

## **The Jeffrey Modell Foundation**

Submission to the Second Public Hearing of the  
World Health Organization (WHO) Intergovernmental Working Group on Public Health,  
Innovation and Intellectual Property, August 2007

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My wife Vicki and I established The Jeffrey Modell Foundation in memory of our son Jeffrey, who died at the age of 15 of a *Primary Immunodeficiency*. Briefly, our Foundation is dedicated to early and precise diagnosis, meaningful treatments, and ultimately cures of Primary Immunodeficiencies.

For over 20 years the main focus of our Foundation has been:

- To affirm its absolute commitment to clinical and basic research in order to better understand and treat Primary Immunodeficiencies.
- To serve as a national and international source for the dissemination of information and education into the diagnosis and treatment of genetic immunodeficiencies.
- To serve as a tireless, compassionate advocate on behalf of patients and families to assure their access to excellent and comprehensive care.
- To promote public awareness of the Primary Immunodeficiency diseases through programs involving our lawmakers as well as lay, scientific, and medical communities.
- To affirm its commitment to turn pain, despair and suffering of immunodeficient children and adults into comfort and hope.

Our Foundation's activities are extensive and wide-ranging. In the early 1990s, we visited each and every member of the United States Congress and staff to advocate for research. We have set up research and diagnostic centers in the U.S., Asia, Europe, Middle East and Canada. There are currently 35 Jeffrey Modell Centers and the next one is scheduled to open in São Paulo, Brazil.

Based on our experience supporting research and advocacy for Primary Immunodeficiencies, we are convinced that the solution to such life-threatening conditions lies in *cutting-edge innovative research*. For such research to occur, the right set of incentives must be in place in order to create an enabling environment for scientists and researchers to develop new drugs, and for institutions and businesses to manufacture and distribute them.

In our view, the only sector that has been able to develop appropriate incentives for such research, and manufacture quality drugs resulting in immense benefits for patients worldwide, is the research-based pharmaceutical sector.

The pharmaceutical sector has been extremely successful in turning promising early research conducted in universities and research institutions, (which we also strongly support) into life-saving medicines—a process which can be arduous, time-consuming and costly. The pharmaceutical sector, in many cases, works collaboratively with academic research centers to move the research and development process in order to bring innovative medicines to the market efficiently and at reasonable prices.

In addition, research for Primary Immunodeficiencies, conducted under the correct incentives, will give rise to valuable and innovative treatments for other life threatening diseases with genetic components such as cancer, lupus and multiple sclerosis.

As your Working Group deliberates on the role that intellectual property should play in innovation and public health, we request you to take into account the following summary of our submission:

**a. As Supporters of Basic and Clinical Research (through our Foundation):**

We strongly believe that to ensure a healthy pipeline of new drugs for Primary Immunodeficiencies and other life-threatening diseases, the incentives created through the current intellectual property system must be protected.

**b. As Patient Advocates through our Advocacy Activities:**

We strongly believe research and development into new medicines saves lives and helps patients to regain their health, livelihoods and quality of life—none of which would occur without the investments made, and the risks taken by the research-based pharmaceutical industry.

**c. As the Parents of a Child who succumbed to a Primary Immunodeficiency:**

We have a moral imperative to provide hope for children and adults suffering from this devastating disease by ensuring that the most promising research is conducted as efficiently as possible, and that new medicines are able to reach those who need it quickly. We believe that we can find the cure for such diseases by encouraging new research through support for innovation.