

CDD Medically Fragile Case Management Newsletter

September 2024



CENTER FOR
DEVELOPMENT
& DISABILITY

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Screening at Newborn (and beyond) Awareness Month

Does your child have symptoms that have puzzled the best doctors attempting to find a cause?



You are not alone.

“At least 1 in 20 children has a genetic condition, which is often rare and can come with a litany of puzzling symptoms.” (Orlovsky, Christina. “DNA Discoveries.” *Rady’s Healthy Kids*, Summer 2024, pp 14.)

With advancements in technology, an individual’s DNA can provide clues, not only to the cause of some symptoms, but may provide a path for possible treatment options. Using a sample of blood, whole genome sequencing can be completed to help determine if any genetic diseases are present. The earlier this whole genome sequencing is completed, the earlier answers may be found, which can help guide care and treatment.

New Mexico’s newborn screening currently only screens for 53 conditions. [Find numbers for other states here.](#)

Whole genome sequencing, can screen for almost all DNA mutations, which can assist in solving the symptom puzzle. Read this story about a little boy, who at age 1 started having trouble, and how whole genome sequencing helped solve the puzzle as to why - [Hudson's Heroism.](#)

DetECCIÓN en el Mes de Concientización sobre el Recién Nacido (y más allá)



¿Su hijo tiene síntomas que han desconcertado a los mejores médicos que intentan encontrar una causa?

Usted no está solo.

"Al menos 1 de cada 20 niños tiene una condición genética, que a menudo es rara y puede presentarse con una letanía de síntomas desconcertantes". (Orlovsky, Christina. “DNA Discoveries.” *Rady’s Healthy Kids*, Summer 2024, pp 14.)

Con los avances de la tecnología, el ADN de un individuo puede proporcionar pistas, no sólo sobre la causa de algunos síntomas, sino que también puede proporcionar un camino para posibles opciones de tratamiento. Utilizando una muestra de sangre, se puede completar la secuenciación del genoma completo para ayudar a determinar si hay alguna enfermedad genética presente. Cuanto antes se complete toda la secuenciación del genoma, antes se podrán encontrar respuestas, lo que puede ayudar a guiar la atención y el tratamiento.

Actualmente, las pruebas de detección de recién nacidos en Nuevo México solo detectan 53 afecciones.

[Encuentre números para otros estados aquí.](#)

La secuenciación del genoma completo puede detectar casi todas las mutaciones del ADN, lo que puede ayudar a resolver el enigma de los síntomas. Lea esta historia sobre un niño pequeño que cuando tenía 1 año empezó a tener problemas y cómo la secuenciación completa del genoma ayudó a resolver el enigma de por qué...[El heroísmo de Hudson.](#)

Upcoming Events – Join Us!



Saturday, September 14th – 9-12am in Farmington

Supply Swap Meet at Adaptive Therapies

Bring supplies to exchange, or just come and see if there's something you could use

Location: 804 E Navajo St, Farmington, NM 87401

Tuesday, October 1st – 5:30pm via Zoom

Family Info Session - Led by parents

Tips and Tricks on feeding, G-tubes, G-J tubes, etc.

Very informal. You do not have to have your camera on.

Come share your tips and tricks or come just listen in.



Zoom link: <https://us06web.zoom.us/j/81729412221>

Tuesday, October 15th - 5:30pm via Zoom

StationMD is coming to Medically Fragile Waiver!

“StationMD is high-quality medical care for people with intellectual and/or developmental disabilities (I/DD) anytime they need it, no matter where they are in the US.” -

<https://stationmd.com/> Care provided by doctors who are specially trained in this population, via telemedicine.



Learn more - Zoom link: <https://us06web.zoom.us/j/81308351406>

Saturday, October 26th - 1pm to 3pm at Nativity Church

Second Annual Trunk or Treat

Costumes optional. Lots of fun is waiting - face painting, treats, and games!

Location: 9502 4th St NW, Albuquerque, NM 87114

Bringing a trunk? Please arrive at 12pm for set up and bring treats for about 75.



More Upcoming Events – Save the Date!



Tuesday, November 5th - 5:30pm via Zoom

Medically Fragile Family Advisory Board Meeting

Looking for a way to advocate for change? Want to learn?

