ISSUE 25 VOLUME 3 YEAR 2010

FAMILY VOICES OF NORTH DAKOTA®

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"***

Creating Partnerships for ND families

From the Director-
Since our last publication many events, trainings, workshops, support and assistance to families and providers alike have transpired.

Donene is the co-chair of the National Family Voices Policy team and has also been busy assisting other states identifying partners, and understanding systems issues. (this on her spare time)

I am involved, nationally, with a work group through Justice For All and the Association for Persons with Disabilities as the sole representative for families and children. I have learned a lot from this group and the issues that face our children as they transition into adulthood.

I believe it is important for all of us to identify areas on which we can partner with families. Hospitals, clinics, work groups, committees, state agencies, local agencies, are all areas where it is critical to have a family voice at the table. Input and services look a lot different as the recipient of services. Families bring a wealth of knowledge and expertise to the table.

We will soon be hosting our 4th Family Leadership Institute. With this over 100 families will have been trained on systems, personal skills, communication and partnering. Many of these families are looking for an opportunity to be a voice for others. If you have a committee or work group, please give us a call so we can assist you in locating a family who can be that voice.

We are also excited that later this fall, we will bring together all of the Family Leaders, Experienced Parents, Medical Home family partners, and Parent Navigator Teams to an all day workshop in Bismarck to further their experiences and knowledge. Watch for future updates to come on this opportunity.

Partnerships are the essential core of FVND...Let us know what we can assist you or your organization with today

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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, 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 us today 888-522-9654**

Ethan's Story *by Lisa Radtke*

"I want new legs that work" a families story on finding a treatment to assist their son.

On a day prior to this past Christmas, Ethan was being picked on by his typical brother and sister. In an attempt to resolve the matter, his Mom asked him what he wanted from Santa for Christmas…After thinking about it for a minute he replied with big eyes… "Mom, I want Thomas the Engine Trains and…new legs that work!"

The youngest of 3 children, Connor (7) and twin sister (Ashlee), Ethan Radtke is an amazing five year old with a HUGE smile and a mischievous look. Born with Cerebral Palsy-Spastic Diplegia, the Radtkes have pursued therapy multiple times a week to help with Ethan's tone and to develop much needed skills. Despite the therapies, accompanied by Botox & Baclofen treatments, Ethan's tone continues to be unmanageable thereby making the use of his crutches and walker extremely difficult.

Due to this, Ethan's parents, Lisa and James decided to identify some outside and permanent options to help reduce Ethan's tone and get him on the road to "new legs that work".

While the initial path of research led to a rhizotomy, it wasn't until a news story on the Today Show focusing on umbilical stem cells was watched. Unfortunately, this wasn't an option for the Radtkes as they, like many parents, had not banked their cord blood.

Further research ensued, and Lisa stumbled upon the Xcel Center in Germany where they use Adult stem cells drawn from the patient's own bone marrow. Needless to say, the thought was initially dismissed due to the cost. Ironically, some weeks later, Lisa became acquainted with another mother from Kansas, who also has a child with Cerebral Palsy. They too had done some research and opted to apply for the stem cell treatment in Germany. Thus the interest in the treatment resumed.

After watching the results and seeing a little boy walking on his own 8 days after treatment, Ethan and his parents are now going to take the trek to Dusseldorf, Germany for the treatment at the Xcel Center. The treatment, scheduled for July 12th, is being used to treat all neurological disorders, including Cerebral Palsy.. Under general anesthesia, marrow is extracted from the patient's hip. The next day the cells are sorted & processed in the laboratory whereby the following day, the cells are then reinserted with some spinal fluid back into the patient via a lumbar puncture. Patients are then released to return home within the next 24-48 hours. The entire procedure is an outpatient procedure with minimal risks with successful results being seen.

Due to the fact that this is not an approved form of treatment in the US, the procedure is not covered under insurance; thereby financial help is being sought. The cost of the treatment is approx $12K USD + Travel/hotel/meals. Donations are being accepted online at http://www.giveforward.org/ethanwantstowalk/ or at any Wells Fargo bank (Ethan Radtke benefit fund). Should anyone have any questions, please feel free to contact Lisa Radtke via her blog at http://ethanwalks.blogspot.com. In addition, should you have additional inquiries on the Xcell center, please visit http://www.xcell-center.com/.

Make An 'I'm Bored' Jar this Summer

Kids always look forward to summer, but after several days of lazing around, they're likely to start whining "I'm bored". Creating an "I'm bored" jar may help.

At the beginning of the summer, each child makes a list of activities that they could do when they get bored. Examples include; listen to a favorite CD, paint a picture, plan a trip, write a poem, go for a bike ride. They should write each activity on a slip of paper and drop it into the "I'm bored" jar. Each activity needs to be something the child could do alone.

