

AUGUST

Medically Fragile
Newsletter



August 2023 | Medically Fragile Case Management Program |

Inside This Issue

- PG. 2/3 August is SMA Awareness
- PG. 4 Los Lunas Swap Meet
- PG. 5 Help us Help you, ANE reporting UPDATED PHONE NUMBERS
- PG. 6 Program Update! Sept 12
- PG. 7 Human Services is here to help
- PG. 8 Health Well Foundation
- PG. 9 Masks are no longer required
- PG. 10 Meet the Ombud
- PG. 11 Are you at risk of losing Medicaid?
- PG. 12 Chromebooks are available! Autism and the Spanish speaking community
- PG. 13 Adaptive Kayak
- PG. 14 NM Finder - Resource Help
- PG. 15 Weaving Colors
- PG. 16 Parent Support Groups
- PG. 17 CDD Information Library
- PG. 18 Hero's Path Palliative Care
- PG. 19/23 PRO's August Newsletter



Spinal Muscular Atrophy



www.CureSMA.org

is a rare disease that robs a person of physical strength and can take away their ability to walk, swallow, and breathe.

SMA Awareness Month
Cure SMA **BREAKTHROUGHS**
www.cureSMA.org • #CureSMA **Begin with You**



**There are now multiple
FDA-approved therapies for SMA.**

SMA Awareness Month
Cure SMA **BREAKTHROUGHS**
www.cureSMA.org • #CureSMA **Begin with You**

My daughter Quinn was diagnosed with Spinal Muscular Atrophy (SMA) at 14 months old. Quinn was not meeting developmental milestones and her pediatrician was not too concerned. Having three older kids I knew in my gut something was not right. The only milestones Quinn had met by her first birthday were laborious sitting up and rolling. I called Early Intervention to evaluate Quinn after talking to my son's preschool teacher about the situation.

The physical therapist with Early Intervention immediately had concerns with Quinn and recommended that we see a neurologist as soon as possible. In the meantime, my husband hit the internet and researched the term hypotonia since the physical therapist told us Quinn had severe hypotonia. As we met with our pediatrician we brought up SMA and he was confident it wasn't SMA. We persistently asked the pediatrician to request approval from insurance to cover the blood test that could determine if Quinn had SMA. Thankfully our pediatrician listened to us, put in the request and insurance approved the blood test. In the meantime, we met with a very rude and condescending pediatric neurologist who didn't want to do any bloodwork, but rather a CT scan that was months out for an appointment. We asked if he thought she had SMA and he said no and that kids with SMA were very smart. Quinn was 13 months when he saw her and cognitively where she should be. We asked about SMA treatments which we had researched because we felt strongly that's what she had. His response was that it didn't matter if she received treatment at that moment or months later which could not have been further from the truth. As Quinn's neuromuscular doctor said, "time is neurons!" The sooner the better with treatment.

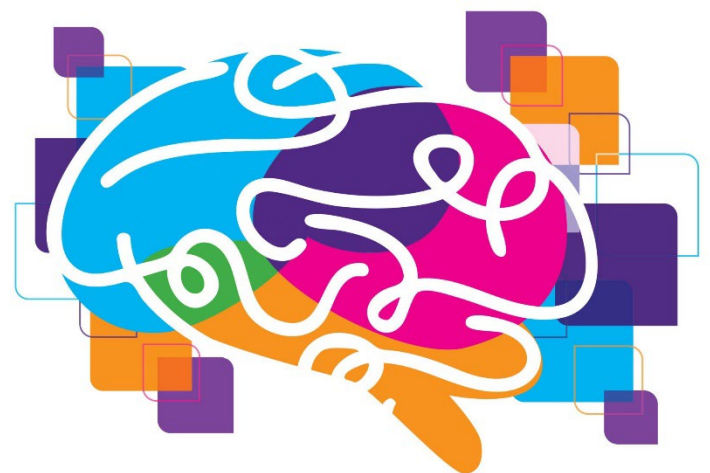
After Quinn was diagnosed with SMA through the blood test we knew immediately that we wanted her to receive Zolgensma, a gene therapy that had been FDA approved a few months prior to her diagnosis. Our insurance gave us some push back since the treatment was over 2 million dollars, but the neuromuscular doctor went to bat for us and ultimately insurance approved the therapy. Quinn received the therapy at 15 months almost exactly a month after being diagnosed with SMA. Zolgensma has stopped the progression of Quinn's SMA and she can crawl, stand and take several steps with her AFOs, uses a manual and power wheelchair, and just started kindergarten.

