

Medically Fragile News

July 2009
Edition 3

Connected



We have had a series of Family Networking Meetings, our first holiday party in December, a St. Patrick's Day gathering, and two Brown Bag Lunch gatherings. The meetings have had good turn out. Those who attended enjoyed connecting with one another and sharing

information. Everyone feels strongly about having our group grow.



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We would like to express our appreciation to Maxim Home Health Care for the publication of this newsletter.

Enclosed is a flyer for our first summer picnic scheduled. Please RSVP me at: legriffin@salud.unm.edu or 272-

University of New Mexico-Health Sciences Center-Center for

University Centers for Excellence
on Developmental Disabilities
Education, Research, and Services



We had a nice family gathering, a brown bag lunch on March 23, 2009. Families had the opportunity to get acquainted and share what was important to them. We had a parent facilitate this meeting. Some of the issues addressed were:

What was it that parents wanted from the program?

- ~ To be able to bypass HIPPA regulations and be able to contact one another freely.
A solution to this may possibly be done through the newsletter to establish an e-mail tree
- ~ The need for a respite care center. One parent would like to get one established and would run it.
The concerns would be liability issues.

Resources shared:

- ~ Health Care for the Homeless accepts donations of medical equipment.
- ~ NMRAM – New Mexico Reutilization and Acquisition Model – www.backinuse.com
- ~ Wheels for the World: we have a parent who is a resource for this national organization. Wheelchair parts are collected and refurbished for redistribution world wide.
- ~ The Independent Living Resource Center (ILRC) is a great resource for architectural design for remodeling for accessibility in the home.
- ~ Horizon Vans for vans with lifts.
- ~ Sunshine Conversions to adapt vehicles.
- ~ BOA lifts

What is the hardest things raising a child with medical needs?

- ~ People just don't understand the day to day challenges.
- ~ Illnesses and hospitalizations.
- ~ Isolation from other families. Even if you have friends and family to support you, they don't really understand because they haven't lived it.
- ~ Commonality with other families who not in the same situation.
- ~ Single parents are out there doing this alone. They have no back up of a spouse for that additional support
- ~ Low income families due to their situation.
- ~ Accessibility everywhere – whether it be just in a family or a friends house. One parents suggestion was to carry two by fours to always be prepared for a ramp.

Aging discussions:

- ~ How staffing issues become more challenging due to the size of a growing child.
- ~ How adult physicians are not prepared and open to accepting our developmentally disabled children.

There was discussion amongst many of us who had children who are raising young adults and/or approaching adulthood. *The discussion included:* How we see siblings and their peers accomplishments celebrated. One parent offered a story of her child and his peers who are in music therapy having a holiday gathering and having a concert to hear their children's accomplishments. These accomplishments many of times go by unnoticed by others who don't have a child with a developmental disability. How accomplishments, no matter how small, need to be celebrated.

We also had family gathering for a Pot Luck dinner celebration for St. Patrick's Day. A new member joined us who has an ongoing interest in the group. This is a friendly gathering to allow families to connect and share. This has been an ongoing meeting for many months.

You know you have a child with special needs when....

- You compare ER's instead of grocery stores
- You compare your child's oxygen saturations
- You view toys a "therapy"
- You don't take a new day for granted
- You teach your child HOW to pull things out off the cupboard, off the bookcases, and that feeding the dog from the table is fun
- The clothes your infant wore last fall still fit her this fall
- Everything is an educational opportunity instead of just having plain old fun
- You cheer instead of scold when they blow bubbles in their juice while sitting at the dinner table (that's speech therapy), smear ketchup all over their high chair (that's OT), or throw their toys (that's PT)
- You don't mind if your child goes thru the house tooting a tin whistle
- You fired at least 3 pediatricians and can teach your family doctor a thing or two
- You can name at least 3 genes on chromosome 21 (You really know your toast if you can spell the full names correctly)
- You have been told you are "in denial" by at least 3 medical or therapy professionals. This makes you laugh!
- You have that incredible sinking feeling that you've forgotten SOMETHING on those few days you don't have some sort of appointment somewhere!
- You get irritated when friends with healthy kids complain about ONE sleepless night when they're child is ill!
- Your vocabulary consists of all the letters OT, PT, SP, ASD, VSD, IFSP, etc.
- You keep you appointment at the specialist even though a tropical storm is raging because you just want to get this one over with.... You waited 8 months to get it"" and besides, no one else will be there!
- Fighting and wrestling with siblings is PT
- Speech therapy occurs in the tub with a sibling
- When potty training is complete, you take out a full-page public notice in the Washington Post
- When the Doctors/Specialist/Hospitals etc. all know you by your name without referring to your chart
- You keep a daily growth chart
- You calculate monthly statistics for the number of times you child vomits, and did this for more then one year.
- You phone all of your friends when your child sits up for the first time, at age two.
- With a big smile on your face you tell a stranger that your four year old just started walking last week
- Her medical file is two inches and growing
- You have a new belief... that angels live with us on earth