When kids are bored they take a slip of paper from the jar. Sometimes just the suspense of not knowing what might come out can add a little zip to the day. What happens if kids are still bored? Well, Mom can post a list of chores she'd be glad to suggest….Weeding the garden, cleaning the closets..the kids may make it through the summer with very few boring days!

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.

Let me start by saying I am the father of an 11yr old boy who carries diagnosis ranging from Juvenile Bipolar to Asperger's to OCD to Tourette's to ODD to ADHD to the newly abbreviated TDD. Add all of that to the fact he is two years ahead in school. This is a recipe for disaster!

I remember the day the doctor said "you're having a boy". My thoughts shifted from "will I have a NBA player, NFL player or more realistically a MLB all-star?" When thinking of names, I kept going back and forth. Either Darin (after Darin Erstad, yes I am an Angels fan) or Tyler. Tyler, Ty, TJ could all be appropriate names for a MLB shortstop or second baseman, right? Was I disappointed the day I realized he would never participate in sports? Of course. Not because of my dreams or him not being "like the other kids". It was that him and I would never share that bonding experience. Who knew our bonding experiences would be over the Greek alphabet, colors, gems and stones, or anything Microsoft??

I have been through a lot of emotions. Denial? Yes, this won't happen to my kid, it's those other kids with bad parents. Anger? Yes, we couldn't go to a circus, basketball game or even church without an outburst or him screaming and covering his ears. Guilt? Yes, what did we do to deserve this? Is he paying for something we did? And after many years and tears- Acceptance? You better believe it. He never asked for any of this. He is our son, we have one chance to take care of him, and I'll be darned if anyone will stand in my way.

I guess my message is this-whatever emotion you felt yesterday, feel today or will feel tomorrow, is perfectly fine. We all go through the stages in our own way. Do what you gotta do-join a support group, become a Parent2Parent Support, step into becoming a leader of a Parent Navigator Team, or write a column for Family Voices, it's all good!

Brad Beck
Mandan ND

The SunWise Program is an environmental and health education program that aims to teach the public how to protect themselves from overexposure to the sun through the use of classroom, school and community based components.

SunWise Kids

This website will help kids learn more about the harmful effects of the sun and teaches ways to protect themselves. With fun activities like the "Who Wants to Be Sun Wise" trivia game and action steps, such as wearing a hat, sunglasses, and sunscreen, kids will learn simple steps to protect themselves.

If your school joins the Sun Wise Program and orders a UV meter, they will receive the SunWise toolkit that includes activities and a UV sensitive Frisbee. With the meter you can measure how much UV radiation reaches your town. You can enter the UV information on the SunWise website. Then look at the data and compare UV numbers with the National Weather Service's UV Index.

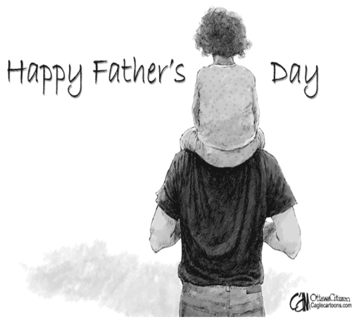
To find out more go to: www.epa.gov/sunwise

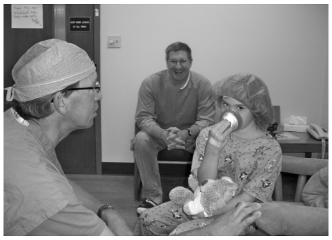
Famous Fone Friends

FAMOUS FONE FRIENDS (FFF) is a non-profit, charitable, 501(c)(3) organization founded over twenty years ago by a group of Los Angeles Board of Education studio teachers. Its purpose is to connect seriously ill children with entertainers and athletes through telephone calls. Hospitals refer patients, indicating specific requests or interests, and FFF then coordinates the phone call from the celebrity to the child. Everyone connected with FFF is a volunteer, enabling the organization to run on a very low annual budget. Donations are never requested from celebrities, hospitals, or families of children called, and thanks to the compassion of the participating actors and athletes, over 10,000 loving connections have been made between celebrities and hospitalized children. This is since its inception in 1986.

Call us at 310-204-5683 (310-204-LOVE) for further information or to volunteer.

Famous Fone Friends
9101 Sawyer Street
Los Angeles, CA 90035
(Donations can be sent to





2010 Timeline for Health Reform Legislation

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 will go into effect immediately, while some will be implemented over the next decade. To help navigate through the legislation, the Commonwealth Fund have created timelines. We have pulled out some of the significant pieces that affect families and children with special health care needs for this year, 2010, To read the complete timeline go to The Commonwealth Fund website at www.commonwealthfund.org

2010

Young Adults on Parents Health Plans. Young adults may stay on their parents health plans to age 26, effective six months after enactment. The provision applies to all health plans, and does not exclude young adults who are married.

