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FAMILY VOICES OF NORTH DAKOTA®

Navigating Crossroads to Hope



The Navigator

FAMILY VOICES OF NORTH DAKOTA-A HEALTH INFORMATION AND EDUCATION CENTER “SUPPORTING FAMILIES HAVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES AND THE PROVIDERS WHO PROVIDE CARE FOR THEM”

Navigating Crossroads to Hope



From the Director-

The Holiday Season is arriving quite rapidly as I write this section. Most likely by the time you are reading this, the New Year will have begun. However, the time is always right to stop and reflect, if only for a moment on all that matter to us.

2010 has been an interesting year to say the very least. Some of us lost family and friends, some of us were witness to a new birth. Many of you have and are a support to one another in good times and in those most painful moments.

2011 is ringing it's bell. It brings to us renewal and hope for a better tomorrow. May it be a gentle to each of you.

I am grateful to all of you and the responsibility each of us shares to our children.

With a new year, let us also make a new vow. Let us be visionary and relentless to assure that our children and youth with special

health care needs receive the services that they need, and that their families are well supported. Let us renew our “promises” to children and families, recognizing the power of partnership that we have in one another.

Let us always remember that each and every family member that you encounter is a “pearl of wisdom”. Their voices recognized for their wealth of knowledge. The voice and wisdom they can provide and offer in the implementation and delivery of care.

Let us renew and remind one when needed “which direction is true north” keeping one another grounded but visionary in a creating and implementing a better system.

Let us renew our investment in Human Capital. What will we create together to see to it that children and families flourish? It is up to each of us to make the most of this opportunity. YOU are who we have been waiting for. Let us not waste another second. Happy 2011!



Bloom Where You're Planted

Family Voices of North Dakota provides many opportunities for families and providers alike! Staff is located across the state in Dickinson, Williston, Minot, Fargo, Grand Forks, Bismarck and Edgeley to assist families and providers with their needs. Whether it is a workshop, assistance in navigating this complex system, 1:1 emotional support from another family or just to talk. It is our mission to assist you in whatever your needs may be. Raising a child with special health care needs is life changing and a challenge. You don't have to go it alone. It may change the path you were on, but it does not need to change who you are! We are here to help! **“Bloom Where You're Planted” Call 888-522-9654**



Ethan's Story *by Lisa Radtke*

In the last issue we published the story of Ethan, who was going to Germany for a stem cell procedure. Today we have his follow up story to his trip.

I remember sitting here in this same place last Christmas listening to my then 5 yr old son Ethan, asking us for new legs that work ...ironically

enough, this year he came to us and requested a bike, since "My legs work this year!" Ahhh...such blessed words to hear.

The 5 months that we've been back from Germany have been filled with new adventures on a daily basis. Thanks to the Adult Stem Cell procedure, Ethan can now do so much more than before, from wiggling his toes (for the 1st time) to being able to sit criss-cross applesauce. His tone has shown to us to be the biggest success as its been significantly reduced and can only be compared to the results of a dorsal rhizotomy surgery. Ethan's balance, speech and impacts to his hands too have been positively seen and noticed.

In September, we traveled to Sioux Falls for an Achilles tendon lengthening as due to the extreme tightness over the years, Ethan's muscles had not had a chance to stretch and develop despite therapy. Today, he is learning to stand and is using his walker. His steps have never looked as smooth and natural as they do today. We just keep proceeding day to day with Physical and Occupational therapies and are excited to see what new thing Ethan will show us.

I'm asked often if we would do it again... My response is an overwhelming YES!!". We have no regrets taking the chance that we did. As for further stem cell treatments, we certainly could go back for additional treatments to see if we can gain more changes but at this point, due to the amount of tone we've lost, we are satisfied with where we are at this time and are giving our therapists time to do their thing.

I am thankful for the opportunity we were given to make such a positive impact to our child's life. Today Ethan has never been happier or so full of energy. His eyes light up every time he does something new for the 1st time and he is so excited to try new things that he's never been able to do before. In the words of Ethan's new favorite hero...Buzz Lightyear... he is truly going to Infinity and Beyond!

Happy Holidays!

CareCalendar



CareCalendar is a web based system to organize meals and other help for families during a time of life changing event. So often family members or neighbors create a

help team, a group that provides assistance during a time of need. This may be in the form of meals, housework, yard work, childcare, transportation, visitation, and many other things.