My husband and I learned at the beginning of Quinn's diagnosis that we have to be her biggest advocates. There were many times when we had to push and be persistent with doctors to get results and we're so grateful we did. We are also teaching Quinn to advocate for herself which we feel is equally important. Quinn has physical therapy and occupational therapy each week at Sandia Sunrise Therapies and we have learned the importance of a good team of therapists and doctors. We are so grateful for Quinn's therapists and the progress they have helped her make along with navigating mobility aids, school, and all the things that come with having a disability.

A little over a year ago we had a victory in New Mexico when they added SMA to the newborn screening panel. There are currently 3 FDA therapies for SMA and we could not be more grateful. Curesma.org is a great resource for more information. My name is Annie and my husband is Joe, we are the Chapter Leaders in New Mexico for Cure SMA, so if you have any questions please contact us at annferg033@hotmail.com or cyrusjwiseman@gmail.com.



SMA Awareness Month
cure SMA **BREAKTHROUGHS**
www.curesma.org • #CureSMA **Begin with You**



SMA does not affect a person's ability to think, learn, and build relationships with others.

SMA Awareness Month
cure SMA **BREAKTHROUGHS**
www.curesma.org • #CureSMA **Begin with You**

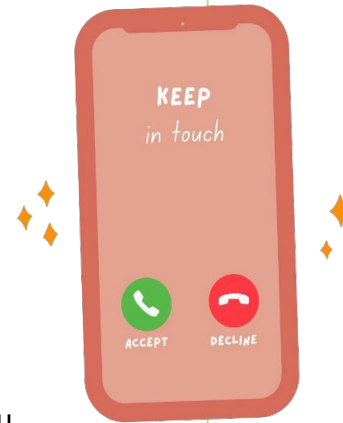
Just a gentle reminder.... please, please stay in touch. Help us, Help you!

A month can be a long time.

Please let your nurse case manager know if anything comes up between your monthly visits.

We **especially** need to know right away of the following:

- Hospitalization
- ER visits



In the event of hospitalization and ER visits, we want to be there to support you.

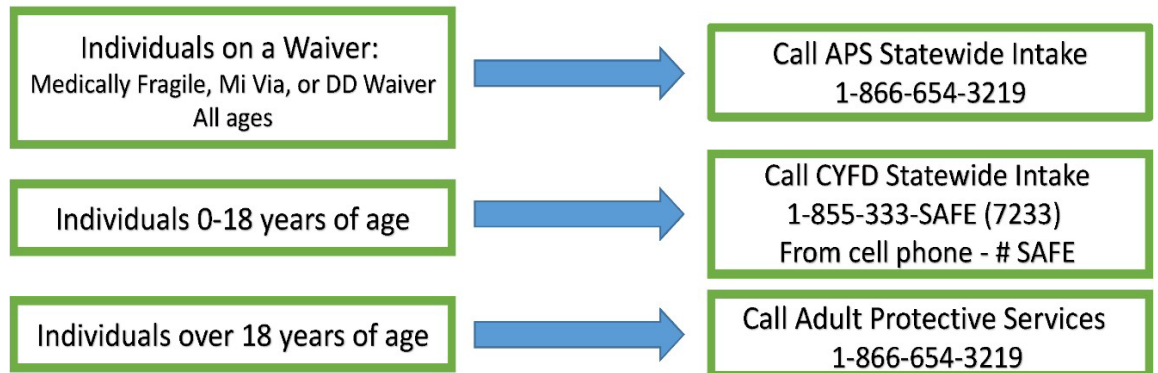
Please share with your hospital staff that your loved one is on the Medically Fragile Program. Please share your loved one's nurse case manager's name and number.

We want to help make sure you have everything you need at discharge, so it is a safe, smooth transition home.

**ATTENTION! PHONE NUMBERS TO REPORT ANE HAVE CHANGED!!
PLEASE SEE NEW NUMBERS BELOW!**

ABUSE, NEGLECT, EXPLOITATION REPORT IT!