Prohibition on Preexisting Condition Exclusions for Children. Insurers are prohibited from excluding coverage for preexisting conditions for children in the individual market, effective six months after enactment. (September 23, 2010)

Prohibition Against Rescissions. Group health plans or insurance companies providing group or individual market coverage are prohibited from rescinding coverage once an enrollee is covered under a plan, except in the case of an individual who has performed an act or practice that constitutes fraud or makes an intentional misrepresentation of material fact. Effective six months after enactment. (September 23, 2010)

Prohibition Against Lifetime Benefit Caps. Group health or insurance companies providing group or individual market coverage are prohibited from setting lifetime limits on the dollar value of benefits and from setting unreasonable annual limits on the dollar value of benefits, effective six months after enactment. (September 23, 2010) Annual limits will be banned completely in 2014.

National High-Risk Pool. People with preexisting conditions will be eligible for subsidized coverage through a national high-risk pool, beginning 90 days after enactment. People who have been uninsured for at least six months and who have a preexisting condition will be eligible for subsidized coverage through a temporary national high-risk pool, to be established by the Secretary in 2010. High-risk pools will not impose preexisting condition exclusions and plans will be required to cover on average no less than 65 percent of medical costs (actuarial value) and to limit out of pocket spending to that which is defined for health savings accounts, or $5950 for individual policies and $11900 for family policies. Premiums will be set for a standard population and cannot vary by more than a factor of four based on age (i.e. 4:1 age bands). The Secretary will receive $5 billion to carry out the program. North Dakota Insurance Commissioner Adam Hamm, in a letter to the United States Secretary of Health and Human Services (HHS), said that North Dakota will not operate the federal government’s new temporary high risk health insurance pool. Hamm wrote, “I have carefully analyzed and considered this issue, including conferring with elected state leaders and the Board of Directors of North Dakota’s existing high risk insurance pool (Comprehensive Health Association of North Dakota (CHAND). I have come to the conclusion that at this time the State of North Dakota will not seek to operate this new temporary federal insurance program.”

Limits on Share of Private Premiums Insurers Spend on Non-Medical Costs. New limits will be set for the percent of premiums that insurers can spend on non-medical costs. Beginning in 2010, health plans are required to report the proportion of premiums spent on items other than medical care. Beginning in 2011, health plans in the large group market that spend less than 85 percent of their premiums on medical care and health plans in the small-group and individual market that spend less than 80 percent on medical care will be required to offer rebates to enrollees.

Annual Review of Premium Increases. In 2010, effective immediately, the HHS Secretary and states will establish a process for annual review of unreasonable premium increases. Health insurers will be required to submit to the Secretary and the relevant state of a justification for an unreasonable increase prior to implementation of the increase. The information will be required to be posted on insurers’ web sites. The bill appropriates $250 million to the Secretary for grants ($1m to $5m) to states between 2010 and 2014 to review and approve carrier premium increases. As a condition of receiving a grant, state insurance commissioners will be required to provide the secretary with information on trends in premium increases in the state and make recommendations to the state insurance exchanges on whether particular insurance carriers should be excluded from participation based on a pattern of excessive or unjustified premium increases.

(cont. on pg. 9)

News from staff across the state

FVND staff are in Bismarck, Dickinson, Fargo, Grand Forks and Edgeley
Call us at 888-522-9654

Missi in Dickinson- There is never a lack of work to be done across the state! Winter was long with many rescheduled events due to weather. I spent many weekends traveling to different parts of the state to meet with parents and professionals for the Parent to Parent and Parent Navigator Workshops. It was nice to meet new people and to put faces with so many people's names! I am excited that we now have parent navigator teams up and running all over the state and are still working on visiting more parts of North Dakota to help people get one going in their region. It has also been great to be able to offer the Parent to Parent workshop to all of the regions this year, in a face to face format. Last summer we started a new online support group "BigTent". It has been a great success! If you haven't checked it out yet, take a minute to do so at: **www.bigtent.com/groups/ndp2p**.

In May I attended the Pathfinder conference in Minot. What a great opportunity to listen to such great speakers. I had the chance to present on technology with my good friend, Vicki and also to co-present with my 12 year old daughter, Tashina. Tashina did great and definitely made me proud!! We are currently planning for our fourth Parent Leadership Institute in Edgeley! We are looking forward to a great weekend of discovery with 25 new parents! I am sure the summer will stay busy as we continue to have the great opportunity to help families find resources and information as well as support. We are always eager to assist in any way we can! My summer will be capped off in August with me finishing my degree in Social Work! It seems like a long (and short) three years of going back to school and I am very excited to be done and focus on all the great things we have going on at FVND! I hope everyone has a great summer!