Provided by parent on program: Jessica Abeyta

Source website: http://www.tracheostomy.com/misc/fun/special_needs.htm

Information is now just a call or click away



Visit the new website for information and updates of the Resource Directory at CDD:

<http://cdd.unm.edu/>



The **Information Center for New Mexicans with Disabilities and BabyNet** launched a statewide Resource Directory on the internet. Find help on the web with this searchable database of New Mexico programs, providers and resources. To ensure up-to-date information, the database will be updated regularly by Information Center staff.

Do you have questions about Medicaid, SSI, waivers, therapies or other programs? Are you looking for a support group, training or disability related materials? Do you need information about Autism/ASD, Down syndrome, ADHD, early intervention or other disability related topics?

Our Resource Specialists continue to be available to answer questions and provide additional information regarding programs and resources. Call us at the

Information Center for New Mexicans with Disabilities and BabyNet:

1-800-552-8192 or 505-272-8549

We can help!

FYI's

MI VIA: *Public Partnerships* (PPL) has recently disseminated new packets of paperwork to participants on Mi Via making it more user friendly. They recently offered training throughout the regions in the state on some upcoming changes. I attended our local training and many questions were answered by the participants, employers, and employees. I found it to be very informative. When trainings are scheduled in the future, if you receive a notice and you are struggling with the paperwork, I would recommend you attend. I also would be happy to help in any way I can if any additional assistance is needed.

Lynn Griffin: 505-272-8801 or legriffin@salud.unm.edu

Changes coming soon: Vendors will be able to be paid with direct deposit. Time sheets will be able to be

Equipment donated:

Zippy Wheelchair which was fitted a boy who was 4' tall, but can be adjusted up in size.

It has a jell seat, an adjustable head rest, safety strap and harness, two attachable trays, arm rests, IV pole. It does have a child's name embroidered on it.

Please contact **Lynn** if you know of anyone who is in need. 505-272-8801 or legriffin@salud.unm.edu

Until we have an equipment exchange website, I would be happy to post any DME donations.

The New Mexico Human Services Department is pleased to announce that there is currently no waiting list to enroll in the State Coverage Insurance (SCI) Program. *Insure New Mexico!* Solutions Reaches out to Partners to Increase Enrollment in SCI

The SCI program is a public/private program for adults between 19-64 years old with incomes below 200% of the Federal Poverty Level.

For information the SCI program and other publicly funded health coverage programs, including the New MexiKids/NewMexiTeens program, the Premium Assistance for Kids and the Premium Assistance for Maternity along with several other programs, please contact the *Insure New Mexico!* Solutions Center at 1-888-997-2583 or visit www.insurenewmexico.net

LEARNING OPPORTUNITIES



Parents Reaching Out

1920 B Columbia Dr., SE, Albuquerque, NM
To register call (505)247-0192 or 1-800 524-5176

Jul 23, 2009

Next Steps to Success

Thursday, 1:00pm - 4:00pm

Albuquerque, New Mexico

Jul 30, 2009 - Advocacy and the IEP Process

Thursday, 8:30am - 3:00pm

Albuquerque, New Mexico

Aug 06, 2009 Functional Behavior Assessment/

Behavior Intervention Plans

Thursday, 9:00am - 12:00pm

Albuquerque, New Mexico

The Division for Early Childhood (DEC)

is excited to announce an opportunity for families of children with disabilities and other special needs! DEC will offer 25 stipends covering the cost of registration for the *25th Annual International Conference for Young Children with Special Needs and their Families* which will be held at the Albuquerque Convention Center from:

