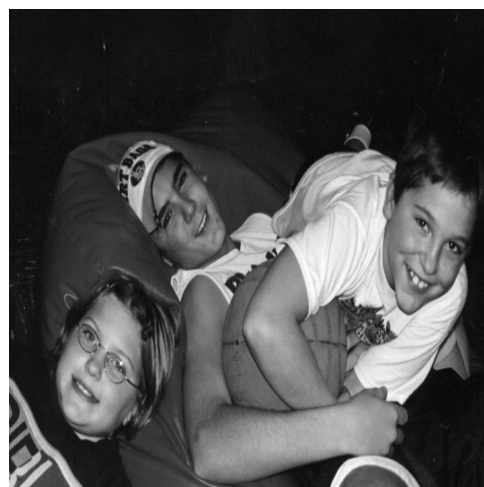


Family Voices of North Dakota Creating a Strong Start

Strive for Five Campaign for Family Support

A Statewide
Health
Information
and
Education
Center



Family Voices of North Dakota
Creating Partnerships for
North Dakota Families of
Children with Disabilities and
Chronic Health Condition

A Family Needs You!

FAMILY VOICES
OF NORTH DAKOTA[®]

Putting Families First

11/01/2009



A Family Needs You to *Stand In The Gap* For a Strong Start

What We Do

Our Mission

Family Voices of North Dakota aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our statewide network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

- ♥ Assist families as they navigate public and private systems, including health systems and insurance plans.
- ♥ Educate families about how to access services for their children and assist in communicating with providers.
- ♥ Listen to families as they describe their encounters and help guide them to possible solutions.
- ♥ Promote discussion and linkages among families, providers, and policymakers to better serve the health care and related needs of children and families in North Dakota.

We do this through:

Resources

Workshops

Listening

Presentations

Family
Centered
Care

Blogs

Online
Bulletin
Boards

Regional Parent
Navigator Teams

Trainings

Helping Hands
Program
donations will
assist family with
equipment or
conference

Ongoing staff
support across
the state

1:1 Matches
with
another
parent

Family
Leadership
Institute
Weekend

Family/Professional
Partnerships

ND Children and Youth

**1 in every 5 households
in North Dakota
has a child
with special health care needs,
disability or a chronic
health condition**

We thank our professional partners who have entrusted us to assist families:
Maternal and Child Health Bureau; ND Department of Health/Children's Special Health Services Division; ND State Council on DD; ND Integrated Services

This publication was made possible through the Robert Wood Johnson Foundation

STRIVE FOR FIVE! CAN WE COUNT ON YOU?

1 in every 5 households in North Dakota has a child with special health care needs, disability or a chronic health condition

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. THE STRIVE FOR FIVE CAMPAIGN honors the 1 in every 5 households in North Dakota who has a child with special health care needs.**

"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: Support, information, and training. 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. Each month, more and more visitors found essential resources on our website. 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.

During the past year **over 4700 phone calls** and emails were received from parents and professionals seeking information and assistance. The weekly Share the Wealth E-news is going out to **over 3200 individuals**; the Quarterly newsletter is being received by **over 4700 individuals**; Over **5700 parents and professionals** received education through workshops and meetings; We have developed over 75 publications for families and providers that may be accessed on our website; and in 2008-2009 **distributed 15,000 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 check helps a family in your community be connected to emotional support, receive ongoing information, attend a conference or training. Now is the time to help make that difference.

Can we count on you?

Please give generously. We urgently need your support.

Whether it is \$5 or other donation, each gift ensures that families have the resources and information they need.



**Your tax deductible donation can be sent to:
Family Voices of
North Dakota
PO Box 163
Edgeley, ND 58433**

Donors Needed	Amount	Donation Pays for Activities for Families and Providers
Many	<u>\$5 (\$60 yr) \$10 (\$120yr) \$25 (\$300yr)</u>	Make easy payments through a Monthly Donation plan
Many	\$25	Buys a web cam families in other regions to talk and see each other by computer. GOAL: 200 webcams
Many	\$62.50	Quarterly newsletter: printing, mailing to 4,700 ND families and providers. Annual cost: \$7,000.
Many	\$50-\$100	Sponsors a food at a monthly parent support group in 4 regions
Many	\$150-\$200	Pays for 8 onsite workshops and 4 informational conference calls.
Many	\$200-\$350 \$100-\$175	100 Families can attend a parent to parent regional workshop
Many	\$350 - \$500 \$175- \$250	Pays for 25 family leaders to be able to attend the three day Family Leadership Institute. Includes travel, lodging and meals.
		<i>Vivian Modin Helping Hands Program</i> helps families pay for equipment or medical support GOAL: Annually raise \$10,000.

