

TETHERED CORD SUPPORT ALLIANCE

NEWSLETTER

APRIL 2026

Welcome back! We are so glad you have joined us again as we continue our mission to improve medical care, awareness, and quality of life for those affected by Tethered Cord.

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

First and foremost, we extend our deepest gratitude to our incredible donors, volunteers and community members who continue to stand with us month after month. Your continued generosity, time, and belief in this mission makes our work possible for us to advocate for earlier diagnosis, better outcomes, and practical resources that truly help families. Because of you, we're able to bring you focused guidance in every issue - like this month's deep dive into pre-operative physical therapy.

This issue highlights an important step many patients overlook before surgery.

Pre-operative physical therapy can play a meaningful role in preparing the body, improving recovery, and helping patients feel more confident going into surgery. Yet, many families aren't aware it's even an option.

In this issue, we'll walk through what pre-op physical therapy looks like and why it matters.



**PREPARING FOR
TETHERED CORD
SURGERY:
WHAT TO KNOW
ABOUT PRE-OP
PHYSICAL
THERAPY**





Danielle Jolliff, PT, MSPT, CAFS

PREPARING FOR TETHERED CORD SURGERY: WHAT TO KNOW ABOUT PRE-OP PHYSICAL THERAPY

Tethered Cord Syndrome is a rare neurological condition affecting the spinal cord and many important nervous system functions throughout the body. It occurs when a portion of the spinal cord is abnormally attached or “tethered” within the spinal canal. This creates tension on the neural tissue and restricts the cord’s normal movement during spinal motion, which can lead to progressive neurological and functional decline. Surgical detethering is a primary treatment, and patients may be referred to physical therapy before surgery.

For patients: if you or your child has been diagnosed with tethered cord syndrome and surgery is scheduled, pre-operative physical therapy may be a helpful part of your preparation. Pre-operative PT helps establish baseline function, build strength safely, and prepare both patients and families for what’s ahead.

[Read More](#)

For physical therapists: tethered cord is a rare condition where the spinal cord is already under tension within the spinal canal. Pre-op physical therapy requires thoughtful consideration of avoiding interventions that could increase this tension, such as trunk flexion, aggressive stretching, or movements that stress the nervous system. By focusing on neutral spine positioning, conservative approaches, and close neurological monitoring throughout treatment pre-op PT can support preparation for surgery as well as post-operative recovery.

[Read More](#)

PRE-OPERATIVE PHYSICAL THERAPY FOR TETHERED CORD SYNDROME REQUIRES SPECIALIZED KNOWLEDGE AND CAREFUL MONITORING. THE PRIMARY GOALS ARE TO OPTIMIZE THE PATIENT’S FUNCTION WITHIN SAFE LIMITS, ESTABLISH BASELINE MEASUREMENTS FOR TRACKING POST-OPERATIVE PROGRESS, AND PREPARE PATIENTS AND CAREGIVERS FOR RECOVERY—ALL WHILE AVOIDING INTERVENTIONS THAT COULD WORSEN NEUROLOGICAL SYMPTOMS.

April 7th @ 7:00 pm – 8:00 pm CDT

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

April 21st @ 12:00 pm – 1:00 pm CDT

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

April 14th @ 12:00 pm – 1:00 pm CDT

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.

April 28 @ 7:00 pm – 8:00 pm CDT

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 (3-18).
- 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.

April Webinar

HOLLY S. GILMER M.D.
PEDIATRIC NEUROSURGEON

APRIL 21ST 7:00-8:00 CENTRAL TIME

JOIN US THIS APRIL FOR A LIVE WEBINAR WITH DR HOLLY S GILMER AS SHE SHARES INSIGHT ON TETHERED CORD, ANSWERING QUESTIONS AND EXPLORING THE LATEST IN CARE AND AWARENESS

[REGISTER HERE](#)



VOLUNTEER SPOTLIGHT

Rebecca



Rebecca is passionate about supporting families as they navigate the educational system and access the support their children need to succeed. Through her work in education, particularly with diverse learners, she has seen firsthand how meaningful guidance, clear information, and compassionate advocacy can empower both students and their families.

She grew up in Maine but now lives in Delaware with her husband and their two children where they recently moved from Washington, DC for a slower pace of life.

Her personal journey as the parent of an eleven-year-old daughter with a tethered spinal cord and chiari malformation has deepened her commitment to helping families feel informed, supported, and confident when working with schools. Supporting a child with a chronic illness can be an isolating experience that at times is difficult to share with others, and having the ability to connect with others in a similar situation has been helpful to her family.

She recently started working as an educational advocate through Small Steps to Success, has experience developing individualized supports that help students thrive, and has a strong understanding of special education bringing particular insight into evaluations, IEPs, and 504 plans. She has seen firsthand how clear information, collaborative problem-solving, and individualized care can empower families to participate confidently in educational decision-making and ensure that students receive meaningful support. As a mentor with TCSA, Rebecca enjoys connecting with other families, sharing practical knowledge, and helping parents feel supported as they navigate the educational and medical journey.

Outside of her professional work, Rebecca enjoys spending meaningful time with her family and traveling to visit extended family whenever possible. She loves spending time at the beach, exploring local thrift and antique shops in search of unique finds, and relaxing with puzzles.

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 like Rebecca who can answer questions and help you navigate your own tethered cord journey.



SUPPORT THE MISSION

CLIMBING KILIMANJARO TO RAISE AWARENESS WITH PATTY STOTT

Years ago, Patty was among the growing number of adults developing tethered cord symptoms alongside complex conditions like EDS, POTS, and MCAS. What followed was a long and difficult journey marked by declining health, limited access to care, and the many challenges so many in our community know all too well. Patty didn't stop there.

Through years of learning, persistence, and dedicated rehabilitation work, she has made incredible progress, going from severe limitations to now preparing to hike Mount Kilimanjaro this summer, a goal that once felt completely impossible. Now, Patty is turning her journey outward.

She is raising funds to support the Tethered Cord Support Alliance (TCSA) and help address critical gaps in awareness, diagnosis, and care, especially for those with occult or acquired tethered cord, where understanding is still far too limited. If you're able, please consider supporting Patty's fundraiser or sharing it with others. This is how we move our community forward - together!

Support Patty's fundraiser:

<https://givebutter.com/patty-stott-fundraiser-campaign-ivhe7m>

FOUNDED IN 2024, THE TETHERED CORD SUPPORT ALLIANCE IS THE FIRST EVER 501(C)(3) DEVOTED SOLELY TO TETHERED CORD SYNDROME

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

[SUBSCRIBE](#) TO OUR NEWSLETTER TO STAY IN THE LOOP!

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