Congrats Vicki Peterson and Missi Baranko! FVND staff! At the Annual Pathfinder Family Center Conference both Missi and Vicki received the Glenda Schepp award. Thank you Vicki and Missi for all you do for families in North Dakota!

Vicki in Bismarck- It was a very busy winter and spring. I continue to work with families to help with systems navigation, education, support and connecting them with resources. I participate in the Region VII Parent Navigator group, F.R.I.E.N.D.(Friends, Resources Energizing, ND); group of parent and professional volunteers concerned about issues involving children with disabilities and special healthcare needs. We have a "Lunch Bunch "group to get to know each other and also have discussed several options for projects. I facilitated a support group for parents whom have children and youth on IEP/ IFSP/ 504 Plan/or with special needs at school. I have decided to start again in early fall with meetings again. My hope would be someday to start a SEPTA organization ; (Special Education Parent Teacher Association). I have made many new connections with professionals this year working in the areas of children with special healthcare needs. Thank you.

One of the strongest increases in areas for families has been an increase in emotional support and has been helping families in this area and directing them to local resources. I participated in several workshops this early spring, including presenting with Missi Baranko on technology. On a personal note; my oldest son Erik graduated high school, May 2010 and will be attending Jamestown College in the fall; Aaron 9 has autism) had a wonderful year at school. I would like to take this opportunity to thank my wonderful director, co-workers, parents, professionals, trusted friends, and all of whom I have formed relationships with , a wonderful and safe summer.

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 across the state

FVND staff are in Bismarck, Dickinson, Fargo,
Grand Forks and Edgeley
Call us at 888-522-9654

Brenda in Fargo-
Greetings from Fargo!
The 2009/2010 School year has come to a close. Hannah our daughter had a great first year at Carl Ben Eielson as a 6th Grader thanks to the hard work and dedication of her amazing team. Hannah is the only child who uses a wheelchair in her school. I am happy to report that Hannah has been accepted and treated well by her fellow students. Hannah's transition to Middle School reinforced the need to partner with Fargo School District. I started attending FEET (Family Education Enhancement Team) meetings. At the FEET meetings we discussed the need for an "After School Program" for children with special needs. The "After School Program" is no longer just a discussion it is an actual work-in-progress thanks to John Yates, Special Education Director. One other project that I would like to see get off the ground is the implementation of "Spread the Word to End the Word". To learn more about this project visit www.R-word.org . If you are interested in becoming part of the FEET Committee, please contact me. Together we really can make great things happen in our schools.
On June 17th we will hold our monthly Support Group for Parents/Guardians of Children with Special Health Care Needs at the Bestwestern Doublewood Inn – Fargo – at 7:00 p.m. in the Executive 2 Meeting Room. The support group has far exceeded my expectations. The group offers such great support for one another. The 2 hours is filled with support, sharing and learning…it is terrific and I want to thank all of the parents that have participated in the past for making this support group so great.

I will be hosting a family get together for the support group participants sometime in July, keep a look out for that announcement

On August 12th Hannah will be participating in the "Stroll for Epilepsy" in Fargo at Trollwood Park. She has named her team, "Team Schmidy". I encourage anyone who is interested in is raising money for programs for people and families affected by epilepsy and want to help create awareness to build a team or join "Team Schmidy". To register for the stroll go to: www.efmn.org or call 800-779-0777 ext. 2310. To join "Team Schmidy" email me: schmid@cableone.net or call 701-235-1781.
Over the past year I have had the wonderful opportunity to serve on the Family Advisory Council (FAC) at Meritcare Children's Hospital. It has been a valuable experience for me. I have learned a lot from the Meritcare Professionals that serve on the council and I have contributed productive feedback and solutions from my real life experiences at Meritcare. I recently recruited 4 more parents to serve on the council and am really looking forward to working on future FAC projects.

As many of you know Family Voices of ND offers a Parent to Parent Program. The program provides one-to-one matches of families who have similar needs and experiences. If by chance your child is admitted at Meritcare Children's Hospital or Innovis, I am right here in Fargo ready and willing to help in any way that I can. Hospital stays can become very lonely and isolating I would happy to come and visit. If you have any questions/suggestions or want to participate in any of these, contact me at 701-235-1781 or email: schmid@cableone.net.
On a personal note I am committed to spending as much time as possible with my daughter Hannah this summer. She turns 13 years old on June 4th . Hannah's birthday is a reminder as to how fast time goes by. We are going to make this a great summer filled with fun, family and friends I hope you do the same.

