

TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

MAY 2026

Welcome back! We are so glad you're here. Each month, this space is a reminder that no matter where you are in your journey with tethered cord, whether newly diagnosed, searching for answers, or years into navigating symptoms, you are not alone.

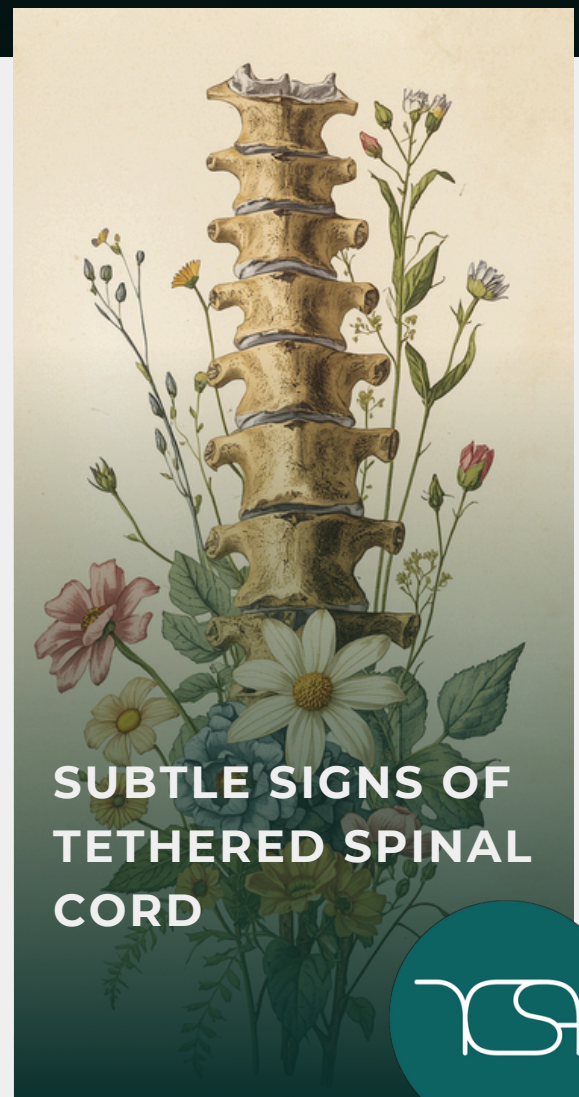
As we welcome May, we're grateful for the continued strength and connection within the Tethered Cord Support Alliance community. This past month has been filled with meaningful progress, learning, and shared experiences that remind us why our mission matters so deeply.

In this issue, we're excited to bring you a recap of our recent webinar featuring Dr. Holly S. Gilmer, whose insights continue to empower patients and families navigating tethered cord syndrome. We're also honored to share a powerful patient story that reflects both the challenges and resilience within our community. In addition, you'll find information about our upcoming TCSA Annual Report, offering a closer look at the impact we've made together over the past year.

None of this would be possible without the unwavering support of our volunteers and donors. Your generosity, time, and commitment are the foundation of everything we do, and we are truly thankful for each of you.

As always, thank you for being part of this community.

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



**SUBTLE SIGNS OF
TETHERED SPINAL
CORD**





SUBTLE SIGNS OF TETHERED SPINAL CORD

Holly S. Gilmer, MD

Dr. Gilmer is a board-certified neurosurgeon specializing in pediatric neurosurgery and peripheral nerve surgery. She graduated *cum laude* from Harvard University and earned her medical degree from the University of Michigan, followed by neurosurgery residency at UC Davis and advanced fellowships at LSU and Children’s Hospital of Michigan. She currently serves as Chair of the Michigan Board of Medicine. Dr. Gilmer is widely recognized for her work in conditions such as Chiari malformations, spinal dysraphism, and tethered cord, and has delivered more than 80 lectures nationally and internationally while contributing extensively to leading neurosurgical journals.

In this month's webinar with Dr Gilmer, she offered a clear reminder that tethered spinal cord is often far less obvious than many clinicians are trained to expect. While the classic image is a low-lying cord anchored by a lipoma, many patients fall into a more subtle category where MRIs are read as normal. Dr Gilmer pointed to patterns that can raise suspicion, including a cord that appears unnaturally straight, shifting from front to back within the canal, or a conus positioned toward the back rather than centered. A thickened or fatty filum can also be a clue. Still, the central message was that tethered cord is not purely a radiologic diagnosis. History and physical exam remain the foundation, with imaging used to help locate the problem rather than confirm its existence.

