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 MFCMP Family Specialist
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MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM

Connected



The Road Always Leads Home

Welcome to our first Newsletter, *Connected*.

We are very excited about establishing our first newsletter. This is the first step in getting our families connected. The Medically Fragile Case Management Program (MFCMP) is committed to bringing you information from many different sources that you may find both helpful and informative.

Our first issue will briefly discuss the importance of a Parent Advisory Council. Our intent was to enclose a *clipette* of helpful information included in each newsletter.

We plan to have a family and case manager highlight in every edi-

tion. Everyone has a story to share. If you would like to do a story about your family, please contact Lynn Griffin. We invite your ideas regarding the contents of the newsletter for future publications and ask for your participation. Someone has suggested having family *TIPS* included. Please forward any suggestions.

After having spoken with numerous families, many have expressed an interest in networking with one another. Our first meeting has been scheduled; date and time is posted on page 3. The interest in a web based information exchange for families seems to also be of interest. I would like to start collecting email addresses

Clipette: Did You Know?

America the Beautiful—National Parks and Federal Recreation Lands Pass— Access Pass —Free. <http://www.nps.gov/fees>



Several of our families have participated in CDD's LEND Program which is an interdisciplinary pre-and post-service graduate leadership training program. One family hosted the student, Laura Ferguson, MD, who she was assigned as a trainee. During the time everyone is getting acquainted, there becomes a focus from the directive of the family for the student to research. This particular family choose which parks were accessible to wheelchairs within a two hour drive.

The National Parks visited by *Laura Ferguson* were **Bandelier:** main path is paved and accessible although must climb stairs to peer in cave dwellings, 1/2 mi. in length. Second path down to "Alcove House" is sandy forest soil but quite flat and wheelchair accessible, **El Morro:** 1/2 mi. path to the rock is paved and has only a slight uphill grade going toward it, **Fort Union:** Flat gravel paths very assessable, **Salinas Pueblo Missions:** very wheelchair accessible and flat.

There is a lifetime pass for U.S. citizens or permanent residents with permanent disabilities. Documentation is required to obtain the pass. Acceptable documentation includes: statement by a licensed physician; document issued by a Federal agency such as the Veteran's Administration, Social Security Disability Income or Supplemental Security Income; or document issued by a State agency such as a vocational rehabilitation agency. The pass provides access to, and use of, Federal recreation sites that charge an Entrance or Standard Amenity. The pass admits the pass holder and passengers in a non-commercial vehicle at per vehicle fee areas and pass holder + 3 adults, not to exceed 4 adults, at per person fee areas (children under 16 are admitted free). The pass can only be obtained in person at the park. The Access Pass provides a 50 percent discount on some Expanded Fees charged for facilities and services such as camping, swimming, boat launching, and specialized interpretive services. In some cases where Expanded Amenity Fees are charged, only the pass holder will be given the 50 percent price reduc-

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Special points of interest:

- Resources
- Family Highlights
- Enclosure:
UNMCH Families as Partners Newsletter

University of New Mexico-Health Sciences Center-Center for Development and Disability

University Centers for Excellence
 on Developmental Disabilities



Family Spotlight: Meet the Smethurst Family

by Gary and Jane Smethurst

There are also many parent organizations out there, and Gary and Jane Smethurst have a blended family composed of four birth children and four adopted children with similar medical issues. If you like the idea of getting to know someone who is living with the same kind of challenges, give me a call and they are all out in the world enjoying their jobs and starting their homes.

Our four adopted children range in age from 10 to 15.

Our oldest is Joey, who is 15 years old. He has been with us for five years. Joey is a fun loving young man who was born with Hydrocephalus, a condition that severely damaged his brain. Joey also spent the first six years of his life in a family situation that involved a great deal of physical abuse. He has made great progress over the years. He is now an independent eater, has learned to walk using a walker and most importantly he has learned to accept and return love. He gets real joy interacting with others and loves to

York. She has developmental delays due to Fetal Alcohol Syndrome. She has learned to read at a 3rd grade level, loves to do chores around the house and is big fan of "High School Musical".