Joan in Grand Forks-
In Grand Forks Joan has been busy assisting families, attending events in the Grand Forks and surrounding areas, such as the Health Fair at Spirit Lake Reservation.

Additionally, Joan assists with a play group and support group in Grand Forks.

New partnerships have been established with the military base and providers of which we are excited about.

Joan is also the new outreach staff for Pathfinder Family Center. Partnerships continue to grow and be strengthened.
KUDOS TO ALL OF THE STAFF AND THEIR WORK

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.

Parent Navigator Teams!
Each Region Now has a PNT!

Each Region in the state now has a Parent Navigator Team! Additional teams which are being pursued are in New Town and Fort Yates. If you would like more information for your region or would like to start a team Contact Missi Baranko (701-290-8711 or 888-522-9654 or missi.baranko@gmail.com)

Parent Navigator Teams are teams that work to strengthen families, especially those with disabilities and special health care needs, through a region wide parent-led volunteer network. Navigator Teams help to find or develop resources to meet the unique needs of their region. They serve as a point of contact in the community, work in partnership with local leaders, share their knowledge of local resources and provide guidance to other families. Navigator Teams are a project of the ND Parent to Parent Program under the supervision of Family Voices of ND.

The Navigator Team is a diverse blend of parents, professionals and community leaders. Each team has:

- **A Leader** who oversees the activities of the local team. This person serves as a main point of contact for each Navigator Team.
- **Members** who attend meetings, help plan events, receive information and help to do the work that needs to get done.
- **A Resource Network** composed of agencies or other interested parties that collaborate with the Navigator Teams on activities and events.

What's Happening

Parent Navigator Team in Devils Lake

The North Central Crew Parent Navigator Team has had two family get togethers in the past few months. We had a bowling get together and a swimming/potluck gathering. We are currently working on recruitment and have printed several hundred brochures that a few of our regions Special Ed directors have agreed to send out to the families with children on IEP's.

We will have another family fun activity in June and have had discussions on working with our local Special Ed unit to put on a Parents Day out in the fall. Marcia Schneider Team Leader

Parent Navigator Team in Dickinson

The Region 8-The Dynamic Western Edge Parent Navigator Team has had quite a busy year so far and is anticipating a rewarding and fun-filled summer ahead! We started the year off with a fund-raiser that we called, "Flamingo Flocking." What we did was place two plastic flamingo's on friends and family lawns (yes, in the middle of winter we were out there putting pink flamingo's in snowbanks!!) along with a packet of information and prepaid mailer envelopes for donations. The fund-raiser went off well and the Dynamic PNT raises around $800.00!! We have already used some of the funds to help needy families in our area.

As I stated above we assist needy families within our area with "caring" baskets that contain an array of items such as: gas cards, food cards, books, small toys for the child with a diagnosis, snacks, or anything that we as a group can come up with to bring a moment of joy to a family that is going through a difficult time. We are using the funds we raise, along with community business sponsorship to fund the "caring" baskets.

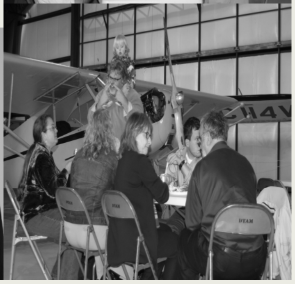
With summer in full swing we are also anticipating an upcoming summer picnic that will be held on June 28th. It will be held at the Optimist Park in Dickinson from 5:30-6:30 and will be collaboratively organized and funded with The K.I.D.S Program. Everyone is welcome!!

Well, that's it for now from the Dynamic Western Edge PNT, but I am sure that by the end of the summer we will have much more to report and exciting events on the horizon. Hope you all have a wonderful summer!

Parent Navigator Team in Bismarck

Here's a little rundown on Region 7, the F.R.I.E.N.D (Families, Resources & Information Energizing North Dakota) PNT.
We are still in the process of getting to know each other and find our "identity" in our region. Our core group is starting to develop.
We had a small fundraiser for a family from Emmons County.
If you are in our area, please join us the last Monday of each month at 6:30 at BECEP.
Please join our fan page on Facebook. If you have any questions, please contact Brad @701-214-2707 or friendpnt@gmail.com

Thank You Pathfinder Family Center for a great conference! We love our partnership with you!



Parent to Parent Helping One Another

I actually contacted FVND through Red Door and then you got a hold of me, and then through our conversations I was introduced to your parent-to-parent mentor program. I was so excited! I have been a mom for almost 19 years now to four boys with Autism along with a host of other disabilities that require a lot of time and effort from myself and their stepdad, George who came to us by way of a national chat room for Special Olympics for athletes, their parents and families and friends.