In Case of an Emergency call 911



Lines are open 24/7. You can request to remain anonymous and all information is kept confidential.

FAMILY PROGRAM UPDATE

Zoom Link to come

September 12, 2023 @ 5:30

Any questions please email nichole at nrajala@salud.unm.edu or reach out to your case manager



Update

Please join us to go over important program updates, State updates, and FAB information!

ZOOM ENLACE POR VENIR
12 DE SEPTIEMBRE DE 2023 A LAS 5:30
SI TIENE ALGUNA PREGUNTA, ENVÍE UN CORREO ELECTRÓNICO A
NICHOLE A [NRAJALA@SALUD.UNM.EDU](mailto:nrajala@salud.unm.edu) O COMUNÍQUESE CON SU
ADMINISTRADOR DE CASOS

The Human Services Department (HSD) wants to help

Have questions about the Medically Fragile Waiver?

Have concerns about Medically Fragile Waiver services?

Want to share a success story of services you've received through the Medically Fragile Waiver?

★ Contact HSD's Medically Fragile Waiver team by emailing - ★

MFWaiverHSD@hsd.nm.gov

Looking at a transition to Mi Via?

Have questions or concerns about Mi Via services?

Contact the Mi Via Waiver team at HSD by emailing - MVWaiverHSD@hsd.nm.gov

Having trouble accessing email, but have questions, concerns, success stories to share?

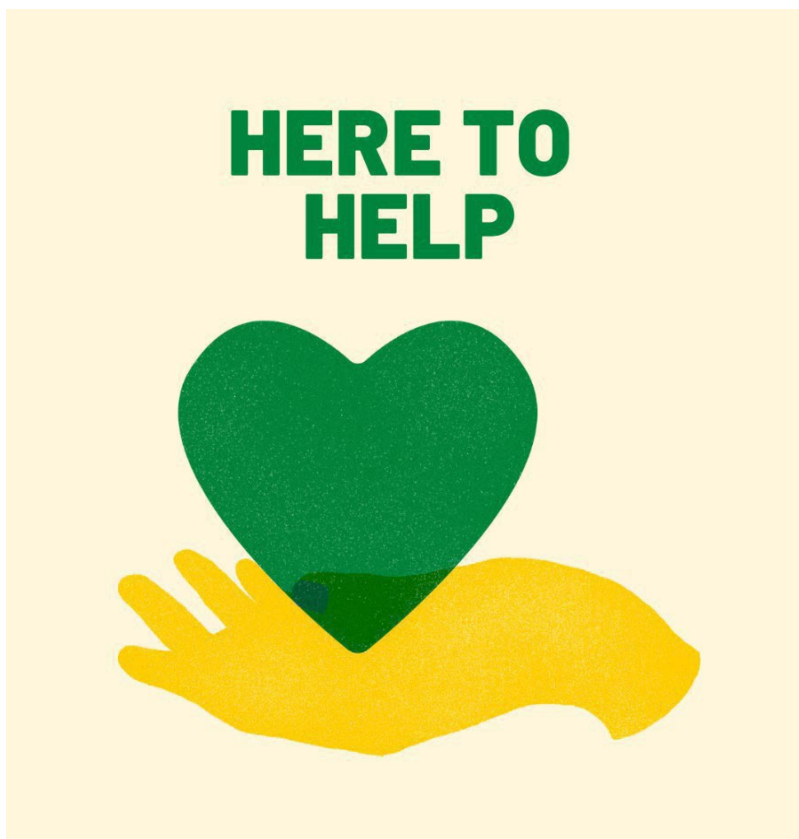
Contact Deanna DeHerrera

Mi Via & Medically Fragile Waivers Staff Manager

Exempt Services & Programs Bureau

Monday 7:30-4:30pm, Tues-Fri 7:30am to 4:00pm

Cell 505-629-7260





HEALTHWELL
FOUNDATION®

When health insurance is not enough.®

Our Mission: To reduce financial barriers to care for underinsured patients with chronic or life-altering diseases.

The HealthWell Foundation is a leading independent non-profit dedicated to improving access to health care for America's underinsured. When health insurance is not enough, we fill the gap by assisting with copays, premiums, deductibles and out-of-pocket expenses. In 2022, we awarded more than \$896 million in grants through our Disease Funds, and since 2004 we have helped more than 822,000 patients afford essential treatments and medications. HealthWell is recognized as one of America's most efficient charities — 100 percent of every dollar donated goes directly to patient grants and services.