Join other amazing parents on the Medically Fragile Family Advisory Board

Zoom link - Pending

Saturday, December 7th - 2pm to 6pm at Nativity Church

Holiday Party - Santa will be coming to town

We will be joining efforts with the Cerebral Palsy Parents'

Association on their annual Holiday Party. More details to come, but save the date!

Location: **9502 4th St NW, Albuquerque, NM 87114**



Resource Highlight



A network library of the [National Library Service for the Blind and Print Disabled](#)

The [NM State Library](#) serves New Mexicans statewide who are unable to read a standard printed book due to a disability such as:

- blindness,
- visual impairment,
- a physical, or
- reading disability

Provides digital audio books online and by mail.

Learn more [About Us](#) and check our [Eligibility Requirements](#) to find out if you or someone you know qualifies for our program.

Your child's provider or Medically Fragile RN Case Manager can assist you in applying. [Application in English](#)



Una biblioteca en red del Servicio Nacional de Bibliotecas para Ciegos y Personas con Dificultades para acceder al Texto Impreso

La Biblioteca Estatal de Nuevo México presta servicios a los nuevomexicanos en todo el estado que no pueden leer un libro impreso estándar debido a una discapacidad como:

- ceguera,
- discapacidad visual,
- un examen físico, o
- discapacidad de lectura

Proporciona audiolibros digitales en línea y por correo.

El proveedor de su hijo o el administrador de casos de enfermera registrada médicamente frágil pueden ayudarlo a presentar la solicitud. [Individual Application en español](#)

Resource Highlight



Icing Smiles is a nationwide nonprofit organization that delivers dream cakes at no charge to kids impacted by critical illness or complex medical challenges. (And to their siblings, too!)

[Medical Eligibility Form](#)



[Los Ojos de la Familia](#) provides assistance for any need which interferes with one's ability to move beyond their current status. [General Assistance Application – Fillable](#)

They also provide scholarships for post-high school education - <https://www.losojosdelafamilia.org/general-scholarship/>



New Mexico Ramp Project is a nonprofit that provides free ramps for older adults and individuals with mobility issues, who meet the criteria, such as [income](#) and living in Bernalillo, Chaves, Cibola, Dona Ana, Eddy, Lea, Los Alamos, Luna, Rio Arriba, Roosevelt, San Juan, Sandoval, Santa Fe,

Torrance, or Valencia County. Your provider can complete an application at <https://airtable.com/appVSw3sTGGNxxqgf/shr0vxrlaiFBv58Ac>.



[Information Network Portal](#)

[Tip Sheets](#)

Informational tip sheets covering numerous disability-related topics

[Videos & Resources](#)

Watch instructional videos, presentations, and download local resources

[CDD Library](#)

Special collections library containing electronic and hard copy materials



[Exceptional Parent – EP Magazine](#) is an award-winning publication serving the special needs community.

Free digital subscription at [Subscribe](#).

View current copy or view [the archive](#) for past copies.

Resource Highlight



Icing Smiles es una organización nacional sin fines de lucro que entrega pasteles de ensueño sin costo alguno a niños afectados por enfermedades críticas o problemas médicos complejos. (¡Y a sus hermanos también!)

[Formulario de elegibilidad médica](#)



[Los Ojos de la Familia](#) provides assistance for any need which interferes with one's ability to move beyond their current status. [Solicitud de asistencia general: rellenable](#)

También brindan becas para educación post-secundaria - <https://www.losojosdelafamilia.org/general-scholarship/>



New Mexico Ramp Project es una organización sin fines de lucro que proporciona rampas gratuitas para adultos mayores y personas con problemas de movilidad que cumplen con los criterios, como ingresos y vivienda en Bernalillo, Chaves, Cibola, Dona Ana, Eddy, Lea, Los Alamos, Luna, Rio. Arriba, Roosevelt, San Juan, Sandoval, Santa Fe, Torrance o el condado de Valencia. Su proveedor puede completar una [Solicitud](#).



Information Network Portal

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Family Voices es una organización dirigida por familias que transforma los sistemas de atención para que funcionen mejor para todos los niños y jóvenes, especialmente aquellos con necesidades especiales de atención médica o discapacidades. Al poner a las familias a la vanguardia y centrar su liderazgo y experiencia vivida, construimos una cultura que incluye a todos y fomenta resultados equitativos. [Recursos en español](#)