TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

SEPTEMBER 2026

ILLUMINATE PATHS TO COMMUNITY AND CONNECTION FOR THOSE WITH TETHERED CORD

As a new school year begins, families everywhere are settling into new routines, new schedules, and all that comes with a fresh start.

For families navigating tethered cord syndrome, “back to school” can look a little different. From accommodations and advocating for your child’s needs to managing symptoms, fatigue, pain, and the unexpected challenges that can come with a new school year, we know this season can bring both excitement and uncertainty.

In this month’s newsletter, we’re sharing helpful resources to support you as you navigate school with TCS, along with upcoming events and opportunities to connect with our community. We’re especially excited to share details about our upcoming webinar with Dr. Klinge - an opportunity to learn, ask questions, and connect with others on this journey.

Whether your child is heading back to the classroom, learning from home, or taking a different path this year, we hope this month’s resources remind you that you don’t have to navigate it alone.

Here’s to a new school year and to meeting each season with knowledge, support, and community.

BACK TO SCHOOL WITH TETHERED CORD

The beginning of a new school year brings new opportunities and new excitement! For families of children with tethered cord syndrome, it can also bring concerns about how to ensure your child receives the support they need to thrive in the classroom.

Since children with tethered cord syndrome have unique needs that can be difficult to see on the surface and fluctuate from day to day, it is important to work with your child's school to develop a plan that meets their needs.

Start the conversation early! The more your child's teachers and administrators understand about their condition and individual needs, the easier it will be for them to help. It is better to think ahead so everyone involved can be prepared, instead of waiting for difficulties to develop.

Remember that many educators have never heard of Tethered Cord Syndrome. Providing clear, targeted information can go a long way toward helping them understand that your child's needs are real, even if they are not always visible.

Consider scheduling a meeting with your child's teacher, school nurse, counselor, and/or the school's 504 coordinator or special education staff. During the meeting, share information about your child's diagnosis, explain how TCS affects them personally, and discuss any accommodations that may help them be successful.

A 504 Plan is a formal accommodation plan created under Section 504 of the Rehabilitation Act of 1973. Its purpose is to ensure that students with disabilities have equal access to education by removing barriers that may interfere with learning.

Unlike an Individualized Education Program (IEP), which provides specialized instruction, a 504 Plan focuses on accommodations that allow a student to participate in the general education classroom.

Your child qualifies for a 504 Plan if their medical condition substantially limits one or more major life activities, such as walking, standing, sitting, concentrating, learning, or caring for bodily functions.

With appropriate accommodations and a collaborative partnership between families and schools, many students with tethered cord syndrome fully participate in school while managing the unique challenges of their condition. You can begin by contacting your school's principal, counselor, or designated 504 coordinator. The process generally includes:

1. Submit a written request asking that your child be evaluated for Section 504 eligibility.
2. Provide medical documentation describing your child's diagnosis and functional limitations.
3. Participate in a meeting with school staff to discuss your child's needs.
4. Work together to develop accommodations that support your child's success.
5. Review the plan periodically and request updates if your child's needs change.

To make the accommodation process easier, the TCSA offers a downloadable letter to educators that explains Tethered Cord Syndrome, helps you describe specific symptoms your child might have, and includes suggested school accommodations commonly needed by students with the condition.

Letter to Educators

For families, these insights offer hope and practical next steps. For clinicians, they reinforce the importance of tailoring rehabilitation to the unique needs of individuals with TCS and recognizing that thoughtful, individualized therapy can have a meaningful impact on long-term outcomes.

This letter serves as a helpful starting point for developing a school accomodations plan, helping make the process more straightforward and effective for everyone. It can be signed both by you and your child's physician, or you can fill out and sign the form yourself, providing medical documentation by downloading your child's school health summary or relevant office visit notes. Communicating early with your child's educators can reduce stress, prevent misunderstandings, and help ensure your child starts the year with confidence.

If you have questions or would like to request additional help from a tethered cord-informed educational advocate, please fill out the form below and we'll be happy to connect you. One-on-One Peer Support

"I used the TCSA accomodations letter for my daughter's 504 plan this year, and it worked beautifully! Since we had an official letter instead of just me trying to explain what I think she might need, the discussion stayed focused on how to make it happen and nothing got left out or swept under the radar!"

ACCOMMODATION LETTER

Upcoming Events

SEPTEMBER 2026

September 4th @ 7:00 pm – 8:00 pm CDT

Tethered Tuesday (virtual support group for adults)

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

September 8th @ 12:00 pm – 1:00 pm CDT

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

September 15th @ 12:00 pm – 1:00 pm CDT

Tethered Tuesday (virtual support group for adults)

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

September 22nd @ 7:00 pm – 8:00 pm CDT

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

SEPTEMBER 15TH 7-8PM CDT

The History of Occult Tethered Cord: A Journey Starting in 1953

Step into the evolving story of occult tethered cord syndrome in this engaging and thought-provoking webinar led by Dr. Petra Klinge.

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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