

TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

JUNE 2026

As we welcome June, we are reminded once again of the strength, compassion, and resilience that define the Tethered Cord Support Alliance community. Whether you are newly diagnosed, advocating for your child, supporting a loved one, or continuing your own long journey with tethered cord syndrome, we want you to know that you are not alone. This community exists so that no one has to walk this path without connection, understanding, and support.

**ILLUMINATE PATHS TO
COMMUNITY AND
CONNECTION FOR THOSE
WITH TETHERED CORD**

This month, our newsletter focuses on one of the most important parts of our mission: advocacy and support. Advocacy takes many forms, from educating others and sharing reliable information to simply showing up for one another, listening without judgment, and offering encouragement during difficult moments. Through programs like Tethered Tuesdays and Peer Support, we continue building spaces where individuals and families can learn, connect, and walk side by side through every stage of the tethered cord journey.

In this issue, we are also excited to highlight one of the incredible volunteers who helps make our community possible. Our volunteers are at the heart of TCSA, offering their time, compassion, lived experience, and dedication to supporting others.

To all of our volunteers, donors, families, caregivers, and community members, thank you. Your support helps us continue creating resources, connection, and hope for those navigating tethered cord syndrome. As always, thank you for being part of this community as we continue moving forward side by side.



**WALKING SIDE
BY SIDE**



WALKING SIDE BY SIDE

Walking Side by Side: Support, Connection, and Community at TCSA

A tethered cord journey can feel overwhelming at times, filled with questions, uncertainty, decisions, and moments where it may seem like no one truly understands. For adults living with tethered cord syndrome, parents caring for a child with tethered cord, and families navigating the unknown together, the journey can often feel isolating and unpredictable. For some, the journey begins after years of unanswered symptoms and searching for explanations. For others, it begins with the fear and uncertainty that comes after hearing a diagnosis for their child, or receiving one themselves. Many face difficult medical decisions, surgeries, symptom flare-ups, lifestyle changes, and the emotional exhaustion that can come from trying to balance everyday life with ongoing health challenges.

There are moments when people simply want someone who understands. Someone who knows the stress of waiting for appointments and test results. Someone who understands the emotions behind advocating for a child, navigating school accommodations, managing chronic pain, or trying to make the best decisions possible with limited answers. Sometimes what people need most is not only information, but connection, reassurance, and support from others who have walked a similar path.

At the Tethered Cord Support Alliance (TCSA), one of our most important goals is to make sure no one has to walk that path alone. We believe there is strength in community, comfort in shared experiences, and hope in knowing there are others willing to walk side by side through every stage of the journey. Through programs like Tethered Tuesdays and Peer Support, we create spaces where individuals, parents, caregivers, and families can connect with others who understand not only the medical side of tethered cord syndrome, but also the emotional and everyday realities that come with it.

Tethered Tuesdays: Stronger Together

Tethered Tuesdays virtual support groups are a place for community, education, and conversation. These online gatherings give people an opportunity to come together in a supportive and welcoming environment to discuss experiences, ask questions, and learn from one another.

Conversations often include:

- Treatments and procedures, we share what has worked for us
- Experiences with doctors and specialists, breaking down appointments and follow ups
- Research and scientific information, highlighting the newest tethered cord related data
- Daily habits and lifestyle strategies, addressing tethered cords dynamic symptomology
- Personal victories, challenges, and milestones, building bonds by knowing & being known by others with similar stories

What makes Tethered Tuesdays so meaningful is the collaboration between information and connection. Our meetings are educational, social & casual, and every session reminds participants that there is strength in shared experiences.

Sometimes simply hearing, “I’ve been through that too” or experiencing an entire room nod along in agreement can remind an individual they are not alone. If you haven’t yet, we hope you participate soon to witness our loving & growing community of others who care. It can make a difficult day a little lighter.

Peer Support: One-on-One Connection When It Matters Most

There are moments in every medical journey when individualized support can make all the difference. Our Peer Support program offers one-on-one connection focused on listening, understanding, and helping people navigate the challenges in front of them. Peer Support is not about having all the answers; It’s about being present. Whether someone is facing a new diagnosis, preparing for surgery, processing symptoms, or trying to make difficult, short-term decisions, peer support volunteers walk alongside them with compassion and understanding. They can help individuals explore resources, discuss lifestyle strategies, and talk through practical or technical concerns in a safe and supportive space. For many members of our community, knowing someone is willing to sit beside them during uncertain moments provides comfort, reassurance, and hope.

The Power of Walking Together

Advocacy is not only about awareness. It is about connection. It is about building a community where people feel supported, informed, and seen. At TCSA, we believe healing and hope are strengthened when people walk side by side. Through Tethered Tuesdays and Peer Support, we continue to create spaces where no one has to face tethered cord syndrome in isolation.

