, or large international organizations creating the "commodity fiction," the common denominator connecting them all is *people*.

The fact that Marx's aforementioned tendencies became such defining characteristics of the global economic capitalist system is because certain actors aggressively shaped the global economy to be this way, consequently benefitting certain people while disadvantaging the overall majority. Thus, having looked "outwards" at globalization in terms of a larger historical process of capitalist expansion, it is important to take Rosenberg's advice and turn the scrutiny "inwards" at the events and actors which have propelled the processes of a neoliberal economic globalization.

The "End of History": The Spread of Neoliberalism in the 1980s and 1990s and the Expansion of the Market Domain

The sudden acceleration of Marx's tendencies of capitalism during the 1990s made it seem as though the phenomena taking place were completely new. It begs the question: "Why was there this sudden acceleration during this decade?" The reason for the intensification of these tendencies is two-fold: (1) the rise of neoliberal economic policies in the West and (2) the collapse of the Soviet Union (USSR) in the East.

World-renowned economist John Keynes is famous for his approach to nation-state governance of the economy which became the standard practice in Western economies following the Great Depression of the 1930s. This 'Keynesian' approach touted that the public sector should intervene in the market to stabilize the economy whenever necessary. The failure of the Keynesian approach in solving the recession of the 1970s led to a new trend of economic policies: the 'Reaganism' [of United States (U.S.) President Ronald Reagan's administration], 'Thatcherism' [of United Kingdom (UK) Prime Minister Margaret Thatcher's administration], deregulation, and privatization of the 1980s—the start of a neoliberal era.

"Neoliberalism posits that the rational, isolated individual is the fundamental unit of society, and the market, the natural and just distributor of societies' needs" (O'Manique, 7). From this ideological perspective, the role of the state is to free markets so that all spheres of human life can be governed by the market's 'natural' rules of supply and demand; that if completely untouched by human intervention, the market would 'naturally' run its course to solve all of humanity's ills. Theoretically, the self-interested and competitive drive of individuals' actions in this free market domain should not only lead to their own personal development, but the development of their society on the whole.

When the Soviet Union (USSR) collapsed, it seemed that only a neoliberal capitalist order was left standing as a viable system of organizing the economy. Francis Fukuyama theorized this as being "the end of history" because the fall of the USSR superpower was also the crumbling of any strong counter-balance to capitalism as the primary system for organizing society; all ideological alternatives to capitalism seemed to be effectively obliterated. In his book *The End of History and the Last Man*, Fukuyama said:

> if we are now at a point where we cannot imagine a world substantially different from our own, in which there is no apparent or obvious way in which the future will represent a fundamental improvement over our current order, then we must also take into consideration the possibility that History itself might be at an end (Fukuyama, 51).

He reasoned that it would be impossible to imagine ordering society in any way other than through a capitalist liberal democracy—it had proven to be the ultimate stage of 'progress' for humanity.

After the collapse, many countries seemed to agree with Fukuyama's standpoint since countries that had not been previously receptive to capitalistic influences all scrambled to get in with the 'right' balance of power, opening up their economies for capital-market liberalization. Countries saw capitalism as having defeated communism and therefore wanted to become part of the capitalist world order for fear of being left behind. Thus, a rapid intensification of a capitalist economic and ideological globalization followed suit. As a result, "the ascendancy of market-based , liberal approaches to trade, finance and development policy, and the diminishing roles of national government ownership and regulation of enterprises, are among the defining characteristics of world politics since 1980" (Nelson and Dorsey, 187).

Governments turned to "laissez-faire" economics and embarked on a campaign against the welfare state by decreasing funding for welfare, further deregulating the market, and privatizing important public infrastructure and services. The neoliberal belief of less state control and more corporate freedom for the 'free market' to rule as an uninhibited supra-entity became the mantra in geopolitics. The idea of the 'free market' being governed by the invisible hand of supply and demand without governmental intervention was deemed the best and only way for both nation-state economic governance and global governance. Global trade was a particular area which promoters of the neoliberal agenda sought to vigorously reform.

The Rise in Free Market Ideology: Establishing Free Trade for Whom?

Promoters of free trade argue that when more countries 'open up' their economies to free trade, that is, eliminating barriers to trade (such as cross-border taxes or duties), it allows for the growth of a global network of production and consumption which should supposedly benefit all citizens and all participating national economies. Individual citizens should benefit because with national economies open to imports and exports, companies can produce a wider range of consumer products and can tailor cheaper production processes through economies of scale and through taking advantage of different production conditions in other countries. Therefore, theoretically, consumers would have a wider variety of products and services to choose from at a cheaper cost. In addition to benefiting consumers, the argument follows that the deregulation of trade barriers would boost each country's economy through increased trade and direct foreign investments.

As early as 1817, with his original concept of "comparative advantage" free trade theory, British theorist David Ricardo cautions that free trade would only be mutually beneficial to all parties involved

> *if* the participating countries both have full employment, *if* the total trade is balanced, *if* capital is prohibited from traveling between high- and low-wage countries and *if* under these conditions the countries could produce an item at comparative advantage, *then* trade would be mutually beneficial (Starr, 11).

In theory, with this idea of "comparative advantage," all nations would have a level playing field in the global marketplace because every nation would produce what they were best at producing and in turn, each nation would be competitive and prosperous. In practice, however, free trade has not been "mutually beneficial" among all national economies and consumers since the rules of global trade set by the dominant international organizations have been formatted to advantage developed countries at the expense of developing countries.

The WTO has proven to be a clear advocator for private interests in creating a specific kind of capitalist world order whereby rich nations have made certain areas of the global market free where they have dominance [such as intellectual property rights (IPRs)], while simultaneously protecting areas of the market where they are the most vulnerable and areas where developing countries would profit the most (such as in agriculture and textiles). For example, in terms of agriculture, "Europe, the United States [*U.S.*] and Canada massively subsidize their agricultural sectors to the tune of about $360 billion per year—subsidies that were effectively locked into the WTO agreement on Agriculture" (McNally, 70). Nothing clarifies the power imbalance of what has become of 'free trade' more than the WTO's creation of the Trade Related-Aspects of Intellectual Property Rights (TRIPS) agreement which created an international regime protecting intellectual property rights that includes the international protection of patents for pharmaceutical processes and products. (The critical nature of this particular agreement's impact on the state of access to antiretroviral medicines for HIV/AIDS will be discussed extensively in Chapter 4). This trend of free trade has created stark power relations between the developed world and the developing world producing a larger disparity between the poor and the wealthy within and between nation-states.

The neoliberal agenda of putting private interests above the welfare of people also proliferated into the World Bank and the International Monetary Fund (IMF) creating what is known as "the Washington Consensus." It is important to note that this "Washington Consensus was no accident but was the culmination of years of efforts by business and their lobbyists in government to consolidate their power, especially in response to the counterculture movement of the 1960s and 1970s" (Banerjee, 133). Corporate interests were successful in their influential

promotion of trade liberalization and privatization but their efforts also had grave consequences for the poor.

Neoliberal Policies as a New 'Miracle Drug' for International Development

International organizations increasingly followed the logic of the old 'modernist' paradigm of development and 'progress' that was introduced during the 1940s and 1950s whereby it was presumed that "only through material advancement could social, cultural, and political progress be achieved. This view determined the belief that capital investment was the most important ingredient in economic growth and development" (Escobar 39). Thus, theoretically, if wealth is generated from the greed and pursuit of self-interested individuals, then that wealth should eventually 'trickle down' to everyone else in the economy. Thus, free market ideology and neoliberal policies were implemented to *cure* the economic ills of countries throughout the 1980s and 1990s, quickly becoming a mainstream development strategy supported by the "Washington Consensus." This was the strategy used when the IMF and World Bank tried to cure the international debt crisis which had reached astronomical proportions by 1981 (Robbins, 102).

Countries were forced to take on more debt by getting short-term loans from the World Bank and the IMF and were told to correct their 'balance-of-payments' problems by adhering to prescribed Structural Adjustment Programs (SAPs). SAPs demanded that governments commit to such actions as: privatizing government properties; devaluing their currency by making their goods cheaper for customers in other countries but pricier for the people in their own country; and reducing public spending on social services like healthcare, education and welfare. SAPs continued to be used as a developmental strategy throughout the 1980s and 1990s.

It was hoped that SAPs would stimulate economic growth and promote development in these countries by turning these national economies into 'self-regulating' markets so that the accumulation of private wealth would spread throughout the rest of the population. In reality, asking countries with already weak public health systems and social services to cut back even more funding towards these social safety nets and privatizing these services instead means that people have less support, especially when facing an epidemic like HIV/AIDS.

> The imposition of 'user-fees' for primary healthcare drove large numbers away from public health services, contributing to increased rates of sexually transmitted diseases. Moreover, cutbacks in the public sector helped send health professionals to the private sector or abroad and reduced investments in healthcare delivery systems (Cheru, 304).

Under these conditions, an epidemic like HIV/AIDS becomes more severe and, to use Jeffrey Sachs' term once again, it becomes more of a "poverty trap" for people in developing countries. Ironically, the policies meant to deliver the hoped-for economic development, made the possibility of achieving that goal even more difficult.

Besides the destructive actions taken to fix the debt crises of countries, health systems were further weakened in the early 1980s when the wave of neoliberal ideology influenced a switch in the global health agenda from the Primary Health Care (PHC) approach to a new mantra of increasing the privatization of healthcare and implementing Selective Primary Health Care (SPHC).

From "Health for All" to "Health for a Select Few": A Revised, Neoliberal Friendly, Global Health Agenda

The communitarian stream of thought in the development field of the 1960s and 1970s also overlapped into the field of global health with the Primary Health Care (PHC) and Country Health Planning movements which emphasized the prevention of illness through ensuring good quality primary/basic health care service. "The PHC approach embodied the ideas that health

depended on improving socio-economic conditions and alleviating poverty, and that the process should be community-based and should support health priorities at the local level" (O'Manique, 51). The movement came to its symbolic fruition in 1978 during the World Health Organization (WHO) and United Nations Children's Fund (UNICEF) sponsored International Conference on Primary Health Care in Alma-Ata, Kazakhstan. This was where the WHO announced its "Health for All by 2000" initiative—the objective being to deliver basic healthcare to all the poor of the world by the year 2000. The "Health for All by 2000" strategy called on nation-states, local communities and the international community to be key actors in accomplishing the ultimate goal.

As worthy an ambition as the initiative was, the oil crisis, global economic recession, debt crisis, and the rise of neoliberal ideology, all worked to block the previous communitarian line of thought in development aid as well as stunt the growth of the Alma-Ata "Health for All" movement by the year 1980 (Epstein, 257). Selective Primary Health Care (SPHC) introduced in 1984, aimed to target only the hardest-hitting diseases of the developing world instead of working towards achieving universal basic healthcare. "Underlying the SPHC was the argument that given economic recession and shrinking health budgets, health indicators would improve only with a few carefully selected, cost-effective, and carefully targeted interventions" (O'Manique, 52). The main priority for global health became financing as opposed to making health accessible to all.

Therefore, along with the rise of neoliberalism throughout the 1980s and 1990s, there came an increasing commodification of health. As health is moved from the public domain to the private market domain, healthcare becomes a service like any other market commodity that one

can only access if one can afford it. Consequently, there is a shift from perceiving health as a public good to perceiving health as a private good and the significance of this shift is profound.

Moving Health from the Public Domain into the Market Domain

The market domain is the sphere of consumption where private goods (which can be objects or social relations) are bought and sold. Private goods, or commodities, are owned by private interests whether by a person or a company, and therefore are protected within the property rights system. One can only operate effectively in the market domain and participate in the exchange of commodities if one has money. On the other hand, the public domain is theoretically a domain that should be accessed by everyone wherein people can communicate to meet collective needs.

> The public domain is an area of social life, with its own rules, norms, and practices, cutting across the state and market and other public private agencies. Its values are those of citizenship, services and the notion of the public interest and its has long furnished civil society with the much needed resources to function effectively by creating sanctuaries where the price mechanism does not operate (Drache, "The Market Domain or the Public Domain," 4).

Conceptualization of this domain naturally includes the consideration of the public sector (all services provided by the state) and the public regulatory authority (the government and authoritative branches stemming from it) but also includes public goods which are 'things public' that cannot be privately owned (Drache, "Defiant Publics," 57).

The traditional criteria for a public good are: (1) a requirement of non-rivalry, meaning that people do not need to compete in order to use the good and, (2) one person's use of the good should not limit the use of the good by other people (Parmet, 78). For example, a road may be considered a public good because everyone can benefit from it, no one has to compete against anyone else in order to use it, and one person's use of a road does not restrict another person

from getting the same use value. To further develop the concept of what is 'public,' the notion of the 'Commons' is used to depict the public domain and the goods within it.

The Commons are any spaces, resources and goods not expropriated by the private property rights system, meaning that they are not owned by any particular private body; in addition to the Commons signifying traditional goods like water for example, it can also signify more abstract things such as the communicative practices and collaboration between individuals. Therefore, ensuring that the Commons or public goods are easily accessible and regularly maintained means that there is an overall service or advantage to the community as a whole. Access to healthcare and medicine presents an interesting predicament within this public good versus private good debate.

Healthcare and Medicines: 'Public' or 'Private' Goods

Medicines and treatments for health are privately consumed and can greatly affect the health of the individuals who take them, so from this standpoint, labelling them as private goods seems valid. However, from a public health perspective, medicines could be labelled as public goods since: they prevent the spread of infection; the improper use of medicines can lead to the development of resistant bacteria and viruses that could undermine the efficacy of an antibiotic for others; medicines can keep populations healthy which would maintain higher levels of employment and theoretically less orphaned children; and in the case where a public healthcare system is in place, medicines can reduce shared healthcare costs by treating the onset of an ailment so that more drastic and expensive treatments are not needed in later stages of illness which adds extra burden to a public health system (Parmet, 80-81). Essentially, one person's access to medicines can influence the quality of life for others in a profound way.

If viewed as a public good, it would make sense that the production and distribution of medicines and treatments for health would be of public concern and of the state's concern as well. However, if considered a private good, as the neoliberal perspective would deem it, then the distribution of medicine should be governed according to the rules of supply and demand within the market domain. The consequence of considering health and medicine as a commodity like any other determined by a person's private consumption in the market, unfortunately propagates an understanding of access to health and medicine as being part of a 'private' economic sphere and therefore, 'apolitical.'

What is 'Private' is 'Apolitical'? What is 'Public' is 'Political'? Where is Health?

Public versus Private

Communications theorist, Nancy Fraser cautions the discursive distinction made between 'private' and 'public' matters making the case that when issues are categorized "the result is to enclave certain matters in specialized discursive arenas and thereby shield them from broadly based debate and contestation" (Fraser, 132). Furthermore, she argues that these distinctions are used to perpetuate the domination of some social groups over others. To demonstrate this point, Fraser refers to how the traditional classification of one's personal or home life as being 'private' played a part in keeping sexual abuse and 'wife battering' away from broader public deliberation and protest. To label something as someone's "private business" is essentially to say that no one else has any right to pry or intervene. The same rationale can be used when critiquing how the orthodox biomedical paradigm dictates that all matters relating to medicine, illness, and health are deemed 'private' only being discussed by medical professionals, researchers, doctors, and patients. This privatization of discourse also creates power relations due to the notion that the biomedical community "knows best", making patients only objects of speculation (The

significance of the discursive privatization of the biomedical discourse will be further examined in Chapter 2).

Fraser also problematizes the implication of grouping of all economic activity into the 'private' category. She explains:

> The rhetoric of economic privacy ... would exclude some issues and interests from public debate by economizing them; the issues in question here are cast as impersonal market imperatives or as 'private' ownership prerogatives or as technical problems for managers and planners, all in contradistinction to public, political matters (Fraser, 131-132).

The perception follows that when anything is placed in the market domain, its supply and demand is no longer of greater public concern and only becomes the 'private' matter between the buyer and the seller in the market transaction.

'Political' versus 'Apolitical'

In pre-capitalist society, the 'political' (those things either involving the state/public authority or the rights of citizens), did not constitute its own realm of activity. There was "no real separation between 'state' and 'civil society,' no real distinction between the public and the private"—everyone was in servitude to royalty (Rosenberg, "Globalization Theory: A Post Mortem," 20). Under feudalism, the private economic market and social life of the people were '*directly political*' in nature since the hierarchical power relations governing people's lives were visible for all to see, one knew his or her place whether a servant, a lord, or a king (Rosenberg, "Globalization Theory: A Post Mortem," 19-20). Capitalism, on the other hand, ushered in an era whereby the production and distribution of wealth became dictated by the exchange of things through contractual relations among legally equal persons—removing the stark political hierarchies of feudalism but creating subtler power relations in its place.

> For Marx ... this development amounted to nothing less than a structural inversion of the relational architecture of human society: whereas formerly, access to wealth in things had been secured through hierarchies of direct control over persons ... now control over persons was orchestrated through (the exchange of) things (Rosenberg, "Globalization Theory: A Post Mortem," 20).

Moreover, whatever power a person exercises over another through this contractually mediated "exchange of things" in the market domain is understood as largely 'apolitical' (without the involvement of the state or any impact on the rights of citizens). Therefore the price, quality, accessibility and distribution of commodities are thought to be solely orchestrated by the private interests of a faceless amoral market. Let us firstly examine the assumption that the state has no involvement in market relations.

Even though capitalism, especially a neoliberal-supported form of capitalism, is thought to remove the state from the market domain as much as possible, the state still exists as "an 'external' enforcer of contracts and provider of the general conditions under which the new private sphere can flourish" (Rosenberg, "Globalization Theory: A Post Mortem," 22). Herein lies the paradox: that the state is forced to withdraw from these 'private' market relations but must also be present in order to facilitate them through mediating the legalities of the property rights system. The vision of the 'free market' is therefore a fallacy since state public authority is responsible for the legal mediation of contracts and all market relations; thus, the artificial division of the state from the market is somewhat fruitless. Aside from the state's involvement though, can market relations be classified as 'political' by virtue of affecting the rights of citizens? I would argue yes.

To appreciate this viewpoint, one must alter his/her understanding of citizenship from the "state-based" approach to Fox's aforementioned "society-based" approach (Fox, 174). As previously discussed, the traditional "state-based" approach understands citizenship in terms of

the legal rights that an individual is granted due to his/her belonging to a nation-state. The "society-based" conception of citizenship on the other hand sees citizenship as a social process whereby individuals claim, expand, or lose their rights; it looks at the inclusion or exclusion of individuals not just from a nation-state but from civic, social or political communities as well. Thus, as Engin F. Isin and Bryan S. Turner explain:

> The modern conception of citizenship as merely a status held under the authority of a state has been contested and broadened to include various political and social struggles of recognition and redistribution as instances of claim-making, and hence by extension, of citizenship (Isin and Turner, 2).

This modern conception of citizenship is why theorists like Néstor Garcia Canclini argue that there is a new emerging interplay between the concepts of 'citizenship' and 'consumption' which demands the reconceptualization of both of these concepts. He states that "we must approach citizenship without dissociating it from those activities through which we establish our social belonging and our social networks, which in this globalized era are steeped in consumption" (Canclini, 20). Canclini's call to investigate matters of consumption, as well as the social implications and power relations involved in these market 'transactions,' is crucial now more than ever since entities such as healthcare are increasingly being commodified.

The fact that access to health has been increasingly commodified and distributed according to market principles means that the ability to purchase healthcare and medicines determines people's inclusion or exclusion from who is 'healthy' or 'sick' which drastically determines an individual's life opportunities. The fact that access is increasingly determined along class lines of which citizen can afford healthcare and which citizen cannot is 'political.'

The Ideological Illness Takes its Toll on the Public Body

Although neoliberal policies were implemented to serve as *cures* for a troubled state and the global economy in the 1980s and 1990s, there was a distinct pattern of uneven development

evolving which resulted in further widening the "global apartheid" between the 'haves' and the 'have-nots' of the world. Evidently, neoliberalism acted more like an illness damaging the public body, weakening a state's resources or *immune systems* and making states less capable of handling public health concerns. While neoliberal policies were spreading through nation-states, weakening the welfare state and promoting a dangerous commodification of health, a deadly pandemic was spreading throughout populations weakening the immune system of individuals. It is now important to turn our investigation towards the actors and events surrounding the second illness in question, that is, the epidemiological illness of HIV/AIDS.

PART II: The Epidemiological Illness—HIV/AIDS

The Story of the Beginnings of AIDS: A Medically-Sterile Version

Since 1979, there were doctors in New York, Los Angeles and San Francisco who had detected lymphadenopathy (lymph nodes that are constantly enlarged) in many of their gay male patients. They had also started noticing that many of these patients had Pneumocystis carinii Pneumonia (also referred to as Pneumocystis Pneumonia) (PCP) and Kaposi's Sarcoma (KS) ("a cancer of the blood vessels that usually follows a slow and relatively benign course and had most often been found among Central Africans and elderly men of Mediterranean origin") (Grover, 18). Because this PCP/KS complex was initially only found in gay males, the condition was initially labelled as Gay-Related Immunodeficiency (GRID) or Acquired Immunodeficiency (AID) and the popular conception was that the "gay lifestyle" was the root of the complex, with its "fast-lane living" and "too much sex" (Grover, 18). It was later in 1981 that other cases of the illness were found among drug users as well as among heterosexuals in Haiti and across Africa rendering the "gay lifestyle" theory scientifically invalid.

As doctors identified more symptoms and more diseases related to the illness, the medical community diagnosed it as a syndrome (a group of signs or symptoms that occur together and are understood to characterize a medical condition) rather than a complex (a specific set of symptoms that characterize a particular medical condition). In 1982, the United States' Center for Disease Control (CDC) labelled it as Acquired Immune Deficiency Syndrome (AIDS) and in 1983, the Human Immunodeficiency Virus (HIV) was discovered. The relationship between the HIV virus and AIDS is as follows: after the HIV virus is transmitted through blood, sex, or from mother to foetus, it gradually breaks down a person's immune system making him or her susceptible to the collection of seventy or more AIDS-related illnesses that we now know can reveal the face of AIDS. In 1985, the U.S. Food and Drug Administration (FDA) [the U.S. agency responsible for all regulations to do with food and drugs to ensure safety, accessibility, and effectiveness] approved the first test that would detect HIV antibodies in the bloodstream; antibodies that can be identified in the body as early as two or three weeks after a person gets infected with the virus (Pisani, 132). By this time, in 1985, at least one case of AIDS had been reported in each region of the world.

Prior to the mid-1980s, researchers were still learning about the way HIV functions in the body, therefore research efforts were mainly focused on devising ways to boost the immune system for people living with AIDS and focused on the illnesses that infect those living with HIV/AIDS as a result of their weakened immune systems. These are called opportunistic infections (OIs) because they take advantage of the body's weakened immune system. However, during the mid-1980s researchers were able to move beyond just treating the OIs and were now able to develop pharmacological weapons that could actually attack the replication of the HIV virus (Smith, 40). This led to the FDA's approval of Burroughs Wellcome's zidovudine or

retrovir (AZT) in 1986 which would be launched on the market in 1987. AZT was the first antiretroviral (ARV) drug (meaning a drug that slows down the progression of a virus) to treat those infected with HIV/AIDS. Essentially, AZT works to keep the amount of HIV in the body at as low a level as possible in order to prevent the further weakening of a person's immune system. In technical terms, AZT is a nucleoside analog reverse transcriptase inhibitor (RTI) which inhibits the process of reverse transcription (meaning that these drugs block the recoding of viral RNA into DNA) (Smith, 40). Soon after, nonnucleoside RTIs were developed which function similarly to nucleosides but work much faster once inside a person's bloodstream.

At first, researchers thought that there was a period of "clinical latency" (which is the period between a person's initial infection with a disease and when the person starts showing signs of illness and the illness starts replicating in the person's body) of ten years or more that people experienced after getting infected with HIV, but in the years between 1986 and 1995 it was discovered that even if a person did not show signs of an AIDS-related illness, the virus was still replicating in the person's body. Finally in 1996, the big scientific breakthrough of protease inhibitors (PIs) was announced; Abbott's Kaletra is an example of a PI and one of the most widely used on the market. PIs work to prevent an HIV infected cell from replicating more copies of the HIV virus and therefore, with PIs it became possible to combine RTIs and PIs in a daily combination antiretroviral treatment regimen that would better combat the presence of mutated forms of HIV (Smith, 42). This therapy combines a treatment regimen of three or more antiretroviral drugs and is known as Highly Active Antiretroviral Treatment (HAART).

Although factually informative, telling the story of AIDS as an illness within a vacuum-like narrative of medical labels and discoveries, as the biomedical paradigm would dictate it, and as I have been describing thus far, is much too 'neutral,' too 'objective' and ultimately too

narrow a perspective to understand HIV/AIDS because illness is *cultural*, illness is *political*, illness is *social* and illness is *economic*.

> The stories of AIDS are revealing of who is included (socially, politically and economically) and who is marginalized and excluded. And these stories are of great consequence not only because there are tangible benefits to be distributed (such as health insurance, services, care and technology), but because the narratives of medicine and the explanations of how diseases are contracted and how they should be treated are socially constructed (Sontag, 134).

Unfortunately, the initial social construction of HIV/AIDS crafted a very discriminatory and negative construction of both HIV/AIDS and the people who live with it.

The Story of the Beginning of AIDS: A Politically-Charged Version

AIDS Myths in Public Discourse & Silence of Administration

The biomedical establishment may have concretized AIDS with an official name but the everyday discourse surrounding the illness during the 1980s was more mythical than anything else. Some rumours perpetuated the belief of AIDS being "the gay man's disease," other tales circulated about it originating in Haiti and being transmitted through ritual sex and voodoo blood-drinking ceremonies (Irwin, Millen and Fallows, 19), and there were also conspiracy theories about it being produced by organizations like the CIA (Farmer, xxii). Despite this, the administration of the country where AIDS was discovered, the U.S. administration of President Reagan, remained eerily quiet about AIDS. In fact, it was only in late 1985 that U.S. President Reagan even uttered the word "AIDS" in response to reporters' questions and at this point 12,689 Americans had already died of the disease (Pisani, 149).

From the administration's perspective, remaining as quiet as possible about the disease seemed the safest choice. AIDS involved deep-seated cultural taboos that government officials were not comfortable with discussing openly: sex, homosexuality, and drug use. The most influential of the taboos that created the silent standstill was definitely homophobia. Even though

it was as early as 1981 that different cases of AIDS had been discovered among heterosexuals, there was still an overall denial that AIDS could be transmitted heterosexually, totally neglecting the cases that had been discovered in Africa. Acknowledging heterosexual transmission meant acknowledging that AIDS was a pandemic that could spread to far more people than just the homosexual community, which is what initially made the U.S. government and the WHO so lackadaisical about choosing its first response to AIDS—inaction.

Homophobic Stigmatization of People Living with HIV/AIDS

Instead of publicizing AIDS as affecting the heterosexual population as well, the officials let homophobic reactions run their course. The many measures that were suggested to mitigate the HIV/AIDS epidemic in terms of quarantining, implementing mandatory testing, forcing the removal of people living with HIV/AIDS from their jobs, houses, and schools are all what Robert Padgug (1989) classified as following the exact same lines of homophobic oppression throughout history (Stockdill, 5).

Social stigma continued to be lethal. In 1986, a teen in Indiana named Ryan White was banned from attending school. (He later became an important activist who spoke out against the discrimination against people living with HIV/AIDS). In 1986, nine-year old Ricky Ray, who was a haemophiliac and HIV-positive, was also banned from attending his school in Florida because of his diagnosis and the following year his home was burned down by arsonists (Project Inform, www.projinf.org). There were also many religious and conservative right wing individuals who pointed to HIV/AIDS as being God's punishment of homosexuals for living in sin. Televangelist Jerry Farewell stated: "AIDS is God's judgment of a society that does not live by His rules" (Sember and Gere, 968). When Susan Sontag wrote her book, published in 1989, she observed:

> The sexual transmission of this illness, considered by most people as a calamity one brings on oneself, is judged more harshly than other means—especially since AIDS is understood as a disease not only of sexual excess [*people that are promiscuous are deemed more likely to contract AIDS*] but of perversity [*an illness specifically contracted by homosexuals*]" (Sontag, 114).