Ashton is 10 years old. He has been with us for eight years. Ashton was involved in a near drowning incident shortly after his first birthday. He is a very strong and high spirited young man who uses his eyes and various facial expressions to communicate with us. He loves to be read to and likes going out into the world, he especially likes the Balloon Fiesta, and concerts at the zoo.

Our daughter Alexis was with us for 30 months. She was a very loving and happy young lady who delighted all those who were around her. She passed away five years ago due to medical complications from her disabilities.

Jane and I have been so blessed to have eight wonderful children in our lives and we know that

Helpful Information by Lynn Griffin

As many of you are now aware, I am a parent of a child with a developmental disability who is now 22 years of age. I have a lot of background in special education from my previous employment. As I began my position as a Family Specialist with the Medically Fragile Program, I realized that even though the needs are different for education and medical, they both follow some of the similar systems. We are also always establishing relationships, needing two way communication to build partnerships to have our children's needs met.

I am available to all of you as a resource. I also work within CDD in the *Information Center for New Mexicans With Disabilities/BabyNet* which has increased my knowledge of resources available in communities.

The Information Center is located at:

Center for Development & Disability
2300 Menaul Blvd, NE
Albuquerque, NM 87107
Hours: 9:00 am until 5:00 pm Monday through Friday

Phone: 1-800-552-8195 or 505-272-8549.

We can also be reached via email at inonet@unm.edu All of the Resource Specialists at the Information Center are very knowledgeable in resources and service systems.

The Information Center for New Mexicans with Disabilities/BabyNet provides information to individuals with disabilities, families, advocates, therapists and case managers about service providers, support groups and other local state and national resources. The BabyNet information and referral service (a part of the Information Center for New

Mexicans) helps pregnant women and families with small children gain information to access and utilize medical and support services by educating and providing information.

BabyNet promotes baby wellness by identifying and promoting prenatal and perinatal services as well as helping to reduce the incidence and effects of disabling conditions.

In conjunction with the Information Center we have LINC, our *lending library*, which happens to be the most comprehensive collection of disability resources in all of New Mexico. You can search the online collection of books, journals, videocassettes and information kits using our ONLINE CATALOG. Other services, including reference librarian assistance, literature searches, interlibrary loan, access to full text articles and Internet information may be accessed using LINC'S ASK A LIBRARIAN service. The staff is available to do any kind of research of articles pertaining to disability issues. If you have any questions regarding our website or their services, do not hesitate to contact them at:

Library and Information Network for the Community
Center for Development & Disability

2300 Menaul Blvd, NE
Albuquerque, NM 87107
Phone: 800-827-6380 or 505-272-0281
Fax: 505-272-5280
Email: linc@salud.unm.edu

These resources may be of some help to you. I would be happy to assist you with this information.

Also remember, we as families, are each other's best resource and support network, and we would all benefit from being connected with each other. We can help you get in touch with an-

Upcoming Trainings and Conferences

2008 Southwest Disability Conference

October 1-3

Albuquerque Convention Center

Conference Theme: Opening Opportunities

Special emphasis theme:

Supporting Wounded Warriors

Support At-Risk Families When Parents

Have

Cognitive Disabilities

Register online: http://cdd.unm.edu/sw_conf/ or

UNM CCC Disability Conference:

ATT: Conference Registrar

2300 Menaul Boulevard NE

Allbuquerque, NM 87107

Phone: (505) 272-9594

Scholarships available for New Mexicans with a disability, their personal attendants, or immediate

Parents Reaching Out -

Summer Learning Opportunities workshop series is designed for families, providers, educators and staff.

Family Networking

We have scheduled our first *Family Networking* meeting. This can be a starting place and continue to develop into meeting the needs and interests of participants.