June 2nd @ 7:00 pm – 8:00 pm CST

Tethered Tuesday (virtual support group for adults) 7PM CST

- Connect with other adults living with tethered cord syndrome.
- 1st Tuesday of the month at 7pm CST

June 9th @ 12:00 pm – 1:00 pm CST

Tethered Tuesday (virtual support group for parents/caregivers) 12PM CST

- Connect with other parents/caregivers of children living with tethered cord syndrome.
- 2nd Tuesday of the month at 12pm CST

June 16th @ 12:00 pm – 1:00 pm CST

Tethered Tuesday (virtual support group for adults) 12PM CST

- Connect with other adults living with tethered cord syndrome.
- 3rd Tuesday of the month at 12pm CST

June 23rd @ 7:00 pm – 8:00 pm CST

Tethered Tuesday (virtual support group for kids) 7PM CST

- Connect with other kids who are living with tethered cord syndrome! Caregivers are always welcome to listen in and help as needed, but the content and discussions in this group are geared toward children (3-17).
- 4th Tuesday of the month at 7pm CST

TETHERED TUESDAY UPDATE

We've simplified things! Going forward, all Tethered Tuesdays meetings will use one consistent Zoom link. Be sure to save the link or QR code to your preferred device for easy access to all Tethered Tuesdays support group meetings.



Join us

TCSA Annual Report

JUNE 30 @ 5:30 PM – 6:30 PM CDT

Join the TCSA executive board for an annual report of our programs, activities, and progress. We will review outreach, volunteer, and access data from the previous year and present goals, sponsorship/donor opportunities, and upcoming volunteer initiatives. Registration is free and open to TCSA team members, donors, and the public.

REGISTER HERE

COMMUNITY STORIES

KALEIGH BEST

SECRETARY AND PEER SUPPORT PROGRAM COORDINATOR



Hello Tethered Cord Community! I am happy that you found us! I have found it very rewarding to be part of the TCSA community to support others on their Tethered Cord journeys and have hope for the increasing awareness and positive outcomes for those with Tethered Cord.

My family's journey with tethered cord began when my daughter was 9 months old. After she started solid foods, she developed severe constipation — and what followed was years of fighting to be heard. Back home in Kelowna, BC, pediatricians dismissed our concerns, attributing her symptoms to my anxiety and assuring us she would grow out of it. By the time she was nearly three, her constipation had become unmanageable despite medication and enemas, and we still couldn't access gastroenterology support at our province's children's hospital. So we went on a worldwide adventure to get the answers that she needed.

We were fortunate to connect with Dr. Kapavarpu, a knowledgeable and compassionate gastroenterologist at CHOP, who guided us through the diagnostic process. When the MRI revealed Tethered Cord, Dr. Heuer (neurosurgeon at CHOP) explained the diagnosis and surgery with clarity and kindness, encouraging us to return home and pursue next steps locally if possible. Sadly, our local neurosurgeon opted for a very conservative approach and wanted to wait until she had more symptoms (beyond unmanageable constipation, urinary retention, back pain, and fatigue). Our daughter, who loves to travel, excitedly boarded another plane, this time to Spain, where Dr. Hinojosa performed her Tethered Cord Release surgery. His exceptional compassion, skill, and dedication gave our family hope and reassurance.

Three years later, our daughter's health and quality of life has improved significantly! She loves gymnastics, running around and playing silly games, learning in Kindergarten, training puppies, and outdoor adventures! We cannot be more thankful for how far she has come since her surgery.

The road to recovery is not simple, straight-forward, or expected. It has required ongoing monitoring and advocating as she grows and develops. Navigating this tethered cord journey has made me passionate to ensure that others have the courage and resources to find the right supports. After years of helping others in the “Parents of Tethered Cord” Facebook group and serving as a Peer Support Mentor, joining the TCSA this year as the Peer Support Program Coordinator felt like the most natural step in the world. If any part of our story resonates with you, know that you don’t have to navigate this alone – just reach out, we’re here!

[Request Peer Support Here](#)

Every tethered cord journey looks different – the symptoms, the treatments, the twists and turns along the way – and our Peer Support Program is here to offer a listening ear and, when helpful, the perspective of someone who has walked their own path with Tethered Cord. And if you’ve walked this road and feel ready to help light the way for others, we’d love to have you volunteer alongside us!

[Volunteer as a Peer Support Agent Here](#)

TCSA PEER SUPPORT PROGRAM

The TCSA Peer Support Program offers one-on-one support to individuals and families affected by tethered cord syndrome. If you would like to meet with a peer support agent or educational advocate, please fill out [this form](#) to be connected with someone who can answer questions and help you navigate your own tethered cord journey.

OUR MISSION IS TO IMPROVE MEDICAL CARE AND QUALITY OF LIFE FOR ALL WITH TETHERED CORD SYNDROME

Founded in 2024, the Tethered Cord Support Alliance is the first ever 501(c)(3) devoted solely to Tethered Cord Syndrome

SUBSCRIBE TO OUR NEWSLETTER TO STAY IN THE LOOP!

NEWSLETTER COORDINATOR
KIMBERLY ORRISON
KIMBERLY@TETHEREDCORD.COM



CONTACT THE TCSA:
HELLO@TETHEREDCORD.COM
WWW.TETHEREDCORD.COM