This online tool can assist in coordinating efforts. No need to play phone tag or explain needs over and over, volunteers can see what is needed and when and sign themselves up to fill the need.

CareCalendar offers many features including status updates and uploading photos. Each CareCalendar is password protected for privacy and can only be viewed by entering the correct information. Sensitive needs can be setup to allow only pre-approved helpers the ability to sign-up for them.

Give it a try!

For more information:

www.carecalendar.org

Dad's Corner

We will start a new section for the newsletter called Dad's Corner, we hope to provide Dad's and Grandfather's and all of the males out there who make a difference for our children a special place.

"Dad, why are people always trying to change me, why can't they just let me be myself?" This is the question of the summer at my house. It does make me stop and think though, is that really how Tyler perceives our trips to the doctor or therapists? Does he feel that I am not happy with who he is? I try to reassure him that this is not the case. I have, never a once said, I would change my son. What I would like to do is change people's perceptions, expectations and ways of dealing with him. (yeah I know, right after that I will get to the rising cost of health insurance and the increase of nuclear tension in the Middle East). Instead of changing one kid, I will try to change the people around him? Wow, that sounds a little more off the wall on paper than it did in my head! Hear me out though.

What IF I could take away his OCD, would that affect another part of what makes him Tyler? Could it then take away his unique sense of humor, he inherited from some aging guy with a buzz cut? Even at 11 and dealing with what he does, there are times, when we both hear a comment, we get that gleam in our eye that only Beck males do and have a smart one-line comeback. What IF I could take away his sensory issues, could that mess with his stubborn streak (that again runs straight through the paternal family tree branches, thanks Grandpa Jake!). Then I COULD have another concern--peer pressure. I say that because as of today, there is no one (short of the best team of lawyers in the upper Midwest, ah scratch that, we'd need an East Coast law firm for this) that will talk him into anything that he does not want to do. I guess I believe that for every action there is a reaction, so be careful what you wish for. He is who he is for a reason, and a higher power made me his dad, how about everyone just accepts that!

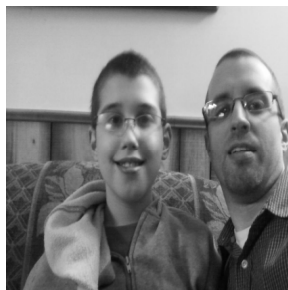
Believe it or not, I will never win a popularity contest. I am the dad you have all heard about. Right or wrong, I speak up, if I don't understand something, I ask. I feel, involved parents are not always appreciated in our area. Despite what you hear, I have never told a doctor how to doctor, a therapist how to therapy or a teacher how to teach. BUT I have questioned what, when, where, how and why, it's okay to question and disagree. The infamous question (thanks Vicki) "how did that work out for you?" is never appreciated but sometimes needs to be asked.

As a parent, we have this little extra thing called experience with our child, why wouldn't people involved in our child's daily life accept that? As Tyler once told me (after having the same incident happen over and over again at school) "dad, some people just have to learn the hard way I guess". The hard way is just that. Their failures translate into Tyler's failures. Tyler and I MUST be wrong, because this whole situation is unique to most people. Square peg-round whole, must change the peg.

I heard a line today, that stopped and made me think again (don't worry, I don't think while I'm driving so no sudden stops, wait.....you know what I mean) anyway, mull this one over- "if you go through the motions or put in just enough effort to make it look like you care, eventually the end result will fall short". Write this in ink, Tyler will NOT fall short because I just went through the motions.

Thanks for reading my ramblings. You can drop me a line anytime at friendpnt@gmail.com. I rarely run out of stuff to talk about!

Brad Beck
F.R.I.E.N.D. PNT Leader



Accessible Children's Literature Videos

From the Described and Captioned Media Program

Have your students watched any good books lately? Captions and description are great tools for building literacy in new and experienced readers. The DCMP has a growing collection of children's literature titles to help foster an enduring love of reading in your children.

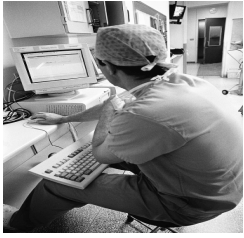
They also have a existing collection of over 150 unique captioned children's and young adults literature videos.

You can access Described and Captioned Media Program at dcmp.org

If successful people have one common trait, it's an utter lack of cynicism. The world owes them nothing. They go out and find what they need without asking permission, they're driven, talented and work through the negatives by focusing on the positives."

