

**Statement of Lisa Grasshoff
Paragon Hemophilia Solutions
before the
Committee on Health, Education, Labor, & Pensions
United States Senate
January 27, 2011**

Good afternoon, Mr. Chairman and fellow Senate Committee members:

Thank you for inviting me to share my story about the positive impact the Affordable Care Act has had on my family. It is both an honor and a privilege to have the opportunity to address this committee and have my voice heard.

My name is Lisa Grasshoff and I live in Houston, TX with my husband, Danny, and our 20-year-old son. Danny and I have been married for 36 years and after 17 years of marriage, we were blessed with the birth of our only child, Joshua. Surrounded by family and friends, Joshua was born 5 weeks pre-mature. Immediately, I noticed that my baby was bruised above his eye and had several other bruises on his body, which did not make sense because he was delivered by C-section. After extensive testing, Joshua was diagnosed with moderate Hemophilia A, or Factor VIII deficiency, which is an inherited genetic blood clotting disorder.

Joshua is an only child and the only grandchild on both sides of our family. So of course, he became the focus for all of us and Hemophilia was often discussed. We began trying to put the pieces of the puzzle together; we just wanted answers...why and how did this happen? Many other questions came to mind and thus, began my 20-year journey in the bleeding disorders community.

Hemophilia is a rare and chronic bleeding disorder affecting about 20,000 people in the United States, most of who are male. People with bleeding disorders require life-long treatment with high-cost clotting factor therapies, which replace the missing or deficient blood proteins that allow blood to clot. Proper treatment, which must be administered intravenously, can prevent debilitating injury and life-threatening internal bleeding episodes.

Factor replacement therapy is very expensive; in excess of \$300,000 annually just to sustain the normal clotting process that most people take for granted. Our community population is small; therefore, there are a limited number of pharmaceutical companies producing factor. Our costs will never decrease, only increase. A generic medication is not even a remote possibility for factor, as it is for many other drugs.

In March 1994, at the age of three, Joshua suffered a life threatening abdominal bleed that required a 7-week hospital stay. He required two surgeries, numerous blood transfusions, and massive doses of factor replacement to stop the bleeding in his stomach. His hospital bill was in excess of \$800,000. However, the medication expense did not stop there...he required factor

replacement daily for the next 4 years and every other day until he was 10 years old. Today Joshua treats 3 times a week to prevent bleeds.

Upon further family genetic testing in 1995, Joshua received a second diagnosis—type III von Willebrand disease which means he is not only deficient in factor VIII, but he does not have the von Willebrand protein needed to form a clot. Both blood proteins must work together in order for the clotting process to be complete. Danny and I received the diagnosis of mild von Willebrand disease at this time as well.

Treatment for von Willebrand disease requires a different type of factor than hemophilia. Our choices are very limited, factor replacement is more expensive, and this placed more pressure on our need for the elimination of annual and lifetime caps. By 1998, Joshua maxed out 3 insurance policies with each having a \$1,000,000 lifetime cap. In order to obtain health insurance coverage for our family, Danny had no choice, but to change jobs making less money; therefore, reducing our income by 40%, yet our bills remained the same. On that same note, due to budget cuts at his company, he was laid off in June 2009, and to date is still not employed full-time. However, I have health insurance through my employer and we do not have to worry about maxing out another policy nor will we have to be concerned about a pre-existing clause when Danny does find full-time employment.

The Affordable Care Act prohibits insurance companies from limiting how much they will pay for during Joshua's lifetime, and will phase out annual caps over the next few years. The new law also allows Joshua to stay on our plan until he is 26 and old enough to become financially independent. More importantly, though, Danny and I now have peace of mind knowing that Joshua will not be denied coverage because of his bleeding disorder. Having access to affordable insurance coverage, and quality medical care, will help him lead a full and active life.

The future for Joshua is much brighter today than before the enactment of the Affordable Care Act and for that I am very grateful. He has the opportunity to reach his economic potential without health insurance rules dictating his choice of profession. His hopes and dreams are now without restriction.

Thank you for your time. I will be happy to answer any questions.