October 15-18, 2008

The stipend covers full conference registration (a value of more than \$195) as well as optional participation in full-day workshops offered on Thursday October 15 or half-day workshops offered Sunday October 18.

Go to www.dec-sped.org and click the "Conference" link to learn more.

This conference provides a unique opportunity to hear from leading experts in early intervention and early childhood special education, become exposed to cutting edge research and ideas, learn about intervention strategies that are being used throughout the world, and see the latest resources. DEC's annual conference is the conference where professionals come to gain access to the information they need, connect with colleagues, learn new strategies, and become re-energized to continue their work with young children and families.

The Executive Board of DEC knows that many family members are also eager for this information and we are committed to providing this opportunity to encourage more parents and family members to participate.

YOU MUST MEET THE FOLLOWING REQUIREMENTS:

1. Be the parent or family member of a child from infancy through eight years of age who has a disability, developmental delay, or other special need.
2. Not be employed full-time in an early intervention or early childhood special education position.
3. Be able to attend at least two full days of conference activity and participate in the following special activities:
 - *Family Consortium Committee Meeting and Luncheon*
 - *Family Consortium Reception*
4. Be willing to complete a written evaluation giving us your feedback and suggestions about the conference.

If you have any questions, please contact the DEC office at 406-543-0872 or dec@dec-sped.org or contact Kimberly Christensen, DEC's national Family Consortium Committee Chairperson at: kchris@bgsu.edu.

Applications must be received by Aug. 1.

Fun for Medically Fragile Families



POT LUCK

Bring the whole family

When ? ~ **August 3, 2009**

What time ? ~ **6:00 – 8:00 PM**

Where ? ~ **Manzano Mesa Multigenerational Center
501 Elizabeth St. NE**

The facility is just east of Costco at the corner of Elizabeth & Southern, in between Eubank & Juan Tabo, south of Central



A Water Sprayground is located outside at the facility

The [water sprayground](#), a fully automated aquatic play environment where all ages can get wet during the hot summer months. Come prepared with towels and dry clothing for those who may participate. We have access to the indoor facility where we have a room reserved for us. We would like this to be a POT LUCK. Being this is scheduled during the dinner hour we would like everyone bring a dish to satisfy our appetites and enjoy the festivities at the same time.

Our library (LINC) and other staff will be attending and providing fun activities for our children

Please RSVP: Lynn Griffin 272-8801 or legriffin@salud.unm.edu

I have a sign up sheet for your contribution

Hope you can make it!

UNM Health Sciences Center
Center for Development & Disability
2300 Menaul NE
Albuquerque, NM 87107

*Medically Fragile Case
Management Program*

Phone: 505-272-8801

Fax: 505-272-8100

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[<http://cdd.unm.edu>]

**“Optimism is the faith that leads to achievements.
Nothing can be done without hope or confidence.”**
Helen Keller

Useful Websites

Pass it on:

Designed to facilitate supply and equipment donations between individual members.

<http://www.tracheostomy.com>

Family Support Center on Disabilities:

Knowledge & Involvement Network, KIN.

A new family-centered clearinghouse established last October by the U.S. Department of Health and Human Services. Offers a centralized resource on the full range of options available.

www.familysupportclearinghouse.org.

Simple Home Modification for the Disabled:

Information available for individuals and family members using wheelchairs. Suggestions are simple and inexpensive and recommended physical dimensions needed offered by the American National Standard Institute.

<http://www.cdc.gov/nasd/docs/d000101-d000200/d000138/d000138.html>

Kids Together, Inc.: Their mission is to promote inclusive communities where everyone belongs.

<http://www.kidstogether.org/>