



## Advocacy with the Price Family *(April 2012 Newsletter)*

**A**fter many hours in the car, we finally arrived in DC to be greeted by unseasonably warm weather, blue skies, and lots of sunshine. It only got better from there. After our four-hour training session, we felt like pros and were confident we would have success this year as advocates.

If you have not been to DC as part of NFXF Advocacy Day, then we encourage you to consider it next year. The day is quite intense, but you leave with a feeling of accomplishment and pride. Pride, not only because of your own efforts, but because we live in a country that allows ALL of it's citizens full, free and equal access to our elected leaders.

What does an Advocacy Day trip look like? The first day begins with an afternoon training session where you are briefed on the legislative agenda that all advocates will discuss in the meetings with their elected officials. The Public Policy group at the NFXF pulls together all of the pertinent information that you'll need in order to speak intelligently about the NFXF agenda. This agenda includes

requests for continued, and increased funding, for Fragile X research and the passage of Bills specific to enriching the lives of individuals with disabilities.

The information pertaining to the Bills and Legislation that you are asked to speak about, however, can often leave you feeling overwhelmed and intimidated. The idea of sitting across the table from your Congressional leader and asking him or her to support our requests can be quite daunting. This was our second year participating in Advocacy Day and we really felt like pros this time around! You have to keep it all in perspective and remember that it is their job to be in DC to represent you and your child. Remember that we, as citizens, all have the right to be in their office to discuss pending legislation that can positively impact the quality of life for our children for many generations.

So the million dollar questions are "Will my efforts really have an impact? Can little ol' me make a difference?" The answer is a surprising "Yes!" You won't go to DC and move mountains the first year and probably not even the

second year. But if you add up the 150 families that traveled to DC this year and the over 400 face-to-face meetings that occurred that day on Capitol Hill, then you will see how the effort of one individual is multiplied many times over having a positive impact on Washington and more importantly on our families.

Why do we go? We go because it is the opinion of the Price Family that the laws today were written a long time ago when our society did not embrace inclusion and independent living. We go because the laws today make it difficult and expensive for a family to save for a loved one with a disability. We go because the research community has made too much progress in the area of Fragile X research and Autism to have the door closed because of funding cuts. We go to ensure Congress that we have been and will continue to be good stewards for federal funding for FXS research and Fragile X Clinics.

Those are our reasons. What are yours?