President Reagan's first mention of AIDS in a formal speech, given to the American College of Physicians in 1987, included him referring to AIDS as "public enemy number one" and he told people that abstinence was the best response to prevent the spread of AIDS. The speech also included the President saying: "'When it comes to preventing AIDS, don't medicine and morality teach the same lessons?'"—a clear-cut example of the kind of disinformation that dominant media and public figures disseminated which reinforced homophobic responses to AIDS (qtd. in Grover, 27). As AIDS was building as an issue in the media, not only was there misinformation in terms of the homophobic stereotyping, but there was still confusion in communicating how the illness is transmitted.

Confusion in Understanding Transmission of HIV/AIDS

The fact that the popular press, government officials and doctors switched from calling AIDS the "Acquired Immune Deficiency Syndrome" to "AIDS ... the disease" created confusion in the public's understanding of the transmission of AIDS. "In discussions of AIDS, because of the distinctions not made—between syndrome and disease, between infectious and contagious—there [*was*] often a casual slippage from *communicable* to *contagious*" and this led to a lot of confusion about whether AIDS could be contracted just through casual contact like drinking from the same glass (Grover, 19). This confusion is best demonstrated by Dan Rather's CBS (Columbia Broadcasting System) televised interview with Bobbi Campbell, an avid activist and 'poster-child' for HIV/AIDS awareness, conducted in 1984. (In 1981, he was the first person to make his diagnosis with KS public to the U.S. in a local gay newspaper called *San Francisco*

Sentinel). For his interview, Bobbi sat in a glass booth so that technicians would not have to come in contact with him when positioning the appropriate microphones—the glass booth sent a message to the public that one should not touch HIV-positive individuals with a ten-foot pole (Friedman, www.globalhealth.org, 5).

Dehumanization of People Living with HIV/AIDS in Discourse

Mainstream sources of information also had a tendency to use the term AIDS "victims" or "patients" which metaphorically dehumanized people who have AIDS as objects of pity and fear, passive and powerless to do anything to improve their condition (Grover, 29-30). Similarly, the tendency in the dominant discourse to single out "risk groups" (i.e. homosexuals) as opposed to "risk practices," further marginalized people who live with AIDS as seemingly deviant from the 'general public,' regardless of the fact that the "risk practices" that can lead to HIV transmission, such as intravenous drug injections and penetrative sex are practised by heterosexuals and homosexuals alike. Sontag discusses the metaphorical implications of these labels when she writes:

> Indeed, to get AIDS is precisely to be revealed, in the majority of cases so far, as a member of a certain 'risk group,' a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbours, job-mates, family, [*and*] friends (Sontag, 112-113).

Thus, from its inception in 1981 and throughout the decade, the mainstream or official rhetoric surrounding AIDS was largely governed by a homophobic, stigmatizing attitude that aimed to disempower and neglect the needs of those living with HIV/AIDS.

Conclusion: Two Illnesses Lead to the Creation of One Powerful AntiBody

This chapter's outlining of the development of neoliberalism as a social illness and HIV/AIDS as an epidemiological illness provides an important analytical base to delve further into this thesis' case study. Firstly, understanding the construction of the neoliberal ideological

climate, as well as the global commodification of health that developed from it, explains the context which allowed for Big Pharma to practise its most irresponsible market-driven logic and which also allowed for the WTO's implementation of the TRIPS agreement. Secondly, one must understand the background of both illnesses prior to learning about the involvement of HIV/AIDS activists in order to fully grasp how HIV/AIDS activists' efforts to transform the public's perception of HIV/AIDS would also transform the public's perception of neoliberal ideology. The HIV/AIDS activists would make both illnesses issues of public contestation, constructing both as roots of public crisis and thus, acting as an antiBody to presentthe spread of both illnesses.

The next chapter will explain the roots of this HIV/AIDS activist antiBody that rose up during the 1980s. It will discuss how people living with HIV/AIDS initially mobilized to fight to end the stigmatizing silence surrounding HIV/AIDS and the discrimination against them. The chapter will also show how they would successfully construct alternative discourses and social meanings surrounding HIV/AIDS. These activists would break HIV/AIDS out of the 'private,' 'apolitical' discursive sphere by dispelling the biomedical paradigm's notion of illness and health as matters only to be addressed by the medical professionals and patients. Instead, they made HIV/AIDS a 'public' issue acting as bridges between the biomedical community and the public.

Chapter 2: The Rise of the HIV/AIDS Activist AntiBody—A Mighty "Counterpublic"

Introduction: The Beginnings of a Movement

Even though the gay community was aware that HIV/AIDS was not an illness exclusive to homosexuals, they also knew that the biomedical establishment (researchers and doctors), the pharmaceutical industry, governments and the public at large, had purposely turned a blind eye to HIV/AIDS because of the widespread and false belief that HIV/AIDS only affected gay people. Since the illness had been given a negative connotation as a result of being associated with the gay community, this community embraced HIV/AIDS as their issue—illness became visibly *political*.

> Taking ownership meant on the one hand, that the community would irrevocably be associated with the new and stigmatizing disease. It also meant, importantly, that the community claimed the right to construct the ways in which the disease would be defined and managed. The gay community's decision to take ownership of a stigmatizing disease spread primarily through practices that were morally unacceptable to most Americans was unprecedented (Siplon, 578).

Thus, this body of people came together to form the beginnings of the HIV/AIDS activist antiBody. They would be the first HIV/AIDS activists to band together to produce cultural practices that would transform the context within which HIV/AIDS would henceforth be understood.

This chapter examines the beginnings of this HIV/AIDS activist antiBody and will explore how this antiBody advocated to bring AIDS into the "public sphere" of debate. It discusses how these activists challenged both the dominant construction of HIV/AIDS and the inaction of the "stronger publics" of the government, the media, and the biomedical community. The chapter first explains how HIV/AIDS activists carved out their own cultural space and made HIV/AIDS a public issue people cared about. This forced political leaders and the media to take notice of it as well and would lead to HIV/AIDS as an issue being moved into the global "public

sphere." The chapter then goes on to discuss how these activists raised their voices to wake up the biomedical establishment, challenging the biomedical paradigm, reformulating the clinical definitions for AIDS, critiquing clinical trial processes, and creating their own publications to disseminate scientific information. Therefore, early HIV/AIDS activism would make HIV/AIDS 'public' and 'political' by becoming a legitimate voice from the margins and democratizing biomedical knowledge to become 'public' knowledge. "In their role as translators, AIDS activists have influenced both the private sphere (the patients' choices) and the technical sphere (the way randomized double-blind experiments are performed), but they have done so primarily by making AIDS a public issue"—an issue in the public sphere (Fabj and Sobnosky, 178).

The HIV/AIDS "Counterpublic" Breaks into the "Public Sphere"

The gay community mobilized the same social activist networks which had been created during the gay rights movement of the 1960s and 1970s to combat stigmatization and discrimination against the lesbian, gay, bisexual and transgendered (LGBT) community. Because of these strong activist roots, the gay community was well-versed and well-trained in the tactics of political and social activism. The first mission that these activists needed to accomplish before even beginning to convince the "powers-that-be" to take action for AIDS, was to convince people to care about what was considered to be a "gay man's disease." Thus, one of the biggest undertakings for the gay community was forcing AIDS into what communications theorist Jurgen Habermas referred to as the "public sphere."

Habermas (1989) stated that the public sphere is made up of one overarching large body of affairs and interests, to which, theoretically, all 'citizens' should have access (Habermas, 1989). Nancy Fraser paraphrases Habermas' vision of the "public sphere" as being: "a body of 'private persons' assembled to discuss matters of public concern or 'common interest'" (Fraser

112). Fraser, however, argues that multiple publics exist: "strong publics," "weak publics," and "subaltern counterpublics." What differentiates these publics, she theorizes, is their location within power relations of dominance and subordination and by how much decision-making influence each public holds. Therefore, "weaker publics" have less influence in decision-making while "stronger publics" are more dominant and influential in decision-making. Fraser's subaltern counterpublics, on the other hand, are "parallel discursive arenas where members of subordinated social groups invent and circulate counterdiscourses to formulate oppositional interpretations of their identities, interests, and needs" (Fraser 123).

When the gay community created the first network for HIV/AIDS activism, they were forming a "counterpublic" for HIV/AIDS in order to combat the inaction of the government, the media, the biomedical establishment and Big Pharma, the aforementioned "stronger publics" and 'powers-that-be' at the time. To fight the dominant discourse and inaction of these "stronger publics," the HIV/AIDS activist antiBody or "counterpublic" would have to educate and advocate about the issues surrounding HIV/AIDS by creating alternative flows of information and creating new cultural symbols and readings for HIV/AIDS.

Constructing HIV/AIDS with an Activist's Voice

Rhetorical battles in activist campaigns are important in order to renegotiate the "stronger publics'" dominant rhetoric:

> They are ... processes through which actors renegotiate the meaning and content of social practices ... Negotiated understandings within a campaign is only part of the struggle; activists must also persuade actors that hold power to respond to a campaign's demands. Framing the rights and wrongs at stake is a critical step in the process of negotiating solutions (Hertel, 20).

It was the job of AIDS activists to frame the 'rights' and 'wrongs' of the dominant discourse and challenge it through cultural activism. Staging public demonstrations was one strategy activists used to showcase their cause to the public.

One such example was the candlelight memorials held in major cities across the United States on May 2, 1983 organized by the Mobilization Against AIDS organization and prominent activists like Larry Kramer and Bobbi Campbell, were strategically planned to attract media attention and build public awareness (Behrman, 119). With banners reading "Fighting For Our Lives," activists marched with their candles symbolizing the people that had died from AIDS and those who were living with the disease but who were still being neglected by the government, media and society at large. Using a candlelight memorial for the AIDS movement was brilliant since the media and the public had been accustomed to the gay community holding an annual candlelight vigil since 1978 to commemorate the assassination of San Francisco Supervisor Harvey Milk and Mayor George Moscone and their gay rights advocacy (Friedman, www.globalhealth.org, 5). This memorial attracted some of the first local media coverage for AIDS activists and would also become an event held in 119 countries for years to come.

Because much of the mainstream discourse on AIDS during the 1980s was disseminated through television, activists began embracing video as a medium to reverberate alternative messages and images into the public sphere. Cable and VCRs were becoming commonplace and presented an exciting opportunity to reach people. These videos all aimed to counter the typical images and discourse of the mainstream and were created in a variety of genres: music videos, AIDS educational videos, "art" videos, critiques of the media, documentaries, and videos produced to be broadcasted on television (Crimp, 14).

One of the key renegotiations in the public sphere that AIDS activists took on was to replace the aforementioned disempowering labels often used in the "stronger publics'" dominant discourse to label people who have AIDS as "victims" or "patients." Instead of these terms, activists created and circulated a new point of reference: the term People With AIDS (PWAs).

> At the second AIDS Forum, held in Denver in 1983, a group of men and women with AIDS and ARC (AIDS-Related Complex) met to form an organization that would speak their own needs—in their own words. The Advisory Committee of People with AIDS, forerunner of today's National Association of People with AIDS, issued the following statement: 'We condemn attempts to label us as 'victims,' which implies defeat, and we are only occasionally 'patients,' which implies passivity, helplessness, and dependence on the care of others. We are 'people with AIDS' (National Association of People with AIDS, "Statement of Purpose," September 1986, qtd. in Grover, 26).

From this AIDS forum in Denver, Colorado, the "Denver Principles" were drafted which would act as a statement of self-empowerment for everyone living with HIV/AIDS. The National Association for People With AIDS (NAPWA) was formed and a broader collective was launched known as the People With AIDS (PWA) movement. Today, the categorization of those living with HIV/AIDS, as well as the movement itself, is known as People Living With HIV/AIDS (PLWHA). (The original PLWHA movement has now spread to countries around the world—such as in Canada, Vietnam and Nigeria). Thus, from the beginning of AIDS grassroots activism, there was a concerted effort by activists to prevent the media and everyday dialogue from framing people living with AIDS as weak 'charity-cases' which is typically the standard narrative of the 'sick'. The AIDS Coalition to Unleash Power (ACT UP) was arguably the most significant and powerful collective of the early grassroots efforts stemming from the AIDS activist antiBody which ensured that the public saw PLWHAs as anything but weak.

The Time Came to "ACT UP"

In 1987, the first chapter of ACT UP was established in New York. Unlike other organizations that have been formed to promote awareness about a specific sickness, ACT UP

was an organization that represented the demands of activists. Patricia Siplon uses the Cystic Fibrosis Association as an example of the usual representation of the typical illness-based organization:

> People afflicted with CF are presented to the general public as largely helpless people deserving of sympathy and financial and political support. As victims, however, CF sufferers are not allowed to define their own experience, nor to dictate the policy solutions their diseases require (Siplon, 579).

ACT UP and other HIV/AIDS activists on the other hand, focused their efforts on changing government policy, deconstructing stigmas, and transforming the way their surrounding culture understood the context of HIV/AIDS.

ACT UP was predominantly founded and run by middle-class, white gay males as well as members of the larger LGBT community, but over time, it became a coalition that included a diversity of individuals with varying interests at stake in HIV/AIDS activism such as women's rights advocates. ACT UP members became walking alternative sources of information about HIV/AIDS. They spoke openly about anal sex, endorsing safe sex and throwing condoms at public officials to condemn them for not promoting the use of condoms publicly (Stockdill, 6). ACT UP members could also be found in local gay bars disseminating information about the transmission of HIV/AIDS and giving out condoms.

Significantly, the group's logo was an image of the words "SILENCE = DEATH" accompanied by an image of a pink triangle outlined in black, a logo which was lent to ACT UP by the SILENCE = DEATH project design collective (Sember and Gere, 967). SILENCE = DEATH boldly communicated the activist construction that as much as the "stronger publics" may have wanted to deny the gravity of it, AIDS was a crisis. The pink triangle outlined with black was representative of the gay rights movement of the 1960s which had adopted the triangle from when the Nazis used it to label homosexuals in concentration camps (Crimp, 7). ACT UP's

triangle was symbolic of the LGBT community which was the main group targeted by the "stronger publics'" response to HIV/AIDS and was symbolic of how LGBTs were the main protagonists in the HIV/AIDS activist movement.

One of ACT UP's most memorable forms of cultural activism was in November of 1987 when it put together an artistic display called *Let the Record Show* ... in the window of the New Museum of Contemporary Art in New York. The display featured a photomural of the Nuremberg trials with an additional row of six public figures who are put on trial for "crimes against humanity" for their responses to the AIDS epidemic. Each figure's photo was accompanied by a stone tablet which revealed a statement he or she had said about AIDS. For example, William F. Buckley (founder and editor of the conservative magazine, *National Review*) was one of the six figures who was featured with his statement: "Everyone detected with AIDS should be tattooed in the upper forearm, to protect common needle users, and on the buttocks to prevent the victimization of other homosexuals" (Sember and Gere, 968). The exhibit had little factoids that passersby could read about how the AIDS epidemic progressed and governmental inaction:

> By Thanksgiving 1981, 244 known dead ... no word from the President. By Thanksgiving 1982, 1123 known dead ... no word from the President. By Thanksgiving 1987, 25, 644 known dead ... President Reagan: 'I have asked the Department of Health and Human Services to determine as soon as possible the extent to which the AIDS virus has penetrated our society' (Sember and Gere, 968).

The group was also known for its massive demonstrations, sit-ins, and 'die-ins' (when activists lie down in a group and are symbolically dead)—direct action tactics to vocalize their demands and attract media attention.

Early AIDS activist voices, such as those in ACT UP, broke the silence about AIDS and created different cultural understandings of the AIDS epidemic and of the people affected by it.

They challenged the mainstream discourse, brought AIDS onto the public's radar, and started making AIDS a "hot" issue in the mid to late 1980s and by the early 1990s, AIDS started becoming an issue that was not only advocated for from the margins of society, but activism also started stemming from the mainstream itself.

> Megastars like Magic Johnson—who candidly disclosed his own infection in November 1991—Elizabeth Taylor, and Elton John galvanized Hollywood and called for greater resources. Increasingly well-funded organizations like the Pediatric AIDS Foundation broadened the scope for the AIDS community to include soccer moms and mainstream America (Behrman, 90).

ACT UP chapters and tactics spread across the United States and around the world such as in South America, Western Europe, Australia, and South Africa (Boehmer, 15). An international movement was forming with other types of grassroots groups and non-governmental organizations (NGOs) starting up around the world like The AIDS Support Organization (TASO) in Uganda. Activists had forcefully changed the perception of AIDS and PLWHAs by inserting AIDS into their own domestic public sphere and then their voices began infiltrating the global public sphere of debate as well so that even the world's most powerful multilateral institutions had to take notice.

The "Local" Can Drive the "Global": Moving From a Domestic Public Sphere to the Global Public Sphere

A New International Mobilization for HIV/AIDS

The first National Conference held in the U.S. was in 1983 and it would only be two years later in 1985, when the U.S. Department of Health and the World Health Organization hosted the first International AIDS Conference in Atlanta, Georgia. This monumental event brought together over 2,000 people: members of the biomedical community, policymakers, the media, international institutions, and people living with HIV/AIDS. The International AIDS Conference continues to bring these various groups together and amazingly, this conference now

marks the largest regular conference that takes place for any health or development issue in the world.

Creation of the Global Program for AIDS Later Evolving into UNAIDS

Another significant success stemming from early HIV/AIDS activism was that multilateral institutions began understanding AIDS within a broader political economic framework. Traditionally, health had been viewed as a national issue whereby a nation-state would be responsible solely for the health concerns of its own citizenry, but because of AIDS activists' efforts, public health entered the realm of 'high politics' and made HIV/AIDS a global concern.

> Various clusters of power in the 'AIDS and development' world began to evolve around the mid-1980s. At the centre was the UN [*United Nations*], with WHO [*World Health Organization*] taking the lead role but other UN agencies, in particular, UNICEF [*United Nations Children's Fund*], United Nations Development Programme (UNDP), and the WB [*World Bank*], participating in the WHO/GPA [*Global Program for AIDS*] and also developing their own AIDS programmes (O'Manique, 45).

In 1987, HIV/AIDS was the first disease to ever be discussed at a United Nations General Assembly. Also in the same year, the WHO's establishment of the Global Program on AIDS (GPA) was an especially significant success in making HIV/AIDS a global concern.

The GPA, headed by Jonathan Mann, was responsible for "the establishment of an international discourse around HIV/AIDS that stressed the language of empowerment and participation [*Mann was especially pivotal in moving HIV/AIDS from the initial biomedical discourse to a conceptualization of HIV/AIDS within the human rights discourse which AIDS activists promoted*]; technical support for a number of developing countries in a range of policy and program areas [*helping countries to set up their own National AIDS Programmes*]; and the mobilization of donor countries to support a multilateral response to the epidemic" (Altman, 565-566). Another accomplishment of the GPA, for which Mann had strongly advocated, was the

incorporation of NGOs into its policymaking and decision-making processes, which had been unprecedented in the WHO's traditional operations. This provided NGOs (such as ACT UP and Gay Men's Health Crisis) with a new legitimacy in the global institutional arena. Moreover, because of their involvement in the GPA, these groups and organizations were able to form networks such as the Global Network of People Living With AIDS (GNP Plus), the International Council of AIDS Service Organizations (ICASO) and the International Community of Women Living with HIV/AIDS (ICW).

Despite this promising start, by the early 1990s the GPA was struggling to stay alive due to: lack of funding, tensions within the WHO about whether the organization should adhere to a more technical/biomedical approach or take more of a political approach, the increasing involvement of other UN agencies, and the perception that GPA was unable to handle the inter-organizational disputes, as well as donor countries' dissatisfaction with the GPA's operations (Patterson, 206; Altman, 569; Kohlmorgen, 130; Poku, 288). In 1995, the GPA was dissolved and the United Nations Program on HIV/AIDS (UNAIDS) was established to take its place on January 1, 1996 with Belgian academic Peter Piot being selected as its head.

UNAIDS had six founding members: the WHO, UNICEF, United Nations Development Program (UNDP), United Nations Fund for Population Activities (UNFPA), the UN Educational, Scientific and Cultural Organization (UNESCO), and the World Bank. The main functions of UNAIDS are: "leadership and advocacy for effective action; strategic information to guide the efforts of partners; monitoring and evaluation of the epidemic and the response; civil and technical, and political resource mobilization and tracking" (O'Manique, 60). Continuing the spirit of Mann's GPA, UNAIDS chose to include NGOs on its Program Co-ordinating Board

(PCB) and also included PLWHAs as representatives which was the first time members of affected communities were permitted to be on any UN governing body (Altman, 569).

Thus, HIV/AIDS activists were successful in making their voices heard not only in their domestic public sphere but also in the global public sphere through grabbing the attention of the world's powerful "stronger publics" such as the UN and the WHO and by legitimizing their voice at the table. However, raising public awareness and getting the attention of the 'powers-that-be' was only one of the goals stemming from AIDS activism; another mission that developed was to vocalize concrete demands for better scientific research and better access to treatment for PLWHAs—demands that would shake the biomedical community right down to its ontological foundations.

Biomedical Paradigm for Understanding Medicine: "Leave it to the Experts"

"Scientific experts predict" ... "Clinical M.D. advises" ... "Researchers discovered" ... From the latest research, to the newest drug, to the doctor's recommendation, biomedical knowledge is conventionally boxed into a private sphere of esteemed status that the social and economic factors of the outside world are not supposed to penetrate. The production and practice of medicine is traditionally hailed to be a scientifically methodical and 'objective' process: "it is assumed that it is possible to separate the doctor from his/her subject matter (the patient) in much the same way that a natural scientist is assumed to be separate from his/her subject matter (the natural world), and medical progress is said to be based on the use of the 'scientific method' which supposedly ensures certain and objective knowledge" (Doyal, 12).

It is imagined that each step of the process takes place in an apolitical and morally sterile domain: the researcher learns about a specific illness in the prescribed boundaries of academic experiments and studies, the chemist conducts clinical trials to test out drugs in the confines of a

lab, and an individual deals with his or her personal illness within the walls of a doctor's office. The orthodox view of medicine is based on the "belief that scientific medicine provides the only viable means for mediating between people and disease" (Doyal, 12). Illness and well-being are gauged on indisputable biological indicators, and the answers to any problems that arise are based purely on scientific knowledge; an area of knowledge that is deemed inherently "good," its only main obstacle being the need to disperse it to as many people as possible (Doyal, 12).

The lens of the biomedical paradigm sees an individual body that does not follow the medical definition of 'normalcy' and diagnoses it with an illness but it gives little thought to the broader socioeconomic factors that have influenced the onset of the sickness, nor the factors that will affect the individual's recovery. The main biomedical concern is to isolate the part of the individual's body that needs to be fixed, and then use 'objective' scientific knowledge to fix the problem—each body part and each individual's case is handled one at a time in isolation.

Colleen O'Manique refers to this as being the construction of a biomedical 'hegemonic' reality: "depoliticizing disease; removing the understanding of disease from its social context and placing it back onto the individual body" (O'Manique, 6). In this way, biomedicine completely alienates the individual body from the social-historical public body, choosing to understand the individual as a stand-alone specimen both in terms of contracting an illness and in terms of determining the best route to recovery on an individual basis. Moreover, the assumption of the biomedical paradigm is that the route to recovery is chosen solely by medical professionals. Therefore, the biomedical paradigm labels illness, medicine, and treatment as 'private'; matters that are set aside from public deliberation or contestation and solely the concern of doctors, researchers, and individual 'patients.' By bringing HIV/AIDS into the public sphere of debate, activists would forcefully challenge this notion.

The HIV/AIDS activist antiBody would advocate that illness is a collective experience, open to public debate, and whatever public is affected by an illness should have a voice in defining the illness, the route to recovery, the policy surrounding it and the perception of those living with the illness. The HIV/AIDS counterpublic would force the "stronger public" of the biomedical community to listen to its demands and in turn, activists would break into the biomedical discourse of HIV/AIDS. To do this, the HIV/AIDS antiBody first had to acknowledge that the practice and production of medicine is not neutral.

Recognizing that Medicine is NOT Neutral

The first forms of AIDS organizations were the gay community-based agencies that originated in Los Angeles, New York, and San Francisco to provide social services for gay people living with AIDS such as the Gay Men's Health Crisis (GMHC) and the AIDS Project Los Angeles (APLA). Essentially, the gay activist community compensated for the complete lack of effort on the part of the U.S. government to provide public health services for HIV and AIDS by offering psychological, medical and emotional support for people living with HIV/AIDS (Stockdill, 5). Initially, these agencies were structured along the same lines as any other health-related organization meaning that the general consensus towards the biomedical establishment was noncritical and there was optimism that a cure for AIDS would be found through modern medicine (Boehmer, 13). However, it was not long before there was a significant shift towards a more critical political analysis of medicine.

AIDS organizations became attuned to the fact that the stigma and silence surrounding AIDS was not only preventing the government from disseminating public health information and services, it was also preventing the implementation of any reasonable comprehensive public health interventions to prevent the epidemic from spreading further. Thus, while the government

and public health professionals were turning a blind eye, the gay community-based organizations responded with information campaigns ranging from the aforementioned peer-to-peer education in the local gay bars, to mass forms of education campaigns in the form of posters, displays, and demonstrations. When the government and the biomedical establishment finally acknowledged AIDS as the crisis that activists had constructed it to be, public health officials were asking activists for *their* advice on how to approach HIV/AIDS; a significant step towards the "patient activism" that seems more common today:

> Doctors who regarded patients as problems began to see that with AIDS, the problems could be part of the solution. These days, patient activism is beginning to scratch away at the monopoly that the medical establishment and its buddies in the pharmaceutical industry have maintained over any number of other diseases. But HIV led the way (Pisani, 183).

Taking control of the way in which HIV/AIDS public health information would be disseminated was just the tip of the iceberg in terms of how AIDS activists started inserting themselves into the biomedical sphere of discourse**.** Yet another challenge to the biomedical paradigm's position of privilege was the activists' battle to rewrite the official clinical definitions of AIDS and its related symptoms and illnesses.

Re-Defining Clinical Definitions for HIV/AIDS

At face value, the clinical definitions of illnesses written by institutions like the Center for Disease Control (CDC) in the United States would not appear to be highly controversial. These definitions, however, have tremendous impacts on who gets included in the debate about an illness and in its clinical trial testing for drugs, and who gets easier access to social services that specifically cater to an illness.

Because throughout the 1980s and early 1990s AIDS was perceived to be the "gay man's disease," clinical definition and the definition of AIDS-related illnesses reflected this bias and much of the resources, research and related social services were mainly geared towards the gay

male community, excluding the lived experiences of groups such as HIV positive women, drug users, and children. For instance, when the 1990 Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed in the U.S., it included provisions for AIDS Drug Assistance Programs (ADAPs) which only the people who fit the narrow clinical definition of AIDS could access—primarily gay males (Smith, 44). Therefore, the consequences of the decisions to exclude invasive cervical cancer (strictly a female disease) or pulmonary tuberculosis (a condition commonly found among drug users) as AIDS-related illnesses were grave, essentially determining who would have greater chances for survival.

Activists worked relentlessly to advocate for the expansion of the clinical definition of AIDS to better represent the conditions of excluded groups through direct-action demonstrations, sit-ins and other forms of protest in front of prominent biomedical institutions. One such demonstration specifically pointing to women's exclusion from receiving medical treatment, health and disability benefits as well as other support services was in January of 1990 in front of the CDC.

> To the chants of 'Women Don't Get AIDS, They Just Die from It,' hundreds of activists 'besieged' the Centers for Disease Control headquarters ... with signs, banners, and costumes protesting the CDC's narrow definition of AIDS that excluded gynaecological illnesses among women and illnesses more common among people of color and children. Additionally, they contested the CDC categories for rendering lesbians invisible within the HIV/AIDS epidemic (Elbaz, 59-60).

Activist pressure led to slow expansions of the definition of AIDS to include more AIDS-related illnesses and opportunistic infections, while expanding access to healthcare resources, social services and clinical trials to more people. One of the most substantial victories was in 1993 when the CDC changed the clinical definition of AIDS according to the level of damage that the HIV virus had caused to a person's immune system meaning that "any HIV-positive person whose count of CD4 cells (the type of white blood cell destroyed by HIV) fell below the level of

200 per cubic millimetre" would be diagnosed as having AIDS (Smith, 44). Changing this within the definition meant that other institutions such as the Social Security Administration had to change their parameters of access.

