



MEDICALLY FRAGILE NEWS

Editor: *Lynn Griffin*
MFCMP Family Specialist

Happy Spring



Summer fun is on it's way again! We are pleased to announce our next Medically Fragile Picnic. It is scheduled for July. Please see the inserted flyer for details.

Connected



It has been lots of fun every year and it continues to grow.

The kids have a blast!
Hope to see many new faces this year.! We have been very fortunate to have good weather and lots of good food! Please join us in making connections with other families, old and new,! Everyone has so much to share and so much in common.

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



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





GUARDIANSHIP

With the assistance of technology and medical advancements, our children have far outlived their life expectancy. Guardianship has become a growing concern for families as they age and reach the age of emancipation, age 18. The process can be very costly to families.

Guardianship should be:

- as a last resort;
- only as necessary to promote and to protect the well being of the person (and others);
- designed to encourage the development of maximum self-reliance and independence.
- monitored and have safeguards against wrongdoing;
- available for all “incapacitated persons.”

ROLE OF THE GUARDIAN

- the guardian takes the place of the individual's own decision-making
- coordinates and monitors professional and other services needed
- the guardian's authority is based on the court order - limited or plenary (full)
- individual rights removed from the protected person may vary:
 - determining residence; consenting to medical treatment; driver's license; signing contracts
 - managing, buying, or selling property; owning or possessing a firearm or weapon;
 - filing lawsuits; making end-of-life decisions; marrying.
- Guiding Principle: least intrusive/restrictive measures for most autonomy possible.

The State of NM Office of Guardianship is under Developmental Disabilities Planning Council that offers guardianship information and services. For additional information please visit:

<http://www.nmddpc.com/page/office-of-guardianship>

The NM Office of Guardianship provides a statewide, publicly funded guardianship services program for guardians of “last resort” to incapacitated income and resource eligible. It is designed to help “incapacitated persons” and help families by providing a statewide, publicly funded guardianship services program for guardians of “last resort” to incapacitated income and resource eligible adults.

More assistance on the guardianship process may be available through:

The ARC of NM:

3655 Carlisle NE Albuquerque, NM 87110-1644

(800) 358-6493 Toll Free (505) 883-4630

<http://www.arcnm.org>

Or

PEGASUS LEGAL SERVICES FOR CHILDREN:

3201 Fourth Street NW

Albuquerque, NM 87107

(800) 980-1165 Toll Free Line Statewide for Guardianship of a Child

(505) 217-1660 Service/Intake Guardianship of a Child

(505) 244-0060 FAX <http://www.pegasuslaw.org/>

Through the **library at CDD**, there are materials available to families to assist them through the process.

Your guide to state law on: *Powers of attorney *right to die
*nursing home benefits
*wills *trusts *probate - by Merri Rudd – CDD Library #18033

Financial Planning for Special Needs

We realize that you face unusually difficult planning decisions regarding the welfare of your child. Financial Planning For SpecialNeeds.com – by Theglp.org. CDD library #19155

DVD/folder: Alternatives to Guardianship Training Video, (Introduction, Medical Decision Making, Financial Matters, Benefits, Services & Resources), Funded by the Office of Guardianship, item #19959.

Please contact Jeanne Favret, our librarian, or Scott Reece would be happy to assist you with any requests.

Center for Development & Disability
Information Network
2300 Menaul Blvd NE
Albuquerque, NM 87107
(505)-272-0281 phone
(505)-272-5883 FAX
1-800-827-6380 toll free
jfavret@salud.unm.edu

This bill may provide relief to future family guardians:

US House of Representatives Congressman Ted Deutch (D-FL 19th . Dist) today introduced the “Special Needs Tax Credit” Bill into Congress, designed to provide a refundable tax credit for the expense of establishing guardianship for an individual with disabilities 18 years of age or older.

Initiated in 2006 by Jaret L. Vogel, Director of the Special Needs Tax Credit Alliance, a Florida-based 501 (c)(4) nonprofit social welfare organization, the bill addresses the plight of families with a special needs family member, who need to become legal guardian of their child.

“When an individual with Autism, Down Syndrome, or other developmental disabilities turns 18, they are deemed to have all the legal responsibilities of an adult,” Vogel said. “Like all other young adults,

Initiated in 2006 by Jaret L. Vogel, Director of the Special Needs Tax Credit Alliance, a Florida-based 501 (c)(4) nonprofit social welfare organization, the bill addresses the plight of families with a special needs family member, who need to become legal guardian of their child.