Sometimes the Journey is Short, But What It Teaches US Lasts a Lifetime

Advice with Hindsight & Wisdom from Jodi Hebl, Grand Forks, ND



I am Jodi Hebl and the mother of 5 children and married to an amazing guy named Kelly. We live in Grand Forks, ND

Our 12 year old son is Rally, Shanel just turned 9, Autumn is 3, Cannon Bear would have been 2 in November, and we are about ready to have a little girl in December.

Rally is a football playin' young man; he is very mature and helpful. Shanel is our dram-queen!! Just combing her hair is more dramatic than the norm. Autumn is our passionate one (opinionated and cranky). Cannon was our lovable, cuddly, beautiful boy. And I am scared to find out what this new little lady will be like.

All my pregnancies have been straight out of "What To Expect When Your Expecting," nothing major happening we just assumed Cannon would be also, but after an hour of pushing things went wrong. I got to see him for a few seconds before he was taken to the NICU.

Cannon had been without oxygen for at least 10 minutes when my uterus ruptured, he had to be intubated because he was not breathing on his own anymore and she thought he was having seizures. They let me hold him and all he could do was cry, a cry that was different from any other cry I had felt, that was the beginning of a life stay and a crazy roller coaster ride.

Over the next few weeks Cannon had EEG's that came back abnormal, our neurologist told us that "his outlook was not good" and that he would be behind his entire life. Maybe not walk, talk, smile and other things, I was to mad at him to even hear anymore. After about a week, is when a doctor finally asked us "has anyone talked to you about your son".

NO, no one has told us anything.

THE DIAGNOSIS-

She informed us that Cannon has Hypoxic Ischemia Encephalopathy, and that translates to lack of oxygen to the brain, it took her a half hour to tell it to us in normal terms.

In other words Cannon had suffered severe injury to his brain during and after delivery and that it cannot be repaired. Cannon had lost his suck/swallow reflex and had a g-tube placed and we were allowed to take our Bear home at 22 days old.

On our discharge date we were enrolled into Infant Development and DDCM, which was the start of a great support team.

What I didn't realize is that Cannon was showing me this amazing "other" world, a world filled with these strong and courageous children. A world that almost no one knows exists

Over the next few months Cannon started to smile, giggle and do the things a 1 month old does, but he was 3 months old.

Our world now included many therapists, and many trips to the cities for eye appointments, Shiners Hospital, neurologist and the bi weekly pediatric appointment. The weekly visits with our Infant Development therapist, made me feel normal for at least an hour.

We had great support from family and friends but their children where "normal" and I didn't think anyone felt the loneliness and isolation that I felt.

What I didn't realize is that Cannon was showing me this amazing "other" world, a world filled with these strong and courageous children. A world that almost no one knows exists. In this place milestones are not "baby sat" at this age and "said mama" at this age, but "baby tolerated feeding", "baby is weaned off seizure meds".

ADVICE WITH HINDSIGHT-I had never heard of Early Intervention or Family Voices and all that these programs can offer families. I wish now that I would have used them more and not felt like I was being a burden.

I am happy to say that all that Cannon taught me is going to good use, I work for Infant Development now as an Experienced Parent and cherish every moment I get to spend with our families, it makes me feel closer to our son.

If I could say one thing to every family it would be to use these program to your full advantage and don't feel like you are putting people out, this is what they are here for and are passionate about. These teams are specially formed and built for you and your family.

Accept all the help that is offered to you. And love every moment of your of your new world.

On November 16, 2008 We held him in our arms for hours for the last time, just cuddling and remembering everything we could of our Cannon Bear.

In the nine and a half months of Bear's life we assembled the most amazing support team. But it did not have to have been this hard.....

YOUR DONATION-Will help another family who needs information and support to do the best they can, often under difficult situations. It is amazing what happens when you meet another family whose child's health issues are similar to your child. You are not alone anymore. No family should feel that way.

**Please help make a difference and donate today!
Every donation,
large or small matters!**