Critiquing Procedures in Clinical Trials

The changes in expanding the clinical definition of AIDS also resulted in an expansion of the criteria used to determine who could participate in clinical trials. This criteria had been structured on the same bias of AIDS being the "gay man's disease," consistently excluding the same groups that initial clinical definitions did during the 1980s and early 1990s. Activists criticized the exclusion of other groups from clinical drug trials based on factors other than just due to not fitting the clinical definition of AIDS but rather, for instance, the exclusion of those who were already struck with opportunistic infections (Elbaz, 62), or the exclusion of lower class people. The logic behind their exclusion was that "poor people are less likely to have regular contact with doctors who are infectious disease specialists and less able to fully participate in complicated research studies (Patton 1990; Stoller 1998)" (Stockdill, 12). One significant way that AIDS activists created the opportunity for more people to partake in these clinical trials was through a new research design that they drafted, initially called "Parallel Track," first introduced at the Fifth International AIDS Conference in Montreal, Canada in June 1989.

Within this research design, the drug would be given to anyone who needed it and who had not met the entrance criteria for the official, controlled clinical trial. People would be informed that the drug was still in the experimental stage and would be able to take the drug in their everyday lives (Elbaz, 63). This design was then revised so that a randomization procedure was added to it and was renamed the "Middle Track" (Elbaz, 63). The National Institute of Health (NIH) [the U.S. government-sponsored research institute] and FDA were mandated to

implement the Parallel Track policy by the U.S. Department of Health and Human Services in April of 1992 (Elbaz, 63). "In October 1992, the FDA approved the first Parallel Track Protocol for d4t (Stavuding), an experimental drug treatment for AIDS, developed by Bristol-Meyers Squibb" (Elbaz, 63). In changing the research design for clinical trials to include more people living with HIV/AIDS, they successfully made clinical research more centered on the needs of PLWHAs. Challenging the differential access to clinical drug trials was only one angle of criticism that activists directed towards the conventional procedure of these trials. Their other main criticisms focused on the duration of these trials, and the methods used to carry them out.

AIDS activists would boldly challenge the biomedical community further by analyzing and critiquing the direction and production of AIDS research. To do this, activists needed to participate in what Steven Epstein (*Impure Science: AIDS, Activism, and the Politics of Knowledge*, 1996) calls "lay-expertification." This meant becoming not only knowledgeable about the goings-on of the HIV/AIDS research agenda but also well-versed in the terminology so that 'regular' people would be able to critique and put forth demands with some degree of perceived legitimacy—a strategy AIDS activists still practise today.

Becoming Experts of Science: Starting to Critique Research Practices

Once activists began studying the production and dissemination of AIDS biomedical research, they started to identify some blind spots that doctors and researchers of the biomedical establishment were failing to criticize. One problem within the research paradigm of which activists quickly became aware, was the amount of time it took for the peer review process and publication of scientific results in academic journals. In response, activists started up their own newsletters and hotlines, such as *Project Inform Perspective* newsletter (created in 1985), *AIDS Treatment News* newsletter (first published in 1986), and Project Inform's AIDS treatment

information hotline (the first hotline of its kind, created in 1986), to update PLWHAs with the latest findings before the mainstream medical journals would release the information (Project Inform, www.projinf.org; Fabj and Sobnosky, 175). Besides acting as expeditious relayers of information for the public, activists also wanted to have more input into the types of research pursued.

Through keeping informed about all the on-going AIDS biomedical research projects, AIDS activists have been able to point out the gaps where more research is needed and also suggest possible collaborations between research projects. "Through their constant contact with medical researchers, activists have taken on the role of communicators between scientists, and have become human bridges linking different researchers and their projects together" (Fabj and Sobnosky, 180). Two of the major gaps in AIDS research that concerned activists, is the complete lack of initiative towards researching a vaccine or possible alternative and holistic treatments for HIV/AIDS. Instead, there has been a clear decision on the part of the biomedical community and the pharmaceutical industry to channel most research towards antiretroviral drugs. After further research, activists soon discovered that Big Pharma would be yet another "stronger public" they would have to challenge in their struggle to ensure better access to treatments.

Conclusion: HIV/AIDS Activist AntiBody Successfully Makes HIV/AIDS 'Public' and 'Political'

This chapter has shown that early HIV/AIDS activism successfully constructed an individual's treatment more than a matter dictated by what happens behind the closed doors of a clinical trial or by what a medical professional says within the confines of a doctor's office. The activists' framing of HIV/AIDS transformed the conventional perception of AIDS from being a

private, ‘personal’ issue to becoming an interest of the entire ‘public body’ within the public sphere.

> When AIDS activists publicize technical and private issues surrounding AIDS, they invigorate the public sphere, creating the necessary conditions for democratic decision-making by an informed public (Fabj and Sobnosky, 176).

Moreover, while making HIV/AIDS an issue of the public sphere, activists were also able to act as bridges between the public and the biomedical community as well as bridges between professionals within the biomedical community itself.

Furthermore, activists increasingly constructed HIV/AIDS treatment and health within a political economic framework and exposed the politics within medicine and the social construction of an illness. Using this framework, activists turned their scrutiny towards the choice of research, the clinical testing, and the level of access and price of drugs and in the process of doing so, they started unmasking Big Pharma as a major adversary in their fight to ensure accessibility to medicines and treatment for HIV/AIDS. They quickly realized that Big Pharma plays a massive role in the production and accessibility of HIV/AIDS medicines. Its operations determine what medicines are available on the market and for whom.

Therefore, having traced the roots of the illnesses of HIV/AIDS and neoliberalism in the previous chapter as well as tracing the initial rise of the HIV/AIDS activist antiBody, it is now imperative to delve deeper into the role Big Pharma played in facilitating the spread of both neoliberal ideology and HIV/AIDS as well as how HIV/AIDS activists would start targeting Big Pharma as such a *site of infection*.

Chapter 3: Big Pharma as a *Site of Infection*

Introduction: Medicine Caught Between Two Worlds: "System" & "Lifeworld"

Having traced the development of both HIV/AIDS and neoliberalism as *illnesses* as well as the rise of the HIV/AIDS activist antiBody that formed to counteract both, it is now imperative to discuss Big Pharma's role within this thesis' case study. Identifying Big Pharma as a *site of infection* implies that during the 1990s Big Pharma was an agent whose industry practices arguably worked to facilitate the propagation of both HIV/AIDS and neoliberal ideology. Big Pharma facilitated the perpetuation of both *illnesses* through using the logic of what Jurgen Habermas calls the "system."

In Habermas' Volume Two of his *Theory of Communicative Action: Lifeworld and System: A Critique of Functionalist Reason,* he theorized that society is divided into two domains which he labelled: the "system" and the "lifeworld." The "system" is the domain of system integration that runs on "instrumental reason" which operates based on calculating the most 'efficient' way of doing things, meaning discerning how to produce the desired objectives in the speediest fashion so as to maintain whatever the existing system environment. As Habermas explains it: "the adaptive capacity of an action system is measured only by what the aggregate effects of actions contribute to maintaining a system environment" (Habermas, 160). Also, the system domain functions through "systemic mechanisms" or "steering media" which Habermas identifies as mainly being money and power: "*power* and *exchange relations* are the dimensions in which action systems adapt themselves to the requirements of the functional specifications of social cooperation" (Habermas, 160). Because the system concentrates on calculation, making

money and accumulating power, one could say that the market domain represents a big part of this system.

Therefore, corporations as central social institutions of the market domain should theoretically operate on system mechanisms and system logic. One can liken corporations to what Habermas calls the "norm-free structures" created by systemic interconnections in modern societies. He writes: "In societies with a low degree of differentiation, systemic interconnections are tightly interwoven with mechanisms of social integration; in modern societies they are consolidated and objectified into norm-free structures" (Habermas, 154). Corporations, like those of Big Pharma, personify these "norm-free" structures. Their business practices are focused on accumulating money in the most efficient way possible to achieve more power in the marketplace as opposed to operating on consensual values and dialogue for the common good, which are the driving forces behind the "lifeworld" or in other words, the public domain.

The lifeworld is the domain of social integration based on consensual values. It operates through "communicative action" whereby people come together to rationally discuss what decisions will be best for the common interest of everyone concerned. "Communicative action relies on a cooperative process of interpretation in which participants relate simultaneously to something in the objective, the social, and the subjective worlds" (Habermas, 120). Habermas theorized that the "public sphere" is part of this lifeworld since, as Habermas explains,

> The lifeworld is, so to speak, the transcendental site where speaker and hearer meet, where they can reciprocally raise claims that their utterances fit the world (objective, social, or subjective), and where they can criticize and confirm those validity claims, settle their disagreements, and arrive at agreements (Habermas, 126).

Through the activist antiBody's efforts to insert the demands of people living with HIV/AIDS in the public sphere and to challenge Big Pharma as a "stronger public," these activists frame health and access to medicines using lifeworld logic keeping the public interest as its central focus. The

activist antiBody would use lifeworld logic to voice their claims against Big Pharma so as to expose how these corporations' profit-driven system logic detrimentally impacts the level of access to HIV/AIDS medicines.

To explore Big Pharma as an actor whose system logic made it a *site of infection* which facilitated the spread of both HIV/AIDS and neoliberal ideology, and to illustrate the HIV/AIDS activist antiBody as an actor that used lifeworld logic to 'name and shame' Big Pharma and expose it as a *site of infection*; this chapter will present this analytical discussion in a case study.

Outline of Chapter's Case Study

The first part of this case study will examine Big Pharma's irresponsible business practice during the 1990s. Although mainly focusing on this time period, this portion of the chapter will also discuss significant changes in the pharmaceutical industry structure during the 1980s which help explain the context for the irresponsible business practice that became more pronounced in later years. This analysis will include selective stats from the early 2000s for the purposes of showing how the overall trend from prior years had become Big Pharma's standard practice by that time. Essentially, this part of the chapter's case study will demonstrate how Big Pharma corporations 'went off-the-rails,' straying from corporate social responsibility and perpetuating a market-driven neoliberal ideology.

To illustrate this, this part of the chapter will examine: Big Pharma's industry structure, its controversial relations with the biomedical community (through the manipulation of clinical trials, doctors, and medical results), and its profit-driven research and development (R&D) agenda. The analysis will demonstrate that Big Pharma's actions during this time period consistently prioritized market power over public health. Big Pharma's reckless practices further perpetuated the neoliberal ideological climate of the times, as these corporations carried out a

dangerous commodification of health, similar to the aforementioned trends taking place in global economic restructuring and the global health agenda.

The second part of this chapter's case study will demonstrate how Big Pharma's actions also facilitated the spread of HIV/AIDS and how activists used lifeworld logic to start halting Big Pharma in its tracks. This portion of the case study discusses how the activists used this logic to start connecting Big Pharma's reckless neoliberal narrative with the struggle to fight for their lives starting in the 1980s and proceeding into the 1990s. Activism started exposing how Big Pharma's profit-driven R&D agenda and higher costs had a harmful impact on the accessibility to medicines for people living with HIV/AIDS.

The case study will then conclude with a discussion of how HIV/AIDS activists started using their lifeworld logic to further challenge Big Pharma's system logic on a global scale. With the arrival of HAART, the HIV/AIDS activist antiBody began mobilizing against Big Pharma from different locations around the world, creating a global HIV/AIDS treatment activist movement. The HIV/AIDS activists would be part of a new wave of activists during the 1990s which combated corporate indifference and moved social and economic rights back onto the global agenda. Therefore, in fighting to remedy the spread and treatment of an epidemiological illness, these activists also combated neoliberal ideology as well.

PART I—Big Pharma as an Ideological *Site of Infection*

Three Different Perspectives of Corporate Social Responsibility

There are three central theories in business literature which delineate what obligations or responsibilities a corporation should uphold for society. One stream of thought is "social responsibility" theory. Proponents of this perspective "claim that the greatest social and economic benefit would result if corporations recognized the well being of society as a whole in

their decision-making process" (Chang, 51). Social responsibility theory argues that corporate social responsibility is more than just fulfilling economic and legal obligations but should also involve an extension of responsibilities to the greater society.

A second stream of thought is referred to as "stakeholder theory." This theory states that a corporation must fulfill its obligation to any 'stakeholder,' that is, "any group or individual influenced by [*or of influence to*] the company's operation" with a direct cause and effect relationship (Chang, 49).

A third central perspective is centered on "stockholder theory." This theory argues that "corporate decision-makers have a duty to increase profits for stockholders without the use of deception or fraud" (Friedman, 2002/1971, pp. 33-37)" (Chang, 49). Therefore, from this theoretical perspective, the only obligation a company has is to increase profits via legal means. Milton Friedman, a major proponent of free market ideology, puts forth this argument in an article he wrote for the *New York Times* in 1970 called "The Social Responsibility Of Business Is To Increase Its Profits." He wrote: "I call [social responsibility] a 'fundamentally subversive doctrine' in a free society, and say that there is one and only one social responsibility of business to use its resources and engage in activities designed to increase its profits" (qtd. in Rowland, 95). In deeming the profit motive as a corporation's central social obligation, it would seem that stockholder theory best represents the limited level of social responsibility which neoliberal ideology supports as well. Although Friedman used this perspective to advocate for the protection of private enterprise, this notion of the profit motive has been carried out to justify a dangerous corporate collective indifference to greater social responsibility which is evident in the neoliberal mantra Big Pharma demonstrated during the 1990s.

A Neoliberal Paradigm's Understanding of Big Pharma's Social Responsibility

Just as the biomedical paradigm depoliticizes and individualizes illness because it sees the sick individual body as separate from the political economic factors present within the public body, similarly, neoliberalism sees the public body as being divided into self-interested individuals—consumers in a depoliticized private market. Thus, while the biomedical paradigm says: "Leave medicine to the biomedical experts," the neoliberal paradigm dictates: "Leave medicine to the market." Within this neoliberal paradigm, medicine is deemed a private good that a consumer can choose to buy or not buy in the market domain—an 'apolitical' commodity like any other. Therefore, the pharmaceutical corporation is viewed like any other business in the free market and as such, these corporations should focus all energies on the pursuit of profit. Moreover, its business operations are of the private market domain and thus should be exempt from public contestation or any interference from the state.

Although one might hope that as a producer of medicines Big Pharma would adhere to a greater level of social responsibility, within the time period of this thesis' case study, Big Pharma's actions followed a neoliberal narrative in which the main goal was accumulating profit to a point where these corporations' actions completely neglected the public interest. It is now important to carry out the following case study of Big Pharma's industry practice within the context of the rise of neoliberal, free market ideology in the 1980s and its proliferation in the 1990s to fully comprehend how Big Pharma could be considered a *site of infection* for this social illness.

An Analysis of the Development of Big Pharma's Business Model and Structure

Introducing the "Blockbuster Drug": The New Industry-wide Business Model

In 1981, the launch of Zantac (ranitidine), Glaxo Inc.'s anti-ulcer medicine, was a pivotal turning point in the business model for Big Pharma. Zantac was the first official "blockbuster drug" that the industry had ever seen. By 1986, Zantac had become the world's top-selling medicine. Zantac's billion dollar success proved that a drug did not have to be clinically groundbreaking nor did it need to have a lot of money invested in its research to reap huge profits for a company. It was the success of this drug which ushered in the era of blockbuster medicines.

Creating a blockbuster means researching a drug to treat an illness that affects a large number of people—or more to the point, a large number of people that can afford the medicines being produced. The industry's obsession with blockbusters has shaped the overall agenda so that as of 2001 "approximately four-fifths of Big Pharma's total R&D budget is aimed at providing for one-fifth of the world's population" (Robinson, 12). Therefore, drugs that treat allergies, stomach acid, depression and cholesterol have all been prime candidates to be pumped out of the research pipelines in the hopes of creating a "blockbuster" hit. "Just ten years later [*after Zantac's arrival*], ... 36 drugs were earning no less than $76 billion a year between them. Each of the top 25 drugs of 2000 had higher sales than the number two drug just a decade earlier" (Law, 31).

A necessary element of a blockbuster drug's success is the massive marketing needed to attract as many people as possible and with the rise of the blockbuster model, companies' spending in this area noticeably increased, coming to dwarf R&D expenditures (Law, 10).

Unfortunately, the industry's increasing reliance on blockbusters for revenue created a double-edged sword for pharmaceutical companies in a few different ways.

Mergers and Acquisitions: Industry Coping Mechanisms

As Corey Davis, a drug analyst from Hambrecht & Quist, put it, "to keep a growth pace that pleases investors ... a company with a $4 billion drug today will soon need a $6 billion drug" (qtd. in Fischer and Sherrid, 96). The corporate mandate calls for quarterly results to show that profit-margins are increasing in order for a pharmaceutical company to keep investors happy. Given this stressful business imperative and the rise in communications technology, which better facilitated communications between corporate locations, it is no coincidence that during the 1980s and 1990s, and into the 2000s thus far, the pharmaceutical industry has undergone a steady series of mergers and acquisitions.

A merger occurs when Company (A) and Company (B) come together to form a new entity in the market altogether; creating Company (C). The newly merged company combines both original companies' assets and shares which are divided amongst shareholders through negotiation. An acquisition, on the other hand, is when Company (A) purchases Company (B), thus Company (B) is dissolved and completely integrated into Company (A). "In 1995, twenty-five companies controlled more than half of the global drug market. Five years later, 53 per cent of the market [*was*] in the hands of fifteen companies. The top four alone account[*ing*] for 20 per cent" (Robinson, 35). An article in the *Chemical Market Reporter* written in 1999, comments on the decade of the consolidation in the pharmaceutical industry during the 1990s: "After a lull in M&A [*merger and acquisition*] activity from 1990 to 1993, when the average annual deal was worth only $4.3 billion, the pace of consolidation rose to $20.2 billion in deals in 1994 and $36.7 billion in 1995. Since then, the level of activity has been high" (J. Chang, 14). The trend of

consolidation continued even into the 2000s since as of July/August 2009, the top fifteen mammoths of Big Pharma were: Pfizer, Sanofi-Aventis, GlaxoSmithKline (GSK), Novartis, AstraZeneca, Merck & Co., Johnson &Johnson, Hoffman La Roche (Roche), Eli Lilly & Co., Bristol Myers Squibb, Wyeth, Schering Plough, Abbott Laboratories, Takeda and Bayer Schering (Contract Pharma, www.contractpharma.com).

The stated claim by Big Pharma is that the aim of these mergers and acquisitions is to cut costs in order to support rising R&D costs and to make R&D and marketing more efficient. Oftentimes though, the organizational restructuring of these mergers and acquisitions is costly, the stock prices of the companies drop as investors wait to see if the newly-merged corporation or the acquiring corporation stabilizes, and in the case of acquisitions, the capital required to initially buy a company can be massive. For instance, in 1999, Pfizer spent $70 billion to take over Warner-Lambert. Evidence has shown that "almost every merger since 1970 has led to a subsequent loss in market share [*how much sales a company has within a certain market*]. In the end what many of these mergers become is a substitute for capital investment. The combined companies have more money to spend on marketing"—but no new money is channelled into R&D (Robinson, 35). Instead of a corporation investing time and money into finding ways of generating new capital, such as developing new R&D projects, a corporation will merge with another company in order to report increased capital to their shareholders through the combination of both companies' assets and will often cut hundreds or thousands of jobs to eliminate 'redundancy.' Although producing unemployment, this strategy saves the company money and enables it to report better profit margins to its shareholders.

Mergers and acquisitions have been the main coping mechanism of Big Pharma to deal with the expiration of the patents for many blockbuster medicines and to mitigate the fact that all

the companies seem to be suffering from an industry-wide drought in new products being launched on the market.

The Rise of the "Specialty Pharma" Sector

As the mergers and acquisitions have been taking place at the level of Big Pharma, smaller pharmaceutical companies have been either taken over or have been forced to remain in small markets while bigger companies have to keep spending huge sums of money to maintain their marketing engine and to finance their growing infrastructure. However, as this consolidation has taken place at one end of the industry, there has been an important diversification of companies at the other end of the spectrum whose significance has been steadily on the rise—that of "specialty pharma." These companies tap into areas in which Big Pharma puts less investment.

> Specialty pharma companies are changing the structure of the medical business. Pharma's hold over the industry has not been broken, but as these relatively new players gain strength in numbers, they collectively secure a larger slice of the pie for themselves, and Big Pharma's position is naturally threatened (Law, 82).

An especially significant element within the "specialty pharma" sector, which has been increasing its market share over the years, is the generic drugs industry. Generic drug companies produce drugs that have the same chemical composition as a patented, brand-name drug. They can only manufacture a generic version of a drug after the patent for the original drug has expired, if the company receives a voluntary licence to produce the drug (a licence to produce the drugs granted by the permission of the patent holder), or if a company is granted a compulsory licence (whereby the generic company is granted a licence by the state to bypass the patent holder's permission to produce the drug). (There will be further discussion of the significance of compulsory licensing in Chapter 4).

When generic drugs enter the market, they drive down the prices of Big Pharma's brand-name drugs which is why Big Pharma time and again has tried to extend the patents on their drugs for as long as possible in order to safeguard their temporary monopoly and to block the production of generic versions. Sometimes Big Pharma companies have set up "pseudo" generic companies whereby they produce generic versions of their own drugs to compete with existing generic companies to take back revenue lost to generic competitors. Also, Big Pharma has been known to buy generic companies to clear out their market share. As a recent example, "the world's sixth largest producer of branded drugs, the Swiss company, Novartis spent £ 4.4 billion ($7.9 billion) acquiring two major generic producers in February 2005, making it the world's largest manufacturer of generic drugs overnight" (Law, 176). Moreover, Big Pharma has combated generic companies through 'backdoor' politics by lobbying governments and international organizations to keep their monopoly of patents for as long as possible. (This topic will be explored more fully in Chapter 4 as well).

Aside from investigating Big Pharma's main business model and industry structure, it is now important to examine the development of Big Pharma's controversial relationship with the biomedical community during the 1980s and into the 1990s.

Big Pharma's Invasion of the 'Sanctity' of the Biomedical Establishment

The 1980s Neoliberal Shift: A Closer Relationship Between Big Pharma and the Biomedical Community

Prior to the 1980s, there was a clear distinction between the for-profit pharmaceutical industry and the not-for-profit biomedical sector. The not-for-profit biomedical sector (comprised of teaching hospitals, universities, government laboratories and research institutes) was predominantly supported by public funding and largely conducted 'basic' research. Any research discovery that was financed by taxpayers' money either became the government's

property or remained in the public domain, allowing any company to access the research (Craddock, 1044). Thus, this research was considered part of the Commons, information that no private body should own. “Results were often shared between members of the community, and resources were allocated by competition for grants” (Kaplan, 41-42). Drug companies might give research grants to universities but would have no sway in the research results that would be produced.

I. Creation of the U.S. Bayh-Doyle Act

Because the government took a long time to convert the publicly-funded research into new products for the market (‘technology transfer’), Senator Birch Bayh and Senator Robert Doyle proposed that universities and the NIH should be able to patent their research and then grant exclusive marketing rights to pharmaceutical companies that would then bring the products to market. Therefore, private industry was now allowed to get licences for new products that had been produced using public/government funding (Craddock, 1044). Their proposition, the Bayh-Doyle Act, was passed in 1980 and it completely transformed the relationships between the government, the NIH, and the pharmaceutical industry in the United States.

Faculty researchers took up an entrepreneurial spirit to get patents for their research so that they could get a portion of the royalties and consequently, ‘technology transfer’ offices were specifically set up to handle these business deals and industry relations (Angell, 8). Many academic researchers even started creating their own “biotech” companies (companies that specialize in biopharmaceutical research, working with recombinant DNA technology which can splice genes and create new molecules) to maximize the profits they could get from their work through deals with Big Pharma.

> Usually both academic researchers and their institutions own equity in the biotechnology companies they are involved with. Thus, when a patent held by a university or a small biotech company is eventually licensed to a big drug company, all parties cash in on the public investment in research (Angell,7-8).

Various biotech companies developed around university institutions to carry out a lot of the initial research and development for drugs so that they could sign deals with Big Pharma who would then bring the drugs to market.

II. Cuts to Public Funding and the Rise of the Contract Organization

In addition to the Bayh-Doyle Act, the marriage of industry and the university was further nurtured by the rise of the "contract organization"; companies hired by Big Pharma to set up contracts with doctors whereby data on the doctors' patients could be collected and then used in whatever way Big Pharma saw fit. The growing success of the contract organization also meant that fewer research grants would be given to academic institutions. "Whereas in 1990, about 80 percent of industry-sponsored trials were done at academic institutions, within a decade that share had dropped to less than 40 percent" (Angell, 101).

The pro-privatizing research trend suited the neoliberal climate cultivated during the 1980s and 1990s. The cuts to medical education and hospitals at that time were also done with the same mentality in mind. Having to compete with contract research organizations, academic researchers became far more accommodating to the pharmaceutical industry's demands since it had to compensate for the public funding cuts which affected medical education and hospitals, and these institutions were forced to rely more on private funding from Big Pharma. In her book, *The Truth About the Drug Companies: How They Deceive Us and What To Do About It*, former Editor in Chief of *The New England Journal of Medicine*, Dr. Marcia Angell explains that as a result of this unfortunate ideological trend and reality,

> researchers serve as consultants to companies whose products they are studying, become paid members of advisory boards and speakers' bureaus, enter into patent and royalty arrangements together with their institutions, promote drugs and devices at company-sponsored symposiums, and allow themselves to be plied with expensive gifts and trips to luxurious settings. Many also have equity interest in the companies (Angell, 103).

For example, *The Boston Globe* stated that through consulting fees from Big Pharma, the head of the Department of Psychiatry at Brown University Medical School made over $300,000 in 1998 (Angell, 103). When people like this are on Big Pharma's payroll, it is not surprising that a survey reported that research is four times more likely to be favourable to a company's product when research has been sponsored by the company as opposed to the NIH (Angell, 104). Thus during the 1980s and 1990s, academic research and the pharmaceutical industry were brought much closer together. Not only was Big Pharma dipping its finger into patent deals with the university, it was also tampering with the initial stages of research, distorting the testing and reporting of clinical trials. As Angell writes, "companies are involved in every detail of the research—from design of the study through analysis of the data to the decision of whether to publish the results ... Researchers don't control clinical trials anymore; sponsors do" (Angell, 100).

Manipulating Clinical Trials for 'Profitable' Results

Crafting clinical trials in such a way as to guarantee positive results for Big Pharma became an industry art-form. One industry staple to really 'sell' clinical trial results has been for Big Pharma to get top consultants in the medical field to side with whatever therapy, treatment, or drug they are promoting so that doctors will appreciate the medical authority behind the name and will prescribe the drug accordingly (Law, 36). Ex-insiders like Dr. Marcia Angell and, Dr. Richard Smith, editor of the *British Medical Journal*, speak out about all kinds of tactics used during clinical trials to elicit good news for Big Pharma. Tactics such as: comparing a drug with

a really low or really high dose of another drug so that it looks better by comparison; testing a drug meant to treat a condition that elderly people would typically have on young people who are less likely to have negative side-effects; conducting a series of trials in different countries and then publishing the results of each trial separately to make it look like there were far more trials conducted than there actually were; keep republishing positive trials and of course, the best tactic, to blatantly suppress any negative results (Smith qtd. in Law, 46; Angell, 107-109). For example, in 1998, GlaxoSmithKline actively started suppressing information from the public regarding its blockbuster drug Paxil.

> GlaxoSmithKline did not publish results that showed that paroxetine (Paxil^{TM}) was ineffective for the treatment of depression in children and adolescents because, according to an internal company memo, 'It would be commercially unacceptable to include a statement that efficacy had not been demonstrated, as this would undermine the profile of paroxetine' (Kondro and Sibbald 2004: 783) (Law, 35).

The manipulation of clinical trials is a grave issue but it would seem that Big Pharma was using "system" logic to carry out a cost-benefit analysis that rationalizes collecting profits over improving people's health.

Publishing Medical Results turns into Advertising Big Pharma's Prospective Products

To fully maximize profits from its clinical trial results, no matter how questionable they might be, Big Pharma has been known to occasionally organize its own 'press circuit' to promote a product, otherwise known as scientific meetings and symposiums—the supposed spaces of academic freedom. Speakers would be hand-picked for having an all-around pro-industry view or for their positive views about a specific drug. A communications representative from the pharmaceutical company records the information from each speaker's lecture at the symposium, drafts a collection of articles to be submitted to a medical journal and then the speakers sign onto the facade that they themselves authored the work—a practice known as "ghostwriting."