*Mike Zimmerman
journalist*





How the New Health Care Law Helps YOU

As many of you know health care reform legislation recently passed. This legislation includes provisions affecting health care coverage, the health care delivery system, and sources of revenue for financing reform. Some of these provisions went into effect immediately, while some will be implemented over the next decade. To help you navigate through the legislation we are providing examples of how you will be helped now.

You Can't be denied insurance for a past illness. Children previously treated for diseases such as cancer, cerebral palsy, spina bifida etc. can't be denied coverage starting this year. Adults will be protected by 2014. Also this year, a new coverage program will be set up for adults who can't find or afford insurance and have a pre-existing condition.

You can't be dropped and your coverage can't be capped. Gone are the days when you run out of coverage if you get cancer, or other serious illness: Lifetime limits are banned in 2010 and annual limits will be restricted now and eliminated in 2014.

Small business and nonprofits will get financial help to provide insurance for their employees. Starting now, small business can get tax credits of up to 35% of their insurance costs, rising to 50% in 2014, small employers will be able to purchase cheaper insurance through an exchange.

Seniors and others won't go broke due to high drug costs. Seniors and people with disabilities with high drug costs who fall into the Medicare "doughnut hole" will get a \$250 rebate check this year. By 2020, the "doughnut hole" will be eliminated: only the 25% copay will remain.

Preventive services will be free. Starting in 2010, both people on Medicare and people with private insurance will get preventive services (like check-ups, vaccinations, mammograms, colonoscopies) with no copayments and exempt from deductibles.

Young adults up to 26 have new coverage options. Starting in 2010, due to the new federal law, you can stay on your parent's health insurance plan.

If you can't find affordable, quality coverage, you'll have new options and help purchasing insurance. Starting in 2014, people will be able to buy cheaper coverage through "exchanges"-shopping malls for insurance. Exchanges will also set standards to keep insurers honest and provide value for premium dollars. If you earn up to roughly \$88,000 a year (family of four), you'll be eligible for new premium tax credits to help you afford coverage. For example, a family with \$60,000 income purchasing a \$15,000 plan will receive a subsidy of about \$10,200; a family with income of \$35,000 will receive a subsidy of \$13,600.

While there may be many bumps along the way, Family Voices of North Dakota will help by staying on top of what is happening federally to inform you. What we do know, for children with special health care needs two of the provisions implemented will certainly help our families: elimination of pre-existing condition and elimination of lifetime caps and eventually annual limits.

During the last 30 years, life has changed irrevocably for children and youth with special health care needs. The National Family Voices and state affiliates will continue to discuss these issues that are important for our children, youth and families, to assure the voices for these families are at the table to identify what works, what works well and what isn't working for families. Undoubtedly, together we can make a better system of care for these families.

We will also be monitoring closely implementation changes and how they affect our families to provide ongoing feedback. If you are having difficulty, not sure where to turn, where to locate a resource....Give us a call.

We are here to help.

Navigating Crossroads to Hope....888-522-9654

News from staff across the state

Missi in Dickinson-



Parent Support is growing across North Dakota! I have had the great opportunity to visit many communities across North Dakota in the past months to assist them in starting a Parent Navigator Team. It is wonderful to meet so many fabulous parent leaders in our state! In August I helped to plan the Annual Parent Leadership Institute and in October we had our first Family Leadership Weekend! Both were a great success. Even though I have been to more than one leadership event I continue to learn from each one, especially from all of you who attend!

Right now I am in the process of updating our Parent to Parent Manual as well as our New Beginnings Guide so if you have any suggestions, let me know. Recently I took on some part time work with our local Early Intervention Program as a Primary Early Intervention Professional so if you ever have an Early Intervention question feel free to send it my way. Over the winter I will be hosting once a month conference calls for Parent to Parent Training, so watch for that information coming out soon. I also continue to schedule Parent Navigator Workshops across North Dakota, so contact me if you would like to have a workshop in your area.

FVND staff are now in Minot, Williston, Bismarck, Dickinson, Fargo, Grand Forks and Edgeley

Other than all of that I have been busy writing grants to support the Parent to Parent Program efforts as working closely with Donene to support our new staff as well as our email and mailing efforts. We are always open to suggestions so if you have any ideas, please let us know. Enjoy the winter!!!!



