



Remarks for Susan Belfiore
On behalf of the
Elizabeth Glaser Pediatric AIDS Foundation
Before the Senate Health, Education, Labor and Pensions (HELP) Committee Hearing
Tuesday, March 27, 2007

Mr. Chairman and distinguished committee members. Thank you so much for having me and my family here today. I am Susan Belfiore, mother of 5 children, 4 of whom are HIV-positive.

I want to thank Senator Dodd, Senator Kennedy, Senator Enzi, Senator Alexander, and Senator Clinton for your leadership on this issue. My family and I participated in a press conference five years to announce the new Pediatric Rule legislation. I'm honored to be back again today to let you know the difference it 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. And I wanted to thank you.

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'd like to take just a moment to acknowledge my family behind me -- my husband Bill, and the five reasons why I am here: my children, Ramona, Ionel, Loredana, Mihaela, and Aiden. We are here today because our family -- like so may 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 feel scared. Frustrated. Terrified. Helpless. You put your trust in doctors, and researchers, and the latest medications -- and then you force yourself to believe.

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 the 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 alive.

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, these 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. In it I have cataloged all the details of their illnesses -- everything, including drug regimens, drug reactions, blood work, and

hospitalizations. It's a visible reminder, to me, of the control and responsibility I have against a disease where so much is unknown.

Seven 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 and even die.

Recently I looked at a picture of that press conference from five years ago. 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 this photo, you can really see just how poorly she was doing.

In the last six 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. Her love of horses has grown too.

Thank you.

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. I—and my family—are here for all parents, and especially for all 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 and allergies, to high blood pressure and HIV/AIDS.

As parents, we need to know that we are doing the very best that we can for our children. We never give up. We never say no to what our children need, especially when it comes to medicines that can save their lives. And I can't imagine our government leaders would either.

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. And I know others on this panel will talk to you more about that.

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.

My children come from a country that didn't have the resources to invest in all its children – especially sick ones. Those were horrific times for Romania and they did the best they could. But I'm here to say that we can do better. I'm here today to tell you that my children, and millions of children like them, are worth investing in. It sounds like such a strange thing to say. How can there even be a question?

And this investment doesn't just apply to drugs. Senator Dodd has introduced legislation that applies the lessons we have learned about safe drugs for children to the world of medical devices. Children often rely on medical devices, such as heart pumps and ear

implants, to treat serious conditions and illnesses. Yet there are so few medical devices designed specifically for children. So doctors must improvise, and sometimes, children are hurt in the process. Let us not repeat past mistakes and leave children behind as science and technology move forward.

In the end, this is all about children. These laws are basic investments in our children's future. We know they work and we know they are saving lives.

I appeal to you on behalf of Ramona, Ionel, Loredana, Mihaela, Aiden, 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.