The practice of communications representatives, as opposed to academics, writing academic articles for 'peer-reviewed' journals became a common phenomenon in the medical publishing world. In 1998, an article from the *Journal of the American Medical Association* publicized that there was evidence of ghostwriting in 11 percent of six major American medical journals, and this estimate is understood to be unrealistically low for the amount of ghostwritten articles that are manufactured by Big Pharma each year; in fact, some estimates suggest that as many as half of all the articles published in medical journals are ghostwritten (Elliot, 19). To cite a specific example, in 1996, Wyeth hired Excerpta Medica Inc. to write ten articles promoting a specific obesity treatment at $20,000 per article and then, like a good employee, Excerpta Medica paid $1,000 to $1,500 to 'respected' university researchers to edit their drafts and sign their names on the final draft of the article (Elliot, 20).

From start to finish, it is evident that the research and development of drugs was in line with the demand for profits as opposed to the needs of people, perpetuating a dangerous neoliberal ideological position prioritizing market power at the expense of people's health. Surprisingly, or not, there is evidence that this pattern extended further into the realm of doctors' offices as well.

Manipulation of Doctors

When a Big Pharma company sends out sales representatives to visit doctors' offices to discuss its products, the pharmaceutical companies call these sales visits "detailing." Big Pharma argues that these visits are for 'educational' purposes to inform doctors of new products, however, the manner in which this education is delivered is arguably more in the interests of securing new customers than securing the best health for patients. The aim of this strategy is two-fold. Firstly, sales reps give out free drug samples so that both the doctors and patients get

hooked on the products and the second part of the strategy is for sales reps to give generous gifts to doctors so that the company's name is at the forefront of their minds when they are prescribing.

There is an assumption that doctors recommend drugs that will be the most effective and cost-efficient for their patients. It is very disconcerting to think that doctors might recommend drugs on the basis of the brand-name that was responsible for sending their family on a trip to Hawaii, or giving them money (between $100 to $250) for answering questions in a focus group interview, or providing them with free tickets to a sporting event. When asked, studies show that many doctors claim that sales representatives and their gifts have little or no influence on their prescribing habits. "Marketing activities by the pharmaceutical industry directed at physicians are estimated in the range of $13 billion annually. Others have estimated that the costs are approximately $13,000 per physician per year" (Allman, 155). It would be hard to believe that the pharmaceutical industry would continue to spend exorbitant amounts of money in this area of promotion, if their efforts had no influence on doctor prescribing habits. In Orlowski and Wateska's article called "The effects of pharmaceutical firm enticements on physician prescribing patterns: There's no such thing as a free lunch," they

> document a three to four fold increase in prescriptions written for products which are aggressively marketed to doctors; they further note that the products are disproportionately prescribed in institutions where physicians receive lavish gifts and entertainment from the industry (discussed in Allman, 155).

There are many examples where doctors have chosen to prescribe drugs for hypertension, community-acquired pneumonia and urinary tract infections that were 'detailed' for them by pharmaceutical sales reps while there were clearly less expensive options available (Allman, 159).

"Detailing" became such an industry staple that in 2001, 88,000 pharmaceutical sales representatives visited doctors' offices in the United States so that they could discuss their company's products, give out free samples, and of course, offer personal gifts to the doctors (such as trips, tickets to sports games, etc.) (Angell, 115). Along with the United States, there have been widely publicized investigations into the bribery of doctors by Big Pharma reps in countries such as Italy, Germany and Spain (Turone, 413; Burgermeister, 1333; and Bosch, 1537).

Through these "detailing" visits, Big Pharma has manipulated patients' trust in a doctor's medical authority because a patient will assume that the doctor prescribes medicines that are the most effective and cost-efficient to treat them when really the prescription might be based on the doctor's personal affiliation with a particular Big Pharma company. The increasing control that Big Pharma has over doctors, the publication of medical results and clinical trials is skewed towards making the most profits and this incentive is further echoed in how Big Pharma steers its entire research and development agenda as well.

Big Pharma's R&D Agenda: What is Profitable is What is 'Healthy' for Business

How Much Money Does Big Pharma Invest in R&D?

"Innovation" has always been a mantra of Big Pharma. Naturally, the quest for research and development (R&D) is of central importance to the pharmaceutical industry because the discovery of new drugs is what keeps both the industry and, quite literally, its consumers alive as well. More importantly though, R&D has also been frequently used as the central justification for the critiques against the way these companies have operated. For example,

> *Critique*: "Why are drug prices so high?"
> *Big Pharma's response*: "Because we need money for research and development (R&D)."

Big Pharma's R&D mantra seems like a difficult one to dispute—who would argue with the pharmaceutical industry needing more money to invest in researching lifesaving medicines? Furthermore, the amount of R&D involved to manufacture and bring a new drug to the market has been widely cited by the industry as costing US$802 million; however, the actual validity of this claim has also been widely disputed (Lexchin, 15).

Often when Big Pharma has reported the average R&D expenditure for a drug, they have claimed that they spend more money than they actually do. For example, typically the R&D allotted towards new chemical entities have been the only ones taken into account as opposed to the vast amounts of R&D put into 'copy-cat' drugs known as "me-too" drugs which dominate the market (to be discussed in the next section); the plentiful tax credits a company receives from the government have not been taken into account; only in-house drugs have been used in the figure (totally discounting the many drugs produced out of public institutions like the NIH in the U.S.); and finally, the cost of Phase IV studies of clinical trials that take place after the drug is already on the market is often lumped into this R&D category as well. These Phase IV studies for Big Pharma's drugs are "supposedly for the purpose of learning more about long-term effects and possible additional uses. But many Phase IV studies are mainly ways to introduce doctors and patients to a company's drug by paying clinicians to use it and then report some minimal information back to the company" (Angell, 39).

Ex-insider Hank Mitchell, former CEO of Pfizer, blatantly admits to how the pricing of medicine is treated like a car or any appliance on the market. Mitchell explains:

> 'It is a fallacy to suggest that our industry, or any industry, prices a product to recapture the R&D budget spent in development. Drugs are basically priced the same way as a car or an appliance. It is the anticipated income stream, rather than repayment of sunk costs that is the primary determinant of price' (qtd. in Banerjee, 57).

Therefore, it seems unclear as to what the more realistic amount that Big Pharma companies actually invest in R&D. Big Pharma likes to advocate that the more money it accumulates, the more it is able to invest in research and development (R&D), therefore leading to the creation of more innovative drugs and theoretically, resulting in more lives being saved. However, the argument becomes somewhat futile when studies juxtapose Big Pharma's R&D expense numbers with its astronomical profits and its habitual practice of spending much more money on marketing than any other field in the industry. Interestingly, the amount of money put towards marketing seems to dwarf R&D expenditure by a landslide. As of 2002,

> when the ten U.S. drug companies in the Fortune 500 list had combined worldwide sales of about $217 billion and spent just over 14 percent of that on R&D (about $31 billion), they had a profit margin of 17 percent ($36 billion). Thus, profits were substantially more than R& D costs. Even more startling is the fact that they spent a walloping 31 percent of sales (about $67 billion) on marketing and administration (Angell, 48).

One sees that Big Pharma has used system logic, putting money into areas of business that might elicit the most profits, and if that means more money being invested into marketing rather than R&D, then that would be deemed the appropriate choice for maintaining the corporate 'system' environment. The kind of research that Big Pharma conducts was also dictated by this mandate of profits and led to a situation where the drugs researched were those that would be the most profitable. "In the mid- to late 1980s, 43 per cent of the terminations in the development of new compounds were for economic reasons versus 31 per cent for efficacy issues and 21 per cent for safety problems (DiMasi 1995)" (Lexchin, 13). This profit-driven R&D agenda has steered most of Big Pharma's money towards the aforementioned "blockbusters" as well as what is called "me-too" drugs.

"Me-too" Drugs

"Me-too" drugs, although meeting the legal criteria to be differentiated as a new product name and patent, are not any more therapeutically beneficial in comparison to drugs that already exist on the market to treat the same conditions. There are a few "me-too" drugs that are composed of slightly different chemical compositions but a majority of them have the exact same compositions of drugs already on the market. "Me-toos" have dominated Big Pharma's agenda: "in the United States, between 1981 and 2000, less than 5 percent of the drugs introduced by the top twenty-five pharmaceutical companies represented therapeutic advances, and of these, some 70 percent were developed with government funding" (Orbinski, 367).

Big Pharma has claimed that one of the benefits of having "me-too" drugs on the market is that the increase in products helps to foster competition and to lower prices, however, in reality, this is not the case since being a "me-too" medicine does not necessarily have any bearing on the actual price of the medicine. Another defence used to justify the production of "me-too" drugs is that different versions of the same drug might work better for different individuals, which is often not true since many "me-too" medicines have the exact same compositions. Big Pharma has gotten away with this because during the clinical trial process new drugs only have to be tested against placebos rather than existing medicines that treat the respective condition. Therefore, pharmaceutical companies have only had to prove that a drug is more effective than a patient not being treated at all.

A prime example of this phony innovation was when Schering-Plough took Claritin, which it patented in 1987, and then patented its metabolite (the molecule that Claritin becomes inside the body) in 2001 and labelled it Clarinex—but it was still the exact same chemical composition (Angell 79-80). The company was able to do this since in the initial clinical trials

for Claritin, the drug was only tested for seasonal allergies while Clarinex was tested in clinical trials for both seasonal and indoor allergies and, therefore, the newer version was considered an improvement. Coincidentally, Schering-Plough's exclusive marketing rights for Claritin were set to expire in 2002. Essentially, Big Pharma's concentration on the R&D for "me-too" drugs is often in this effort to "ever-green" patents, that is, to patent a trivial development of a drug that already exists in order to obtain a new patent.

This trend of 'what is profitable is what is developed' reasoning in Big Pharma's research agenda also created a crisis of "neglected diseases": "diseases for which treatment options are either inadequate or do not exist, mainly because they affect patients with little or no purchasing power" (Orbinski and Burciul, 117).

Skewed Research Incentives: A Crisis of Neglected Diseases and Neglected People

Diseases like malaria and tuberculosis, which continue to be serious health issues in developing countries, have typically been marginalized on Big Pharma's R&D agenda while issues like obesity and other 'lifestyle' health concerns (the conditions of industrialized nations) have dominated the top of the priority list. For instance, of the 1393 drugs developed between 1975 and 1999, only thirteen were drugs that treat tropical diseases and moreover, six of these were as a result of veterinary research and four were from military research (Roffe, Spennemann and von Braun, 13; Orbinski, 367). "It is well known that just 10 per cent of the world's health research expenditures is spent on diseases that account for 90 per cent of the global disease burden. And yet, of this US$60 -70 billion, less than 0.001 per cent was earmarked for research into neglected diseases" (Orbinski and Burciul, 118). Of the few medicines that have been produced to cater to tropical diseases, many are unaffordable or completely impractical as they

are not suited to the living conditions of the people that need them in developing countries (Orbinski and Burciul, 117).

In their article called, "Moving beyond charity for R&D for neglected diseases," authors James Orbinski (former director of Medecins Sans Frontiers (MSF)/Doctors Without Borders) and Barry Burciul discuss the serious research gaps that form as a result of the choices made during the R&D stages which have blocked the development of drugs for neglected diseases. They discuss the unfortunate reality that when there is published research that would clearly only be relevant to neglected diseases, there has been a complete lack of initiative to pursue it further (Orbinski and Burciul, 119). Through this cost-benefit analysis, Big Pharma essentially calculates whose life is monetarily worth saving and whose life is not. With this logic, the rich will inevitably win.

Due to what some authors like Susan Craddock call this "medical capitalism" ("a corporate-dominated medical industry reluctant to spend time and money on a discovery with a high potential for saving lives but a comparatively low potential for profits"), the political economy of health both within and between countries is largely dictated by class—who has money versus who does not and Big Pharma's research agenda only perpetuates the problem (Craddock, 1043). Big Pharma's incentive to research and produce the most profitable drugs is what the HIV/AIDS activist antiBody quickly realized dictated the direction of R&D for medicines and treatments for HIV/AIDS.

PART II: Big Pharma as an Epidemiological *Site of Infection*

Big Pharma's Problematic ARV Research Regime

After the initial years of the biomedical community and Big Pharma's complete neglect of HIV/AIDS, the development of AZT (also known as zidovudine or retrovir) in 1986 (the first antiretroviral drug to treat HIV/AIDS), evoked a lot of optimism among PLWHAs that the pharmaceutical industry had finally listened to their cries that HIV/AIDS was a crisis which needed to be addressed. However, their optimism stemmed from the belief that AZT was a temporary treatment solution—they were not banking on AZT becoming the overarching norm for AIDS medicinal research.

Firstly, because ARV drugs have high levels of toxicity, PLWHAs experience a range of harsh side-effects that severely impact their quality of life such as: headaches, nausea, fatigue, anaemia, myopathy (causing muscle pain and weakness), damage to the bone marrow, skin rashes, and neutropenia (causing a greater chance of bacterial and fungal infections). Secondly, these drugs were enormously expensive and still are since they must be purchased for the remainder of a PLWHA's life and, thirdly and most importantly, ARV drugs are not an actual cure for those infected with the disease, nor do they prevent others from getting infected with HIV as a vaccine would for instance.

Big Pharma's Neglect in R&D for Alternatives to ARV Therapy

Activists came to the realization that the fact that there was so much effort put into the continued research of ARV drugs as opposed to an HIV/AIDS vaccine or alternative treatments was based more on profits than on a genuine concern for people's health; part of the "medical capitalism" that HIV/AIDS activists became determined to change.

Unlike the substantial investment that Big Pharma has poured into ARVs over the years, the research and development into HIV/AIDS vaccines has been almost entirely funded and organized by NGOs and the public sector.

> Multinational firms are essentially concentrated in the ARV drug market, only contributing 10 per cent of the total spending from their own resources to the development of HIV vaccines (IAVI, 2006). Representatives of multinationals justify this low investment in HIV vaccine research by complaining that they have few incentive mechanisms to support this kind of research (Global HIV Vaccine Enterprise, 2006)" (de Albuquerque Possas, 161).

One of the main financial drawbacks of pursuing vaccine research is the fact that the HIV virus constantly mutates, meaning that it quickly builds resistance to treatment, thus making this research an extremely costly affair. "'A vaccine made from one strain of HIV could indeed trigger antibodies, but those antibodies would probably work only against a small proportion of the many extant strains of the virus now circulating around the world'" (Jon Cohen, 'Deep Denial', *The Sciences* 4.1 (Jan-Feb. 2001): 22 qtd. in O'Manique, 80). Another drawback is the fact that because AIDS is most prevalent in developing countries, Big Pharma's investment into vaccine research would not be considered a good corporate move since there would not be a good enough profit margin from it (Craddock, 1043). As O'Manique writes in her book: "With almost 80 per cent of the pharmaceutical market based in North America, Europe and Japan, a geographic area constituting less than 5 per cent of new HIV infections, it does not make economic sense to focus on vaccine development for the poor country market" (O'Manique, 81). Also, with a vaccine, a person might only need three doses to last them for many years which is very different from the daily combination of drugs required on a regimen of ARVs, guaranteeing drug companies a steady flow of income (O'Manique, 81).

Like vaccine research, there is also a substantial lack of support for the research into and availability of alternative treatments which caused the holistic and alternative treatment

movement to find a voice in the AIDS activist movement. These activists started drawing attention to how

> alternative and holistic treatments that do not abide by the prevailing AIDS research paradigm, and most importantly, do not yield the expected profitability are disproportionately subjected to the Food and Drug Administration's scrutiny. Although they would save billions of dollars on treatment money, and although 34% of the U.S. population uses them (Eisenberg et al., 1993), alternative treatments, activists complain, are unfairly treated by the FDA (Elbaz, 55).

An example of the FDA's discrimination towards alternative treatments is the case of nutritional supplements. There has been a host of research that shows the positive effects of these supplements to build up the immune system of PLWHAs as well as control weight loss yet the FDA has tried to block access to these supplements through a variety of measures (Elbaz, 55). In 1992, the FDA proposed regulations that would "'set dietary supplement limits' or 'relabel' nutrient supplements as 'drugs'"; activists argued that this would hinder PLWHAs access to these supplements since they would be subjected to a longer drug testing process (Elbaz, 56). Also, because the profitability from these supplements is low, the long clinical testing process would be another reason for drug companies not to develop them. Because conventional Western medicine chooses to neglect alternative medicine from its official discourse, AIDS activists took it upon themselves to publish information on the benefits and failures of these treatments in order to keep PLWHAs informed with a balanced discussion of these alternative treatment options (Fabj and Sobnosky, 175).

Besides the reasons noted above, activists pointed to "conflicts of interest" (when the state, biomedical research and profits are interlinked such as when federal scientists also work in the pharmaceutical industry) as being the predominant reason as to why AZT and other ARV drugs became the focal point of scientific research on HIV/AIDS. AIDS activists brought these conflicts of interest into the public sphere, making the politics of research a public concern such

as when they did this "during the June 1990 International Conference on AIDS in San Francisco, [*when*] ACT UP distributed a Research Agenda in which those interlocking [*conflicts of interest*] were clearly described (ACT UP, 1990)" (Elbaz, 52-53). HIV/AIDS activists made it their mission to take an active role in revealing the politics that had a large hand in determining the course of the scientific research agenda. In doing this, they were able to uncover Big Pharma's unethical price setting practices for AZT.

Big Pharma's ARV Costs Are Met With Activist Confrontation

Burroughs Wellcome (later to become part of GlaxoSmithKline) initially manufactured zidovudine (AZT) to be tested for cancer in the 1960s and when it decided to test the drug for AIDS, the company was permitted to use the U.S. Orphan Drug Act (established in 1984) which meant that "up to 63% of the cost may be claimed as a tax credit by the company, which can also be granted an exclusive licence to market the drug for up to seven years" (Elbaz, 53). The Orphan Drug Act only applies to drugs developed for fewer than 200,000 people which legislators hoped would create the market incentive for Big Pharma to invest in the research and development of these drugs. Even though Burroughs Wellcome was granted this generous subsidy from the government, when AZT was approved by the FDA in 1986 and launched on the market in 1987, it could cost a person living with HIV as much as $10,000 a year. Burroughs Wellcome used the traditional excuse that the drug was so expensive because of the money put into R&D and despite activists' demands, the company refused to reveal the exact expenditures put into the R&D for the drug (Elbaz, 54). Burroughs Wellcome tried to justify the cost of zidovudine by telling the public that rival drugs would soon enter the market to compete with their drug and through competition the prices would be lowered. However, no new drugs came and HIV/AIDS activists responded with protest.

In March of 1987, ACT UP's first ever major demonstration specifically targeted Burroughs Wellcome. They stormed Wall Street to challenge the price of AZT and as a result, 17 activists were arrested. HIV/AIDS activists' campaign against Burroughs Wellcome continued and on September 14, 1989, ACT UP activists went into the Stock Exchange, chained themselves to the VIP balcony, holding a banner saying "Sell Wellcome," and blew foghorns completely disrupting the day's trading. Other ACT UP members took pictures of the demonstrations which they then smartly sent out over newswires. This time activists struck a chord with big business since an integral day-to-day operation for profit was directly affected. Four days after this demonstration, Burroughs Wellcome reduced the cost of AZT by 20%, dropping the price to $6,400 per year (Elbaz, 54-55). With the public interest at heart, activists made Big Pharma's ARV prices an issue of contestation in the public sphere, using "lifeworld" logic to make Big Pharma responsive to their demands.

Soon some doctors and researchers in the biomedical community came to realize that their Big Pharma counterparts were blocking access to lifesaving medicines and started teaming up with activists to challenge these companies. For instance, when Hoffman-La Roche was blocking access to ddC (a nucleoside analog) in 1991, it was doctors who were calling ACT UP chapters to organize action against the company. In response, ACT UP placed an advertisement in a medical journal which encouraged doctors to boycott recommending any Hoffman-La Roche products and prescribe substitutes instead (Elbaz, 65). Doctors responded and followed through with the boycott campaign, creating "the first boycott organized by activists, patients, and health professionals against a drug manufacturer" (Elbaz, 65). Significantly, members of the biomedical community started taking HIV/AIDS activists' side over that of Big Pharma.

Activist efforts to stay informed with the knowledge and practices of the biomedical community, had enabled them to achieve a legitimate voice in the biomedical discourse. HIV/AIDS activists would use their unified voice to continue to put forth their demands for better HIV/AIDS treatment and years later, their demands for advancement in treatment would be fulfilled—but not to everyone's benefit.

Arrival of HAART: A New Chapter in HIV/AIDS Medicine

Even though activist efforts had led to mini-victories in challenging Big Pharma's research agenda and price-setting, there was an undeniable feeling of hopelessness in the early and mid-1990s. People who had been infected in the mid-1980s were starting to die and research had proven that HIV mutated quickly, preventing any existing drug, the AZT monotherapy, or any combination from being viable treatments. In 1996, during the International AIDS Conference held in Vancouver, the discovery of protease inhibitors (PIs) was announced.

PIs work to prevent an HIV infected cell from replicating more copies of the HIV virus and therefore, with PIs it became possible to combine RTIs and PIs in a daily combination antiretroviral treatment regimen that would combat the presence of mutated forms of HIV (Smith, 42). This combination therapy would be known as "highly active antiretroviral treatment" (HAART); a drug "cocktail" that was absolutely revolutionary. HAART lowered the levels of HIV in the bloodstream, decreased the risk of mother-to-child transmission, reduced opportunistic infections, and drastically improved the quality of life for PLWHAs (resulting in the term "Lazarus syndrome" where PLWHAs felt like they had been brought back to life) (Smith, 42). Like all antiretroviral treatments, HAART prolongs the amount of time a person can live with HIV without having the full-blown onset of AIDS. However, as opposed to AZT treatments which could only extend a person's life for 7 and 12 years after a person's initial

infection with HIV, HAART could enable someone to live with HIV for the rest of their lives.

There are still a number of medical drawbacks to HAART: the combination therapy treatment is structured in a rigid and complicated daily regimen; there are still short-term side effects (nausea, diarrhoea, etc.) and long-term side effects (diseases affecting the kidney, liver, heart, etc.); only 80 percent of the people infected with HIV actually respond to the treatment; and some people can get "superinfected" with new forms of HIV that are already drug resistant as a result of trying this treatment therapy (Smith, 44). Despite these drawbacks though, with the introduction of HAART, HIV became more like a chronic illness that could be treated rather than an assured death sentence. Moreover, HAART's introduction did more than just transform the body of the person living with HIV/AIDS but also transformed the HIV/AIDS activist antiBody's movement into another entity altogether.

Arrival of HAART: A New Chapter in HIV/AIDS Activism against Big Pharma

With the arrival of HAART, many of the AIDS activists who had been involved since the early years decided that their efforts were successful and that they had reached their ultimate goal. Activism was not a necessary course of action anymore because a viable treatment existed that enabled someone to live with HIV/AIDS. This caused the dissolution of many chapters like those of ACT UP in developed countries like the U.S. but simultaneously caused the reformulation of those remaining and the rise of a new coalition for access to medicines linking the Global North with waves of activism originating in the Global South.

Prior to HAART, people of high or low income, people living in the developed world and the developing world, were all in the same predicament if they got infected with HIV—sooner or later, they knew that they faced certain death. Of course, those living in developed countries had a better chance of fighting off opportunistic infections but essentially, everyone's fate was still

sealed. After HAART, people who could afford to pay $10,000 to $15,000 a year for the treatment were the ones who benefitted

> which it soon became clear would be fewer than 5 percent of the global population of those living with HIV. For the remaining 95 percent of those living with HIV, especially the more than thirty million in sub-Saharan Africa, the availability of HAART seemed to be almost a cruel joke (Smith, 53).

Thus, the new drug effectively divided the world into those who could afford to live with HIV and those who could not. HAART exposed the fallacy of the market providing equal opportunity for all, and the fallacy of the neoliberal portrayal of the market as the ultimate provider of necessities such as healthcare.

"Before 1996, globally oriented AIDS activism was limited mainly to a few vocal but small groups and individuals such as Paul Boneberg, leader of the Global AIDS Action Network (GAAN), and Eric Sawyer, founder of the Global AIDS Action Committee of ACT UP" (Smith, 54). After 1996, the stark divide in accessibility to medicines between the global rich and the global poor incited a global AIDS treatment activist movement. It is by no coincidence, therefore, that during the same International AIDS Conference when the new drug was announced, Jonathan Mann, who had been head of the former GPA, made a speech which pointed to the shift in thinking that needed to take place:

> 'We have the precious, historic opportunity here, now, today in Vancouver to start or accelerate a profound transformation in the movement against AIDS ... For the future of the global effort against AIDS is, as it has always been, literally in our hands. To create and build a new solidarity in the face of all the standard, historical, expected, routine and powerful status quos which seek to divide us; to contribute to that society transformation which offers hope against AIDS and for the world: this is a task—no, a destiny—worthy of our past, our aspirations, our commitment, our dignity, and our lives'
> (Jonathan Mann (1996). "The Future of the AIDS Movement," qtd. in Smith, 54).

Activists mobilized together to fight for access to treatment around the world. Medecins Sans Frontieres (MSF) or Doctors Without Borders led the call to action by coordinating a global

Access to Essential Medicines campaign. The leaders of the MSF-initiated campaign were: Dr. Bernard Pecoul (who had been the general director of the MSF's office in Paris), Ellen t'Hoen (a trade lawyer), Daniel Berman (a former pharmaceutical marketing executive) and head of MSF at the time, James Orbinski. Orbinski describes MSF's organization of this coalition in his book *An Imperfect Offering: Humanitarian Action in the Twenty-First Century*:

> Throughout 1998 and 1999 we organized a global coalition of more than a hundred NGOs and civil society organizations, among them CPTech [*Consumer Project on Technology*], Health GAP [*Health Global Access Gap*], ACT UP and Oxfam in the North; global NGO networks like Health Action International; and smaller NGO networks in such places as India, Brazil, Guatemala and Cambodia, among them ACCESS, in Thailand, and the Treatment Action Campaign, in South Africa (Orbinski, 354).

MSF officially announced its access to medicines campaign to the world when the NGO received its Nobel Peace Prize in 1999. The HIV/AIDS treatment activism joined many other social movements of the 1990s which switched a critical gaze from solely targeting nation-states to challenging the role that corporations play in creating global social problems as well.

To date, there have been four waves of activism which have developed over the years to hold corporations accountable. The first wave of activism was initiated to fight for a consumer's right to safe products (such as in relation to the tobacco industry or car products, etc.); the second wave that developed was activism against the exploration and extractive industries (such as in the case of Shell); the third wave advocated against the exploitative labour conditions of 'sweatshops' and the like in developing countries; and finally, the most recent fourth wave of activism has been a result of the HIV/AIDS activist antiBody fighting for access to HIV/AIDS medicines (Joseph, 426). Global AIDS activist, Alan Berkman, explained that the decision of activists to mobilize together for HIV/AIDS treatment as opposed to any of the many other aspects of the global AIDS epidemic was not only because this issue was, and still is, urgent but

also because it was thought that this issue would rally the most support for the movement. He said:

> 'I think we correctly grasped the fact that the availability of treatment humanized the issue of global AIDS in a particular way,' said Berkman. 'It was more concrete in that you could actually save lives and in that way more compelling. If we talked about everything we really need to deal with the global AIDS epidemic, we would lose focus and not accomplish anything. And focusing on treatment had a passion to it that was different than prevention. If there was going to be a change in global AIDS policy, we needed to mobilize a base, and in the affected countries, treatment speaks differently to people, it's very clear that it's about saving lives, about saying that you couldn't just write off 35 million people' (Interview with Alan Berkman by Raymond Smith on February 21, 2002 qtd. in Smith, 59).

The HIV/AIDS treatment activist movement was one of many social movements during the 1990s which called for a global social justice for social and economic issues which had been side-tracked in a neoliberal-dominated idea climate. For many years, the neoliberal narrative dominated human rights discourse which meant that the discourse was mainly focused on the protection of civil and political rights. In mobilizing to fight for treatment against Big Pharma, HIV/AIDS activists advocated for a "right to health," bringing public health to the forefront and also establishing social and economic rights as a priority on the global agenda.