My husband is a Special Olympics coach (once a coach, always a coach, lol) and has worked on a long-term basis with Goodwill Industries in West Palm Beach, Florida where he was raised. He has never had children, but this hasn't stopped him from taking over and jumping in with both feet and loving them just like they were his own. He is my partner, my best friend, my confidante and my biggest supporter.

I e-mailed back and forth with our parent to parent match a couple times and then we finally were able to connect on the phone. Oh my goodness, what a relief to know that I wasn't the only parent to be going through what I am! You know, in the back of your mind you know that to be true, but when you're in the thick of it and your special needs child is sitting there hurting themselves to the point that you cry yourself to sleep at night, you feel very alone.

Our Parent to Parent match helped support me not just emotionally as a mom, but as a parent with a child with a severe disability that requires sometimes up to 16 to 18 hours a day to protect him from himself in just keeping an eye on him. Just knowing I had someone to talk to, someone that would just listen and say that not only he understand, but that he **truly** understood meant the world to me.

It's hard sometimes to find parents who are really willing to share and talk about their experiences, and even teach or guide another parent who is going through the same difficulties or similar ones. Our Parent to Parent match is awesome! He is one of the most kindest, gentlest, compassionate people I have ever met and yet has the tenacity of a bulldog when it comes to his son. He reminded me it's okay to cry, to even weep for your children and yet turn around and get angry when you know it's called for. Thank you so much for letting me get involved in your program and for blessing me with the people that have touched not only my life but my whole family's life as well!

Because of this I got an occupational therapy consult for my son, a neurological consult and I am getting everything added to his IEP. I guess in a way our Parent to Parent match just sort of gave me the push I needed to get going again.

What you all do is nothing short of amazing, because of what I have experienced I want to be a parent-to-parent mentor as well! I love helping people and sharing what I know and knowing that I've helped someone makes me feel really good! Thanks to our Parent Match! And thank you FVND! Gwendolyn Warren

Communication Tips for Professionals

The following tips are offered for professionals wanting to better communicate with parents of children with disabilities:
Practice empathy, not sympathy, empathy means to identify with...understanding another's situation. Sympathy can mean pity. Parents need to know you respect them as persons—even in difficult circumstances. Knowing they are respected can lead to trust.

Balance helping with listening. Often the best is listening.

Level the playing field. Use plain, clear language so that parents can understand all the information you are giving. Mutual understanding is key to communication.

Be trustworthy. Follow through. For example, if you say you will contact a parent at a specific time, do so. Even if you cannot provide complete information, let the parent know you haven't forgotten about them and are working on their situation.

Don't take negative comments personally. Parents may be frustrated, angry, or anxious because their child may not be doing well with their health or in school.

Adapted from "PACER Center, INC. Minneapolis MN

Health Reform Legislation

Cont. from page 4

Rebates for Medicare Part D Enrollees in "Doughnut Hole." In 2010, Medicare beneficiaries who reach the coverage gap, or doughnut hole, in prescription drug coverage (2,830) are eligible to receive $250 rebates. The coverage gap is phased out completely by 2020.

Elimination of Cost-Sharing for Preventative Care in Medicare and Private Plans. Preventive care will be strengthened in both traditional Medicare and private plans. In 2010, cost-sharing for proven preventive care services is eliminated in both Medicare and private plans. Medicare beneficiaries will receive an annual wellness visit with no co-payment beginning in 2011.

From Fact Sheet from the White House

Extends the Children's Health Insurance Program
Extends federal funding for the Children's Health Insurance Program (CHIP) through September 30, 2015, and provides states with additional funding to ensure children have access to this proven successful program. Increases outreach and enrollment grants to help reach more eligible children.

Other provisions beyond 2010

Pediatric Benefit Package Includes Oral and Vision Coverage for all Children- Requires coverage of not only basic pediatric services under all new health plans, but also oral and vision needs, starting in 2014. Many health plans do not provide coverage for needed child health services, and 12 percent of children have not had a doctor's visit in the past year.

More Pediatric Providers Where Kids Need Them
Expands the health care workforce – including pediatricians, pediatric nurse practitioners, specialists in pediatrics, and pediatric oral health professionals – to ensure that children will have access to high quality health care. This year, requires that parents enrolled in new plans be allowed to select their child's pediatrician from among any participating provider.

Improve Quality of Care for Children- Develops children's quality priorities and promote children's quality measurement and reporting to improve the care that our nation's children receive. A recent study found that children receive recommended care less than half of the time.