Welcome Paula Burckhard in Minot! My journey really began over 10 years ago when my third child was unexpectedly born with Down syndrome. At first, my husband and I were broken-hearted. But over the years, our hearts healed and then overflowed with love for our special little girl named Grace. Because of Grace, our whole family was changed for the better—we learned to be more compassionate, tender-hearted, and sensitive toward others, especially other families who have a loved one with a special health care need or disability. Over the years, we talked off and on about adopting a child with Down syndrome. Finally that dream came true when we adopted Bella

Bogdana from Ukraine in 2009. This little girl, who is now 5 and happens to have Down syndrome, is the light of our lives. We were so blessed through the miracle of adoption, that we are now in the process of adopting a little 3 year old boy with Down syndrome from Serbia.

My work experience and background includes teaching, working in the non-profit disability field, grant-writing consulting, and volunteering. My husband and I have four beautiful children.

I truly am passionate about supporting families who have a loved one with a disability. It is my hope that in this position as a Family Consultant that I will be able to “pay it forward” for all that has been done to support us throughout the years. I look forward to helping families seek the resources they need to thrive and prosper in their own community.

Besides supporting families, my main goal for the Minot region is to help develop the Magic Parent Navigator Team (PNT).

The Magic PNT has two main purposes of offering a monthly support group for parents who have a loved one with a disability or special health care need and to develop a parent advisory council for our area’s hospital.

North Dakota Parent To Parent



What ND Parent to Parent Offers:

- ☒ One-to-one matches of families who have similar needs and experiences.
- ☒ Emotional support for parents when they learn their child has a developmental delay, disability, or other special health needs.
- ☒ Current information on a variety of disabilities and health issues.
- ☒ Training for parents who would like to become a *supporting parent*.
- ☒ Information on local, state and national resources for the child and family.
- ☒ List of informative books on issues related to children with special needs.

For more information regarding Parent to Parent, if you would like to be matched with another parent or become a supporting parent contact fvnd@drtel.net or call our toll free number at 888-522-9654

News from staff



Vicki in Bismarck-Hello to everyone. Time does really go by fast. I have been busy with new families and continuing to work with the families I have known for awhile now. I have spent most of time helping families with emotional support, understanding the systems their child may enter especially after early intervention, questions and understanding of health-care reform (as we are learning about it), and insurance questions and concerns.

I am participating in several areas as being a member, including Pathfinder Transition, Region VII RICC, SHIW (School Health Integrated Work Group) regional Medical Home calls, and still participating in ACT Early (AUCD) meetings. I am facilitating my own Special Education Support group monthly in Bismarck-Mandan area. Attending our local Parent Navigator group; F.R.I.E.N.D.: and their new project of putting a scrapbook together and doing some outreach at local churches.

I am looking forward to the legislation coming soon, 2011 and attending the local legislative working group and hope to see some more parent involvement. I attended this years, Closing the Gap (large technology conference) to help present on the IPOD Touch. Assistive Technology is a very high interest of mine. I am enjoying new partnerships with professionals such as Experienced Parent, Federation of Families, Pathfinder Board, BPS Transition and Headstart.

I enjoyed our recent Family Voices Reunion Day and seeing so many of our friends.

On personal notes, my son Aaron is 8 and a second grader this year (Aaron has autism). He is doing wonderfully and I thank his wonderful IEP team and everyone at the school for making this another successful year. His biggest step was learning and starting to read and gaining more social skills.

Erik is attending Jamestown College and studying Health and Fitness Administration and playing Baseball (so excited). He is loving college and I am starting to get used to him being gone; starting is the key word here!

As always I would like to thank my director Donene, my coworkers; Missi, Joan, Brenda, Paula and Jocelyn, it's always such a great pleasure and honor to work with all of you. There is lots of work to be done and I hope to continue to help families along the way.



Joan in Grand Forks

Hi to everyone from Grand Forks. It is hard to believe

it is almost the holiday season. Times goes by way too fast and our kids grow up too fast!!

Our Friends & Family Support group has been meeting on a regular basis. I really enjoy getting together with area families. It is fun to see them share information and stories with each other. We are hoping to get our Parent Navigator Team up and running. We had a meeting in October and had a good turnout. Parent Navigator Teams are a group of parents who help strengthen their community for families who have children with disabilities and special health-care needs. To learn more about the team, please contact Sherry at: mullane@gra.micdo.net. We would enjoy having you as part of the group. I attended an conference in Fargo and was able to attend a presentation by Geri Jewell. Geri was "Cousin Geri" on the TV sitcom, "The Facts of Life". She laughs and jokes about her life with Cerebral Palsy. But also has a very serious side of life. She was an amazing and inspirational speaker who had you laughing at times.