Challenging Big Pharma HIV/AIDS activists Advocate for a 'Right to Health': Moving Social and Economic Rights onto the Global Agenda

Although the whole of human rights discourse acknowledges the importance of civil, political, social, economic and cultural rights, the liberal understanding of human rights, which has been dominant for the past century, specifically prioritizes civil and political rights over all others. Placing more emphasis on "negative rights" (civil and political rights) means stressing the importance of an individual's 'freedom from' harm, thus these rights are "fulfilled when all members of a community exercise restraint from doing anything that might violate the freedom of others" (Evans, 200). "Positive rights" (social and economic rights), on the other hand,

emphasize an individual's 'freedom to' increase their capabilities, therefore positive rights "require others to provide the material means of life to those unable to provide for themselves: at a minimum, clean water, shelter, food and healthcare" (Evans, 200). Liberal theories of citizenship emphasize the prioritization of negative rights over that of positive rights since it promotes the notion that the only "role of the state is to protect the freedom of its citizens and that it can best achieve this aim by removing the obstacles to free exchange between individuals in the market place" (Isin and Turner, 7).

The Universal Declaration of Human Rights (1948) acknowledges all of these rights in turn, but when the UN started putting the rights into international law, two separate covenants were drafted: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). Through keeping these covenants separate, civil and political rights were deemed "absolute" and meant to be immediately enforced while social, economic and cultural rights were deemed merely "aspirations" and therefore should be achieved over time. Because of this, human rights literature has created a hierarchy of importance distinguishing a first generation of human rights (political and civil) and a second generation of human rights (socio-economic).

The liberal bias became even more dominant during the 1980s and 1990s after the fall of the USSR because

> it marked the end of a sharp East/ West divide in human rights policymaking that had reinforced the distinction between different types of rights throughout the Cold War years, during which communist states gave priority to economic and social rights whereas capitalist states favoured civil and political ones (Hertel, 4).

With the spread of neoliberalism to nation-states and the agendas of multilateral institutions, the protection of negative rights over positive rights was emphasized since less government control over the production and distribution of resources is fundamental to neoliberal ideology. Although

the international human rights movement was born in the 1970s, for the first two decades of the movement even the activists from the critical margins only focused their international human rights campaigns to fight civil and political abuses following the liberal bias. The 1990s, however, ushered in a plethora of human rights movements, such as that of HIV/AIDS activism, which brought claims for social, economic and cultural rights back to the forefront of the global agenda.

This new rights advocacy

> is the first fundamental challenge to a market-dominated development framework that reshaped national economies and international trade and finance during the 1980s and 1990s. New movements are drawing on human rights standards to challenge the application of market logic to the delivery of water and basic services, to argue for the right to agrarian reform and education, and to assert the primacy of human health consideration in setting national and international policy regarding HIV/AIDS (Nelson and Dorsey, 191).

Not only do these new social movements target nation-state governments as culprits of inhibiting citizens' rights, such as was typically the case prior to the 1990s, but these social movements also challenge transnational corporations (like Big Pharma) and international institutions (like the WTO). The HIV/AIDS treatment activism was an integral part of this "new rights advocacy" (NRA) and moving the framing of citizenship from Jonathan Fox's aforementioned "state-based" approach to the "society-based" approach. They were a part of a "new citizenship [*that*] expresses 'a project for a new sociability', meaning public responsibility for the creation of more egalitarian social relations and implying widespread and reciprocal recognition of 'others' as bearers of rights and interests"—no matter what the nation-state boundaries (Conway, 374). The HIV/AIDS antiBody would force Big Pharma, multilateral institutions, as well as the world at large, to recognize the plight of people living with HIV/AIDS who are deprived of access to essential medicines by framing their plight within a human rights discourse. They pointed to

their exclusion from "the enjoyment of the highest attainable standard of physical and mental health"—a right supposedly guaranteed to every individual, not by virtue of being a citizen of a certain country but by virtue of being a citizen of the world (ICESCR Article 11 qtd. in Nickel, 236).

Conclusion: Big Pharma's System Logic is Rivalled by HIV/AIDS Activist Lifeworld Logic

This chapter's case study of Big Pharma, which has included an investigation of its industry structure, its relationship with the biomedical community, and its R&D agenda, has demonstrated that Big Pharma's business operations during the 1990s used "system" logic to carry out a neoliberal mantra of prioritizing profits over health, making Big Pharma corporations a *site of infection* for the propagation of neoliberal ideology. The latter part of the chapter has demonstrated how activists used lifeworld logic to start exposing the negative impact Big Pharma's business practices have on the R&D, price and availability of HIV/AIDS medicines which made it a *site of infection* for HIV/AIDS as well.

Habermas spent a great deal of time theorizing how the "system" domain can "technize," "mediatize" and "colonize" the lifeworld. He theorized that when "systemic mechanisms" and "steering media", such as money and power, are brought into the usual social interactions of the lifeworld (the public domain) then the communicative action of the lifeworld ends up being superseded by the functions of the system. This process is described by Habermas as follows:

> Media such as money and power ... encode a purposive-rational attitude toward calculable amounts of value and make it possible to exert generalized, strategic influence on the decisions of other participants while *bypassing* process of consensus-oriented communication ... [*T*]he lifeworld contexts in which processes of reaching understanding are always embedded are devalued in favour of media-steered interactions; the lifeworld is no longer needed for the coordination of action (Habermas, 183).

One can see evidence of these processes of the mediatization and colonization of the lifeworld in the standardization and mechanization of work routines and the automated interactions between customers and customer service agents. What Habermas spends little to no time exploring is the possible colonization of the system by the logic of the lifeworld. What if the public through lifeworld logic could colonize the system and influence its operations? Attempting to bring consensus-oriented communication and the public interest into entities governed by the system would mean expanding the influence of the public domain. The interactions between the actors in this chapter's case study points to this kind of a reverse-colonization.

The growing confrontation between the HIV/AIDS activist antiBody and Big Pharma over access to medicines shows how HIV/AIDS activists started overriding the system logic of Big Pharma's operations and its neoliberal orientation. Through calling attention to Big Pharma's skewed research agenda and its pricing of HIV/AIDS drugs, these activists made their behaviour a point of public controversy and debate. They exposed Big Pharma's business model as a reckless one that was hazardous to public health and therefore, constructed access to medicines as a public and political issue. Consequently, Big Pharma's system logic was affected as these corporations were forced to start adjusting corporate behaviour in response to activist demands.

When the HIV/AIDS activist antiBody became a global entity after the arrival of HAART, they politicized the disparity between access to medicines between the global rich and the global poor by advocating for a human right to health. To do so, HIV/AIDS activists' battle against Big Pharma would spill over into the realms of the WTO in the late 1990s and early 2000s. In this monumental time of confrontation, the HIV/AIDS activist antiBody would prove to be one of many "counterpublics" representing a globalization different from the system-

oriented neoliberal economic globalization project crafted from above by those in the higher realms of power such as corporations (like Big Pharma) and neoliberal-minded international organizations [like the World Trade Organization (WTO)]. The HIV/AIDS treatment activism became part of a decentralized, grassroots project of social justice which Arjun Appadurai describes as:

> a series of social forms [*that*] has emerged to contest interrogate, and reverse these [*neoliberal*] developments and to create forms of knowledge transfer and social mobilization that proceed independently of the actions of corporate capital and the nation-state system (and its international affiliates and guarantors) (Appadurai, 3).

The HIV/AIDS activist movement would be part of what Appadurai calls a "globalization from below"—representing a flourishing of the lifeworld and a global antiBody which combated a market-driven neoliberal ideology.

The next chapter will focus on analyzing the confrontation during which the HIV/AIDS activist antiBody would face its most poignant battles against Big Pharma in the fight for access to medicines when issues of global trade, generic drugs, and patents created a perfect storm.

Chapter 4: A Global HIV/AIDS Activist AntiBody Challenges Big Pharma as a Site of Infection

Introduction: Big Pharma's Lobby Power

Big Pharma has been notorious for using its market power to influence political leaders to create industry-oriented policy environments. Its strategies have entailed employing lobbyists to sell favourable policies door to door in the halls of nation-state parliaments and have also included behind the scenes tactics such as backing political party campaigns to ensure governmental compliance (Angell, 197-198). The neoliberal ideological climate during the 1990s facilitated a rapid concentration of corporate power which presented greater opportunities for corporations' political clout to extend beyond just the realms of the nation-state. In 1998, David Held wrote: "MNCs [*multinational corporations*] account for a quarter to a third of world output, 70 per cent of the world trade and 80 per cent of direct international investment" (Held, 17). As a result, many corporations, like Big Pharma, took advantage of their global market power, as well as the neoliberal-friendly political economic environment, and quickly became prominent global actors helping to shape a neoliberal economic globalization that prioritized private interests over the public interest. A clear demonstration of this is illustrated through Big Pharma's substantial role in influencing the World Trade Organization (WTO) to include pharmaceutical products and processes in its Trade Related Aspects of Intellectual Property Rights (TRIPS) agreement of 1994.

This chapter presents the focal point of this thesis' case study as it specifically focuses on select prominent battles between Big Pharma and HIV/AIDS activists in the 1990s and early 2000s. It will highlight how TRIPS and the confrontations between these two actors pointed to socially unjust power relations between the private interests of Big Pharma's intellectual

property rights protection and the interests of those living with HIV/AIDS in developing countries which led to a vigorous engagement of the Global South.

The first part of the chapter begins by outlining the details of TRIPS as a neoliberal piece of legislation and illustrates how TRIPS perpetuated a further commodification of health. This portion will also explain how the agreement was promoted by Big Pharma and the governments of developed countries in the WTO to the disadvantage of developing countries.

The second part of the chapter will examine significant confrontations for HIV/AIDS activists against Big Pharma, and its counterpart the United States government, that now represent important milestones in the global HIV/AIDS treatment activist movement. The milestones to be discussed are as follows: the South African controversy surrounding the legal action the U.S. and Big Pharma launched against the South African government for its introduction of the Medicines and Related Substances Control Amendment Act (1997); Brazilian activists' struggle to construct universal access to health as a human right, its Industrial Properties Law (1996), and its threat to use compulsory licensing; as well as activists' mobilization at the 'Battle of Seattle' against the WTO. Therefore, this chapter is the most significant illustration of how the HIV/AIDS activist antiBody's "globalization from below" would challenge Big Pharma as a site of infection to combat the spread of HIV/AIDS and also to expose the severe shortcomings of a neoliberal political economic globalization.

PART I: TRIPS—Intellectual Property Rights and Public Health Collide

TRIPS Encroaching the Public Domain: Commodifying the Commons

The General Agreement on Trade and Tariffs (GATT), established in 1947, governed trade negotiations and the rules of trade in the global market economy for almost 50 years. The

WTO, located in Geneva, Switzerland, entered the global stage on January 1, 1995, after having been deliberated during the Uruguay Round of trade negotiations conducted from 1986 to 1994. The TRIPS agreement was created in 1994 as a result of the negotiations during the Uruguay Round. TRIPS "introduced, for the first time in an international agreement: the obligation to protect data against unfair competition" (Correa, 400). The agreement set international standards for protecting copyrights, patents, trademarks, and any other issues related to intellectual property rights (IPRs)—which are the legal devices used to protect any creation of the mind such as a song, a design, or a process.

Essentially, intellectual property rights are used to make information that was once public a commodity which can be restricted by whatever private body owns it. Michael Hardt and Antonio Negri explain how information and ideas can be considered part of the public domain or the Commons when they say that:

> The production of ideas, images, and knowledges is not only conducted in [the] Commons –no one really thinks alone, all thought is produced in collaboration with the past and present thought of others – but also each new idea and image invites and opens new collaborations (Hardt and Negri, 147).

Therefore, the production and distribution of information and knowledge not only takes place through interacting with the Commons, but through this process more ideas are created for the Commons which can be used by others as a resource to produce their own ideas as well.

In theory, property rights are granted in order to prevent what Garret Hardin calls "The Tragedy of the Commons," whereby if the Commons were left unregulated people would act in their own self-interest to the point where they would cause the depletion of all the resources. However, as Christopher May rightly theorizes: "If the social good served by knowledge and information is related to availability … then the enforced scarcity of intellectual property becomes problematic" (May, 130). When people can simultaneously use the same knowledge

without limiting the benefits that can be reaped from that knowledge, how does one justify constructing a false scarcity of information through patents which, in the case of access to medicines, can impose such harmful costs to so many people? If creating a scarcity of information does not drive innovation (as Big Pharma's R&D agenda of "me-too" drugs clearly demonstrates), and if information can be used by any number of people without diminishing its use-value, then standard arguments for property rights does not seem to hold true. This presents a problem for justifying the social good involved in the commodification of information and knowledge in TRIPS.

The exclusionary practices of a constructed scarcity of information may be leading to a tragedy of the "anti-Commons," where it is the under-utilization of resources which leads to "universal ruin" (May, 141). "Universal ruin," that is, for the large majority of people who are poor and deprived access to essential medicines and their right to health as a result of the IPRs of the wealthy. An international system of patents protecting pharmaceutical processes and products means that people in developing countries who are unable to afford brand-name drugs do not have access to necessary generic medicines for their survival. Therefore, it seems that the restriction of one public good, that is, information, further restricts another important public good—access to healthcare.

In his studies of Marxist dialectics, history and class consciousness, Georg Lukacs stressed that the legal system plays a crucial role in legitimizing the naturalization of commodity relations. In turn, laws help to build and reinforce the "reified consciousness" that allows capitalist processes to further structure our social worlds and subjectivities. According to Lukacs, breaking free from this "reified consciousness," and building a revolutionary one in its place, requires people to develop a critical understanding of how the groups that write the laws often

create them with their own biases and interests in mind. Lukacs asserts that a legal system "serves purely as a means of calculating the effects of actions and of rationally imposing modes of action relevant to a particular class"—that is, the ruling class which, as Marx's conceptualization of ideology suggests, controls the ruling ideas as well (Lukacs, 109).

To break from "reified consciousness" one must acknowledge that the production of international standards and norms in the WTO is no exception and those who produce these legal mechanisms have tried to shape a certain global political economy of neoliberal organization for their own benefit. Through TRIPS the market domain's influence is expanded and the Commons or public domain is further shrunken—a key goal of neoliberalism. In its commodification of information, this neoliberal regime would clearly advantage the interests of developed countries and corporations like Big Pharma while neglecting those of developing countries.

TRIPS Privileges Interests of Developed Countries over Developing Countries

There was tremendous controversy surrounding TRIPS in regards to how the agreement privileges the interests of developed countries over that of developing countries. Interestingly, the voices of dissent not only came from the critical margins of activists but from conventional and institutional streams as well. Development economists argued that TRIPS unfairly asks developing countries to implement IPR standards that are well beyond their levels of scientific and technological development (Shadlen, "Intellectual Property, Trade, and Development," 171). On the other hand,

> liberal trade economists complain that TRIPS introduces protectionism into an institution geared toward dismantling barriers to the flow of goods and services, and that contentious debates over IP clutter the multilateral negotiating agenda and the WTO's dispute settlement system (Shadlen, "Intellectual Property, Trade, and Development," 171).

Moreover, both the World Bank and the United Nations Development Programme (UNDP) expressed concerns that TRIPS would bring about a large transfer of wealth from developing

countries to the developed countries where the majority of patent-holders are located (Shadlen, "Intellectual Property, Trade, and Development," 171). One economist from the traditionally 'neoliberal-conservative' World Bank even estimated that "the minimum welfare loss to a sample of developing countries (Argentina, Brazil, India, Mexico, Korea and Taiwan) would amount to a minimum of US$3.5 billion and a maximum of US$10.8 billion, while the income gains by foreign patent owners would be between US$2.1 billion and US$14.4 billion" (Correa, 35). This estimate was obviously not unfounded when considering the World Bank publication in 2001 which reported that TRIPS allowed for a transfer of about US$20 billion from technology-importing countries to exporter countries every year (Dutfield, 534). On the whole, TRIPS "raises prices of drugs and educational materials in poor countries, legitimises the 'biopiracy' of genetic resources and traditional knowledge, and blocks transfers of much-needed technologies" (Dutfield, 534-535).

One of the most contested issues stemming from TRIPS, which also specifically pertains to the fight for access to HIV/AIDS medicines for developing countries, was the WTO's decision to make pharmaceutical products and processes patentable for twenty years from the date that a patent application is filed. Prior to TRIPS, each individual country could decide what would be protected under its national intellectual property rights system according to national public interests, as opposed to the 'one-size-fits-all' rule of TRIPS whereby all pharmaceutical patents and processes are required to be protected under patent. Although many developing countries patented the processes used to produce pharmaceuticals, many of these countries did not grant patents on pharmaceutical products. This meant that as long as manufacturers did not use a process that was patented, they could still produce the same drug; this arrangement allowed generic companies to use reverse-engineering (Smith, Correa and Oh, 687). A developing

country had the opportunity to keep costs of drugs lower to ensure better access for its citizens and if the country had a national pharmaceutical industry it could protect it from competition with the more advanced sectors in other countries (Roffe, Spennemann and von Braun, 13).

Needless to say, when the Uruguay Round commenced in 1986 and IPR standards were first introduced into trade negotiations, developing countries were not enthusiastic about the possibility of IPRs being incorporated into the WTO's rules. To understand how the WTO would enable this kind of agreement, one must first understand how corporate interests and the interests of developed countries typically have an upper-hand in the structure of the WTO's negotiations.

WTO Negotiating Space Creates "Stronger Publics" and "Weaker Publics": Corporations and Developed Countries have the Upper Hand

Even though WTO decisions are supposed to be agreed upon by all Member-states (currently there are 153 members in total), with each Member-state getting one vote, in actuality many decisions are made based on consensus between Member-states who are present at whatever meeting is taking place.

When considering that developing countries only have an average of two staff members that they can send for WTO affairs and the European Union has about 140 delegates they can expend, it seems next to impossible for a true 'consensus' to be achieved in meetings where only a select few can attend (Lee and Patel, 417). When Daniel Drache discusses the power imbalance in the WTO in his book *Defiant Publics: The Unprecedented Reach of the Global Citizen*, he calls to mind Nobel-prize winning economist Joseph Stiglitz, who theorizes that the main factor to analyze economic decision-making is the amount of information that each party has when making the decision. Stiglitz posits that in terms of international trade, although everyone is operating in a state of incomplete information, those who have more information will have the competitive advantage (as discussed in Drache, "Defiant Publics," 34).

Oftentimes, delegates of developed countries at the WTO use this competitive advantage to put forth the demands of the corporations based within their countries as result of corporate lobbying. In addition, many corporations station permanent lobbyist representatives in Geneva specifically for the purpose of keeping an eye on WTO proceedings and making sure industry interests are well-represented on the trade agenda (Lee and Patel, 418). Once these corporations convince the governments of developed countries that their interests are of primary importance, delegates from these countries can push their trade agendas in the WTO. Therefore, due to the WTO's process, corporations and developed countries have more decision-making power in establishing international norms and rules which makes them the "stronger publics" in the WTO's legislative process while making developing countries "weaker publics" since they have less influence.

Having discussed the WTO's 'consensus' decision-making process and the influence of corporate interests, one can see why TRIPS was adopted as an international agreement.

> It comes as no surprise then that the current form of trade regulation, founded in econometric analysis and ruled by trade lawyers ... does not benefit the poor. Global free-trade rules have turned out to be very blunt instruments indeed, wielded by the wealthy in the interests of the elite (Drache, "Defiant Publics," 34).

The fact that intellectual property was even classified as a trade-related issue at the WTO was the product of "the intense activism and immense power of the biotech, chemical, pharmaceutical, seed, software, and entertainment industries in the 1980s and 1990s that created the link between IP and trade, and thus made IP 'trade-related'" (Shadlen, "Intellectual Property, Trade, and Development," 172).

Big Pharma and Other Corporations as Cheerleaders for TRIPS

In 1986, U.S. trade negotiators knew very little about patents but by 1990, corporate lobbyists had succeeded in making intellectual property one of the top priorities for US trade

(Heywood, 224). In a speech given to the U.S. Council for International Business in 1995, Pfizer Chairman Emeritus Edmund T. Pratt Jr. boasted of the corporate lobby's accomplishment when he said:

> The Intellectual Property Committee, [which Pfizer helped found] helped to convince U.S. officials that we should take a tough stance on intellectual property issues, and that led to trade-related intellectual property rights being included on the GATT agenda when negotiations began in Punta del Este, Uruguay, in 1986 ... The current GATT victory, which established provisions for intellectual property protection, resulted from the hard-fought efforts of the U.S. government and U.S. businesses, including Pfizer, over the past three decades. We've been in it from the beginning, taking a leadership role (qtd. in Wallach and Woodall, 94-95).

The talented people from multinational corporations like Pfizer, IBM and other multinational corporations lobbied their home-governments to ensure that IP would be treated as an important issue for trade in the WTO. Why, however, did corporations start to specifically take a strong interest in establishing an international intellectual property rights regime?

Manuel Castells argues that we are living in an age where in the dominant 'mode of development' is "informationalism" meaning that "the source of productivity lies in the technology of knowledge generation, information processing, and symbol communication" (Castells, 17). In addition, Hardt and Negri use Marx's concept of "historical tendency" to identify ours as a "hegemony of immaterial production," whereby "immaterial labour" (labour related to information processing, generation and dissemination) structures all other existing labour relations (Hardt and Negri, 141). If information is the most valuable economic resource in "immaterial production" and "informationalism" then it comes as no surprise that the most sophisticated forms of property rights are now intellectual property rights. Therefore, it also comes as no surprise that businesses want to protect these rights as much as possible. Protection means increasing corporations' market power as well.

In particular, Big Pharma became much more concerned with protecting their intellectual property rights when they became aware of two important global projections relating to their industry: (1) the realization that there would be a globalization of certain types of diseases/epidemics and (2) that there was an ever-increasing threat of generic competition in the globalized market. Both were serious incentives for Big Pharma to push for stronger international patent protection:

> changing patterns in global health began to present a threat to the degree of profitability of patented medicines, not only in the domestic market where the generic manufacturer existed, but also in a far more sizeable amalgam of developing country markets. In a globalised world, particularly one that has glorified competition, the existence of interchangeable alternative medicines, costing a fraction of the price of the patented version, was seen as a threat (Heywood, 225).

Since the bulk of pharmaceutical sales takes place in North America, Europe, and Japan (accounting for 75% of all pharmaceutical sales), the biggest fear for Big Pharma is that generic drugs produced in developing countries will find their way to developed country markets where these corporations set higher prices on their medicines and make the most profit (Smith, Correa and Oh, 684). When generic drugs enter any market, prices are driven down enormously.

For this reason, having global rules in TRIPS that restrict the manufacturing of generics in developing countries is an asset. Big Pharma argues that R&D is the main justification for why a strong international intellectual property rights system is important to the industry and the public at large; however, as discussed in the previous chapter, this argument is questionable when referring back to the blatant profit motive driving Big Pharma's R&D agenda. For example, "Medecins Sans Frontieres ... reported in 2000 that Glaxo-Wellcome made $589 million on one AIDS drug in 1999 alone, recouping more than twice its research and development costs in just one year (Medecins Sans Frontieres, 2000b: 45)" (Poku, 293). Clearly, Big Pharma's main concern is more to do with competition from generic companies which

undermine its ability to set prices. Thus, patents provide Big Pharma with the temporary monopoly they need to keep drugs at desirable prices which is why companies fight to extend the life of their patents for as long as possible.

The active role of Big Pharma and other corporations as cheerleaders for TRIPS evidently paid off because by 1989, developing countries were willing to concede to IPR standards to arrange a package of agreements that would secure market access to developed countries in other areas of trade such as agriculture and textiles (Dutfield, 534). There were, however, still safeguards or one could say 'loopholes' put in the TRIPS agreement which are exceptions to the rule and are meant to protect public health. These safeguards or flexibility measures have become a site of much controversy between governments, Big Pharma and the HIV/AIDS "counterpublic"/antiBody.

TRIPS 'Flexibility' Measures

Staggered Deadlines for the Implementation of TRIPS

The TRIPS agreement did carve out some room for leeway so that developing countries could have time to implement TRIPS stipulations into their patent systems and could also have access to certain flexibility measures if necessary.

When TRIPS was established in 1994, the WTO set staggered deadlines for when countries would need to conform to TRIPS regulations depending on if a country was/is considered to be a developed country, a developing country and/or a transition economy, or a least developed country (LDC). It was agreed that developed countries were expected to adhere to TRIPS obligations at the beginning of 1996; developing countries and/or transition economies were given until January 1, 2000 [except for countries (like India and Brazil) that were eligible to take advantage of a provision in Article 65.4 of the agreement which allowed certain developing

countries until January 1, 2005]; and LDCs were expected to comply with TRIPS by January 1, 2006 (later extended to January 1, 2016 by the Doha Declaration of 2001).

Until countries had TRIPS regulations set into their patent systems, the WTO put a "mailbox patent" system in place so that companies could submit an application for a patent to protect a pharmaceutical product or process which would be filed and stored until the patent could be examined under the newly adapted TRIPS system. In addition to the good faith gesture of these staggered deadlines, TRIPS allows the rules of Big Pharma's monopoly on patents to be bent if and when the "flexibilities" written in the agreement are 'appropriately' utilized by Member-states.

Exceptions to the Rule: Research Exception, "Bolar" Provision, Anti-Competitive Practices & Parallel Importation

One of these TRIPS flexibilities is the research exception which enables countries to allow researchers to use a patented invention if it is used for non-commercial purposes and used strictly to advance the learning of the science behind the innovation. The "Bolar" or "regulatory" provision is another flexibility measure which is utilized when governments want to permit generic drug manufacturers' access to all the information for a patented product before the licence has expired in order for the generic manufacturer to get a head start in getting marketing approval for the generic version from the appropriate public health authorities. This enables generic manufacturers to release their generic version of the drug on the market as soon as the patent licence expires. Another example of TRIPS allowing a patent to be overridden is in cases when an owner of a patent has used it for anti-competitive practices (using it in a way that inhibits competition and hinders trade or technology). Parallel importation is a TRIPS safeguard that allows a government to scour the international market for the cheapest price for a patented drug and once the government finds another country where the lowest price exists, the

government can then import the drugs from the other country (Roffe, Spennemann and von Braun, 14). The result of importing these cheaper drugs not only ensures better access to the drugs for the population that needs them, but also drives down the prices of other drugs in the country's market as well. The most controversial of all the flexibilities in TRIPS according to Big Pharma is compulsory licensing.

Compulsory Licences

A compulsory licence allows a government to give a government agency or a private company the right to produce patented drugs under a generic label. A government can issue a compulsory licence without the permission of the patent owner, however, royalties, although minimal, must still be paid to the patent owner for each sale of the generic drug. Because compulsory licensing can successfully decrease the cost of medicines by as much as 95%, it is not surprising that Big Pharma tries to block the use of this flexibility measure (Wallach and Woodall, 95). Compulsory licensing disrupts Big Pharma's price-setting ability which severely cuts into profits and also undermines its monopoly power. To Big Pharma's advantage, however, there were specific conditions attached to the compulsory licence flexibility measure in the TRIPS agreement so as to ensure that its usage would be kept to a minimum.

In the agreement, a government could only issue a compulsory licence on a case by case basis. Also, TRIPS stipulates that before a compulsory licence can be issued, the party wanting the licence must first attempt to negotiate with the patent holder to get a voluntary licence. These negotiations with the patent holder can be bypassed, however, if the country needing the compulsory licence is in a state of "national emergency," or if the government needs the licence to correct anti-competitive practices. Another important condition attached to this flexibility measure is that if a compulsory licence is granted, then it can only be applied with the terms set

when the licence is authorized and the licence can only be used for the domestic market (Roffe, Spennemann and von Braun, 15-16).

These safeguards made TRIPS "unlike many other WTO agreements, [because] within the TRIPS agreement there [was] space to manoeuvre. However, as with all WTO issues, the ability to access this flexibility [came] down to issues of power" (Wallach and Woodall, 95). Oftentimes, Member-state governments have been discouraged from issuing a compulsory licence because they fear retaliation from Big Pharma and the United States and/or the EU which has taken the form of lawsuits or trade sanctions (as will be discussed more fully later in this chapter).

A Hazardous "System" Logic in TRIPS

Interestingly, the TRIPS agreement outlines the largest number of specific obligations in its legal framework which was unprecedented in international trade agreements prior to that point. However, with every official dotted line, row of red tape and stipulation in TRIPS that undermines the ability of countries to produce and purchase generic medicines, there is an ever-present gap in the complex tapestry of the agreement; it is the simple fact that TRIPS rationalizes an international regime which prevents millions of people from accessing essential medicines for their survival.