We provide financial assistance to help with:

- Prescription copays
- Health insurance premiums, deductibles and coinsurance
- Pediatric treatment costs
- Travel costs
- Behavioral health services

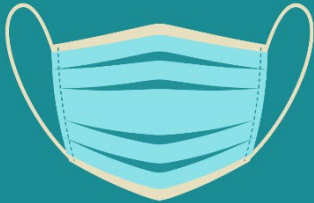
Our Vision: To ensure that no patient goes without health care because they cannot afford it.

<https://www.healthwellfoundation.org/>

Please contact your child's doctor and discuss with your Case Manager if this program is a possibility to help with the cost of medicines or more.

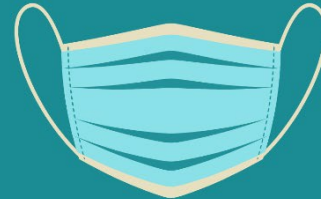
Also, please make sure to look under the Disease Funds to see if your diagnosis is currently available for help.

ATTENTION!



Beginning on 7/10/23 Masks will NO longer be required by the Medically Fragile Case Management staff for face to face visits!
Masks will only be worn during visits if the family requests it, or the RN Case Manager does so on their own accord.

ATTENTION!



A partir del 7/10/23, el personal de administración de casos médicamente frágiles ya NO requerirá máscaras para las visitas en persona.
Las máscaras solo se usarán durante las visitas si la familia lo solicita o si el administrador de casos de RN lo hace por su propia cuenta.

Med Frag Families!

Based on current COVID trends, masks will no longer be required by MFCMP staff for face to face visits beginning 7/10/23.

The exceptions are if families request the RN Case Manager to mask, then the RN Case Manager will mask during visits.
Also, if the RN Case Manager prefers to remain masked, they may do so at any time.

Due to our vulnerable population, we will continue to take necessary precautions, up to rescheduling the visit, if concerns for illness exist.

Según las tendencias actuales de COVID, el personal de MFCMP ya no requerirá máscaras para las visitas presenciales a partir del 10/7/23.

Las excepciones son si las familias solicitan que el administrador de casos de RN se enmascare, entonces el administrador de casos de RN se cubrirá durante las visitas. Además, si el administrador de casos de RN prefiere permanecer enmascarado, puede hacerlo en cualquier momento.

Debido a nuestra población vulnerable, continuaremos tomando las precauciones necesarias, hasta reprogramar la visita, si existen preocupaciones por enfermedad.

Meet the Ombud

Join us on zoom - Monday, August 21st
at 6:30 PM.

DO YOU HAVE A DISABILITY OR NEED HELP WITH SPECIAL ED?

THE OFFICE OF THE SPECIAL EDUCATION OMBUD CAN HELP!

- We advocate for public school students and their families
- We provide comprehensive support for people navigating the special education system in NM



NEW MEXICO Developmental Disabilities Council
nmddc.org

michelle.tregembo@state.nm.us
(505) 841-4565

I encourage you to please join us to learn more about how the Ombud can help you navigate the Special Ed departments in public schools.

Satisfacer la Ombud

Únase a nosotros en zoom - Lunes 21 de agosto
a las 18:30

¿TIENE UNA DISCAPACIDAD O NECESITA AYUDA CON LA EDUCACIÓN ESPECIAL?

LA OFICINA DE LA OMBUD DE EDUCACIÓN ESPECIAL PUEDE AYUDAR!

- Abogamos por los estudiantes de escuelas públicas y sus familias
- Brindamos apoyo integral para las personas que navegan por el sistema de education especial en NM



NEW MEXICO Developmental Disabilities Council
nmddc.org

michelle.tregembo@state.nm.us
(505) 841-4565

Los animo a unirse a nosotros para obtener más información sobre cómo el Ombud puede ayudarlo a navegar por los departamento s de educación especial en las escuelas públicas.

YOUR HEALTH IS OUR PRIORITY

Medicaid and SNAP Renewals are back!
Do you still qualify? Can we help?