My daughter and I attended the National Philanthropy Day events in Fargo on November 15th. Collins Tuohy was the keynote speaker. She is the real life daughter from the movie "The Blindside". She is a very inspirational young lady. She spreads the message of paying it forward and doing something for others.

Family Voices Of ND



One in every 5 households in North Dakota has a child with special health care needs.

Who are these children we speak so fondly about?

They are your next door neighbor, they are the girl in the choir, the boy in Scouts, they are the child under your own roof, they are the alter server, one of the kids who helped sandbag, the football player, the dancer, the piano star, they are a part of each and every one of us.

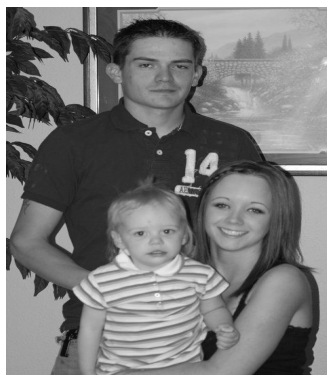
Our role at FVND is to be a network of families, friends and providers whom advocate for health care services that are family friendly, community based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs

Promoting the inclusion of all families as decision makers at all levels of health care and policy.

Assuring services are understood.

FVND encourages, supports and works diligently to assure essential partnerships between families and professionals occur.

News from Staff



Welcome Joscelyn Lynch in Williston!

Joscelyn in Williston-

Hello Everyone,

My name is Joscelyn Lynch and I am happily married with two beautiful children. I am a stay at home mom and I also take online classes to finish my Bachelors in Early Childhood! We were blessed this month with the birth of my son, Nolyn. My daughter who is 3 ½ couldn't be more proud of her baby brother. We are all adjusting to the change but we are loving every minute of it! I am excited to be a part of FV and hope to be a helping hand in any way needed. My daughter was diagnosed with epilepsy at 7 months old and I want to be able to be the comfort I wish I had then. I am thrilled to be able to be a helping hand to others and delighted to start my journey with FVND.

**Thanks to all of the
FVND Board and staff
for their dedication !**

Brenda in Fargo



Life is always busy/busier this time of year with the Holidays and trying to keep our kids healthy. With all the busyness it is hard to take care

of ourselves and keep the stress level to a minimum.

This year I have toned down the decorating of my house. I have done more Christmas shopping on line. I am okay with the fact that the Schmid Family Christmas Cards will actually be Happy New Years Cards. I am focusing more on spending time with friends and family. I even took a nap the other day.

On November 20th Hannah participated in the 1st Annual Hope Inc. Fashion Show. There were 25 beautiful models. They all wheeled the runway like pros. There were about 200 people in attendance. It was a spectacular event.

As usual we (FVND) held our monthly support group meeting. We had a full room. It was great to see so many parents together sharing and supporting one another. If you live in Fargo or the surrounding area I strongly encourage you to attend this positive and comfortable support group.

Each month I also attend the FEET (Family Educator Enhancement) Committee meeting.

F.E.E.T. (Family Educator Enhancement Team) is a committee of educators and parents of children with disabilities who attend Fargo Public Schools. This group meets monthly (every 3rd Wednesday of the month) to organize and promote activities for children with special needs. Monthly meetings are held at Vintner's Celler at 12 North Broadway at 7:00 PM.

I had the opportunity to visit with the Amy Breeher the new Community Outreach Coordinator in Eastern North Dakota for the Epilepsy Foundation of MN. Amy will help support, educate, connect and empower people living with seizures in North

Dakota and Minnesota. I am very thankful to have Amy in our region and look forward to working with her. In her introduction letter she states: "This position is not just a job for me – it's my passion!". Amy's can be reached by email or phone: abeecher@efmn.org - 701-429-1165 and website www.efmn.org.

I am excited to be part of the planning committee for the 8th Annual Assistive Technology Expo and Pre-Conference. The conference will be held on April 27-28, 2011 at the Ramada Plaza Suites, Fargo, ND. For more information you can visit: www.atexpo.org or contact Jenny Davis at jenny@atexpo.org or call: 1-877-760-2939.