Date: Aug 4 @ 7:00pm

Location:

CDD—2300 Menaul NE. Albuquerque, NM 87109

Reply to:

Lynn Griffin: 272-8801 or 1-800-675-2910

Family Advisory Council (FAC)

For more information call:

1-800-524-5176 or 505-247-0192

As we look toward the future, the MFCMP is looking at developing a Family Advisory Council to better serve you. The plan would be to meet two times a year. You may have some questions regarding an advisory group which hopefully will be answered below.

I will be scheduling a meeting date and would appreciate some feedback on times from those that are interested in attending. Please contact Lynn Griffin at 505-272-8801 or 1-800-675-2910.

What is an advisory council?

Within your community or state, there may be many opportunities to serve as part of an advisory group to an agency or organization. Their role is to advise – to offer their expertise—they study the issue at hand, collect input from members of the advisory group and perhaps externally from the community, and report back to the larger agency. Your duties on such an advisory group would probably include attending meetings, gathering information from your community, and certainly contributing your own perspective and expertise. The group would also have to prepare recommendations for the agency.

With all my responsibilities, how can I make time for this?

Yes, time is always a problem. You will be asked to attend meetings, and you may need to do research between meetings. Find out how much of a time commitment is involved, and make sure you have – or can make – the time before you say yes. It may help to look at this time commitment as an investment: an investment in your family, in your community, and in yourself.

Can I really make change happen?

Usually, change happens when people become aware of what needs to happen, how it needs to happen, and care that it happens. You can make

change happen by getting involved, giving your time and energy to the Council, and helping others to get involved.

Impact of Family Advisory Councils:

~ Giving case managers, MFCMP, and State agencies access to an experienced, diverse group of families willing to serve in a consulting capacity for policy and program development and evaluation.

~ Providing the opportunity to give ongoing feedback that goes beyond what would be learned from satisfaction surveys and focus groups.

~ Offering a forum to develop creative, cost-effective solutions to problems.

~ Having a mechanism for receiving and responding to community input on a regular basis.

The work of family advisory council will lead to:

Services and programs that respond more effectively to consumer needs and priorities.

Increased understanding and collaboration between families and staff.

Wiser use of scarce health care resources.

The information on this page about Parent Advisory Councils was taken in part from:

A PARENT'S GUIDE TO SERVING ON BOARDS AND COMMITTEES, by Sherri Coles.

A publication of.....NICHCY

National Information Center for children and Youth with Disabilities:

PO Box 1492

Washington, DC 20013

1-800-695-0285

email: nichcy@aed.org

URL: <http://www.nichcy.org>

And Developing and Sustaining a Patient and Family Advisory Council, by Patty Devine Web-

The University of New Mexico © Health Sciences Center
SCHOOL OF MEDICINE

Center for Development and Disability

Department of Pediatrics

Medically Fragile Case Management Program

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1-800-675-2910

Fax (505) 272-8100

legriffin@salud.unm.edu

<http://cdd.unm.edu>

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Useful websites:

Used equipment available for free or for a cost..

Backinuse.com

Pacer Center:

A Minnesota nonprofit organization that provides services without a fee to families of children and young adults with any disability.

Pacer.org

Wrights Law:

Parents, educators, advocates, and attorneys come to [Wrightslaw](#) for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

Wrightslaw.org

Ability Online:

Is an extraordinary and absolutely free Internet community. Here, young people with disabilities and illnesses connect with all kinds of possibilities

Abilityonline.org

Wheel Chair Vans

http://www.mobilityvansales.com/usedhandicapvans/new%20mexico_vansales.html

We encourage your ideas with the content of the Newsletter.

Send us your ideas via email to:

legriffin@salud.unm.edu

Or mail to

UNM Health Sciences Center

Center for Development and Disability

2300 Menaul NE, Albuquerque,

The best part of life is not just surviving, but thriving – with passion and compassion, and humor and style, and generosity and kindness. *– Maya Angelou*

que, NM, 87107.

It needs YOU!!!

A publication of.....Institute for Family-Centered Care
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email: Institute@iffcc.org
<http://www.familycenteredcare.org>.