“When an individual with Autism, Down Syndrome, or other developmental disabilities turns 18, they are deemed to have all the legal responsibilities of an adult,” Vogel said. “Like all other young adults, they are legally entitled to enter in contracts, make legal, financial and health care decisions. Some of these individuals may not have the judgment abilities to make such decisions, and need support from their parents to live in the adult world. For this reason, legal guardianship is the vehicle established to protect them and ensure sound life-choices.”

Vogel continued, “The guardianship process may cost \$3,000 to \$5,000 or more, and many families simply cannot afford to enter into the process. Many of these families have endured extraordinary expenses already, for years of therapies, medications, supportive equipment, etc. Therein lies the “Catch-22;” the young adult cannot make his own decisions and the parents cannot afford to become guardian.

All American citizens are guaranteed to enjoy Freedom of Speech and Equal Representation Under the Law. An adult with cognitive impairments who does not have a legal guardian is unfortunately excluded from these civil protections.

The Special Needs Tax Credit Bill is designed to make the guardianship process more affordable for more families. If the family can find the funds for legal expenses short-term, knowing it would be refunded, more persons who need a guardian would have one, and consequently less strain on the state court system to appoint a guardian ad litem, or emergency guardian, if none exists. Hence, a savings to the court system.

If passed, attorneys might see more business from these families, which would create more taxable income back to the IRS, and a partial offset to the net cost to the government.

The text available at www.thomas.gov; Search for HB 878, or at: <http://www.thomas.gov/cgi-bin/thomas>

Upcoming Events

Southwest Conference on Disability

October 5 - 7, 2011 ~ Albuquerque Convention Center
MAIN CONFERENCE THEME: Inclusion: How We All Fit Together
SPECIAL EMPHASIS THEMES

- ◆ Aging Well With a Disability
- ◆ Creating Inclusive Behavioral Health Services Through Collaborative Partnerships
- ◆ Using Technology to Promote Inclusion for People With Disabilities

Southwest Conference on Disability •

505-272-6247 • swdisabilityconference@salud.unm.edu

<http://cdd.unm.edu/swconf/pdfs/RegistrationForm2011.pdf>

If you wish to apply for a 100% Registration Scholarship please contact the Conference Registrar.



Additional Resources

FCA—Family Caregiver Alliance : National Center on Caregiving Offers everything imaginable for caregivers and offers it in other languages.

FCA operates the National Center on Caregiving, through which we produce legislative analyses, reports, newsletters, and research documenting public policy, emerging trends and caregiver needs and services. Consultation on program development and Best Practices in caregiving services is available to assist in the development of caregiver support services throughout the country.

<http://caregiver.org/caregiver/jsp/content/pdfs/2010-Caregiver-Guide.pdf>

My Community NM: Bilingual directory of social service and health resources -

My Community NM is the State's only bilingual, on-line resource directory. The project, which began in 2002, has been developed through an ongoing partnership with community leaders from La Comunidad Habla.

www.mycommunitynm.org

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is an income support program that provides monthly payments to children and adults who have disabilities and limited income and resources.

Social Security has two programs that provide monthly payments for people with severe disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

SSDI is an insurance program that workers and employers pay for with their Social Security taxes. Eligibility is based on work history and the amount of the benefit is based on earnings.

SSI benefits are paid to people with disabilities who have low income and limited resources to families or individuals that:

- disability;
- limited income; and
- limited resources

These are the three pieces of the SSI system.

Eligibility for SSI

To be eligible for SSI:

- A child's (birth to 18) impairment must result in "marked and severe functional limitations" that last at least 12 months
- Adults (18 and older) must have
 - A medically determinable physical or mental impairment that interferes with basic work activities
 - A gross income of not more than \$800 per month
 - No more than \$2,000 worth of personal assets or resources

Applying for SSI Benefits

Applying for benefits is a multi-step process

- Call the Social Security Administration at 800/772-1213; applications can be taken over the telephone, online, at a local Social Security office, or by mail
- Staff will ask for information about the applicant's disability, health care received, medical records, medications currently taken, personal resources, and income and employment information
- Once the SSA receives the application and information the office will make a determination about eligibility

Applying for SSI can be a lengthy and complex process. However, if they keep in mind the three eligibility "pieces" of SSI it should become less complex. The Social Security Administration requires documentation of an applicant's disability; they also require employment history and salary; and an accounting of an applicant's financial resources.

