Neglected Diseases
The Cost of Our Health Revolution

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BIANGA HAD BEEN ILL FOR TEN MONTHS. SHE HAD become too weak to work in the fields near her home in Omugo, Uganda, fetch water, or care for her six-year-old son, Lino. At first, Bianga found herself sleeping all day long, but lying wide awake at night. Then, her behavior changed: she would run out into the street, shouting loudly at the sky. At this point, her husband left her. Bianga and her son went to live with Bianga's elderly mother in her small hut. With no one in the family able to earn money or produce food, they were penniless. Lino became malnourished.

Finally, in despair, Bianga's mother took her to the hospital to see if something could be done. The doctor discovered that she was suffering from sleeping sickness. She was admitted directly to the treatment center where she was given a course of melarsoprol. Although the treatment was painful, she began to feel better. After the 20-day course, she was able to return home and resume her life again. After a month, Bianga began behaving strangely again, and Lino brought her to the hospital. It was discovered that she had gone into relapse. Her ankle had to be tied to the bed to prevent her from running away and getting lost. Bianga received another course of melarsoprol, but this time her condition did not show much improvement. With no other treatment available and little hope for recovery, she was sent home. For Bianga, some of the treatments that are only now becoming available arrived too late (MSF, 2001).

In the last thirty years, the Western world has seen unparalleled medical advances and gains in life expectancy of up to four months per year (WHO, 2000a). This health revolution has eradicated the threat of infectious diseases from the developed world, but has left the rest of the world behind in its wake. Individuals in these underdeveloped countries cannot afford treatment developed by pharmaceutical companies in the developed world. Alternatively, they may suffer from a lack of treatment all together because research into diseases that affect these populations fail to be profitable. The benefits of this 'global health revolution' have not been dispersed uniformly. Millions continue to die each year from preventable diseases – in 1999 communicable diseases killed 14 million people worldwide, mostly in developing countries (WHO, 2000b).

The cause of this unabated tragedy lies in the fact that most of the diseases affecting the developing world are 'neglected'. In recent years, the term 'neglected diseases' has, like so many other phrases involved in social justice nomenclature, become a buzz word to describe all the health related ailments of developing countries, even spawning further classifications of 'most neglected' diseases (MSF, 2001). In fact, a disease may be considered 'neglected' if "there is a lack of effective, affordable, or easy to use drug treatments" (Yamey, 2002). As it is clear that most individuals suffering from said diseases live in developing countries, for obvious economic reasons, the pharmaceutical industry has traditionally ignored these diseases in their research and development. It is appalling that while the developing world constitutes 80% of the world's population, treatments for neglected diseases account for a meager 20% of worldwide medicine sales (MSF, 2001). Less than 10% of global spending on health research is devoted to diseases that account for 90% of the global disease burden (Global Forum for Health Research, 2002). For individuals affected with these diseases, the disparity is fatal.

Over the last ten years, promising efforts from the public sector have resulted in public-private partnerships between the public sector and pharmaceutical companies to tackle diseases such as HIV/AIDS, tuberculosis, and malaria (Yamey, 2002). At the same time, these partnerships still overlook some of the 'most-neglected' diseases, such as Chagas' disease and sleeping sickness. Sleeping sickness alone affects 500 000 people, threatens another 60 million in Africa, and claims thousands of lives annually (MSF, 2001; Yamey, 2002). Currently, the drug of choice for treatment of sleeping sickness is Melarsoprol, an arsenic-based drug developed over fifty years ago

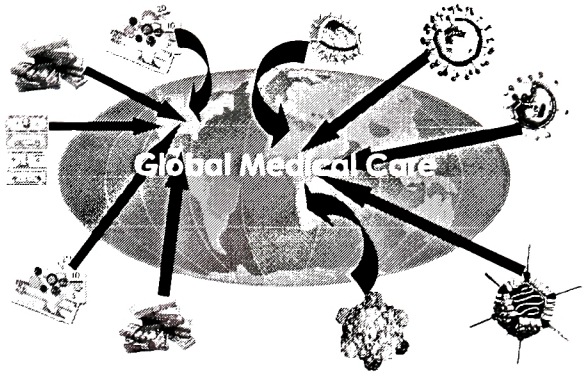

Figure 1
Although the developing world represents the majority of the world's population, only 20% of worldwide medicine sales are devoted to these areas (MSF, 2001).

that kills up to 10% of its users, and in some cases resistance to the drug results in its ineffectiveness in up to one-third of the population (Yamey, 2002). A more effective, less toxic treatment (Eflorithine) was developed; however, the company that developed it stopped production in 1995, claiming the drug was a commercial failure (Yamey, 2002). African patients were unable to afford the drug. Ironically, Eflorithine was re-introduced into the market later in the U.S. because it was found to reduce unwanted facial hair in women (MacDonald, 2001). For Chagas' disease, the story is much simpler. Effective treatment for this disease, which threatens one-quarter of the population of Latin America, is only available for children because no effective treatment for adults exists (MSF, 2001).

So why have these diseases, which have proved to be the most devastating, been ignored? The answer lies in the nature of the contract that exists between the public and private sector. The public sector traditionally invests money in the development of medicines for diseases, alongside the research and development that major pharmaceutical companies undertake. Unfortunately, both of these sources of funding for new drugs tend to focus on diseases that affect the developed world. The public sector is influenced by politicians who have a responsibility to their own constituency and the private sector is driven by more profitable diseases than those 'eradicated' from the developed world (MSF, 2001;Yamey, 2002). If the private sector sees economic potential for a drug, the public sector has some leverage to lobby for funding in research and development. Without this potential market, as is often the case for diseases afflicting the poverty stricken of the developing world, the partnership deteriorates (MSF, 2001). As a result, even though these neglected diseases form 10% of the disease burden in the world, only 16 of the 1393 drugs developed between 1975 and 1999 targeted these diseases (Trouiller et. al, 2002a).

The major group lobbying this issue is the Nobel Prize-winning *Médecins sans Frontières (MSF)*. MSF believes that the key to resolving this issue is for the public sector to accept full responsibility for drug development, making it an issue for the public sector to resolve. They are currently lobbying to test the theory that a drug research and development network can be established in the developing world through a centralized management structure. The venture will require immense public support, but currently, there is presently little hope for the thousands who are suffering and dying from curable infectious disease.

It is a cause for concern that the developed world believes the war against infectious diseases has been won. We believe that the battle has been won because we do not encounter infectious diseases to the same degree as other less fortunate countries. This belief overlooks the possible evolution of new and more virulent pathogens. For example, HIV/AIDS and TB may mutate to pose a heightened threat in the coming years. It also dismisses the threat of bio-terrorism and biological warfare (Henderson, 1998; Feldmann, 2002). Although we have been relatively fortunate thus far, our protection against these threats may falter. Our interventions to control disease may fail because of increased pathogen resistance and variance in efficacy due to epidemiological surroundings (Morel, 2003). Long term, sustainable solutions require the effective application of health research to policy-making (Sauerborn, 1999). They should include ammendments to distribution procedures and preventative public education policies in developing countries. Countries must unite to develop a new international pharmaceutical policy to address the concerns of all neglected diseases (Trouiller, 2002b). Only then can it be said the war has been won. M