What stood out just as much was how wide-ranging the symptoms can be, and how easily they are dismissed or approached in isolation. Bowel and bladder changes were described as the most consistent thread, but many patients also present with gait abnormalities, leg asymmetry, pain, or sensory changes that evolve gradually, often during growth spurts. Some cases extend even further, with fatigue, sleep disruption, or recurrent illness entering the picture. In infants and children, small skin findings along the midline can be an early clue that something deeper is going on. The encouraging piece is that untethering can lead to meaningful improvement, especially when done early, though the risk of retethering remains, particularly in more complex cases. **The broader takeaway is a familiar one in medicine but easy to overlook in practice: when the story does not quite add up, it is worth taking a closer look.**

[FULL WEBINAR](#)

May 5th @ 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

May 12th @ 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

May 19th @ 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

May 26th @ 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

For more information about Tethered Tuesdays, including upcoming dates and how to join, please reach out to us at TetheredTuesdays@gmail.com. We'd love to connect with you.

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

FROM TETHERED TO TENACIOUS: A PERSONAL JOURNEY WITH TETHERED CORD SYNDROME BY JUSTIN PETTYJOHN

For as long as I can remember, I knew I had Tethered Cord Syndrome. It was never something that defined my childhood. It was just a fact, something in the background of my life, not the center of it. I was active, independent, and able to move through life without limitations. For years, there was no real reason to believe that would change. At 18, I underwent a detethering surgery that was meant to prevent future complications. Instead, it changed everything. The surgery left me with permanent nerve damage.

The body I had trusted no longer responded the same way. Pain became part of daily life. Movement required thought. Things that once felt automatic became intentional. But even more powerful than the physical changes was something I carried mentally: fear. For years, I lived with the thought of retethering in the back of my mind. It wasn't always loud, but it was always there. The question of what if followed me through decisions, relationships, and planning my future. And then, the thing I feared most happened. I retethered. More surgeries followed. More uncertainty. And eventually, I found myself facing a reality I had spent years fearing. I ended up in a wheelchair.

For a long time, I didn't know what that life would look like. I had imagined it in pieces, but always through the lens of fear. Loss of independence. Change in identity. How others would see me. But something unexpected happened when I finally reached that point. The fear disappeared. Not because everything became easy, but because the unknown was gone. I was no longer living in anticipation of something happening. I was living in it. And in that, I found something I didn't expect. Acceptance. And with acceptance came freedom. I no longer wake up wondering if things will get worse in the same way. I am not consumed by the what ifs that used to follow me. Instead, I focus on building, adapting, and continuing forward with what is. I do not care the same way about how people perceive me, whether it is how I walk, how I move, or the fact that I am in a wheelchair. Because I have already faced the thing I feared most. And I am still here.



Living with Tethered Cord Syndrome has forced me to redefine what strength really means. It is not just physical. It is the ability to adapt when life changes without asking for permission. It is learning to let go of the version of life you expected and still choosing to move forward. It is finding confidence not in what your body can or cannot do, but in who you are regardless of it. For me, strength now looks like perseverance. It looks like showing up. It looks like continuing to build a life with intention, even when it looks different than I once imagined.

Through all of this, something meaningful took shape. Kaitlyn and I built Reclaim Therapy and Coaching not because everything was figured out, but because we understand what it means to rebuild when life shifts. It is not the center of my story. But it is a reflection of it. A reflection of resilience, perspective, and choosing to move forward instead of staying stuck in fear. If you are living with Tethered Cord Syndrome, you know this journey does not follow a straight line. There are seasons of uncertainty. Fear of what might come. And sometimes, the reality of those fears becoming true. But I can say this from the other side of that fear. There is still life here. Not the life you may have imagined, but a life that can still be meaningful, full, and worth building. For me, the greatest shift was not the surgeries or even the wheelchair. **It was moving from fear to acceptance. And once I found that, everything else became something I could face.**

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!

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