Maintain Medicaid - <https://renew.hsd.nm.gov/>

In response to the COVID-19 public health emergency, the federal government did not require people to renew their Medicaid or SNAP.

Due to new federal laws and guidelines, everyone will now need to renew their Medicaid and SNAP eligibility when they are notified.

How to renew:

Make sure your contact info is correct. The New Mexico Human Services Department will need your current contact information to send your Medicaid renewal packet when it is time for you to renew.

If you do not renew your eligibility, you will lose your Medicaid benefits.

Online tips:

- The fastest way to update contact information is through [online chat](#).
- The fastest way to renew is online by signing in at www.yes.state.nm.us
- If you forgot your username or password, click Forgot User ID or Password and follow the instructions to reset.
- If you have previously signed in to yes.state.nm.us do not click the Create an Account button. This may result in a duplicate account, and you will need to call 1-800-283-4465 to update your account before you can renew online.
- If you do not see a renew button when you sign in at yes.state.nm.us, you will need to call 1-800-283-4465. Your account may need to be updated before you can renew online.

<https://renew.hsd.nm.gov/qas/>

Important: If you previously qualified financially for Medicaid, but no longer qualify, or are at risk of losing Medicaid due to a change in financial status, please contact your Medically Fragile RN Case Manager. They can explore options available to maintaining your child's Medicaid.

CHROMEBOOKS

WE STILL HAVE CHROMEBOOKS AVAILABLE! IF YOU WOULD LIKE ONE, PLEASE CONTACT YOUR CASEMANAGER OR NICHOLE AT NRAJALA@SALUD.UNM.EDU



¡AÚN TENEMOS CHROMEBOOKS DISPONIBLES! SI DESEA UNO, COMUNÍQUESE CON SU ADMINISTRADOR DE CASOS O NICHOLE EN NRAJALA@SALUD.UNM.EDU

Please join us for our August session of Hilos Sobre el Autismo: Autism and Spanish Speaking Community

Title of Session: Raíces y Ríos: Organización Comunitaria Para Las Comunidades Más Afectadas / *Roots & Rivers: Community Organizing for Most Impacted Communities*

Presented by: Luis Colunga and Alejandra Gonzalez from Together for Brothers

Thursday, August 10, 2023 from 1:00-2:15 pm (MST)

To register for the presentation, click on the link below:

https://reg.abcsignup.com/reg/event_page.aspx?ek=0033-0021-13c7dcff1a9244d9a4b0c994513e8717

KAYAK NEW MEXICO, INC.

Adaptive Kayaking Event – for anyone with a physical or developmental disability, special need, or medical issue

We welcome family and friends as well as providers/therapist of those with special needs to join us and support them.

Price = FREE; donations always welcome!

Sierra Vista Outdoor Pool

5001 Montañó Rd NW, Albuquerque, NM 87120

Saturday July 15, 2023 – 5:30pm to 7:30pm

Saturday August 5, 2023 – 5:30pm to 7:30pm



PLEASE REGISTER HERE: http://www.kayaknewmexico.org/?page_id=125

ONLINE WAIVER: <http://www.smartwaiver.com/v/knmwaiver>

Questions? Contact Jane at jane@kayaknewmexico.org or 505-980-7207

Kayak New Mexico, Inc. is recognized as a non-profit organization by the IRS under code 501c(3).

All donations are tax deductible to the extent permitted by law.

Our Vision:

We believe Adaptive Kayaking will transform lives, not just through recreation, but through paradigm shifts of what an individual believes is possible, through quality of life, and through health and wellness, while proving to themselves and others that their identity is not related to their abilities. We believe if we can help individuals mentally, the physical, social, and emotional well-being will soon follow.

Upcoming Events:

Currently Scheduled Adaptive Kayaking Events:

August 5, 2023 – 5:30pm to 7:30pm – Sierra Vista Outdoor Pool

5001 Montañó Rd NW, Albuquerque, NM 87120

Future Events:

September 9, 2023 – 6:00pm to 8:00pm – Rio Rancho Aquatic Center

https://www.kayaknewmexico.org/?page_id=125

FINDER

New Mexico Disability Resources

Seek. Discover. Connect. Inform.

NM FINDER is a **free** online resource that gives you 24/7 access to the service providers, programs, equipment and community advocates that can improve your quality of life.



