

Medically Fragile News



Red Maple Planted at Memorial Site

Establishing roots and shedding new light for our children's lives....

Sadly, we have had many passings of our children this past year as with many from previous years. Through this time of sorrow, the Medically Fragile Program would like to express our deepest sympathy to all of our families. You are held in the highest regard for the ongoing, heartfelt care that has been provided by you day in and day out for your child. Our thoughts and prayers remain with all of you as you and your family enter probably one of the most difficult chapters of your lives. Our hopes are your children are shining bright somewhere over the rainbow. That they have reached their pot of gold where they are now free of pain and are able to do all of the things they were unable to do while they were here with us. We look at them as our heroes for all of the daily struggles they encountered but doing it with such vigilance and personal strength.

During this time of sorrow, building a memorial site for our children seemed to be appropriate in the memory of the lives of all of our precious children.

UNM Tree Dedication for Medically Fragile Children

Summer 2014
Editor: Lynn Griffin

Inside this issue

Memorial Site	2
Fundraiser.....	3
Disability policy.....	4
Family Spotlight.....	5
Important news.....	6

Enclosure: WELCOME TO HOLLAND



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



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



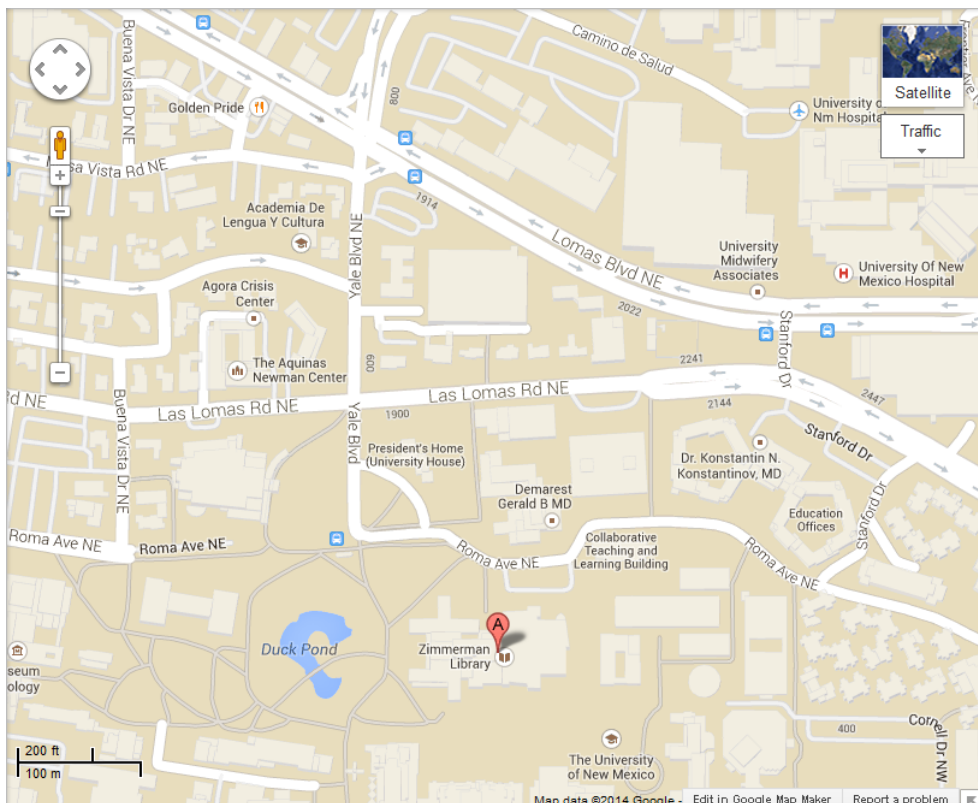


Plaque Inscription

Our Tree Dedication at UNM was organized by the Family Advisory Board (FAB). They also participated in a tree planting ceremony. The event took place on April 7, 2014. Flowers were donated by UNM. The FAB members got busy that day planting flowers that set our roots firm into the ground. A Japanese Red maple has been planted where all of our children's lives continue to grow. A plaque was placed in honor of our medically fragile children. We were fortunate in having UNM Mariposa, the hospice team, attend. Everyone added their own personal touch to the ceremony.

The site is located near the UNM duck pond off of

Yale on the south side of Lomas. The setting is just beautiful. It is located behind Zimmerman's Library in a quiet circular courtyard with a fountain in the center. It is open to everyone to come and visit to feel the connection amongst our families who have experienced a similar loss of their child. It is a quiet place for resolve and reflection. It is close enough to the duck pond for those of you who may wish to



A special thanks to UNM Environmental Services for their genuine thoughtfulness during this process in helping making this happen for our families. Also to the Medically Fragile Foundation Fund for funding this effort.

