



Summary of Testimony of Susan Belfiore
On behalf of the Elizabeth Glaser Pediatric AIDS Foundation
Tuesday, May 22, 2007

I am Susan Belfiore, mother of 5 children, 4 of whom are HIV-positive. I am here today because our family -- like so many other families throughout the country -- is dependent on medications to keep our children healthy.

And that is why the Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act are so important.

I understand that testing drugs for use in children is an additional expense for drug companies. And I also understand that it can be difficult to conduct the studies because of a variety of enrollment issues. That's why BPCA includes an incentive for companies to do pediatric studies. That law is working well and should be continued.

But this issue cannot just be about profits and the bottom line. It must be about the value of a child's life. As adults, we wouldn't take medications that were not tested for us. So why would we give them to our children? And that is why I strongly believe that the Pediatric Research Equity Act should be made permanent.

I appeal to you on behalf of my children, and millions of other children just as precious and important as they are, to reauthorize these laws as soon as possible. Surely we can agree that our children deserve nothing less than the same information about the safety and dosing of drugs that we demand for ourselves as adults.



Testimony of Susan Belfiore

On behalf of the

Elizabeth Glaser Pediatric AIDS Foundation

Before the House Energy and Commerce Committee, Subcommittee on Health

“Programs Affecting Safety and Innovation in Pediatric Therapies”

Tuesday, May 22, 2007

Mr. Chairman, Ranking Member Deal and distinguished committee members. Thank you so much for having me here today. I am Susan Belfiore, mother of 5 children, 4 of whom are HIV-positive. I'm honored to be here today to let you know the difference pediatric drug legislation has made in our lives and why it's so important that medications continue to be specifically tested for use in children.

This issue is not settled, by any means, but the progress we have made is because of you. You are all true champions for children.

I'd also like to thank the Elizabeth Glaser Pediatric AIDS Foundation for everything they do for children and families. Our children are living healthier lives because of their work.

I am here today because our family -- like so many other families throughout the country -- is dependent on medications to keep our children healthy. As you just heard, four of our five children are living with the AIDS virus. Mihaela and Loredana are taking life-sustaining medications.

So clearly, this is an issue that I hold close to my heart. As a parent, there is nothing more difficult than knowing your child is sick. You can often feel scared and helpless. Our family believes in miracles. But miracles won't happen without the correct medication and their correct dosing. Both of these can be achieved only through pediatric testing.

I still remember the first time we put our then eight-year-old daughter Mihaela on a cocktail of drugs used by many AIDS patients. We took the medications out of the pill boxes and put them into a container decorated with horses. Mihaela loves horses. We had a silly hat party at the dining room table. We wanted to turn the whole event into something that was positive, instead of focusing on the fact that for the rest of her life, Mihaela would be dependent on the latest medications to keep her healthy.

But the truth is that Mihaela and Loredana and thousands of children like them ARE dependent on the latest medication to keep them healthy and strong and alive. And that is why the Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act are so important. Unless these laws are continued, many kids won't have a chance. They cannot afford to rely on guesswork. We've tried that, and I can tell you personally that it just doesn't work.

This binder is the story of my children's medical life. For the last 14 years, I have cataloged all aspects of their health. Charting their blood work every three months, their medications, and their reactions to these medications.

Ten years ago, we thought Mihaela was taking an effective drug regime for HIV. She was not. It turns out she had been undermedicated because the drug she was taking had not been studied sufficiently for use in children. Mihaela's health suffered. Her virus increased. Once again, she started to pick up opportunistic infections.

Mihaela had only used this medication for a few years before forming a resistance. As a mother, resistance is a very scary word because it means your child has lost access to one more drug regime, one in a very limited supply of options. And when the options run out, children suffer.

Recently I looked at a picture of Mihaela from five years ago when we first came to Congress to advocate for the Pediatric Research Equity Act to become law. I was shocked when I saw Mihaela. She was underweight. She looked sick. When you're in the moment, you don't realize it, until you go back.

In the last five years, though, things have been different. For the first time, Mihaela has taken medication that WAS tested specifically for use in children. The results have been

dramatic. Mihaela has grown, put on weight, and has been free of infections. And for the last four years she has had undetectable virus. She now rides horses more than ever.

My family's personal struggle is with HIV. But I have to point out that the value of these laws goes beyond HIV, beyond my individual family. My family and I are here for all parents and children, not just those living with HIV and AIDS. We've all heard the statistic: About three-quarters of prescription medications have not been tested for use in children. These are drugs for everything from asthma to cancer to HIV and AIDS.

Now, I understand that testing drugs for use in children is an additional expense for drug companies. And I also understand that it can be difficult to conduct the studies because of a variety of enrollment issues. That's why BPCA includes an incentive for companies to do pediatric studies. That law is working well and should be continued.

But this issue cannot just be about profits and the bottom line. It must be about the value of a child's life. To be honest, I wonder why the idea that all medications should be studied for children is even a question. As adults, we wouldn't take medications that were not tested for us. So why would we give them to our children? And that is why I strongly believe that the Pediatric Research Equity Act should be made permanent.

I appeal to you on behalf of my children, and millions of other children just as precious and important as they are, to reauthorize these laws as soon as possible. Surely we can agree that our children deserve nothing less than the same information about the safety and dosing of drugs that we demand for ourselves as adults.

Thank you again for inviting me here today. And on behalf of all parents, thank you so much for all you do for our children. I can tell you personally, you are making a real difference.