NMFinder.org



CENTER FOR
DEVELOPMENT
& DISABILITY

Supported by UNM Center for Development and Disability

Weaving Colors:

AUTISM & THE NATIVE COMMUNITY

A presentation series for families dedicated to discussing important topics on autism and how they are viewed and addressed in the native culture.

**Join us Wednesday, August 16th and
Wednesday September 20th 1 pm – 2:30 pm MT
as we welcome back**



Dr. Joshua Allison-Burbank

***Honoring Indigenous Knowledge
of Neurodevelopment and
Childrearing***

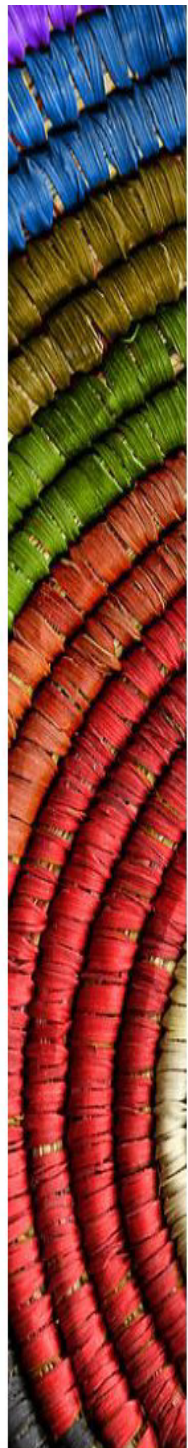
This two-part presentation will explore neurodevelopment and child development from an Indigenous lens. Cultural attitudes towards Disability will be discussed and methods for improving Indigenous connectedness during interventions will be highlighted.

As a reminder, you will need to register for both presentations

[Click here](#) or scan the QR Code:



For more information, please contact
HSC-AutismPrograms@salud.unm.edu Attn: Weaving Colors



Support Groups

Med Frag Mom wanted to share information on 2 support groups that she joins when she can:

Pediatric Ostomy Group #480

Bridget Dorsey: 801-829-8579

1st Thursday of every month
from 6-7pm via zoom

PLEASE JOIN US

Caregiver and Adult Patient Support Group

International Center for Colorectal and Urogenital Care

Thursday, August 17, 2023
11:00am-12:00pm Mountain Time

Topic: Colorectal Parent Support Group
Join Zoom Meeting

<https://ucdenver.zoom.us/j/96779667503?pwd=cXVZWjdzQ0dINWFMeVI0ZHBoLzlkdz09>

Meeting ID: 967 7966 7503
Passcode: 015463


Open by Appointment!

As of July 1, 2023, the UNM CDD Information Network Library is open by appointment.



EMAIL OR CALL TO BOOK YOUR APPOINTMENT TODAY.

 hsc-infonet@salud.unm.edu

 505.272.0281

INFORMATION NETWORK LIBRARY

Available by appointment, our library is free and open to all New Mexicans. We house the most extensive disability-specific collection of hard copy and e-materials in New Mexico.



OUR LIBRARY RESOURCES & SERVICES INCLUDE

- On-site Services by Appointment
- New Patron Registration & Book Check Out
- Research Assistance & Homework Help
- Free Mailing & Return Shipping of Materials
- Cloud-based and Cell-friendly eLibrary Catalogues
- Specialized Disability Collections on Topics such as ASD, Deaf/Blind, Dyslexia, Down Syndrome, Early Childhood, Education & Employment, Native Topics, Self-Advocacy, and More!
- Hojas de Consejos en Español

New to the CDD Information Network Library?

We're here for you! We are open to any resident of the state of New Mexico. You can sign up for a library card today. Why get a library card? It's the best way for us to help you access everything we have to offer. Have questions about getting a library card? Contact us today at hsc-infonet@salud.unm.edu or 505.272.0281.



2300 Menaul Blvd NE
Albuquerque, NM 87107

Outside Resources from our Partners



Upcoming Events

1) ABQ Biopark Zoo 🐾

📍 903 10th St SW

Saturday, August 19, 10am

Together, we will explore our wonderful zoo and learn about our local animals, how they arrived at the zoo and hear about some conservation projects our Biopark is working on!