*"The best and most beautiful things in the world cannot be seen or even touched.
They must be felt with the heart."*

Helen Keller

When My Child Dies...

When My Child Dies

We trust that beyond the absence, there is Presence.

That beyond the pain there can be healing.

That beyond the brokenness, there can be wholeness.

That beyond the anger, there is peace.

That beyond the hurting, there may be forgiveness.

That beyond the silence, there may be compassion.

That through compassion, there may be understanding.

That through understanding, there is love.



Ryan Steward: July 5, 1992 - December 19, 2013
One last joyous occasion at Balloon Fiesta Park with Mom, Lori.

Author Unknown

Home on the Range—Good News, Good Food!

The Center for Development and Disability has developed a business relationship with Home on the Range Restaurants, which is inclusive of The Range Café and Standard Diner. This is a fundraising effort for The Center for Development and Disability (CDD) which will directly benefit families. A percentage of the proceeds from this business venture will benefit the Medically Fragile Foundation Fund and the Autism Program's Summer Camp. The plan is to have discount cards which will also help identify what proceeds will go to CDD. This has not been finalized as yet. More to follow.

The Range has been a Bernalillo icon for many years. They are known for their good food that is reasonably priced along with their friendly service. They serve breakfast, lunch and dinner.

They have 4 locations.



The Range
Wyoming
(505) 293-2633
4401 Wyoming Blvd NE
Albuquerque, NM 87109

The Range Menaul
(505) 888-1660
2200 Menaul Blvd NE
Albuquerque, NM 87107

The Range Bernalillo
(505) 867-1700
925 Camino Del Pueblo
Bernalillo, NM 87004

The Standard Diner
(505) 243-1440
320 Central Ave SE,
Albuquerque, NM 87102

Civil Rights – Disability Rights Leadership Institute on Bioethics

Led by Not Dead Yet, the Disability Rights Education and Defense Fund (DREDF), the Autistic Self Advocacy Network, and several other national disability organizations, leaders in disability rights and bioethics met April 24-25 to discuss the growing threats to people with disabilities of withholding of medical treatment on the basis of disability; assisted suicide laws; and ethical issues of genetic and reproductive technologies. Concerns are growing both within the United States and in-

ternationally regarding the threats to people with disabilities inherent in possible health care rationing, assumptions by others about what makes life worth living, and laws and policies that allow physicians to withhold life-sustaining treatment over the expressed objection of the individual or their surrogate. The Arc participated in the conference, which ended with plans for working together further to address the issues raised by the speakers and participants.

Association of University Centers on Disabilities (AUCD) Updates: 6 by 15 Campaign Launched

2015 will mark 40 years of IDEA and 25 years of the ADA. Honor the legacy of our past and help build a new future by joining our effort to achieve six national goals by the end of 2015.

<http://sixbyfifteen.org>

- 1) Employment: Six million working age adults with disabilities will be part of the American workforce
- 2) Community Living: At least six states elect to implement the Community First Choice Option so that their Medicaid recipients with disabilities have access to long-term services and supports in the community.
- 3) Education: At least six additional states graduate at least 60% of their students with disabilities with a regular high school diploma
- 4) Transition: At least six states commit to supporting successful and outcome-based programs and strategies for high school transition services and closing the labor force participation gaps for youth and young adults with disabilities
- 5) Healthy Living: At least six states commit to including people with disabilities as an explicit target population for all state public health programs.
- 6) Early Childhood: At least six states increase by 15% the proportion of children ages 0-3 who receive recommended developmental screening

Civil Rights / Education

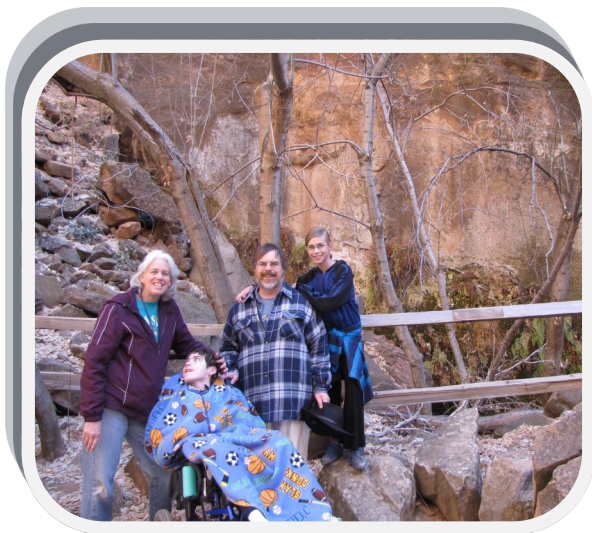
Legislation Introduced to Ensure Charter Schools Enroll and Retain Students With Disabilities

Representatives John Kline (R-MN) and George Miller (D-CA) introduced H.R. 10, the Success and Opportunity through Quality Charter Schools Act, which would help ensure that Charter Schools enroll and retain students with disabilities. The bill would require states to ensure that charter schools can meet the needs of students with disabilities and meet their obligations under the Individuals with Disabilities Education Act (IDEA) and Section 504. The Arc joined other organizations in supporting H.R. 10.