On a daily basis I visit with and support families who have children with special health care needs. Sometimes I feel guilty that I even call my position with Family Voices a "job". I read a quote the other day that clearly defines what it feels like to work for Family Voices of ND. "In helping others, we shall help ourselves, for whatever good we give out completes the circle and comes back to us." In the process of helping other families and working with service providers I gain more knowledge, build relationships and break down barriers that we too may face having a child with special health care needs. I am very proud to be a part of the special needs community. We are an united front and together we can accomplish a lot.

On a personal note Hannah continues to keep us very busy. She is involved with sports and recreation through Hope Inc. She has a very active social life filled with wonderful friends. She loves to travel to Grandma and Grandpas house on the weekends to visit with family. And in her spare time she enjoys baking with dad, reading, playing on her iPad and shopping.

If you have any questions about any of the information in this article, please do not hesitate to contact me at: 701-235-1781 or email: Schmid@cablone.net.

Parent to Parent Helping One Another



My family and I have been a part of the North Dakota Parent 2 Parent Program for quite some time now. The ability to meet a family who is going through a similar situation as you is unfortunate but fortunate. The connection between families is something unlike any other families imagine. When I first found out my daughters diagnosis, my husband and I didn't have anyone to talk to and essentially went through it alone, we did have unconditional support from our families, but in a sense they really didn't know what we were going through physically, emotional or mentally.

My family and I were connected with a family about 90 miles from us regarding our daughters who have a similar but very rare diagnosis. I immediately contacted the mother and we clicked through e-mail for months, sending pictures and sharing stories that only we could understand. We finally met each other and our daughters for lunch

not that long ago. I looked at her daughter and had numerous flashbacks about what we went through in the four years prior with our own daughter and the fact that we didn't have many resources to talk to anyone.

I am so happy to be a part of this other family's life and to know we will always have a connection and share something so rare. We e-mail each other weekly and give support when it comes to hospitalizations, medications and the many doctors' appointments our daughters have to attend. I feel as if I am contributing to something great being able to help this family through the "tough stuff". As long as I am able I will gladly be willing to share and continue learning through this process we call life. Amy Meyer



I just wanted to take a few minutes to say how wonderful Family Voices of ND is and how much of an impact they have made on our family. My name is Cassie, I have 2 sons. Carter turned 3 on June 15th and Carson turned one on October 23. My first son was born at 41 weeks, perfectly healthy and the best baby ever. We were so happy we couldn't have asked for a better gift! Life was perfect! In February of 2009 we found out we were having another baby. Life couldn't get any better, we were so excited. Everything was going good until May 20th, 2009, that day changed my life forever. We went in for a routine appointment and for the big ultrasound and they noticed something looked different with Carson's brain. After that appointment we saw specialists from the Sanford Health Clinic. After extensive ultrasounds and an amniocentesis we got news we would have never thought. Carson has Trisomy 13.

Over the rest of my pregnancy we talked with doctors and specialists and found out the odds of a child living with Trisomy 13. It wasn't looking good and we were prepared to not bring a child home. October 22nd rolled around and I had not been feeling good so I decided to go into the Emergency Room. I had pneumonia and a horrible upper respiratory infection. I was within hours of my own life ending. The doctors intubated me, but there was no way to save my life while still being pregnant. The next day the doctor took Carson via emergency c section. Carson was not doing well, he stopped breathing more than once and laying him on my chest was the only thing that helped him breathe again. Carson went home on hospice 2 days later and I came home when he was 21 days old.

After being home a week I decided it was time to get Carson into a pediatrician and after extensive testing the doctors and specialists concluded that Carson will more than likely live past a year old. So Matt and I decided that it was time to take Carson off hospice and try and give him the most normal life possible. That was all I knew. I didn't know anyone who had gone through anything like this before or what to do or where to go. I talked to my WIC nutritionist and she pointed me in the direction of Missi Baranko at Family Voices. I started talking to Missi and she got me pointed in the right direction. I can't even tell you how grateful I am for Family Voices. They have made a huge impact on my life and so many others, they truly deserve the funding. I don't know how long my son will be here but what I do know is that he is a miracle and every day is a blessing with him, and no matter what happens I know with Family Voices I have such a huge family full of support and Matt and I will never go through anything alone. Cassie Keller & Matt Reid. ***On January 5th, 2011 Carson made his journey to Heaven. He will be remembered by all who knew him. He touched many lives and will continue to touch the lives of others as he lives on in our memory. To view a tribute to Carson's life, go to <http://animoto.com/play/jll7bO5d0fgcgleXpFz23g>***

The Family Voices History

It is impossible to pinpoint when things for children and youth with disabilities began to change. In any case by the end of the 1970's, families and professional partners agreed that children, disabled and nondisabled, with chronic conditions belonged with their families, in their communities, and with their friends...They belonged at home.