The four ways that people with disabilities can apply for benefits. Parents can call the toll free number to find the Social Security field office closest to them. Turn-around time for applications varies; beneficiaries have been approved in as little as a month or as long as several months. Providing the SSA with complete information can speed up the process.

When to apply for benefits:

- Youth under the age of 18 can receive benefits if they meet the eligibility requirements for children
- Once they reach their 18th birthday they are considered adults and must go through a redetermination process
- Begin application and redetermination process one month before student's 18th birthday

Children qualify for SSI based on their disability and their income and assets. The Social Security Administration has defined eligibility for a child with a disability as follows:

- She or he has a physical or mental condition (or combination of conditions) that result in marked and severe functional limitations.
- The condition must last or be expected to last at least 12 months or be expected to result in the child's death.
- The child must also not be working at a job the SSA considers to be substantial work.

A parent's income and assets are considered for children under the age of 18, a process called "deeming." Once a youth reaches their 18th birthday, the SSA considers only the youth's income and resources and not the parents'. However, if a youth continues to live with her or his parents after qualifying as an adult and does not pay for food and shelter, a lower SSI payment rate may apply.

Children who are eligible for SSI benefits in the month before their 18th birthday must go through a process to have their eligibility re-determined under the adult program.

SSI Benefits

SSI benefits include:

- Monthly checks dependent on income. Amount is adjusted annually
- Eligibility for Medical Assistance/Medicaid (generally)
- Eligibility for food stamps (generally)
- Eligibility for Vocational Rehabilitation Services

In calculating the level of SSI benefits, the SSA considers all earned and unearned income (from other resources) and the deemed income of parents and spouses. Note for beneficiaries living with their parents, the SSA could reduce the benefit by as much as one-third, based on whether the beneficiary pays a reasonable amount of household expenses. After certain deductions, beneficiaries lose \$1 of benefits for every \$2 of employment earnings.

Youth who qualify to receive SSI are generally eligible to receive supports from several other programs including Medicaid, food stamps, and Vocational Rehabilitation.

Material provided by Pacer.org

FAMILY SPOTLIGHT: The Dean Family

The parents of two amazing boys who are the light of their parents world. Scott and Rebekah reside in Aztec NM. They have been married for almost 16 years and value each day that they have with their wonderful family. Scott is a Graphic Designer by trade, and Rebekah is a licensed k-12 School Counselor, both currently work in the school system. They have learned to take one day at a time and help the boys attain the best possible quality of life. They consider themselves happy people who appreciate a good laugh as often as possible, sometimes having an odd sense of humor, but they find this so necessary for stress relief!

Cody is 15 and enjoys classical music and books on tape. His favorite subject is history, especially the wars! When he smiles, he lights up the room and brings joy to those around him. Cody has a peaceful presence about him that even those who just meet him recognize. Cody receives homebound services. He has never attended school as his medical issues have always left him at risk for infection and he is easily over-stimulated and sleeps to avoid the stimuli. Cody has a seizure disorder for which he takes medication and is on the Ketogenic Diet. He also has the diagnosis of irretractable seizures, CP, CVI, Scoliosis/Kyphosis, Restrictive Lung Disease, Chronic Lung Failure, chronic constipation, Asthma, Osteoporosis, and Apnea. He is fed by NG tube, is non-ambulatory, non-verbal, and requires assistance with all aspects of daily living. Cody loves his little brother, Jeffrey, and is very protective of him.

Jeffrey is 7 and the life of the party! He is such a happy kid, who loves to be around people, loves to be tickled and has such an infectious giggle! Jeffrey attends school as often as is possible and receives homebound services when necessary. Jeffrey has similar diagnoses to his brother, seizure disorder, CP, CVI, Osteoporosis, hearing loss. He has a g-tube (Mic-Key), is on the Ketogenic Diet, he is non-ambulatory, non-verbal and also requires assistance with all aspects of daily living. His personality is truly what sets him apart from his brother.

It's that time of year again!
Fun for Medically Fragile Families

Come join the fun for our third annual event

POT LUCK



When ~ Monday, July 18, 2011

**Where ~ Manzano Mesa
Multigenerational Center
501 Elizabeth St. SE
Albuquerque, NM 87102**

What time ~ 5:00 PM - 8:00 PM



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

We will be meeting in a different location this year
THE WESTSIDE SOCIAL HALL

A Water Sprayground is located outside at the facility

The water sprayground, is 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.

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

HOPE YOU CAN MAKE IT!