Family Spotlight: THE MULLEN FAMILY

I hope you have all read the essay “Welcome to Holland” by Emily Perl Kingsley about special needs parenting. This essay was given to me years ago when I was a new mom of a disabled and medically fragile baby. It has really been a comfort and guiding principle for me throughout our family’s journey.

Daniel is our smiling, happy, wheelchair bound, nonverbal now 16 year old son who suffered a massive stroke at nine days of life. We had no prior warning, no risk factors and no clue. We were suddenly overwhelmed and lost in “Holland”. Over the years and among many, many tears, wonderful “tulips” and “Rembrants” have been experienced. Let me tell you about a few “Holland” experiences.



The wisest child I’ve ever met was a 4 year old stranger in Kmart who innocently said “that is not the right kind of stroller”. He could not have known that it was our very first outing with my son’s 1st “wheelchair”. That wheelchair had been sitting unused in our living room for over 6 months. We just couldn’t bear to admit we needed it. Luckily, the conversation continued and I learned the child’s worry was purely functional. “It needs to fold up so it can go in the trunk” he told me. Once he knew that the wheelchair folded and could travel, all was fine. This stranger child taught me not to worry about stares and differences but just to get out there and explore “Holland”. The only thing that matters is figuring out how to do things in this “new uncharted land”. We have been exploring ever since including two trips to Hawaii and many many driving trips to National Parks.

Other wonderful people have shown us ways to live in this unexpected country. The scariest thing I have ever done is to have another child. Suddenly after Daniel’s birth, there was nothing routine or safe about pregnancy or childbirth or even the days afterward. Everything was terrifying. But some of my “Holland tour guides” who had been there and done that, walked this path with us. These dear friends and mentors have been constant support, cheering squad and confidants. So, our family was blessed with a terrific little girl. Diana, who is now 13 years old is the best sister a special needs boy could ever have. She has lent balance and excitement to our lives.

We could no longer focus only on issues associated with special needs and medical problems. Instead we learned a new normal---alternating between “normal Italy” and “unknown Holland” and experiencing the best and worst of each place. Our children know both “countries” and have friends in both countries. But they are also ambassadors and guides connecting “Italy” and “Holland”. I think that is the goal for true compassion, understanding and inclusion---connecting the different places and helping them work together.

May you too learn, with us, that if you spend all your time grieving the loss of “Italy” that you will never be able to enjoy the “tulips of Holland” and experience the best and bravest you can be despite disability.

Our family (Dana, David, Daniel and Diana) encourage you this summer to

STOP AND SMELL THE TULIPS.

Dana Mullen May 2014



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INCOME SUPPORT DIVISION (ISD)

Office for Recertification

Paperwork

Most of you are familiar with this process. In some cases the paperwork is related to your child's eligibility for Medicaid coverage, in other cases the paperwork is related to your child's Medically Fragile Wavier eligibility. Either way, it must be submitted on time.

The ISD computers send out an automatic reminder letter to each family. Reminder letters are sent out 45 days before the expiration of the paperwork and again 30 days before the expiration date.

Remember it is your responsibility to notify the ISD office if you have moved or your contact information has changed.

If your re-certification paperwork is not received in time, your child's file will be closed.

Many of you have received closure letters. Your child's medically fragile case manager usually receives a copy as well. If you receive a letter, please contact your ISD office right away and let your case manager know.

Because the ISD offices statewide have moved to a new computer system, there have been more issues related to paperwork and the re-certification process.

Important News

NEWS FROM DEPARTMENT OF HEALTH/DDSD AND MEDICAID:

The decision has been made to keep the Medically Fragile Waiver at the Department of Health. The **Medically Fragile Waiver** will **NOT** be carved into the **Centennial Care Waiver** as planned in 2015. If you have any questions, please contact your Medically Fragile Case Management Program case manager.

Dear Families & Friends ~ It is with mixed emotions that I write this note to let you know that I will be leaving Medically Fragile effective 5/15/14 to take on a position with Molina Healthcare as their Director of Healthcare Services. MFCMP has been the constant in my world for the past 12 years and so making this decision has not been an easy one for me. I can honestly say that I have never had a job I have loved more. Thank you to all of you who have made this job so rewarding.

With warmest regards, Cathy G

Cathy Geary,- Operations Manager ,MFCMP