In 1981 Ronald Reagan approved Medicaid Home and Community Based Waivers which created a new way for caring for children and adults with disabilities. Medicaid Waivers were conceived by Julie Beckett, an Iowa mom who is the former Director of National Policy at Family Voices. As a result, thousands of children who lived in hospitals or state institutions now live at home. We train families and professional partners in applying for waivers, assist individual families with waiver problems, keep updates on policies and worked towards improvements. This is when it all began for Family Voices. **2011 is Family Voices of North Dakota's 15th year of assisting other families.**

We Help Other Families-One of the founding purposes is to assist veteran parents to help other families raising their children with special health care needs. Experienced families listen and answer new families questions about a diagnosis, an accommodating dentist, negotiations with insurance companies and enroll a child in the neighborhood school. We help with language and racial barriers, explain difficult system rules, advocate for better preschools. We are a clearinghouse of information and support. We have a variety of ways to support families: web, topical calls, trainings, Parent to Parent support, written materials, We publish guidance materials and information. Join one of our Parent Navigator Teams across the state to work with other families and provider partners to improve needs in local communities. We assist with a variety of issues from emotional support, to education and informational support and how to locate community resources in raising your child and youth with special health care needs. Our assistance is based on what the "families needs are".

We Improve Hospital and State Policies-Many of the Family Voices leaders got their start as advocates when their children were hospitalized. Years ago, when a child was hospitalized, hours were restricted, and could only visit during certain parts of the day. Families are now acknowledged as part of the healing team. Some of us serve on hospital advisory boards, provide support in intensive care units. We know that quality improves and satisfaction for everyone soars when families and family centered care permeate an institution. FV leaders keep abreast of policy and regulatory developments that might impact a state's children and youth with special health care needs. We work with state agencies, place families on state and local government advisory commissions and as citizens we participate in the legislative process.

We Believe Every Child Has The Right To Go To School-We partner with special education parent training organizations and agencies. We serve on state and local advisories, mentor and guide families new to the complexities of inclusive education, provide support for health in the IEP. We also in several areas of the state provide support for families in the school system.

We Are Fathers and Advocates-Family Voices would not exist if fathers were not involved. They have a unique role as mentors to other dads who are also actively engaged in raising and advocating for their children.

We Seek Cultural Competence-We strive to provide culturally and linguistically competent assistance and materials. Because we understand and experience racial disparities in the provision of health care and disability services we are part of a bigger group that focus on underserved communities. Which is why it was also important for us to start the Parent Navigator Teams in rural areas and on the American Indian reservations.

We Live Family Centered Care-the principles of family-centered care are embedded in all that we do. Families must be included as equal partners. The family is a child's most consistent health care provider. Every child deserves a consistent source of medical care, a medical home with policies to reflect those principles for children and youth.

We influence federal policy-We helped through the State Children's Health insurance program, coalitions during IDEA reauthorization, we fought for the least harm when social security came under fire from Congress. We know that million of middle class families have private insurance that did not cover critical services, recommending a change in the Medicaid law, in the Family Opportunity Act and development of Family to Family Health Information Centers.

We Encourage Youth to Speak Out- "Nothing about us without us" Assisting youth in their advocacy journey.

We Train New Leaders-we must continue to assist new families on this journey. It is vital for us to assure that new leaders have training, materials and moral support. Our annual Family Leadership Retreat and connections to other areas continues to help with this growth. New families, new ideas which leads to further improvements of our systems of care. Call us, send an e-mail. Feedback for improvements are always welcomed!

Other Trainings and Opportunities

Parent Support is growing across the state! Support groups are being held. Community projects are being tackled. Families are feeling supported! North Dakota has amazing parents leading the way to providing support to families across the state! If you are interested in starting a Parent Navigator Team in your community, contact Missi at 701-290-8711 or 1-888-522-9654 or email her at missi.baranko@gmail.com. Parent Navigator Teams are groups of individuals (both parents and professionals) that work together through a parent led volunteer network. Teams help to find or develop support and resources to meet the needs in the community.

