

Family Voices of North Dakota Annual Appeal



11/01/2007

Family Voices of North Dakota

Dear Friends,

All parents want to go to sleep each night knowing that they've done everything in their power to maximize opportunities for their children with special health care needs. Family Voices of North Dakota is here to inform, educate and empower families to make that happen. **Please help us sustain this important work by donating to FVND.**

"I first turned to Family Voices of North Dakota for help when I became aware of my child's disability. Family Voices of North Dakota was there to teach me to advocate for my child, and now I guide others through the maze of special needs services." - Parent of a child with disabilities and advocate.

The demand for our services continues to rise. Every year, families in North Dakota turn to Family Voices of North Dakota to help them navigate the confusing and seemingly endless array of organizations, agencies and policies that affect their children. During the past year **over 3500 phone calls** and emails were received from parents and professionals seeking information and assistance. Each month, more and more visitors found essential resources on our website. The weekly Share the Wealth E-news is going out to **over 2200 individuals** and the quarterly newsletter is being received by **over 3400 individuals**. Over **5400 parents and professionals** received education through workshops and meetings. Family Voices of North Dakota works side by side with families and providers to enhance education, health care and community participation for their children with special needs.

Family Voices of North Dakota has also developed 45 new publications for families and providers that may be accessed on our website and in 2007 distributed 12,749 materials to families and providers.

"The materials you have provided for families and us as a professional have been wonderful... I no longer have to search for hours to find materials to assist a family member, and I know just where to turn when I need to locate information. Thanks so much for all of your hard work on behalf of families...." — Comments from a professional .

Your gift ensures that families have the resources and information they need.

Your support provides workshops and conferences to educate parents and professionals, supplying the tools and knowledge to empower parents.

See one of our family stories on the back page. Please give generously. **We urgently need your support.**

 Sincerely,

Donene Feist
Executive Director

Check with your employer's human resource department to see if your company matches gifts. You could double or even triple your gift!

Hi, my name is Jennifer Restemayer. I want to share with you part of our family story. Our daughter, Allison, is 6 years old and was diagnosed with Mucopolysaccharidosis type 1 (MPS1) on January 8, 2003.

MPS 1 is an inherited lysosomal storage disorder caused by the deficiency of an enzyme called alpha-L-iduronidase. This enzyme is required for the breakdown of certain substances in the body known as glycosaminoglycans (commonly referred to as GAGs).

Glycosaminoglycans are complex substances produced by the body that are found in all types of connective tissue. Connective tissue provides structural support to organs and tissues and makes up the cartilage of growing bones, joints, and heart valves. Without sufficient quantities of this enzyme, GAGs accumulate in virtually all organs of the body.



The incidence of MPS I is estimated at about 1 in 100,000 births. Even though many patients with this disease may have the same enzyme deficiency, patients with this disease can have a wide range of symptoms and experience variable degrees of disease severity. Allison received her first infusion of Aldurazyme on May 28th, 2003! This is the enzyme utilized to replace what her body is missing.

Allison is a very bright and active child. She amazes me every day with her unique personality, persistence and curiosity. I have the same dreams for Allison that any mother has for her daughter. I dream of Proms and High School graduations, of helping her move into her college dorm. I dream of her College graduation, her wedding, and the birth of her first child. With the help of the Enzyme Replacement Therapy, good medical care and preventative services such as Speech therapy and Physical Therapy, these dreams can come true for my baby. Without them, Allison's physical well being and mental capacity will deteriorate and her life expectancy will be in her teens.

As a mother, I believe that Family Voices of ND helped me find my voice. They helped me to speak out for Allison's needs through information, education and emotional support. I have had many opportunities, big and small, to ask questions and to question answers. I honestly do not know that I would have had the ability or the confidence to do what is needed without the knowledge that Family Voices helped me gain. As a result of my questions, I know without a doubt that our family is better off as Family Voices of North Dakota has been with us at every step.

I am extremely thankful for Family Voices of ND for giving me the access to information, and the encouragement. Family Voices of ND gave me a voice by being a much needed resource. I know this is the time of year many of you are inundated with requests in the mail for donations. You are receiving this letter today because you either have a personal or professional connection, with a family or families that have children with special needs. You understand the value of family support.

I wanted to share my journey with you, and ask you to help other families and **please give generously to Family Voices of North Dakota** so that they may continue to support families we already know, but also to reach that parent who is perhaps right now receiving a new diagnosis, or the one who is sitting in a hospital room with their child as I was 6 years ago.

As I reflect back along the path, I see a constant marker along the way that is Family Voices of North Dakota. I know that I can look forward to the path ahead as the support continues. I thank Family Voices of North Dakota for their support to help me along the way, and for those families just beginning their journey.