One could say that TRIPS is governed by the logic of Habermas' system domain. In its aims to mainly protect corporate money and power, TRIPS further distances the WTO's dialogical processes from the organization's basic objective, that is, to achieve fair, consensual agreement between all Member-states. If enacted properly, fulfilling this objective would make the WTO a space representative of the communicative action of the lifeworld domain. Instead, through TRIPS the WTO's discursive space was further thwarted by "systemic mechanisms" of

power and money. Therefore, TRIPS is a prime example of how Habermas theorized the system's colonization of the lifeworld:

> these systemic mechanisms—for example, money—steer a social intercourse that has been largely disconnected from norms and values, above all in those systems of purposive rational economic and administrative action that ... have become independent of their moral-political foundations" (Habermas, 154).

TRIPS' international IPRs regime is such an example of an economic, administrative action. It rationalizes the calculation and application of a standardized international patent system that prioritizes corporate interest to a point where it is completely disconnected from the overall public interest.

Ulrich Beck discusses the dangers of a rationality that calculates and reasons everything but increasingly loses touch with the fundamental material reality, a rationality that reasons larger risks and hazards that are detrimental to humanity. Beck's concepts of "industrial fatalism" and "organized irresponsibility" can be used to describe the ideology stemming from Big Pharma and TRIPS as well as that of the overall ideology driving a neoliberal organization of the global economy that enabled the commodification of health and of lifesaving information.

Beck raises the question: "What good is a legal framework that prosecutes technically manageable small risks, but legalizes large-scale hazards on the strength of its authority, foisting them on everyone, including even those multitudes who resist them?" (Beck, 69) Beck asks this question in regards to global ecological concerns but one could apply this question to the issues involved in TRIPS. When one looks between all of the legal technicalities and stipulations in TRIPS, there is a foundational gap: this international regime of enforced protection of IPRs restricts access to medicines which is a matter of health or illness and life or death for the people who need the medicines to survive. Big Pharma may argue that keeping this patent protection is necessary in order to fund a good level of R&D to save future generations but what of the

millions of lives that are being lost right *now*? These statements may sound dramatic and 'radical' but are they? Perhaps we can be so "imprisoned by our dependence on rationality," as Beck describes, by following the organized standards of 'red tape,' that we are incapable of seeing beyond it, incapable of seeing the exploitation and therefore, incapable of deconstructing issues with a simpler rationality and responsibility—that is, saving lives versus not (Beck, 58).

The HIV/AIDS activist antiBody understood this simpler rationality that TRIPS was a serious roadblock preventing developing countries from accessing ARVs and other essential medicines. They understood the power relations of TRIPS in advantaging the "stronger publics" of Big Pharma and developed countries while disadvantaging a vast majority of "weaker publics" living with HIV/AIDS in developing countries. Therefore, the HIV/AIDS activist antiBody and "counterpublic" brought the issue of HIV/AIDS, trade and access to medicines into the global public sphere of debate. In doing so, they reframed the issue with lifeworld logic instead of system logic in putting the public interest first. They took their first big global stand against Big Pharma, and its counterpart the U.S. government, in the controversy of the South African Government's Medicine Act (1997).

PART II: Milestones in Global HIV/AIDS Activist Treatment Movement (1990s- early 2000s)

Milestone I—South African Controversy

South African Government Makes A Bold Legislative Move

The South African government made a bold move when it established its Medicines and Related Substances Control Amendment Act in December 1997 because the government wrote

TRIPS flexibility measures into national laws, creating a better opportunity to increase its citizens' level of access to essential medicines. The Act:

> encourage[d] the use of generic drugs, prohibit[ed] pharmaceutical companies from paying doctors bounties for prescribing their products … and institute[d] parallel importing as a means to control pharmaceutical costs. The Medicine Act also allow[ed] the government to require compulsory licensing (Wallach and Woodall, 96).

Since TRIPS already allows countries to use compulsory licensing and parallel importation, it might seem as though the government's Act was redundant and not that revolutionary. However, taking the step to include these flexibilities in national legislation makes them socially acceptable and more feasible to use.

Before the legislation was even in place, Big Pharma began protesting its implementation, making visits with South African representatives and lobbying the U.S. government to take action against the South African government. For example, in June 1997, the Vice-President of Johnson & Johnson and Chairman of the U.S.-South Africa Business Council wrote a letter to U.S. Secretary of Commerce William Daley that the new Amendment Act would have "grave consequences for not only the U.S. pharmaceutical industry, but all U.S. direct investment in South Africa" (qtd. in CPTech, "Timeline of Disputes," http://www.cptech.org). In July 1997, the Pharmaceutical Researchers and Manufacturers' of America (PhRMA) met with South Africa's Health Minister Nkosazana Zuma and other representatives from South Africa in Washington to discuss their position on intellectual property rights and pharmaceuticals. The U.S. government was made acutely aware that Big Pharma felt its industry would be severely impacted by the South African legislation.

The main point of controversy was the wording in Section 15C of this new legislation as infringing on international patent rights since it supposedly gave the South African Minister of Health too much power. Section 15C was "designed to override the exhaustion of rights problem

by giving the Minister of Health new over-riding administrative discretion" (Cleary and *Ross*, 450). Big Pharma and the U.S. government feared that if this was interpreted broadly, the legislation would enable the Minister to neglect following the due process of the Patent Act and start 'fast-tracking' compulsory licences.

U.S. Government Protests South African Government Legislation

At first, the U.S. sent Secretary of Commerce William Daley to South Africa to negotiate a revised version of the legislation with President Nelson Mandela's administration that would be better suited to the U.S. and its industry's interests. Yet, even after a revised version was drafted, the U.S. decided to engage in a "full court press" in late 1997 with the hopes of getting the South African government to cancel the Act altogether (Wallach and Woodall, 96).

In February 1998, the U.S. Office of the Trade Representative (USTR) received a letter from PhRMA saying: "South Africa has become a 'test case' for those who oppose the U.S. government's long-standing commitment to improve the terms of protection for all forms of American intellectual property, including pharmaceutical patents" (qtd. in CPTech, "Timeline of Disputes," http://www.cptech.org). Also in this letter, PhRMA asked that the U.S. government designate South Africa as a country on the "Special 301" Priority Watch List, which could lead to the U.S. employing trade sanctions against South Africa (Roffe, Spennemann and von Braun, 16). This sentiment was echoed by many U.S. Members of Congress who also petitioned the USTR for South Africa to be placed under the Special 301 review.

In the same year, Daley travelled to South Africa again to meet with the South African Minister of Health. Rosa Whitaker, the U.S. Trade Representative for Africa, was also sent to discuss the issue (Wallach and Woodall, 96). Even U.S. Vice-President Al Gore himself went to talk to President Mandela in person to urge the government to drop its legislation. Similarly, "the

vice president of the EU, the French and Swiss presidents and the German chancellor all levied similar trade pressure during visits to South Africa"—not coincidentally the countries where Big Pharma corporations are based (Orbinski, 355). Consequently in May 1998, South Africa was put on the Special 301 Priority Watch list. The U.S. government was not alone for long in its legal fight against the South African government because its allies in Big Pharma were quick to bring more legal action against the government.

Big Pharma Takes Legal Action against South African Government

In most of the other areas covered by the WTO, only a country's government can take legal action against another country for not complying with an agreement using the standard Dispute Settlement Understanding (DSU). The DSU permits a country to apply sanctions against another country for not having complied with WTO regulations. Under TRIPS, national governments are not the only ones who can take legal action against a government for non-compliance with TRIPS, private parties can also sue governments through the WTO—private parties like corporations (Stiglitz, 363).

On February 18, 1998, thirty-nine pharmaceutical companies represented by the Pharmaceutical Manufacturers' Association of South Africa (PMA), and backed by PhRMA, launched a lawsuit against President Nelson Mandela and the South African Department of Health. PhRMA labelled the South African legislation as "piracy" and justified the legal action by claiming that the Act did not comply with TRIPS obligations or the South African constitution and followed the U.S. government's lead in pointing to the disputed Section 15C as the main problem. PhRMA's representatives argued that the "arbitrary power" of the Minister of Health was a serious danger to protecting patent rights. In actuality, the only danger Big Pharma feared was the prospect of compulsory licensing being used—more than anything else, these

companies were worried about protecting its profits. The HIV/AIDS activist antiBody was not going to stand idly by. They were concerned about protecting the public health and their voice emerged in a strong global outcry against Big Pharma and the U.S. government.

The Voice of the South African Treatment Action Campaign

The Treatment Action Campaign (TAC), South Africa's most prominent grassroots HIV/AIDS activist organization, was well-accustomed to fighting injustice to protect the rights of PLWHAs living in South Africa. The TAC is primarily made up of "social marginals" from working-class communities who are largely poor, young black women who are either infected with HIV/AIDS themselves or have family members who are/were. The TAC offered a chance to not only fight for the socio-economic rights that PLWHAs have often been deprived of in South Africa but also offered a new support network and a chance to embrace a positive social identity instead of drowning in the negative stigma of being HIV-positive.

Zackie Achmat, a gay activist and a former antiapartheid activist who is HIV-positive himself, is the main leader of the organization along with other African men and women who started off volunteering and later moved into leadership positions (Robins, "From 'Rights' to 'Ritual'", 315-316). This group of activists has worked hard to fight against discrimination and stigmatization of PLWHAs in schools, hospitals, and workplaces. They have also worked to dispel cultural myths surrounding the spread of HIV/AIDS, promoting access to ARVs, and have protested for better governmental policies at the national level (Robins, "From 'Rights' to 'Ritual'", 315).

Through partnership with MSF, the TAC started up ART (antiretroviral treatment) programs in Khayelitsha, Cape Town, and Lusikisiki, Eastern Cape Province (Robins, "From 'Rights' to 'Ritual'", 316). Thus, although these activists were already making such waves at the

local and national level, the controversy over the Medicine Act propelled the TAC into the international arena. For a change, they were able to fight on the same side as their domestic government. They saw the significance that the new legislation could have for its government to issue compulsory licences or parallel importation for cheap generic antiretrovirals and also saw the potential for a national ARV treatment plan to finally come to life. Thus, the TAC turned their efforts to bring international pressure against Big Pharma and the United States government. The TAC launched its campaign in the national and global media, on the Internet, in publicized acts of 'civil disobedience,' and by networking with South African and international civil society organizations. It used David and Goliath imagery to personify the struggle between HIV/AIDS activists and the South African government versus Big Pharma and the U.S. government. Their efforts to target these powers were reinforced with international pressure.

AIDS Activists Mobilize for South Africa

As previously mentioned, after the introduction of HAART the HIV/AIDS activist antiBody became more globally conscious and started concentrating efforts on improving access to HIV/AIDS treatment in developing countries. The South African controversy would mark a visible shift from earlier AIDS activism which had solely focused on pressuring domestic governments to better the treatment situation of PLWHAs.

With South Africa's fight for HIV/AIDS medicines, HIV/AIDS activists and the MSF-led Access Coalition, campaigners from around the world had the opportunity to mobilize around the same goal to show unified action as a global social movement. Activists from groups such as: ACT UP, Health GAP, Medecins Sans Frontieres (MSF), Health Action International, James Love and the Consumer Project on Technology (CPTech) [now known as Knowledge Ecology International (KEI)], and Paul Farmer's Partners in Health all realized not only the

importance of South Africa's struggle but the struggle of all developing countries struggles for access to medicines and they began focusing their efforts to support the TAC's campaign. The first strategic action that members of these groups took to defend the South African government's legislation was to make Al Gore a visible target of public pressure.

Gore was a prime target for activist pressure for a variety of reasons: he was the most vulnerable senior member of President Clinton's administration since he was running for President in the U.S. Election in 2000 and his election campaign was backed by PhRMA companies. In addition, he

> had headed a binational commission with South African deputy president (and later president) Thabo Mbeki in which many of the substantive issues of bilateral U.S.-South African relations were discussed. It was through this commission that Gore had in 1997 and 1998 threatened South Africa with U.S. trade sanctions if it were to violate the strict U.S. interpretation of international patent law (Smith, 64).

To single Gore out in the public eye, activists had the idea of organizing Gore "zaps" to disrupt his campaign trail beginning in June 1999.

AIDS Activists "Zap" Public Consciousness During U.S. Election of 2000

Strategically, activists chose to organize the first zap on June 16 while Gore was making a speech in his hometown of Carthage, Tennessee, during which he would announce his candidacy for presidency. Activists caught Gore off-guard by blowing whistles and yelling "Gore's greed kills" and "Gore kills Africans" in the middle of his speech and proceeded to interrupt the next three stops on Gore's campaign trail which activists cleverly coined as the "Apartheid 2000 Campaign" (Smith, 66). Another significant stunt against Gore was held on June 28 at a fundraising dinner in Philadelphia where activists flaunted a life-size marionette of Gore whose strings were controlled by Big Pharma executives (Smith, 66). The series of demonstrations made for good media coverage since it was perceived that Gore had a "lack-

lustre" campaign anyway, and the demonstrations clearly made Gore and the Clinton administration nervous since campaign officials contacted the activists to put an end to the public protests (Smith, 66).

In early Fall 1999, they protested in front of the U.S. Trade Representative Charlene Barshefsky's office in Washington DC, and even occupied her office. Some activists going as far as chaining themselves to her balcony, throwing empty pill bottles from it and holding a banner that read: "Essential Medications for all Nations" (Smith, 67). Barshefsky later professed ignorance about the cause behind activists' stunts: "'I was certainly not aware of this at all ... In years past, this issue was treated purely as a trade issue and an intellectual property rights issue'" (qtd. in Behrman, 157). Unwittingly, she highlighted the exact ideological problem that activists were working so hard to correct—that in fact, the issue of pharmaceuticals and public health cannot be lumped together with any other area of trade or IPR—that in fact, the issue of access to medicines is much more politically-charged.

Global Civil Society Force U.S. to Finally Drop Legal Action

As activist "zaps" took place in the U.S., the Access coalition and other HIV/AIDS activist groups organized street demonstrations all over the world. Also, "Ralph Nader, MSF and others published open letters to the White House demanding that it drop its threats against South Africa" (Orbinski, 356). While these efforts focused on targeting specific U.S. representatives, other NGOs and movements started introducing "counter-concepts" such as "no patents on life" and "patents kill" into the public consciousness to further politicize the cause against Big Pharma and the U.S. government. [These concepts would be later used by developing countries in formal proposals to the WTO and World Intellectual Property Organization (WIPO) (Dutfield, 538)]. MSF, and other leading NGOs, began using academic consultants with legal experience and

other staff to specifically dedicate their time to IPR; these organizations continue to hire these "counter-experts" to address these issues (Dutfield, 538).

Because of mounting international public pressure, the U.S. administration lifted all threats of trade sanctions against the South African government within ninety days of the initial protest in Carthridge, and Vice Presidents Al Gore and Thabo Mbeki came to a resolution. Al Gore said that he "was not afraid to stand up to the pharmaceutical industry" and unfortunately for Gore, the PhRMA companies switched their funding to back a new presidential candidate (Orbinski, 356-357). Therefore, the U.S. had officially dropped its case against the South African government. On December 1, 1999 (World AIDS Day), during the WTO Ministerial Conference in Seattle (the site of the momentous 'Battle of Seattle' to be addressed in a later section), President Bill Clinton announced a shift in U.S. policy whereby the U.S. government would start considering the public health implications of its trade policy stating that the U.S. would: "henceforward implement its health care and trade policies in a manner that ensures that people in the poorest countries won't have to go without medicine they so desperately need" (qtd. in MSF News, May 11, 2000). The activists' success in influencing the U.S. government to shift its policy continued to make profound ripple effects into the year 2000 when on May 10th "the Clinton administration issued an executive order stipulating that the United States would not challenge TRIPS-compliant policy measures to make AIDS medicines available anywhere in sub-Saharan Africa" (Wallach and Woodall, 96). Although many NGOs and activists such as those of MSF were critical of the U.S. administration's selectivity in only mentioning sub-Saharan Africa in this executive order, this was still an important move in the right direction.

AIDS Activists' Focus on Making Big Pharma Back Down

Thanks to negative publicity and international pressure, the PMA had dropped its case in 1998, but reopened it again in January 2001. The PMA presumed that it would have a better case against the South African government since, in accordance with TRIPS deadlines, South Africa had to start complying with TRIPS regulations as of January 2000 (Wogart et al, 151). With the case reopened, activist efforts were specifically geared towards pressuring Big Pharma.

In response to PhRMA's renewed legal action, the TAC decided to launch its own legal action against the Big Pharma companies. Jamie Love's "CPTech, brought together legal scholars and academics from every continent and submitted a legal briefing to the South African court, adding its weight to the global campaign against PhRMA" (Orbinski, 359). In addition, activists gathered to protest in front of several major pharmaceutical companies located in Europe and North America and there was a sustained effort to keep negative publicity of Big Pharma in the media (von Soest and Weinel, 215-216). "Intellectual property rights activists tended to demonize the large pharmaceutical companies as a core part of their political strategy, and linkage of this campaign to the southern African HIV/AIDS epidemic clearly enhanced popular interest in the case" (Cleary and *Ross,* 453).

MSF researched the difference between the costs of patented versus generic antiretroviral drugs in different countries and posted the results online in order to expose the arbitrary nature of Big Pharma's pricing of patented drugs. One such case that MSF posted was that of "fluconazole, a drug used to treat AIDS-related meningitis, cost 70 cents U.S. a day in Thailand but $20 a day in Kenya. The drug was patented in Kenya, which meant only one company had the right to produce it and could charge whatever it wanted" (Orbinski, 358). The Access coalition organized street protests in New York, Copenhagen, Bangkok, Pretoria, Manila, and

other places around world while other coalition representatives focused their efforts on lobbying governments worldwide to support the South African government. In response, the EU passed a resolution that urged PhRMA to drop their case against South Africa, a complete change from its previous stance which had argued that offering technical advice on trade issues was all that was needed to solve the access problem in developing countries (Orbinski, 357).

In 2001, as an act of defiance against Big Pharma's patents and for increased public exposure, MSF purchased ARVs from a Brazilian generic producer through cooperation with TAC. TAC imported them into the country and MSF prescribed the drugs for free to 150 patients in the TAC/MSF Khayelitsha clinic in South Africa. At the time, Khayelitsha was "home to at least 450,000 people, more than half under the age of thirty, living in brick or corrugated-iron shacks, with raw sewage streaming alongside dusty dirt roads" (Orbinski, 359). TAC and MSF wanted to prove that unlike what Big Pharma public relations was arguing in its battle against the South African government—that it does not make sense for the governments of developing countries to spend money on ARVs when developing countries do not have the infrastructure to support treatment (i.e. running water, refrigerators, etc.)—people living with HIV/AIDS *could* be treated in resource-constrained conditions (Orbinski, 359).

A monumental event which supported the activist stance that HIV/AIDS could be treated in poorer countries was when the *New York Times* released an article in February 2001 which publicized that Cipla, a major generic drug manufacturer in India, lowered the cost of its triple combination antiretroviral treatment to $350 per patient per year, meanwhile the same drugs sold by Big Pharma at the time would cost between $10,000 and $15,000 (Poku, 296; MSF Article, Nov. 18, 2002). Not only did Cipla's offer raise public debate regarding the 1000% mark-up of Big Pharma's costly prices for ARVs, but it also triggered a fierce price war between generic and

brand-name manufacturers which drove down the prices of ARVs and led many political leaders to reconsider the possibility of treating AIDS in developing countries (Joseph, 434; MSF Article, Nov. 18, 2002).

A final surge in the campaign against Big Pharma occurred in March 2001, when Ellen t'Hoen launched an MSF "Drop the Case" Internet petition against the pharmaceutical companies and subsequently collected over 300,000 signatures from people in over 130 countries (Loff, MSF Press Release, Nov. 11, 2002). "Interestingly, the government, HIV/AIDS activists, scientists, and other previously divided stakeholders joined hands to win the court case against the TNPCs [transnational pharmaceutical companies], although they followed different agendas" (von Soest and Weinel, 216). This network of activists succeeded in their quest, PhRMA and the 39 companies dropped their case against the South African government on April 19, 2001.

Success of AIDS Activists and Access Coalition Against Big Pharma

When it was all said and done, the Act was largely unaltered and the South African government reaffirmed its commitment to adhering to the obligations in TRIPS but, activists were victorious in ensuring that TRIPS flexibilities would be interpreted so that public health needs would be addressed first and foremost (von Soest and Weinel, 216). Activists' success laid the groundwork for their campaigns to bring about a national treatment program in South Africa which came to fruition two years later in 2003.

Also, amazingly, "by the end of the year [*2001*], the per-patient price of ARVs had fallen from $15,000 a year for patented drugs to less than $200 for generic versions of the same drugs" (Orbinski, 362). In addition, MSF was able to expand its programs like the ARV treatment program in Khayelitsha to other places all over the world proving that, although challenging, it is possible to have people on ARV treatments in resource-constrained countries if there was the

necessary political will. By 2003, MSF was treating over 40,000 with ARVs in thirty developing countries (Orbinski, 370). The success of the South African government and the HIV/AIDS activists gave the Kenyan government the extra incentive that it needed to pass its own legislation on June 12, 2001, which permitted the use of parallel importation to get cheaper drugs, making it the second African country to do so (Siringi, 2034). Another positive outcome of the South African controversy was that "preparation for the court case ... consolidated TAC's ties with international NGOs" and in general, a more solidified, global treatment access movement took shape (Robins, "AIDS Activism, Science and Citizenship", 664).

Brazilian activists and their government have also encountered friction with Big Pharma, and its counterpart, the U.S. government in their effort to maintain a good level of access to ARVs for its citizens. Brazil's success is yet another example of the rising power of the HIV/AIDS activist antiBody movement.

Milestone II—Brazil's Resilient Fight For Access to Medicines

Brazil's Universal ART Access Program & Advocacy for the Right to Health

Brazilian NGOs and activists played an active role in facilitating prevention and care programs for PLWHAs in Brazil and advocating for a human right to health. Throughout the 1980s and 1990s, "NGOs actively contributed to the adoption of laws and administrative decisions to protect the rights of HIV-seropositive patients and, with the contribution of lawyers, worked to make them effective" (Le Loup et al, 112). It was the work of these activists that motivated the Brazilian government to include the right of universal access to health as a duty of the state in the 1988 Brazilian Constitution (Wogart et al, 149). In 1996, the advocacy of HIV/AIDS activists reaped the success of their efforts to ensure access to healthcare when the

Brazilian government introduced a universal access program for antiretroviral treatment as part of its healthcare policy. This "guarantee[d] the entire population prevention and treatment for HIV/AIDS, the right to diagnosis, and the right for universal and free access to all resources to treat the disease" (Wallach and Woodall, 99). The program provides seventeen antiretroviral drugs to Brazilian citizens for free—eight of which are generic drugs that are produced in Brazil and nine of which are brand-name drugs imported from other countries (Cohen, I-17). As a result of this program, by 2002, there was a 70 % decline in hospitalizations, a 70% decline in mortality, an 80% decrease in morbidity and the Brazilian government saved an estimated US$2.2 billion in public funding (de Albuquerque Possas, 152).

U.S. Brazil's Industrial Patents Law of 1996

In 1996, the same year that the ART treatment program was implemented, then-President Fernando Henrique Cardoso and the Brazilian government decided to make the appropriate changes to its Industrial Properties Law on May 14th so as to make Brazil's patent system TRIPS-compliant. Prior to this point, the Brazilian government's patent law excluded the protection of pharmaceutical products. This exception had made Brazil a prime target for PhRMA which started lobbying against the government for this reason in 1988. The Law provided a high level of protection for intellectual property rights but still allowed for a liberal interpretation of TRIPS to safeguard public health. In particular, the revised patent law included a specific provision which caused some controversy for the U.S. and Big Pharma: "Paragraph 68 forced TNPCs [*transnational pharmaceutical corporations*] to produce their drugs locally within three years of patent approval, non-compliance allowing the government to issue compulsory licences" (Wogart et al, 150). It was because of this paragraph that the United States government brought legal action against Brazil at the WTO through the DSU system in June 2000.

The U.S. disputed the terms of Paragraph 68 because there is no stipulation in TRIPS which indicates that a country can force Big Pharma manufacturers to produce within the country nor is there any provision that allows for the granting of a compulsory licence just because a drug is produced outside of the country (Wallach and Woodall, 99). However, by having this provision in its Patent Law, Brazil was ensuring that medicines would be less expensive for its citizens because either brand-name manufacturers would produce them locally or the government could issue a compulsory licence which would bring down the cost of the drugs substantially.

Due to international pressure from activist groups, the "USTR [United States Trade Representative] announced a consultative mechanism to promote cooperation with Brazil on HIV/AIDS issues in June 2001," and in the end, the U.S. government dropped its complaint against Brazil (Wallach and Woodall, 99). Brazil and the U.S. reached an agreement whereby Brazil would issue compulsory licences in cases of national health emergency.

Brazil Rivals Big Pharma's Dominance

Between its many private manufacturers and public laboratories, the generic pharmaceutical industry has grown considerably, which has given it power to rival Big Pharma. Brazil's "ability to produce certain first-generation ARVs locally and to import APIs (active pharmaceutical ingredient) from China and India enabled Brazil to negotiate price reductions with multinational pharmaceutical firms" (de Albuquerque Possas, 155). Because Brazil has the domestic generic drug manufacturing capacity, Big Pharma takes the government's threats to issue compulsory licences very seriously. Therefore, Brazil has often used the strategy of threatening to issue a compulsory licence in order to force companies to cut the cost of their brand-name drugs by 40% to nearly 65% at times (de Albuquerque Possas, 153).

For example, after Brazil's Ministry of Health discovered that four ARV drugs (Merck's efavirenz, La Roche's nelfinavir, Abbott's lopinavir/Kaletra, and Gilead Sciences' tenofovir) dominated 70% of the Ministry's budget for its ART program, the government put the wheels in motion to see how it would go about getting a compulsory licence for one or all of these drugs (de Albuquerque Possas, 156). The government tried to negotiate with Hoffmann-La Roche Inc. but when the negotiations failed Brazil's Minister of Health, Jose Serra, threatened to issue his country's first compulsory licence for nelfinavir in August 2001. Serra argued that La Roche had left the country in a state of emergency because the price of the drug was so high. The Brazilian government successfully used this threat of compulsory licensing to drive down the price of La Roche's ARV drug Nelfinavir by 40% (Cohen I-17). Brazil's strong history of balancing intellectual property rights and its nation's public health interests sets an amazing precedent that social activism and the governments of developing countries have the power to make their own agenda according to their own people's needs, regardless of big industry interests.

The action of HIV/AIDS activists around the world in places like South Africa and Brazil is a testament to what activists today stand for in the face of decades of profits being put before people.

> Like the revolutionary activists of the nineteenth century who struggled for a better life for all citizens, activists today want to make things political that have been removed from the public eye by cynical politicians whose sole concern is the wealth of their nation. They are intent on repoliticizing and extending the public sphere after two decades of its persistent hollowing out (Drache, "Defiant Publics," 48).

Their efforts would repoliticize health so that the public's interest would be prioritized above trade ambitions; this would reframe the previously untouchable decisions within the WTO's agenda and the signature symbol of this was at the famous 'Battle of Seattle.'

Milestone III—"Counterpublics" Mobilize at 'Battle of Seattle'

The neoliberal promise of a free market creating an equal playing field for all and trickling the wealth down to the poor was not at all coming into fruition and activists around the world wanted to take a stand against a globalization that checked humanitarian concerns at the door. On November 30, 1999, AIDS activists were among the tens of thousands of protesters and members of NGOs that collected in front of the conference center in Seattle where the WTO's Ministerial Meeting was taking place.

Activists shouting and holding signs about labour issues, war, the environment, human rights, and unfair trade agreements that neglect the needs of developing countries created what we know now as the 'Battle of Seattle'—a signature "icon of dissent" for the anti-globalization movement.

> The 'Battle of Seattle' was the catalyst for the legitimization of the anti-globalization movement that burst onto the world stage when thousands of activists disrupted the WTO's ministerial. They wanted inside the closed decision-making process of the world's fully realized global governance institution. Most of all they wanted accountability and transparency—in short, they wanted a responsive and truly public form of economic governance. Activists had begun to punch holes in the Hayekian vision of seamless markets and limited public intervention (Drache, "Defiant Publics," 79).