Coverage for Children Aging Out of Foster Care- Makes mandatory the current state option to extend Medicaid coverage up to age 26 to foster children who have aged out of the foster care system, effective 2014. Children aging out of the foster care system face many challenges, including finding quality, affordable health insurance.

Expands Coverage to Improve Access to Care
Provides health insurance choices through state-based health insurance Exchanges to families without job-based coverage and provides tax credits to those who can't afford it. Expanding insurance to all children will enable them to access needed care which is proven to enhance their development and learning, laying the foundation for a healthy life. Children who are uninsured have decreased access to well-child care, immunizations, basic dental services, and prescription medication.

More Affordable Choices
Creates state-based health insurance Exchanges to provide families with the same private insurance choices that the President and members of Congress will have, including multistate plans to foster competition and increase consumer choice.

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Insurance Security
Ensures that children have access to affordable child-only health insurance policies, regardless of whether their parents change jobs, leave a job, move, or get sick. Parents should be able to provide health coverage for their children regardless of their job situation.

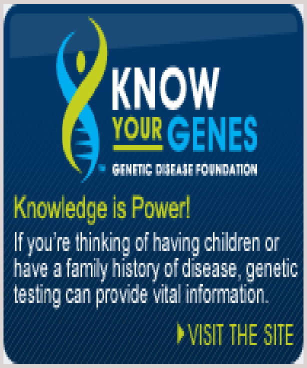
Know Your Genes

Know Your Genes is a public service provided by the Genetic Disease Foundation. Depending on your ancestry and family medical history, you may want to learn more about genetic disorders. While these diseases occur in all ethnic groups, some of them are far more common in certain populations than in others.

Inherited genetic diseases cannot be cured, but they can be prevented. Know Your Genes helps with questions like:

How to start compiling your medical family tree
Talking to your family about their health
What to look for in your family history
What if I am adopted?
What to do with the information you collect.

For more information go to
www.knowyourgenes.org/



A carrot, an egg and a coffee cup...You will never look at a cup of coffee the same

A young woman went to her mother and told her about her life and how things were so hard for her. She did not know how she was going to make it and wanted to give up, she was tired of fighting and struggling. It seemed as one problem was solved , a new one arose.

Her mother took her to the kitchen. She filled three pots of water and placed each on a high fire. Soon the pots came to a boil. In the first water she placed carrots, in the second she placed eggs, and in the last she placed ground coffee beans. She let them sit and boil; without saying a word.

In about twenty minutes she turned off the burners. She fished the carrots out and placed them in a bowl. She pulled out the eggs and placed them in a bowl. Then she ladled the coffee and placed it in a bowl. Turning to her daughter, she asked, “Tell me what you see.” “Carrots, eggs, and coffee,” she replied.

Her mother brought her closer and asked her to feel the carrots. She did and noted that they were soft. The mother then asked the daughter to take an egg and break it. After pulling off the shell, she observed the hard boiled egg.

Finally, the mother asked the daughter to sip the coffee. The daughter smiled as she tasted its rich aroma. The daughter then asked, “What does it mean mother?”

Her mother explained that each of these objects had faced the same adversity: boiling water. Each reacted differently.

The carrot went in strong, hard and unrelenting. However, after being subjected to the boiling water, it softened and became weak. The egg had been fragile. Its thin outer shell had protected its liquid interior, but after sitting in the boiling water, its inside became hardened. The ground coffee beans were unique, however, after they were in the boiling water, they had changed the water.

“Which are you?” she asked her daughter. “When adversity knocks on your door, how do you respond? Are you a carrot, and egg or a coffee bean?

Think of this: Which Am I? Am I the carrot that seems strong, but with pain and adversity do I wilt and become soft and lose my strength?

Am I the egg that starts with a malleable heart, but changes with the heat? Did I have a fluid spirit, but after a death, a breakup, a financial hardship or some other trial, have I become hardened and stiff? Does my shell look the same, but on the inside am I bitter and tough with a stiff spirit and hardened heart?

Or am I the coffee bean? The bean actually changes the hot water, the very circumstances that bring the pain. When the water gets hot, it releases fragrance and flavor. If you are like the bean, when things are at their worst, you get better and change the situation around you. When the hour is darkest and trials are greatest, do you elevate yourself to another level? How do you handle adversity? Are you a carrot, an egg, or a coffee bean?

May you have enough happiness to make you sweet, enough trials to make you strong, enough sorrow to keep you human and enough hope to make you happy. The happiest of people don’t necessarily have the best of everything; they just make the most of everything that comes their way. The brightest future will always be based on a forgotten past failures and heartaches. When you were born, you were crying, and everyone around you was smiling. Live your life so at the end, you’re the one who is smiling and everyone around you is crying.