Space is limited so please RSVP for this family event by August 11th so we can purchase admission and schedule with our nurses.

RSVP to jenb@herospathpalliativecare.org

2) Picnic and STEM Crafts 🍷 @ Open Space Visitor Center

📍 6500 Coors NW

Saturday, September 16th 11am

It's going to start cooling off so that means...PICNIC TIME! Enjoy the breathtaking landscapes at one of our favorite locations. We will have fun STEAM crafts and a delicious lunch. Please let us know if you have any food restrictions.

Please RSVP for this family event by September 8th so we can order lunch and schedule with our nurses.

RSVP to jenb@herospathpalliativecare.org

3) Parent/Caregiver Night OUT!

📍 **Date and Location TBD**

You deserve some YOU time out while we (along with our nurses) spoil and have a blast with the kids!



We want to invite you to come to the workshops and support groups we are having this month. We offer a variety of workshops to meet the needs of families and professionals across the state at no cost. If you are in need of sign language interpretation or any other assistance accessing the workshops, please call us when you register or at least a week prior to the workshop at (505) 247-0192.



Keeping It All Together

Tuesday, August 8th

10:00am - 11:30am

Learn about record keeping for your child's healthcare and education information. Learn how to organize and utilize these documents in advocating for your child.

[Register](#)

Early Childhood Transitions, Next Steps to Success

Tuesday, August 22nd
10:00am - 12:00pm

Learn about Early Childhood Transition, parents' rights, and special education procedures. Discover tools for home and school partnerships including communication, record keeping, and more.

[Register](#)



Parents Reaching Out

Making Connections Virtual Parent Support Group

A photograph showing several hands of different skin tones stacked together in a supportive gesture. The image is set against a background of a patterned geometric design.

Making Connections Virtual Parent Support Group

Wednesday, August 23rd
10:00am - 11:30am

[Register](#)

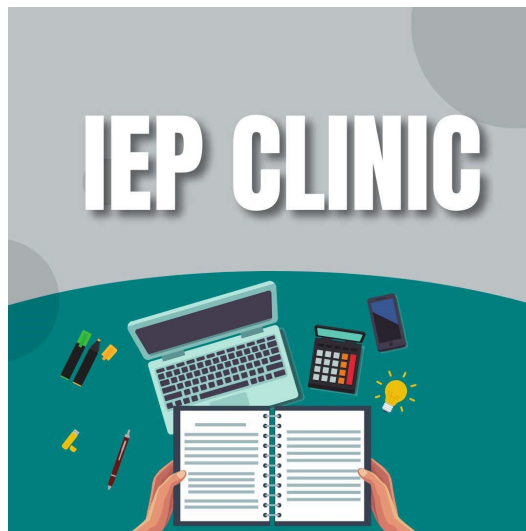
IEP Clinic:

Essential Components of the
Individualized Education Program.

Monday, August 7th
4:30pm

An IEP helps to outline goals and tools and services to support you in meeting your goals throughout the school year. This workshop will provide participants the components of what a well written IEP should contain.

[Register](#)





Forward @ 14:
Transition IEPs
Wednesday, August 9th
5:30pm

Learn about transition IEPs and how they can assist students during and after high school. Reflect on your student's individual needs, strengths, skills, interests and preferences as you plan for adulthood.

[Register](#)

Forward @ 14:
Road to a Good Life
Wednesday, August 16th
5:30pm

Reflect on transition goals and interests that will lead to a productive life after leaving high school. Take a look at your tools and skills that will support those goals and pave the road to a good life.

[Register](#)





Forward @ 14:
 Road to Education and Employment
Wednesday, August 23rd
5:30pm

Learn how to navigate the ins and outs as you plan for success in education and employment after high school.

[Register](#)

Forward @ 14:
 Road to Independence
Wednesday, August 30th
5:30pm

Review services and resources that support your independence into adulthood. Learn how to navigate available, adult services after you finish high school.

[Register](#)



Pro's Student Snapshot

Prepare for the upcoming school year with the Student Snapshot. Review your goals for the year and create a personalized plan for your success.

[\(click here for link\)](#)



Parents Reaching Out

Save the Date

19th Annual
Family Leadership Conference
Providing Real Opportunities

March 22, 2024



Attend

Sponsor

Present

Exhibit



Parents Reaching Out

