TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

NOVEMBER 2026

Welcome back to the Tethered Support Alliance newsletter! We're so glad you're here and grateful to have you as part of our community.

ILLUMINATE PATHS TO COMMUNITY AND CONNECTION FOR THOSE WITH TETHERED CORD

To our readers, supporters, and generous donors: thank you for being part of this mission. Your continued support helps us create a community where individuals and families navigating TCS can feel informed, encouraged, and less alone. We truly couldn't do this without you.

As we head into November, we're turning our attention to something that may not always be top of mind but can make a meaningful difference: preparing for the year ahead. With open enrollment season underway for many, this month's newsletter explores ways to better understand your healthcare benefits, make the most of your FSA or HSA, and think strategically about upcoming appointments and year-end healthcare costs.

Our hope is that these reminders offer a little extra clarity and confidence as you navigate the many moving pieces of healthcare. As always, thank you for being here, for supporting one another, and for helping make the Tethered Support Alliance community what it is. Wishing you a November filled with connection, gratitude, and support.



Tetheredcord.com

OPEN ENROLLMENT: THINK ABOUT THE CARE AHEAD

November is open enrollment season for many, making it an important time to review your healthcare coverage and prepare for the year ahead. For individuals and families navigating tethered cord related care, healthcare needs can extend well beyond a single appointment. Care may involve specialized neurosurgeons, urologists, orthopedic specialists, physical or occupational therapy, MRIs, urodynamic testing, and ongoing follow-up after surgery.

For some families, finding a provider with specific tethered cord expertise may mean traveling out of state or seeking care outside their insurance network. These situations can bring additional costs, including out-of-network deductibles, coinsurance, travel expenses, and lodging. Reviewing your plan's provider network, coverage for specialized services, referral requirements, and out-of-network benefits can help you better understand your options before care is needed.

Review Your Coverage

When comparing health insurance options, look beyond the monthly premium. Consider whether your specialists and preferred hospitals are in-network, how your plan covers MRIs, procedures, therapy, and follow-up care, and whether referrals or prior authorizations are required. If you receive care out of network, check whether your plan offers any out-of-network benefits and what additional costs you could be responsible for. Understanding these details can help you make a more informed decision about the coverage available to you.

Check Your FSA or HSA

Look into a Flexible Spending Account (FSA) or Health Savings Account (HSA). Take a moment to review your balance, eligible expenses, and account deadlines. Some FSA funds may expire at the end of the plan year, although certain plans allow limited carryover or a grace period. HSA funds generally roll over from year to year. Knowing your account's rules can help you plan for eligible healthcare expenses and make the most of the benefits available to you.

Think Ahead About Appointments

If you've already met your annual out-of-pocket maximum, additional covered, in-network care may cost you less before your plan year resets. If you haven't met it, your situation may look different.

Consider reviewing your remaining benefits and asking your healthcare team whether any recommended appointments, imaging, or follow-up care could appropriately be scheduled before the end of your plan year. Keep in mind that your plan year may not follow the calendar year, and medical needs should always come first.

A little planning goes a long way. Navigating tethered cord care can involve many moving pieces, from coordinating specialists to managing insurance and unexpected expenses. You don't have to figure everything out at once

DAWID'S STORY



Dawid

For most of my childhood, I was healthy. I had some posture problems growing up that seemed minor at the time - I now know they were connected to tethered cord syndrome all along, I just didn't have a name for it yet. Around 2020, I started noticing my legs would go numb when I bent forward. It was strange, but it didn't stop my life. I was a fairly ordinary teenager.

That changed in October and November of 2023. Symptoms accelerated fast. It started with heavy brain fog, headaches, dizziness, constant exhaustion, and my legs feeling tired all the time in a way that had nothing to do with how active I'd been. Something in my body had shifted, and I could feel it, even before anyone could explain it to me.

Getting answers turned out to be its own battle. Before I had a diagnosis, I saw a neurologist who decided my symptoms were psychological - that I simply didn't want to go to school - and prescribed an antidepressant, telling me it would fix everything. Not long after, I was hospitalized on a pediatric ward and discharged that December without any diagnosis at all. If anything, that only pushed me to search harder on my own.

