

TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

OCTOBER 2026

Welcome back! October is here, bringing cooler temperatures, changing leaves, and the feeling that the year is beginning to wind down. As we settle into the rhythm of fall, we're grateful to have you here and to continue sharing information, resources, and connection with the Tethered Cord community.

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

In this month's newsletter, we're looking back at our recent webinar with Dr. Klinge, "The History of Occult Tethered Cord: A Journey Starting in 1953." We'll share highlights and key takeaways from this insightful presentation, and if you missed the live event, give you a chance to catch up.

We're also excited to introduce you to an emerging conversation that could have meaningful implications for the future of neurological and connective tissue research: the **Neuro-EDS Initiative**. This developing effort is exploring the connections between neurological manifestations and connective tissue disorders. We're looking forward to sharing more about this important work and what it may mean for the Tethered Cord community.

You'll also find upcoming dates and events, ways to stay connected with the Tethered Cord Support Alliance, and a few ways you can support our mission and help us continue serving the Tethered cord community. Grab your favorite fall drink, get cozy, and let's take a look at what's happening this October.



**WEBINAR
RECAP**



[Tetheredcord.com](https://tetheredcord.com)

THE HISTORY OF OCCULT TETHERED CORD: A JOURNEY STARTING IN 1953



Dr. Petra Klinge's recent webinar, "The History of Occult Tethered Cord: A Journey Starting in 1953" offered more than a history lesson; it was a look at how far our understanding of tethered cord syndrome has come, and how much there is still left to learn. Beginning with the early physicians who recognized that a tight or abnormal filum terminale could cause neurological problems, Dr. Klinge traced decades of research, debate, and discovery. At the heart of her presentation was an important reminder: patients are more than their MRI images. She emphasized the importance of listening to the full clinical picture, including leg weakness and fatigue, pain, sensory changes, bladder and bowel symptoms, scoliosis, and subtle neurological findings. For patients whose imaging does not show a clearly low-lying conus, that message can be especially meaningful.

Dr. Klinge also shared newer research exploring why occult tethered cord can cause symptoms even when the conus appears to be in a normal position. Her team's work suggests that the filum itself can be structurally and mechanically abnormal, with changes involving collagen, inflammation, and its ability to absorb mechanical forces. She discussed the connection between these findings and connective-tissue disorders such as hypermobile Ehlers-Danlos syndrome, as well as her team's development of a 15-item clinical scale to better capture the complex combination of neurological, pain, and bowel/bladder symptoms seen in patients with occult tethered cord. While research continues and many questions remain, the presentation reflected something deeply encouraging: the story of occult tethered cord is still being written.

Perhaps the most powerful part of the webinar was the reminder that progress often begins with people willing to keep asking questions when the existing answers don't fully explain what patients are experiencing. Dr. Klinge acknowledged the controversies and limitations in the research while sharing the evidence her team has gathered over years of clinical and scientific work. Her message was ultimately one of continued curiosity, collaboration, and the hope that by listening closely to patients, studying the underlying biology, and continuing to challenge what we think we know, we can move toward better recognition and care for people living with tethered cord syndrome.

FULL WEBINAR

NEURO-EDS INITIATIVE

A New Conversation Is Emerging: Introducing the Neuro-EDS Initiative

For years, the Tethered Cord community has recognized that the clinical picture is often far more complex than a single diagnosis, a single MRI finding, or an isolated symptom. Patients frequently experience a constellation of neurological, spinal, autonomic, and connective-tissue-related manifestations, yet these features are often evaluated and treated in isolation instead of as part of a much larger picture.

The Neuro-EDS initiative seeks to define a new phenotype within the group of heritable connective tissue disorders that includes EDS/hEDS and HSD. The pre-print paper “Defining Neuro-EDS: A Neuro-Predominant Phenotype in hEDS/HSD and Related Heritable Connective Tissue Disorders” presents Neuro-EDS as a distinctly recognizable pattern of overlapping symptoms and conditions that tend to show up together in certain patients. The authors propose that this phenotype needs to be recognized clinically as it warrants different treatment strategies and recommendations from the general population, and even from groups of patients with a single overlapping neurological condition.

The proposal divides the neuro-EDS phenotype into two separate domains: Cranial-Spinal and Neuro-Autonomic/Inflammatory. Tethered cord syndrome, including occult tethered cord syndrome, is one of the conditions commonly manifested as part of the proposed Cranial-Spinal domain. This means that people with tethered cord syndrome and other related conditions such as chiari malformation, craniocervical instability, syringomyelia, and/or CSF concerns would be supported by this new clinical framework.

Rather than viewing these complex manifestations in isolation, this emerging initiative seeks to bring together observations that patients and clinicians have been seeing for years and consider how they may fit within a larger neurological and connective-tissue framework.

This is still an evolving area of research, but the potential is significant: greater recognition, new avenues for research and collaboration, and perhaps a more comprehensive way of understanding patients whose experiences have never fit neatly into a single diagnostic box.

We’re excited to share more about the Neuro-EDS Initiative and the work surrounding it in the months ahead.

Resources that provide helpful context on the initiative:

Preprint: [Preprint](#)

Video: Dr. Bloom explains the initiative and the thinking behind it: [Video](#)

October 6th @ 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

October 13th @ 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

October 20th @ 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

October 27th @ 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

OCTOBER WEBINAR

Frequency-Specific Microcurrent Therapy for Tethered Cord Syndrome

Speakers: Jessie Tierney, PT, DPT, E-RYT
Patricia J. Stott DPT, MS, ATC, CHT

Oct. 13th at 6:00 PM MST/7:00 CST/8:00 EST

[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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