Each month Family Voices of North Dakota hosts two conference calls for **Parent Navigator Teams** and those interested in being part of a Parent Navigator Team. During these calls we share ideas, ask questions and brainstorm together. The calls are on the **FIRST WEDNESDAY OF EACH MONTH** FROM 12:00-1:00 (central time) and on the **THIRD TUESDAY OF EACH MONTH** FROM 8:00-9:00 p.m. (central time). Join us to find out more about the Parent Navigator Teams across North Dakota.

Are you interested in learning more about Parent to Parent (P2P) Support

Sign up for the upcoming ND P2P Phone Conference Workshops.

You can do it from the comfort of your home and it is FREE!

All you have to do is let us know you want to participate and we will send you a toll free number to use to call in on the date of the workshop. We will also send out training materials that allow you to follow along during the conference call. Below are the workshop dates and times. You do not have to complete them in order, so if you miss one, you will be able to catch it again during the next go around. For questions, contact Missi Baranko at 1-888-522-9654 or

missi.baranko@gmail.com

Thank you!

Title	Date	Time
Part 1: Welcome to P2P	Thursday, January 13	8:00-9:00 p.m. (CT)
Part 2: Communication Skills	Thursday, February 10	8:00-9:00 p.m. (CT)
Part 3: Grieving Process and Coping	Thursday, March 10	8:00-9:00 p.m. (CT)
Part 4: Family Centered	Thursday, April 14	8:00-9:00 p.m. (CT)



Family Leadership Retreat

This fall FVND held a Family Leadership Retreat for families who have attended our annual Family Leadership Weekend, families who serve on the RICC, are part of the Parent Navigator Teams or are an Experienced Parent across North Dakota.

The day happened thanks to the Early Childhood Comprehensive Systems through the Department of Health. A huge thank you to them for making it happen!

Over 60 families attended with their children, who were provided child care through the University of Mary.

Governor John Hoeven sent a letter of welcome to all of the families and continued encouragement as they continue their leadership path.



Guest speakers from various agencies were represented to identify within their agencies avenues for family leadership. Represented were: Protection and Advocacy, Early Childhood Comprehensive Systems, Federation of Families for Children's Mental Health, Department of Human Services and Divisions, Vocational Rehabilitation, Pathfinder Family Center, Department of Public Instruction, State DD Council and Children's Special Health Services.

Family Leaders shared experiences of their journey offering encouragement to others.



Jodee Bock spoke with Family Leaders, guiding them in taking their skills to the next level.

The day concluded at Papa's Pumpkin Patch with a wonderful afternoon and picnic at the Patch and entertainment with the children by Penny and Pal's. Thanks to all who attended and volunteered their time to make the day a success!



IN OTHER NEWS



Supporting Feeding and Oral Development in Young Children: Guidelines for Parents

This booklet was developed and is being distributed by Down Syndrome Ireland. It is an excellent resource for parents and is intended to be used in the first 2 or 3 years of life. It addresses feeding issues for young children with Down Syndrome, congenital heart disease and/or feeding difficulties. Contents include: how feeding works, principles of good feeding, feeding problems with certain medical and genetic conditions and a chapter of coming off a feeding tube.

It can be down loaded from Down Syndrome Ireland at: <http://www.downsyndrome.ie> or FVND has a copy which we can share.

Accessing WEB RESOURCES

More and more we have been including web resources in our newsletter.

Please remember if you DO NOT have access to these web based resources and information, FVND would be pleased to send you whatever information you would like printed out.

Just call us at:

888-522-9654



Donene Feist, Director

PO Box 163
Edgeley, ND 58433
Phone: 888-522-9654
Fax: 701-493-2635
Local: 701-493-2333
E:mail:
fvnd@drtel.net

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NON-PROFIT
PAID PERMIT #27
EDGELEY, ND
58433

How Can We Help You and You Help Us? Support FVND by becoming a member or donor today.

You could help us by assisting in workshops, writing articles, being a Support Parent and much more...Or you can provide a Cash Donation by making a contribution to FVND which will assist with workshops, matching a parent 1:1 for emotional assistance, Regional Parent Navigator Teams and much more!

_____To be used where needed _____Endowment _____
_____In honor/memory of _____Living Tribute for _____

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Enclosed is my tax deductible to FVND

Donation of _____ \$250 _____ \$100 _____ \$50 _____ \$25 _____ \$10 _____ \$5

Fill out this form, cut out and mail to Family Voices of North Dakota PO Box 163 Edgeley ND 58433

We Thank Our Professional Partners



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