The massive demonstration was a remarkable display of "counterpublic" power and gave public awareness a much-needed jolt. Seattle also allowed for many like-minded activists to network together to achieve future goals, and this was certainly the case for the global movement for access to HIV/AIDS treatment. "Shortly after Seattle, a global alliance began to take shape drawing together AIDS activists not only from North America and Western Europe but also Brazil, Thailand, South Africa, and other countries and regions of the globe" (Smith, 70).

Just as new communications technology allowed corporations such as Big Pharma to expand and consolidate in size and power during a time of globalization, so too did the same

technology facilitate the rise in transnational social movements such as the HIV/AIDS activist antiBody's movement for access to medicines. In his piece, "The Globalization of the Public Sphere," James Bohman comments on these paradoxical phenomena of globalization when he says: "Although globalization spreads through the escalation of power in larger and larger social systems and institutions, it has also produced an increase in the power of transnational civil society" (Bohman, 200). In activists' struggles to rival Big Pharma, the U.S. and the WTO, one sees how there is evidence of devolution of power to the level of citizens which has enabled activists to challenge global actors.

Activists and the governments of some developed countries had shown the WTO that trade was no longer a realm solely governed by corporate interests and the traditionally powerful wealthy countries of the world. They forced open the closed-door politics of the WTO and made the issue of trade and health a truly public affair; an affair in which they were adamant to have a say. The now global "counterpublic" had made the "stronger publics" of Big Pharma, U.S. and the WTO take notice of their demands.

Conclusion: The HIV/AIDS Activist AntiBody Takes a Global Stand

This chapter has explained how the WTO's TRIPS agreement as a neoliberal international regime enacted a commodification of lifesaving information which promoted market interests over the interests of those living in developing countries. The chapter has also discussed how the protection of pharmaceutical products and patents in TRIPS was pushed for in the WTO by Big Pharma corporations and developed countries. Moreover, significant confrontations in the late 1990s and early 2000s between the HIV/AIDS activist antiBody, Big Pharma, the U.S., the WTO, and the governments of South Africa and Brazil which were

important milestones in the creation of a powerful global HIV/AIDS activist movement were examined.

These confrontations point to the fact that power can be found not only at the higher echelons of international institutions and multinational corporations but can also be found from below—just as the global can drive the local, so too can the local challenge the global. HIV/AIDS activism set an amazing example of how citizens can challenge closed-door politics and back-handed corporate moves by bringing important issues into the public domain so as to make actors like Big Pharma, the U.S. and the WTO more accountable to public demands. The outcomes of this HIV/AIDS activism would have a profound impact on the WTO, the global health agenda and Big Pharma's course of action. Thus, it is the outcomes of this thesis' case study which we will examine next.

Chapter 5: The Public Body in a State of Recovery

Introduction: Signs of Recovery

To this point, this thesis has examined the parallel narratives of two illnesses: neoliberal ideology as a social illness and the epidemiological illness of HIV/AIDS, starting in the 1980s and proceeding into the 1990s. This thesis has also analytically traced the activist antiBody that would work to combat both illnesses through making HIV/AIDS an issue of public contestation which also would inevitably call into question neoliberal ideology as well. Moreover, this thesis has examined Big Pharma as a site of infection for both illnesses due to its socially irresponsible business practices during the 1990s, which made Big Pharma a target for global activism in the late 1990s and early 2000s when issues of IPRs and public health collided. As a result of the confrontations between activists, governments and Big Pharma during this time period, HIV/AIDS activists were effectively able to: influence the WTO's agenda, to put access to HIV/AIDS medicines at the forefront of the global health agenda, and were able to change Big Pharma's business model.

Outcome I—HIV/AIDS Activists Command the WTO's Legislative Process

Activists' Success in Gaining a Legitimate Voice in the WTO

Especially after the 'Battle of Seattle,' the WTO was eager to befriend NGOs and activists so as to avoid a similar scene at the next Ministerial Conference in Doha, Qatar taking place November 9-14, 2001. They wanted NGOs to be informed of WTO proceedings and more importantly, the WTO wanted the inside scoop on any issues or concerns that NGOs felt should be addressed in the upcoming conference. Thus, in the months leading up to it:

> The WTO organized presentations by selected NGOs to Members in Geneva, held briefings and workshops with NGOs, established a public discussions forum (still in place) on its website for organized and self-initiated discussion, circulated NGO views and papers to Members and published a monthly bulletin on NGO/WTO contacts and events of interest to NGOs (Gallagher, 105).

The WTO set up an NGO conference centre for the 365 NGOs attending the Conference right next to the main conference centre. In it, the NGOs were given office and workshop space to facilitate their own separate conferences and press conferences as they saw fit and also allowing them a greater opportunity to network with other NGOs. Senior WTO officials and WTO ministers reported information to NGOs on a daily basis to keep them up to date on discussions as well (Gallagher, 105).

A better information-loop between NGOs and the WTO provided the actors of global civil society with greater knowledge and more forums through which to voice their opinions allowing them more agency in the legislative process to implement change. Significantly, the Doha Ministerial Conference had an unprecedented amount of NGO involvement compared to any prior to it. Another momentous change that Doha represented was the effort to put the trade agenda of developing countries at the forefront, which is demonstrated through the resulting Doha Declaration on TRIPS and Public Health. However, the road leading up to the final Declaration revealed the standard cracks of division at the WTO between the interests of developed countries and industry in contrast to those of developing countries.

Conflictive Interpretations of TRIPS Leading Up to Doha

TRIPS was an agreement that different parties wanted to interpret in different ways depending on their interests. In April 2001, 'the African Group' (a coalition of African countries) requested a Special Discussion on Intellectual Property and Access to Medicines with the TRIPS council (Dutfield, 538). This African group, along with sixteen other developing countries

(Brazil included) as well as support from MSF, HIV/AIDS activists and other NGOs, "sought legally binding language stating that the TRIPS Agreement 'shall' be interpreted and implemented to allow compulsory licensing and other public health measures" (Wallach and Woodall, 100). At the Special Discussion in June 2001, these countries put forth a proposal that would interpret TRIPS with more open-ended language giving countries the leeway to use TRIPS flexibilities in any situation they deem necessary for their own national interest. These countries wanted a formal WTO declaration to state this. The parties involved also pushed for the creation of a provision that would allow countries without drug manufacturing capacity to issue a compulsory licence so that they could import the needed medicines from another country with the capacity to produce the drugs.

Contradictory to this, Big Pharma and countries such as the United States and Switzerland drafted their own proposal using much more specific language which narrowed the parameters within which TRIPS flexibilities could be utilized. They wanted to specify that compulsory licences could only be issued in cases of extreme emergencies and/or specifically for the HIV/AIDS pandemic and did not want compulsory licences to be issued for use outside of a country's domestic market (Wallach and Woodall, 100). Ironically, the U.S. would weaken its own arguments of keeping IPR protection high by contradicting its stance, as well as the interests of Big Pharma, when it was faced with its own public health crisis in 2001.

Activists Speak Out Against U.S. Hypocrisy Revealed in Anthrax Scare 2001

In October 2001, just weeks after the September 11th terrorist attacks, the United States faced a public health scare when Anthrax had been sent via mail to different people in the U.S. government. In response, the government decided to stockpile Bayer's Cipro in case more instances were discovered. "Tommy Thompson, the Secretary of Health and Human Services,

threatened Bayer that if they did not halve the price he would acquire the drug elsewhere. At one stage, he even raised the possibility of asking Congress to pass legislation exempting the government from compensating Bayer for ignoring its patent" (Dutfield, 539).

Five people were killed and seventeen people were infected and sickened by Anthrax but thankfully, it did not affect the larger population as the government had feared. It is interesting to note though that if it had become a full-blown crisis, the United States would have hypocritically enforced its own compulsory licence to mitigate the problem. Unknowingly or not, the U.S. sent a strong and clear message when it threatened to issue a compulsory licence—it implied that TRIPS flexibilities are acceptable when they are used to save certain people (Americans) but unacceptable when used to save others (those living in developing countries). In response, "around the world, the [*Access*] campaign coalition hammered home the hypocrisy of Western governments' invoking the threat of compulsory licensing in the face of anthrax while denying the same right to the developing world in the face of HIV and AIDS" (Orbinski, 372). It would be only a short time later on November 14, 2001 when the Doha Declaration on TRIPS and Public Health would be adopted by the WTO within which Big Pharma and the U.S. position would be compromised.

A Monumental Victory for Activists: Doha Declaration on TRIPS and Public Health

The WTO's Doha Declaration on TRIPS and Public Health "affirmed that the TRIPS Agreement 'can and should be interpreted and implemented in a manner supportive of WTO Members' right to protect public health and, in particular, to promote access to medicines for all'" (Correa, "Bulletin of WHO," 400). The Declaration affirmed the freedom of Member-states to use their own discretion in determining the circumstances under which they choose to use any of the TRIPS flexibilities, including the use of compulsory licences. Moreover, it specifically

outlines that HIV/AIDS, tuberculosis and malaria would be deemed situations of national emergency that would justify the use of TRIPS flexibility measures. The Declaration acknowledged a country's right to block the patenting of trivial developments ('ever-greening') and also affirmed "the freedom of each member to determine its own regime regarding the exhaustion of intellectual property rights (that is, what point of sale the patent right ceases to apply)" (Love, 210). The Doha Declaration also extended the deadline for LDCs to implement TRIPS-compliant regulations for pharmaceutical patents from the original January 1, 2006 to January 1, 2016. On the whole, the Declaration represented a political triumph for the global treatment activist movement and for developing countries.

There was, however, still the unresolved issue of what to do about countries that do not have the capacity to manufacture their own generic drugs if there were to be a national emergency. The TRIPS agreement only allowed compulsory licensing for domestic markets, making the export of drugs issued under these licences illegal. No agreement was reached during the Doha Round since there were arguments regarding: what countries would be allowed to import drugs; what specific diseases would be considered justifiable to use an importer/exporter provision or if this would be left up to the discretion of each country; and what kinds of safeguards would need to be in place in order to make the importer/exporter system work (Fink, 189).

Since there was no resolution, a deadline was set in the Declaration so that the WTO would have to come to a decision on the importer/exporter issue by December 31, 2002. Unfortunately, the December deadline was not met because the United States blocked a proposed compromise. In February 2003, another attempt to reach a consensus on the issue failed once again. With the WTO's failure to come up with a solution, NGOs like Oxfam and MSF exerted

pressure on the WTO to expand Article 30 of TRIPS so that compulsory licence could be issued to a drug manufacturer solely with the purpose of exporting the drugs to a country without the manufacturing capacity to produce the drugs itself (Loff , MSF Press Release, Nov. 11, 2002).It was not until a WTO General Council meeting on August 30, 2003 that the issue was finally resolved.

One Step Forward, Two Steps Back: The WTO's Contentious "Waiver Decision"

The "Waiver Decision" waives the restriction in TRIPS that prohibits countries from issuing compulsory licences to export generic drugs to another country in need. Under this new system, a country without the manufacturing capacity to produce its own drugs could issue a compulsory licence to obtain drugs from a country that is able to manufacture and export the necessary drugs. It was agreed that any LDC could use this provision or any other country that encounters an emergency situation where it does not have the manufacturing capacity to produce the drug in need. (Although these arrangements were decided upon in 2003, the TRIPS Agreement was not amended to include this new provision until December 6, 2005).

There were many countries that actually decided to either opt out of the new system or limit their possible future use of this new provision right away. Several countries [such as Israel and Mexico) (Fink, notes, 195)] stated that they would only use the importation of compulsory licensing if there was a national emergency, while most OECD countries and some countries that recently joined the EU (Malta and Slovenia), twenty-three developed countries total, decided to opt out of using the Waiver Decision system altogether (Fink, 191). However, there were other countries that took the opportunity to implement the terms of the new agreement including the conditions of the Waiver Decision in their national patent legislation. Canada was the first country to reform its legislation to include the terms of the Waiver Decision. The legislation was

passed in May 2004 and was first called the "Pledge for Africa" but is now known as the Canadian Access to Medicines Regime (CAMR). Soon after, Norway and Switzerland would establish their own patent legislation to follow suit.

At the time the Waiver Decision was announced, WTO Director-General Supachai Panitchpakdi optimistically stated that: "The final piece of the jigsaw has fallen into place, allowing poorer countries to make full use of the flexibilities in the WTO's intellectual property rules in order to deal with the diseases that ravage their people" (Gallagher, 112). Some shared his initial optimism about the new possibilities that the "Waiver Decision" was heralded to open up but many were sceptical as to how much this policy change would actually better the prospect of countries using compulsory licences to increase access to generic drugs. One of the main criticisms heard from academia and the activist networks was regarding the amount of regulations set out in the new provision. As Drache comments:

> The rules are so byzantine and strict that generic producers are not able to use them. Of course, this is what branded pharmaceutical manufacturers wanted. They were afraid of a global marketplace where low drug prices in poor regions drove down global prices (Drache, "Defiant Publics," 33).

In order to even take advantage of the new provision, both the importing country and exporting country have to fulfill a series of requirements.

The importing country is obligated to: notify the WTO of its intention to grant a compulsory licence; show that it does not have the manufacturing capacity to produce the drugs in question (unless the country is an LDC); list the names and the quantity of the product(s) needed; and confirm "that it intends to grant a compulsory licence where the pharmaceutical product in question is already patented in the importing country, in accordance with Article 31" (Love, 210). The exporting country must: indicate in its request for a compulsory licence the quantity of drugs that it intends to produce, the generic manufacturer that will facilitate the

request, and the country or countries where the drugs will be exported; clearly label and mark the drugs it produces; take measures to try to ensure that these drugs do not get re-exported somewhere else (especially to developed country markets); and finally, the exporting member must inform the TRIPS Council of all the aforementioned details and must outline all of these on the designated website (Love, 210). Moreover, the compulsory licence must only be granted on a case by case basis between the importer and exporter. This means that multiple orders for the same medicines cannot be applied for under the same licence therefore the time-consuming process needs to take place every time, even if the importing country just needs to obtain more of the same medicine from the same manufacturer. As MSF's Orbinski comments, "presented as a gift to the poor, it created a maze of red tape and hurdles that, once passed, could in theory allow for export of generic versions of patented medicines to a requesting country" (Orbinski, 373).

Despite the evident drawbacks of the many requirements of the Waiver Decision, undeniably, the fact that the Doha Declaration on TRIPS and Public Health and the "Waiver Decision" even exist demonstrates the mounting power that developing countries and activists are gaining in the global public domain through holding powerful global actors like Big Pharma and the U.S. accountable for crafting a neoliberal political economic order through an international organization like the WTO.

Big Pharma & U.S./EU Evade WTO by using 'TRIPS-plus' conditions in RBTAs

Having experienced the intensity of public pressure and because developing countries have a more assertive role in the WTO, both the U.S. and Big Pharma have protected IPRs for industry interests via regional and bilateral trade agreements (RBTAs) by including 'TRIPS-plus' conditions (conditions that protect IPR at an even higher level than those written in the TRIPS agreement).

RBTAs present an ideal avenue for the U.S. and the EU to manipulate developing countries into agreeing not to use TRIPS safeguards to the fullest extent in exchange for better market access in other areas of trade. In 1990, there were only 20 bilateral and regional agreements of which the GATT was informed but by 2007, the number had jumped to 159 of these agreements reported to the WTO. TRIPS-plus protection can include a variety of stipulations such as:

> extending patents and copyright to new kinds of subject matter; eliminating or narrowing permitted exceptions including those still provided in U.S. and European IPR laws; extending protection terms; introducing new TRIPS-mandated IPR rules earlier than the transition periods allowed by TRIPS; and ratifying new WIPO [World Intellectual Property Organization] treaties containing TRIPS plus measures (Dutfield 535).

Another condition not imposed through TRIPS which countries have signed onto in these agreements is the linkage of drug registration and patent protection which means that if a pharmaceutical product is patented then a generic version of the drug must be denied marketing approval unless the patent owner consents to it being allowed (Correa, "Bulletin of WHO," 401). Although the EU and U.S. push for 'linkage' in these agreements with other countries, they actually do not have this stipulation in their own patent systems. There have been four bilateral agreements with Australia, Jordan, Singapore and Vietnam that set restrictions on the use of compulsory licensing to only antitrust remedies, emergency situations and cases of public non-commercial use, clearly going against the Doha Declaration that had made it clear that WTO Member-states could implement compulsory licences when they saw that it was needed for the health of their citizens. Also contradictory to the spirit of the Doha Declaration, is the U.S. bilateral agreements with Australia, Morocco and Singapore that permit patent holders to block parallel importation (Fink and Reichenmiller, 290).

The consequences for breaching intellectual property rights in these agreements also surpasses the enforcement measures allowed for in TRIPS because these free trade agreements impose fines irrespective of the damages suffered by an IPR owner and they explicitly set out what IPR infringements would necessarily lead to criminal action (Fink and Reichenmiller, 293).

All of these TRIPS-plus conditions can severely impact a country's level of access to essential medicines. An Oxfam analysis of the impact of the U.S.-Jordan Free Trade Agreement found that the prices for medicines increased by 20%. Moreover, the agreement effectively delayed generic competition and the high cost of drugs threatened the sustainability of government public-health programmes (Oxfam Briefing Paper, "Investing for life," 19). Why do developing countries agree to these terms then? The answer could be one of many: the desire to get political or some other kind of support from developed countries; the belief that there will be an increase in foreign investment; the effort to avoid trade sanctions; to gain better access to developed country markets; or because they have been persuaded by lobbying efforts from industry, the World Intellectual Property Organization (WIPO), and/or patent offices from developed countries (like Australia, the EU, and the U.S.) (Shadlen, "Intellectual Property, Trade, and Development," 174; Smith, Correa and Oh, 688).

Therefore, Big Pharma lobbies the U.S. and the EU to manipulate the more equitable playing field in the WTO by circumventing this forum altogether and instead utilizing RBTA. However, they do so in the midst of NGOs and activists' outcries against them. The governments of developing countries also continue to put forth the same demands, in calling for the prioritization of health above trade into realms other than the WTO in order to counteract the TRIPS-plus conditions in RBTAs. For example,

> in 2004, under the leadership of Argentina, Brazil and Kenya, developing countries pushed negotiations for a 'Development Agenda' in WIPO and a medical R&D treaty in WHO, hoping to provoke further discussion of the value and the optimum timing of IPR legislation in developing countries (WIPO, 2005)" (Wogart et al, 143).

Such is the game of shifting power in the global arena as is evidenced by the case of activists forcing the U.S. and Big Pharma to drop their court cases and in successfully redirecting the WTO's legislation. This is also demonstrated in HIV/AIDS activists' success in putting access to HIV/AIDS treatment on the global health agenda as well.

Outcome II—HIV/AIDS Activists Put Access to HIV/AIDS Treatment on the Global Agenda

For many years, a behavioural change hypothesis dominated both bilateral and multilateral responses for fighting HIV/AIDS in the developing world. This response involved pushing education and information campaigns as the sole efforts to prevent the spread of HIV/AIDS in the developing world; this kind of prevention was deemed the only feasible intervention, and public health officials, AIDS experts and policymakers considered treatment a 'pipedream' for any HIV/AIDS initiative in a developing country. "In 2000, at the International AIDS Conference, for example, WHO officials presented the fragile health systems of most developing countries as arguments against an aggressive effort to expand HIV treatment access" (Russel, 231). Moreover, myths permeated the Western/Northern discourse (and still do) about both the spread of HIV/AIDS and the impossibility of treatment in developing countries. Examples of these myths include: that it is mainly spread through promiscuity in these countries; that any efforts to combat HIV/AIDS with treatment will essentially be ruined by inevitable corruption; that AIDS treatment is impossible in resource-constrained settings; and that AIDS prevention and treatment are two completely separate responses to AIDS (Farmer, xviii-xix).

Sachs comments on the substantial ideological block that existed against treatment interventions before 2001:

> As of early 2001, the donor world still shunned the idea of using anti-AIDS drugs in low-income countries to save the lives of people with late-stage AIDS disease. The donor world viewed anti-AIDS drugs as hugely expensive and technically impractical—in short, not cost-effective. Getting global financing for them in Africa was still a huge uphill struggle. The most common claim was that anti-AIDS treatment wouldn't work anyway. Impoverished and illiterate patients would not be able to comply with complicated drug regimens (Sachs, 205).

It was the efforts of global activism, the highly publicized South African, Brazilian cases and the 'Battle of Seattle', as well as the subsequent stark decline in the price of ARVs from generic competition which transitioned international institutions into accepting treatment as a feasible response to HIV/AIDS in the developing world.

The United Nations General Assembly Special Session on HIV/AIDS (UNGASS) from June 25-27, 2001 brought together activists and representatives from NGOs, the private sector, governments and private foundations. "This meeting addressed the many facets of the HIV/AIDS epidemic, including human rights issues and the public health, social and economic effects, as well as the developmental impact of the epidemic" (Lampety, Ruckstuhl and Cates, 177). This special session led to the creation of the UNGASS Declaration of Commitment on HIV/AIDS (2001) which states both prevention and treatment as obligatory goals for successfully combating HIV/AIDS at a global level. The effect of the Declaration was substantial:

> Since then many countries, through the support of intergovernmental organizations and donors, have definitively demonstrated the feasibility of delivering HIV treatment in even the most resource-limited settings. Access to treatment has helped mobilize communities in the response to HIV, preserved the health and viability of households vulnerable to HIV, and strengthened HIV prevention efforts in many parts of the world (UNAIDS, Policy and Practice, HIV Treatment, www.unaids.org).

The Declaration stated support for both research-based Big Pharma companies and generic companies being involved in the response to better access to HIV/AIDS medicines and also

called for the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria (to be discussed in greater detail later in this chapter).

Also as a result of the recent AIDS activists' struggles and global public controversy, the World Health Organization's policy response towards HIV/AIDS in developing countries became more specifically geared towards treatment as well. In April 2002, the WHO announced that it would add twelve AIDS medicines to the 13th version of its Model List of Essential Medicines. The WHO's Model List is meant to be an example that nation-state governments can use to construct their own national lists of essential medicines—that is medicines "that satisfy the priority health care needs of the population" (www.who.int). The medicines included on the list are chosen based on the quality and cost-effectiveness of the medicines as well as the prevalence of the illness or disease that the medicine treats. The initial high costs of ARVs deterred the WHO from putting these drugs on the list but the decline in prices from generic competition after 2001 made their inclusion feasible. The fact that ARVs were added to the WHO's list indicates that HIV/AIDS is more likely to be addressed as a public health priority and that ARVs are more likely to be added to national essential medicines lists meaning that governments should make more of a concerted effort to ensure a good level of access to those medicines. When Lee Jong-Wook became the WHO's director-general in 2003, he called the lack of access to HIV/AIDS medicines "a global health emergency" and in December of the same year, the WHO introduced its "three by five" initiative which aimed to have three million people in developing countries on ARV treatment by the end of 2005 (Orbinski, 370). The funds donated by various countries were late in arriving and less than initially pledged and the WHO failed to achieve its goal, since there were only 1.3 million people receiving ARV treatment by 2005. However, the WHO then

quickly came up with the "Universal Access by 2010" initiative which aimed to have 6.5 million people on ARV treatment by 2010.

The new global health agenda's commitment to integrate the provision of treatment into plans to mitigate HIV/AIDS, along with prevention, is the result of activists' efforts in advocating for the individual's right to health and fighting to make medicines more affordable. In doing so, AIDS activists successfully framed access to essential medicines and healthcare as a public good that citizens should be able to access—they successfully framed the illness of AIDS and AIDS treatment as political by constructing medicines as public goods and access to health as a human right.

> It has become apparent that AIDS is a *political* issue that requires leadership and state capacity. The realization that health and politics are interrelated is crucial not only for policymaking on HIV/AIDS but also for the development of a larger commitment to public health (Patterson, 217-218).

The HIV/AIDS antiBody's success is further evident in how activists' lifeworld logic actually changed Big Pharma's system logic since these corporations began making more of a concerted effort to take part in corporate social responsibility initiatives to improve access to ARVs in developing countries.

Outcome III—Activists Force Big Pharma to Change its Course

HIV/AIDS Activists Problematize Big Pharma's Public Image

The naming and shaming tactics of AIDS activists successfully chipped away at the power of Big Pharma by making people far more aware of the industry's darker details, costing Big Pharma its reputation and money. "According to a major consultancy firm, a loss of faith in the industry on the part of its investors has so far cost pharmaceutical's shareholders $1 trillion dollars" (Oxfam Press Release, 2007-11-21). In her article, "The Reputation, Image and

Influence of the Pharmaceutical Industry: Regaining Credibility" in the *Journal of Medical Marketing*, Jane Parker discusses how media and popular culture representations of Big Pharma led to a public relations crisis for the industry. From Michael Moore to *The Simpsons* to Jay Leno to *The Constant Gardener*, Big Pharma has been portrayed in a negative light. Parker states the problem quite simply when she says: "the true and harsh reality is that, today, perception is the only thing that matters. Although some now argue that perception *is* reality, it is what is now done about mistakes by individuals and by corporations and by the industry that will set it apart" (Parker, 310). In a mass media environment of continuous information flows, the importance of maintaining a good public relations image for any corporation is crucial.

> Indeed, CEOs understand that if they neglect the nonmarket side of their activities, they can risk the very success of the company. The reputational costs to business of blocking solutions to vital challenges can be devastating to shared values, customer loyalties, worker morale, the ability to recruit new employees, and even the social acceptability of their continued operations (Sachs, "Common Wealth," 320).

Increased public pressure regarding access to ARVs created a public relations debacle that made these corporations' old business model, which had completely ignored the access problem to HIV/AIDS medicines in developing countries, completely unviable. One of the ways in which Big Pharma has adjusted its business practice is through granting more voluntary licences for generic producers to manufacture HIV/AIDS medicines.

Big Pharma's More Lenient Stance on Voluntary Licences

Since the early 2000s, Big Pharma corporations have been much more willing to agree to grant voluntary licences for generic drug production of HIV/AIDS medicines to improve access to medicines in developing countries which is a tremendous change in the industry's more stringent position. However, this position needs to be shifted even further as most of the licences granted have been for first-line antiretroviral drugs. First-line antiretroviral drugs are the drugs a

person living with HIV/AIDS takes during his or her initial treatment regimen and are of an older generation of HIV/AIDS drugs. Second-line antiretroviral drugs are needed usually after a number of years when a person's HIV virus becomes immune to the previous first-line treatment regimen and therefore, he or she requires a new combination of drugs for treatment to work. There are also third-line drugs which is another combination of drugs that are required if a person stops responding to the second-line treatment regimen.

Because of generic competition, the prices of first-line drugs are no longer as serious an issue while second-line and third-line drugs are much more expensive. Since the second-line drugs are increasingly becoming an issue in terms of cost and access, Big Pharma is reluctant to grant voluntary licences for them because they do not want generic competition to throw off their current price-setting ability. As a result, Bristol-Meyers Squibb has been the only Big Pharma company which has issued a voluntary licence for a second-line antiretroviral drug when it granted one to the Indian generic manufacturer Emcure for the drug Atazanavir (Oxfam, "Investing for Life," 21). Even though Big Pharma's granting of voluntary licences has been thus far primarily for first-line ARVs, these are still positive moves in industry practice. Yet another way in which Big Pharma has adjusted its business agenda to be more socially responsible with regards to access to ARVs has been Big Pharma's donation programmes and its tiered-pricing.

Big Pharma Starts ARV Donation Programmes &Tiered-Pricing

In response to the global public controversy that HIV/AIDS activists created, Big Pharma companies responded by starting up their own individual philanthropic donation programs whereby they donate ARVs to needy communities in developing countries. Some examples of these initiatives include: GlaxoSmithKline's Access to ARVs Program, Merck & Co., Inc.'s Access to ARVs Program, and Abbott's Program for Expanding Access to Testing and

Treatment. Although well-intended, the donation programme strategy has demonstrated its share of inefficiencies such as unpredictable flows of products, products that are unsuitable to local needs and those that are near their expiration dates. Moreover, donations completely undermine market competition "as generic companies cannot compete with free drugs: the ability to predict demand is necessary if they are to use their innate efficiencies to achieve low prices" (Oxfam, "Investing for Life," 23).