Our thanks go to those people who mean something; to those who have touched our lives in one way or another; to those who make us smile when we really need it; to those who make us see the brighter side of things when we’re down; to those whose friendships we appreciate; and to those who are so meaningful in our lives.

May we all be COFFEE…..

We at Family Voices of North Dakota are grateful to each one of you. Thank you from all of the staff,
Donene, Missi, Vicki, Brenda and Joan

Identifying Appropriate Recreation Programs

Sometimes it takes a little time to discover what's out there, but the results may be worth it! Here are some helpful hints for finding and selecting activities in the community.

If possible, start with your child's recreation interests. Encourage your child to make decisions regarding free time. Direct or motivate him/her toward decisions that are necessary.

Choose age-appropriate activities.

Explore community resources to find out what is available. Visit programs and facilities. Be organized and systemic.

Meet and talk with staff. Provide information which assists them in understanding and including your child. If extra supervision or assistance is needed, consider finding a family member, friend or neighbor to take the class or attend the program with your son or daughter. Don't make your child's unique needs sound like babysitting is required.

Don't limit choices to "special" programs. Encourage involvement with non-disabled peers. Insist, if necessary. Sometimes that includes inviting a peer to your home of offering other encouragement initially.

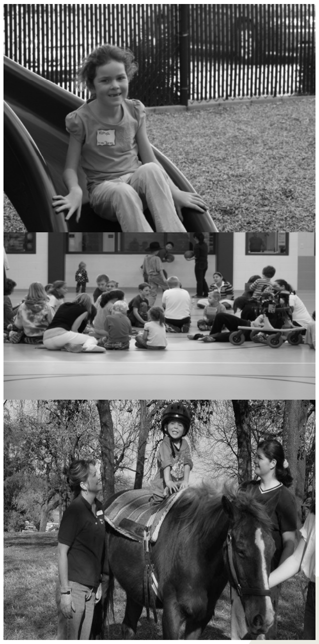
(Taken in part from the Parent Training Guide to Recreation, University of NC at Chapel Hill)

Community Recreation Resources

Town Recreation Department or Park Board
Drama, musical or dance groups
Health or diet workshops
Arts, hobby, or craft shops
Scouts, 4-H, Camp Fire
Sports leagues or camps
Baseball programs, such as T-ball, Midgets, Babe Ruth
Colleges /Vocational Tech Schools
Skating Rinks
Malls
Environmental Groups
Service Organizations continued

Community Recreation Resources Cont.

YMCA/YWCA
Tennis Clubs
Ski areas
Civic Clubs
Garden Clubs
Movie theaters
Bowling alleys
Miniature golf parks
Golf Courses
Horse and Riding Clubs
Swimming pools
Church Groups



It is important to look in your hometown whether small or large and identify what is available, you may be surprised

Integrated Services Grant and Medical Home Update-

Moving to Year 3

This May we are wrapping up our 2nd year on the NDIS project. Looking back at the past 2 years, we are definitely making strides in the right direction for North Dakota. This is what we have all contributed towards our project goals:
7 Medical Home Pilot Sites in ND
5 Healthy Transition Pilot Sites in ND
Development of 2 Curriculum Modules (Care Coordination and State & Local Resources)
2 Stakeholder Meetings
12 Learning Collaboratives (Medical Home, Healthy Transition, Family Involvement/Cultural Competence combined)
Development of NDIS newsletter
612 Children & Youth with Special Healthcare Needs (CYSHCN) identified
52 Care Plans developed
Contributed to School Plans for 433 Children

As we move ahead into Year 3, we still have many things to accomplish and more excitement to come. Thank you to everyone on our Advisory Committee, participants in our Learning Collaboratives, our Medical Home and Healthy Transition Pilot Sites, Stakeholder attendees and other supporters for your commitment to improving the quality of life for Children and Youth Special Healthcare Needs in our state.

For more information go to www.ndcpd.org/ndis or contact Kora Dockter, Project Director at 1-800-233-1737 or kora.dockter@minotstateu.edu

IN OTHER NEWS

Epilepsy and My Child

If you have a child with Epilepsy, this website is for you! Whether your child was just diagnosed, or you have specific concerns about medications, getting support at school, or another issue, the goal of the Epilepsy Foundation is to provide the information you need.

Topics include:
About Epilepsy
Just Diagnosed
Living with Epilepsy
Treatment
Raising Awareness
Resources and Connections

www.epilepsyandmychild.org

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

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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_________________

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Enclosed is my tax deductible to FVND
Donation of _______ $250 _____$100 _____$50 _____$25 _____$10 ______$5

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