I started digging into my own symptoms and found a Polish patient community online, first around a different suspected condition, then around craniocervical instability, which seemed to match what I was feeling in my neck. Treating it that way brought some real improvement at first, which only made the real answer harder to see at the time. Through that same community, a woman who had tethered cord syndrome herself reached out and suggested it might be behind what I was going through. Over the following weeks, my symptoms made it clear she was right, and some simple things we tried together confirmed it. She pointed me to the surgeon who had operated on her, and once I got in front of him, he confirmed tethered cord syndrome and scheduled me for surgery two months later.

When I finally got my diagnosis, the overwhelming feeling was relief. For the first time, I had a real answer and a real treatment plan, instead of years of guesses and dismissals. That said, I still remember how stressful the appointment itself was - relief and fear can show up in the same room at the same time.

Even after that, the disbelief didn't fully stop. Between my first and second surgery, I ended up on a neurology ward where, despite the fact that retethering had already been documented on an MRI the same hospital's own radiologist had reviewed, the doctors told me it was all in my head. Being disbelieved like that, after already having a confirmed diagnosis, while your body is clearly telling you something is wrong, is its own kind of exhausting.

If I'm honest, the hardest part hasn't been any single event. It's just feeling unwell, day after day. That kind of ongoing physical struggle wears on you in ways that are hard to explain to someone who hasn't lived it. The medical gaslighting I went through has also left its own kind of trauma.

What's carried me through has been my family - they never once doubted that something was genuinely wrong with me, even when doctors did. That mattered more than I can fully put into words. More recently, being active on social media has changed me, too. It's made me more emotionally open than I used to be. And discovering that a surgery called spinal column shortening existed gave me real hope - a concrete reason to believe recovery was possible, not just something to wish for.

Right now, I'm preparing for a trip to the United States for consultations that could shape what comes next for me. It's stressful, honestly, because I don't know yet what will come of it. But underneath that stress, I'm genuinely grateful and excited. There's a real chance, even a partial one, that I could get some of my health back.

If there's one thing I want other people to know, it's this: patient support is not optional, it's essential. If it weren't for another patient sharing her experience, I might never have found my diagnosis. I could have kept wandering, and honestly, I might have ended up hurting myself trying to find answers on my own. I can't imagine going through this without friends who are living through something similar. That kind of support is on a completely different level than support from people who haven't been through it, no matter how well-meaning they are. If you're struggling right now and feel alone in it, find your people. They might be the reason you find your way through.

Upcoming Events

NOVEMBER 2026

November 3rd @ 7:00 pm – 8:00 pm CST

Tethered Tuesday (virtual support group for adults)

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

November 10th @ 12:00 pm – 1:00 pm CST

Tethered Tuesday (virtual support group for parents/caregivers)

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

November 17th @ 12:00 pm – 1:00 pm CST

Tethered Tuesday (virtual support group for adults)

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

November 24th @ 7:00 pm – 8:00 pm CST

Tethered Tuesday (virtual support group for kids)

- 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

NOVEMBER WEBINAR

Surgical Management of Tethered Cord Syndrome: History of Techniques, Clinical Presentations, and Emerging Research

Speakers: Dr. Kaveh Asadi, Neurosurgeon

Nov 10, 2026 06:00 PM MST

REGISTER HERE

TETHERED TUESDAYS

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.

LOOKING FOR WAYS TO SUPPORT OUR PROGRAM?

The Tethered Cord Support Alliance (TCSA) is a 100% volunteer-led organization. Every program, resource, and event we provide is made possible by the dedication of volunteers and the support of our community.

YOU CAN HELP ADVANCE OUR MISSION IN SEVERAL MEANINGFUL WAYS:

- Request TCSA resources for your local hospital, clinic, or therapy practice to help raise awareness and connect patients and providers with trusted information.
- Share grant opportunities by letting us know about local, regional, or national funding opportunities that could help support our programs and outreach.
- Attend, volunteer, and participate in our events. Whether you lend your time, expertise, or enthusiasm, your involvement helps us expand our impact and strengthen the TCS community.
- Make a financial gift to support our mission.

SUPPORT OUR MISSION



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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