As opposed to donation programmes, other companies opted to implement tiered-pricing which maintained regular market prices in developed countries but reduced the cost of ARVs for developing countries. The pricing scheme is negotiated with each respective country on a case-by-case basis depending on the country, the region, the drug and the volume of drugs in question. After interviews with representatives from the top twelve Big Pharma companies, Oxfam deduced that:

> a number of companies [*such as Novartis, Johnson & Johnson and Eli Lilly*]—somewhat simplistically—segment the market into two in some developing countries; rich and middle-income people for whom medicines are priced at a level similar to those in the developed world, and poor people, who are provided with drugs at allegedly non-profit prices through philanthropic programmes and partnerships via patient-access programmes (Oxfam, "Investing for Life," 14).

Organizations like Oxfam criticize the case-by-case basis method of negotiating prices because it is difficult to determine Big Pharma's price-setting strategy making the process less than transparent and advocates that Big Pharma should introduce a standardized tiered-pricing system which applies to all essential medicines and would be based on ability to pay. The fact that Big Pharma has been compelled to even initiate these programmes is at least a step in the right direction.

Another demonstration of corporate social responsibility which Big Pharma became much more involved with in the late 1990s and early 2000s was public-private partnerships (PPPs).

Big Pharma Gets More Involved in PPPs

Public-private partnerships for health can involve any variety of partners in interesting hybrids made up of governments, NGOs, corporations, and/or multilateral institutions. The Initiative on Public-Private Partnerships for Health (IPPPH) defines these partnerships as: "arrangements that innovatively combine different skills and resources from institutions in the public and private sectors to address persistent global problems" (Bull and McNeill, 66). The purpose of each partnership varies whether created to develop a product, coordinate different groups, distribute donated or discounted drugs for disease control, educate people, improve health infrastructure and services, or improve the quality or regulation of products (Widdus, 717).

The increase in Big Pharma's involvement in PPPs for HIV/AIDS in the late 1990s and into the 2000s, must be understood within the context of the aforementioned confrontations. As Caroline Thomas explains:

> As global protests and increased campaigning in the light of the heavy-handed approach by transnational pharmaceutical companies and the US government began to make the neoliberal stance less acceptable, attempts at a diffusion of that stance came under way. It is in this context that the latest proposals for public-private partnerships have to be understood and evaluated (Thomas, 262).

The market-driven logic with which Big Pharma and its U.S. counterpart were operating had been named and shamed by HIV/AIDS activists, making the general public contest the actions of these actors as well. Since its strict neoliberal paradigm for conducting business had come under global attack, Big Pharma was forced to show a more socially responsible side.

In some cases Big Pharma started getting more involved in partnerships to fill in the blind spots in the R&D agenda such as working with the International AIDS Vaccine Initiative (IAVI). IAVI is a major public-private partnership which collaborates with academic, governmental and commercial institutions to supplement the pharmaceutical industry's gap in HIV/AIDS vaccine research by "funding of clinical trials, and to ensure that any vaccine that displays sufficient efficacy will be cheap and readily available to the regions of the world where it is needed most" (Chataway and Smith, 17). Big Pharma has also been known to collaborate with the Drugs for Neglected Diseases initiative (DNDi) to compensate for another R&D gap in the industry. The DNDi is a public-private partnership initiated by the MSF-led Neglected Diseases Working Group that involves industry, NGOs and academics to invest research in medicines that would benefit the poor but for which the pharmaceutical industry has little market incentive to invest on its own.

Another significant area in which Big Pharma has readily joined in public-private partnerships that provide medicines to developing countries in need, the most significant of which is the aforementioned Global Fund to Fight AIDS, Malaria and Tuberculosis (Global Fund).

Big Pharma Becomes a Partner in the Global Fund

The Global Fund was officially announced at the African Summit on HIV, Tuberculosis, and Other Related Infectious Diseases (ORID) in Abuja, Nigeria in April 2001. The Global Fund had been driven by the momentum of the Millennium Development Goals (MDGs) in 2000. Goal #6 of the MDGs was set to stop the spread of the HIV/AIDS by 2015. Both the MDGs and the Global Fund were sparked by HIV/AIDS activists' and the Access coalition's demands and were then pushed forward through the bureaucratic channels by two key figures: Jeffrey Sachs,

head of the UN Millennium Development Project and chair of the Commission on Macroeconomics and Health of the World Health Organization, and UN Secretary General, Kofi Annan.

The aim of the Global Fund is to mobilize resources to fight AIDS, Malaria and Tuberculosis. As its official website states:

> The Global Fund is a unique global public/private partnership dedicated to attracting and disbursing additional resources to prevent and treat HIV/AIDS, tuberculosis and malaria. This partnership between governments, civil society, the private sector and affected communities represents a new approach to international health financing. The Global Fund works in close collaboration with other bilateral and multilateral organizations to supplement existing efforts dealing with the three diseases (www.theglobalfund.org).

The Global Fund is based in Geneva, Switzerland but its organizational structure and operating mechanisms are quite decentralized and span different countries. The first core structure of the Global Fund is the Country Coordinating Mechanism (CCM) which is the local level public-private partnerships that act as the primary entity in each country which receives grant proposals and then channels them forward. Thus, the initiative starts at the local level whereby proposals from civil society organizations and groups in different communities and regions are sent to the CCMs. These proposals are then subsequently forwarded through other structures (Secretariat, Technical Review Panel, etc.) until funding approval is finally either granted or denied depending on whether the proposed projects and initiatives fit the Global Fund's mandate. The governing Board has the most power in accepting or rejecting these grants and it is made up of twenty-three representatives including: government officials (with equal representation from developed and developing countries), two representatives from NGOs (one from a developed and another from a developing country), two private sector representatives,

one person living with HIV/AIDS, malaria or tuberculosis, and the involvement of multilateral institutions (UNAIDS, World Bank, and WHO).

It is significant that there must be a person living with HIV/AIDS as a Board representative because this is yet another testament to how activists were able to secure a legitimate voice at the table in the global arena. As a result of their fight for access to medicines, PLWHAs attained a position that would allow them to have a direct say in the Global Fund, arguably one of the most influential organizations that affect how access to medicines for the developing world will be addressed. Activists' former adversary, Big Pharma, secured a place within this partnership as well. Big Pharma's job as a partner is of central importance as it provides discounted drugs for initiatives approved by the Global Fund. Big Pharma most likely realized that working towards a solution to the access to medicines problem via the Global Fund would not only be good for the public at large but would also be good for business since not only did involvement in the Global Fund present a great public relations opportunity, but it also presented predictable demand and a larger market for drugs. "The Global Fund could affect the operations of pharmaceutical companies through providing larger markets for drugs. Purchase of drugs and commodities consumed 46 per cent of the funds in 2002/3 (Global Fund 2003)" (Bull and McNeill, 80).

There has, however, been criticism from academia and NGOs who opposed Big Pharma's involvement in the Global Fund rather than having generic manufacturers involved. Through basic economies of scale in purchasing generic drugs, the Global Fund could have contractually driven the cost of ARV drugs lower through generic competition which would have consequently benefited the people and projects that are currently not supported by the Global Fund. One academic voiced her concern at the time:

> A decision to permit generics to bid on procurement contracts will institutionalize market competition and drive prices—including those of new drugs—downward. Exclusion of generics will help consolidate the brand-name cartel and perpetuate their hideously indefensible strategy of putting profits before lives (Poku, 297).

Many countries have had serious distribution problems since the trickle of drugs that comes in 'rounds' is so small that the question of where to send them becomes an ethical issue. For example, when Uganda was granted its first round of drugs through the Global Fund, there was only enough for 3000 people. For a country that has 40 different ethnic groups, 5 major religions, 13 regions, 60 districts, 300 parliamentary constituencies and more than 200,000 people in need of ARV treatment, it would be extremely difficult to equitably allocate these drugs (Mugyenyi, 254). Many believe this problem might have been helped by procurement of generics.

Even still, since the Global Fund became operational and gave out its first round of grants in 2002, the Fund has had amazing success "with approved funding of US$ 11.4 billion for more than 550 programs in 136 countries. It provides a quarter of all international financing for AIDS globally, two-thirds for tuberculosis and three quarters for malaria" (www.theglobalfund.org). Big Pharma's involvement in making the vision of the Global Fund a reality cannot be underestimated because Big Pharma's line of vision has clearly been infiltrated so that these corporations' business plans now extend beyond the dollar signs of the market domain and now also take into account issues of access.

An Activist AntiBody Successfully Commandeers the Course of Two Illnesses

From its original formation in the 1980s, the HIV/AIDS activist antiBody has been successful in helping to fight the spread of HIV/AIDS and a market-driven neoliberal ideology.

Successfully Combating HIV/AIDS

Initially, the main concern of these activists was to provide the public with HIV/AIDS information and constructing new understandings of the illness and of people living with it so as

to counteract the associated negative metaphors. Activists mobilized as a "counterpublic" combating the mainstream discourses and responses of the "stronger publics" and making HIV/AIDS an issue of contestation in the public sphere, at first domestically and then globally. Thus, the activist antiBody successfully fought ignorance and stigmatization related to HIV/AIDS, winning over celebrities, governments and the UN—the world started paying attention to HIV/AIDS as a crisis.

These activists also broke out of the conventional 'patient' role and instead took an active role in the biomedical sphere of debate. They published research results, critiqued practices in clinical trials, redefined the clinical definitions related to HIV/AIDS and as a result, they revealed the politics of medicine to the public. As opposed to the research agenda and practice of medicine being closed off in the private sphere of the biomedical establishment, activists broke open the doors making HIV/AIDS public. In doing this, activists would also gain a respected voice in the biomedical discourse to the point where medical professionals began teaming up with HIV/AIDS activists for campaigns. Thus, in this aspect, the activist antiBody fought the biomedical paradigm to claim issues of illness and health for the public domain.

Finally, these activists would challenge Big Pharma; contesting its profit-driven research agenda and pricing of HIV/AIDS treatments. Their contestation against Big Pharma politicized access to medicines, setting them apart from other commodities in the marketplace and instead framing medicines as public goods and framing the access to treatment within a human rights discourse. In response to activist demands, Big Pharma corporations reduced the cost of medicines. Thus, activists also successfully fought for access to HIV/AIDS treatment and by doing so, simultaneously fought against the neoliberal, system logic of Big Pharma.

This fight for access led to a global mobilization of the HIV/AIDS activist antiBody which would successfully change WTO's agenda to prioritize health over trade, make HIV/AIDS treatment a central point on the global health agenda, and would also change the course of Big Pharma's business practices, all of which provides the public body with more resilience in fighting the HIV/AIDS pandemic.

Successfully Combating Neoliberal Ideology

The voice of the HIV/AIDS activist antiBody and the governments of developing countries disrupted the neoliberal political economic globalization that the 'powers-that-be' crafted; presenting an antiBody to the neoliberal illness of ideologically prioritizing the market over people. The successful story of HIV/AIDS activism is an example of how Drache explains:

> Micro-activism has exploded as a global phenomenon, and the great reversal of our age is that the list of what is shared in common is no longer shrinking. The pessimism of the neo-liberal age is challenged by the skepticism of dissenting publics and rebellious activists (Drache, "Defiant Publics," 167).

In targeting the powerful global actors of Big Pharma, the WTO and the U.S. government, activists exposed the public to the underpinnings of the global commodification of health that had been carried out as a result of the spread of neoliberalism. The growth of the HIV/AIDS activist antiBody and the access to medicines movement demonstrates the decentralized grassroots social justice globalization project rivalling the prescribed neoliberal economic globalization that had ideologically prioritized private interests over people.

The fact that HIV/AIDS activists and developing countries highjacked the neoliberal agenda to instead put forth their interests on the world's trade agenda, the global public health agenda and multinational corporations' business agenda, demonstrates that activists do have power to vocalize their demands in the global public sphere of debate by tapping into the power of a new transnational civil society. Through these processes one can distinguish "these

transnational social forces as creating an alternative globalization, 'globalization-from-below', to offset the cooptation of governments by the market-oriented forces associated with 'globalization-from-above'" (Falk, 14).

One of the primary ways in which the HIV/AIDS activists, as part of this "globalization from below," were able to inoculate the public against the spread of neoliberal ideology was by showing people that if they accept the power of their own political agency, they can have an impact even within the seemingly supra-entities of global institutions and the global marketplace—which by a neoliberal reading could only be 'apolitical' in nature. A citizen can look to the example of the history of the HIV/AIDS activist antiBody and recognize that the making of things once private and apolitical as 'public' and 'political' can be the making of social change. This is why this thesis' case study has reverted away from globalization theory's deterministic reading of the processes and events during the1990s since this theory writes out a pivotal element in any time period—that is, agency. Instead, this thesis' case study has used the aforementioned theoretical framework that has drawn from critical political economy, critical communications theory, and citizenship studies to explore this topic in order to further inoculate the public against the illness of social indifference.

Unresolved Issues & Policy Recommendations

Although optimistic about the prospect of further social change, one must keep in mind that the problem of access to HIV/AIDS and other essential medicines for the poor is far from being resolved and there are still considerable roadblocks in the way of achieving the goal of universal access for all. Change is still necessary in international and national policy, in Big Pharma's business operations, and in the initiatives used for health and HIV/AIDS in developing

countries. I would like to address some key recommendations that might be beneficial for future considerations.

Filling in the Gaps: Revitalizing R&D for Neglected Diseases

As evidenced by Oxfam's interviews with the top twelve largest pharmaceutical companies in 2007, some of them have increased their R&D into diseases severely affecting developing countries, the majority of which has been geared towards HIV/AIDS, malaria and tuberculosis, but there is still a lack of target expenditures for R&D for neglected diseases being published by the industry (Oxfam, "Investing for Life," 16). However, through this series of interviews, Oxfam also discovered that there is an industry-wide belief that establishing public-private initiatives is the best solution for pursuing the much-needed R&D into diseases that are prevalent in developing countries. Therefore, the industry would rather choose to rely on partnerships with such initiatives as the aforementioned International AIDS Vaccine Initiative (IAVI) and the Drugs for Neglected Diseases initiative (DNDi) to solve the industry's lack of R&D into neglected avenues of research that would benefit the poor.

Optimism is appreciated as these initiatives are noble in goals, but unfortunately according to Oxfam's records, "only one product—a non-patented once-a-day fixed-dose combination for malaria—has made it to the market as a result of such partnerships (Oxfam, "Investing for Life," 16). This malaria drug was developed out of a partnership between Sanofi-Aventis and the aforementioned DNDi. In the case of this malaria drug, Sanofi-Aventis agreed not to patent the drug so that it could reach as many people as possible but this decision is left up to the discretion of the company involved in any of these partnerships. Novartis, for instance, states that it will patent whatever drug is produced out of one of these partnerships. Also, because most companies involved in these partnerships do not publish any specific targets about

timelines or financial or technical contributions, it makes it difficult to monitor how effective or serious the companies' commitments are within these initiatives (Oxfam, "Investing for Life," 16). Although IAVI, DNDi and other similar collaborative are beneficial, they act as 'band-aid' temporary solutions to the underlying problem that currently Big Pharma's R&D is not based on innovation or need but rather on profits. If the R&D agenda of the pharmaceutical industry was rerouted then IAVI and private foundations would not be needed. Pharmaceutical companies should be incorporating R&D for neglected diseases as part of their 'business-as-usual' routines and thus, multilateral institutions and governments should be creating more incentives not only for the industry, but also for universities and research institutes to invest in R&D in these areas.

The WHO already uses "push" and "pull" mechanisms to provide this incentive and should continue to do so. The WHO implements "push mechanisms" by funding research projects of its choosing, thereby pushing R&D for specific diseases it deems a priority through its collaboration with different research institutes and universities. The WHO's "pull mechanisms" involve giving money to public programmes so that they can buy large amounts of specific drugs and vaccines in order to create a demand which the industry would have to supply (Bull, 67). UNICEF also procures vaccines with this goal in mind. Nation-state governments, with the necessary political will, can also provide push and pull mechanisms of their own to entice industry "such as public investment in basic research, sharing the costs of efficacy trials or other aspects of development, sharing the costs of production facilities, harmonizing international regulatory requirements, and introducing tax credits for investment in research and development" (Widdus, 716).

In February 2004, 162 scientists, public health experts, law professors, economists, government officials, members of parliament and civil society organizations came together to

sign a treaty which was submitted to the WHO's Executive Board and the World Health Assembly Committee on Intellectual Property. This treaty specifically dealt with the matter of improving the legal global framework for supporting R&D in order to increase access to medicines (de Albuquerque Possas, 162). On another note, if any public-private initiatives are to be effective for R&D into neglected diseases, there needs to be closer monitoring of goals and the commitment of companies to the cause so that any PPP amounts to more than just a public relations gimmick.

Given the current lack of new marketable drugs and a wave of expiring patents, even if solely for the sake of pleasing its investors, Big Pharma has to break away from the blockbuster model of R&D and diversify its portfolio to spread the risk in investments (Oxfam, "Investing for Life," 27). Furthermore, from a business perspective, there has proven to be considerable market potential in developing countries which is why Big Pharma should direct more investments towards diseases in these countries. "According to recent estimates, by 2020, Brazil, Russia, India, China, South Africa, Mexico, and Indonesia could account for up to one-fifth of global sales" (Oxfam, "Investing for Life," 28). Big Pharma would need to adapt its current operations for these markets by: lowering prices, possibly moving to a high-volume, low-profit margin model, using flexible distribution systems and of course, moving away from the blockbuster line of R&D (Oxfam, "Investing for Life," 28).

Increasing Access to Medicines for Developing Countries

Although NGOs, grassroots movements, and private foundations do their part in trying to increase the level of access to medicines in developing countries through a plethora of decentralized civil society initiatives, there are other possible avenues.

First of all, although NGOs and the like can provide local communities with HIV/AIDS treatment, nation-state governments need to become central providers of treatment. Elizabeth Pisani points to the limitations of ad hoc initiatives and the importance of a comprehensive state response when she says:

> We need 'good enough' services for everyone who needs them. We need to shift from the boutique, community-driven, bend-over-backwards approach and go instead for the discount supermarket approach. Pile it high and sell it cheap. Look around. Who provides mediocre services to vast numbers of people? Governments (Pisani, 176).

It is also important to note, however, that in order for the government to even be able to implement such programs the state will need to collaborate with existing NGOs to find the best course of action.

> Many of the best government programmes are the ones that have co-opted the NGOs, sucked in their experience, their know-how, sometimes their staff. More and more, governments and NGOs are working together in teams, with one side providing the design tools and the other the production volume (Pisani, 180).

Therefore, the key is collaboration between the two: NGOs can advise governments of local needs and of strategies that have worked or failed in smaller-scale initiatives, while governments can implement a comprehensive strategy on a larger scale.

Another avenue to address when considering the access problem is to look to Big Pharma. To make even more of an effort to increase the level of access to HIV/AIDS medicines and other essential medicines in developing countries, Big Pharma needs to create a transparent tiered-pricing system. To do this, the industry must stop its current practice of negotiating varied, discounted pricing on an individual basis depending on region, country, drug and volume through partnerships and donation programmes. As stated earlier, donation programmes have proven to be ineffective due to unpredictable flows of products, products that are unsuitable to local needs and those that are near their expiration dates. To make a real difference, companies

must move beyond such scattered philanthropy and bring structural change to the way the entire industry sets prices. As NGOs such as MSF and Oxfam have often argued, Big Pharma must "implement systematic and transparent tiered-pricing mechanisms for all essential medicines of therapeutic value to poor people in developing countries, where prices are set according to a standard formula which reflect ability to pay and the price of generic versions where they exist" (Oxfam, "Investing for Life," 22).

Yet another area in need of reforms in order to increase the level of access to medicines is in the realm of patents and international trade. Cohen and Illingworth suggest that the World Bank could do its part in solving this problem by buying the patents from Big Pharma and giving them to generic manufacturers in developing countries to produce and distribute medicines to people in need (Cohen and Illingworth, 35). Notably though, the multilateral institution that can have the most impact on the matter is not surprisingly, the WTO.

With the rise in bilateral and regional free trade agreements that blatantly run contrary to the safeguards written into TRIPS and the spirit of the Doha Declaration, the WTO should have measures in place to block these agreements or should at least provide developing countries with a dispute mechanism that would help them defend their rights within the negotiations of these agreements. Because the WTO's current dispute settlement mechanism is enforced through trade sanctions, developing countries do not have much leverage. However, intellectual property rights scholar Ken Shadlen proposes procedural reform for the WTO which would empower developing countries to dispute against developed countries when they are being pressured in trade agreements as is currently the case with TRIPS-plus conditions being slipped in by countries like the United States. Shadlen recommends that "a reformed system would ... allow developing countries to retaliate by withholding what the developed country most values,

protection of IP. Were a developing country to respond to a US violation in this way, US trade officials would indeed take notice" (Shadlen, "Intellectual Property, Trade, and Development," 176). This could possibly create a better balance in the North-South power relations in the WTO and hopefully, countries would not be pressured into giving up the right to use compulsory licensing or parallel importation which would secure better access to medicines for citizens in developing countries.

Another beneficial measure would be for the governments of developing countries to legislate these TRIPS safeguards into their national laws not only to better protect themselves from Big Pharma lawsuits or United States WTO complaints, but also to have the national bureaucratic steps in place in order to obtain drugs more efficiently if and when they are needed (Russel, 241). However, because there is still much confusion in nation-state governments about the implementation of these safeguards,

> an immediate policy priority is ... to address these misunderstandings and misperceptions, together with greater support for development within developing countries of legal and technical expertise to incorporate and implement TRIPS flexibilities in national policy (Smith, Correa and Oh, 690).

With the 2003 Waiver Decision, any country with generic manufacturing capacity should also adjust its national laws so as to enable the government to produce generics should a compulsory licence need to be issued for a developing country. Also, the notion of nation-state governments in the South creating South-South partnerships to collectively implement TRIPS flexibilities is another avenue which many feel bears consideration.

Moreover, Big Pharma has to cooperate further by giving up its crusade to protect patents at all costs. This would mean that Big Pharma would stop bringing developing countries to court for using TRIPS safeguards; would desist from devising clever ways to extend the length of its patents such as marketing 'me-too' extensions of a pre-existing drug with no real therapeutic

gain; would not unjustly hinder generic manufacturers from their production; and would not lobby the governments of developed countries to do its bidding in trade agreements.

Investing in Public Health Systems in Developing Countries

To successfully mitigate the AIDS crisis in developing countries, a variety of health interventions and structures need to be put into place: antiretroviral treatment programs, treatment for opportunistic infections, support and counselling for PLWHAs, HIV testing, prevention programs, orphan support, prevention of mother-to-child transmission and measures to ensure that HIV infected blood is not transmitted through transfusions (Sachs, "Investing in Development," Appendix 1, 273). However, in order for HIV/AIDS drug treatments, prevention and support programs to have a full impact in developing countries, public health must be revitalized. To do this, public health professionals, activists and NGOs like MSF are calling for

> a well-resourced and responsive public sector health system as well as empowered, knowledgeable, and 'responsibilized' client-citizens. They are calling for an effective health system together with new forms of community participation and citizenship—what Arjun Appadurai (2002) has described as 'auto-governmentality' or 'governance from below' (Robins, "From 'Rights' to 'Ritual'", 321).

There needs to be participatory development in the building of these health care systems so that local priorities and needs are shaping the programs and facilities as opposed to relying on a patchwork of private charity, PPPs, and a plethora of disease-specific initiatives. David Fidler talks about this situation creating a 'tragedy of the global health Commons'

> [whereby] critical parts of the global health Commons, particularly developing and least-developed countries, cannot adequately support the ongoing proliferation of activities, which tend to fragment already fragile local and national capacities for public health and health care (Esser, 230).

Sachs and the UN Millennium Development Project, promotes strengthening health systems as opposed to vertical initiatives for health interventions: "While many of these interventions could be delivered through disease-specific vertical programs ... in most cases they

are best provided through an integrated district health system centered on primary care and first level referral hospitals"—moving back towards the aims of the Primary Health Care approach (Sachs, "Investing in Development," 77).

Nation-state governments should do their part to take measures to implement policy, build infrastructure and put resources towards better health systems so that these countries are better able to deal with health challenges, including HIV/AIDS. In order to help developing countries to accomplish this goal, the IMF and World Bank should consider 100% debt cancellation for all those countries in need so that they would not have to dedicate an exorbitant amount of income towards paying this off each year and should instead put it towards social support systems, especially health care. "According to an independent audit by two leading British accounting firms, the IMF and the World Bank could afford 100% cancellation of HIPC debt [*Heavily Indebted Poor Countries*] without negatively affecting their own credit ratings (Drop the Debt, 2001:4)" (Cheru, 310).

Action Needed Now

Thanks to activists there is proof that the consensual values and concerns for the public interest inherent to the lifeworld can permeate the system, there can be reverse-colonization. The HIV/AIDS activist antiBody was able to bring a right to access to medicines and thus, a universal right to health to the forefront and achieve a legitimate voice which could influence globally powerful "stronger publics" and also steer the global agenda so as to incorporate their demands. The success of HIV/AIDS activists lies in their invigoration of the public sphere in making illness and access to medicines an issue of public contestation outside of the protected private spheres of biomedical discourse and the neoliberal discourse of the market and by doing

so, they also invigorated the public health agenda. Thus, it is safe to say that the HIV/AIDS activist antiBody presented a mighty force to help rejuvenate an infected public body—however, the activists' fight continues.

Innovative changes are needed now, especially in light of the current crisis of access to second-line antiretroviral treatments. For instance, the UN estimates that antiretroviral drugs only adds about four or five years on to the lives of PLWHAs living in Africa as opposed to the decades it adds on to the lives of PLWHAs living in developed countries.

> This is because HIV mutates and soon becomes resistant to one or all of the cocktail drugs. Therefore, patients must eventually switch to a new cocktail and then to another one. In Western countries, patients have twenty different drugs to choose from, but patients in Africa, even with all the funding for treatment programs currently available, so far have a choice of only six. For now, the others are too expensive or too difficult to administer in countries without reliable health infrastructure, including health workers, electricity supplies, and refrigeration (Epstein, 265).

As these drugs have recently come under patent protection for new second-line ARVs, Big Pharma needs to concede to more voluntary licences for these ARVs and/or more compulsory licensing and parallel importation needs to be utilized. There are advances being made to impose human rights duties on multinational corporations so that just as there are currently repercussions for war crimes and genocide, there would be consequences to any Big Pharma company found to inhibit access to medicines in developing countries (Joseph, 437-438). New business models are needed within the pharmaceutical industry to better operate for the public interest and the corporations that choose to ignore this business opportunity would most likely end up regretting it later.

> Each company needs to be part of the solution and needs to stretch its activities beyond normal market activities. This does not mean to turn the company upside down or into a charitable institution, but rather to identify the unique contribution the company may make as part of a broader effort to solve a major social challenge. This is the real meaning of corporate social responsibility: to operate in a manner that promotes broad business

> principles, values, and practices. It means much more than simple corporate philanthropy. It demands creativity (Sachs, "Common Wealth", 321).

Further research is needed to invent creative solutions to this problem inside and outside the industry and from the grassroots NGO projects to the higher echelons of the multilateral institutions.

Just as the motives in the women's rights movement and civil rights movement sought to defend marginalized populations and institutionalize equality for all, so too does the fight for access to medicines seek to institutionalize the demands of a marginalized population as well. The current social movement's cause is not related to a gender or a race being discriminated against—rather its reason for existence is to fight for an entire class of people that is too poor to afford the cost of their own lives. When considering the previous monumental movements one finds an interesting and promising interdependence between the "state-based" approach and "society-based" approach of citizenship since in both cases of the women's rights and civil rights movements, the demands and claims vocalized within the movements also became accepted as legal rights. From this viewpoint, there is "a long tradition of comparative historical-sociological analysis ... [*that*] shows how waves of collective action made individual rights possible (e.g., Tilly 1998)" (Fox, 174). Thus, access to medicines for all becoming a guaranteed right of the individual might not be that far-fetched, but it still requires citizen action.

Until there is a solution, each one of us must ask ourselves a significant question which I reference from the lyrics of the Coldplay song, "Clocks." We must ask ourselves: "Am I part of the cure? Or am I part of the disease?" Because until people have access to decent health care and medicines across the entire globe, the role of the concerned citizen still remains to carry on declaring that: "Healthcare *is* a right" and if as the activist chant goes, "We won't give up the fight" then we may just have a shot at making the actualization of that right a reality.

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