

TETHERED CORD SUPPORT ALLIANCE

# NEWSLETTER

FEBRUARY 2026

Welcome to our very first newsletter! We are so grateful you're here and excited to share the latest developments in our mission to improve medical care, awareness, and quality of life for those affected by Tethered Cord Syndrome.

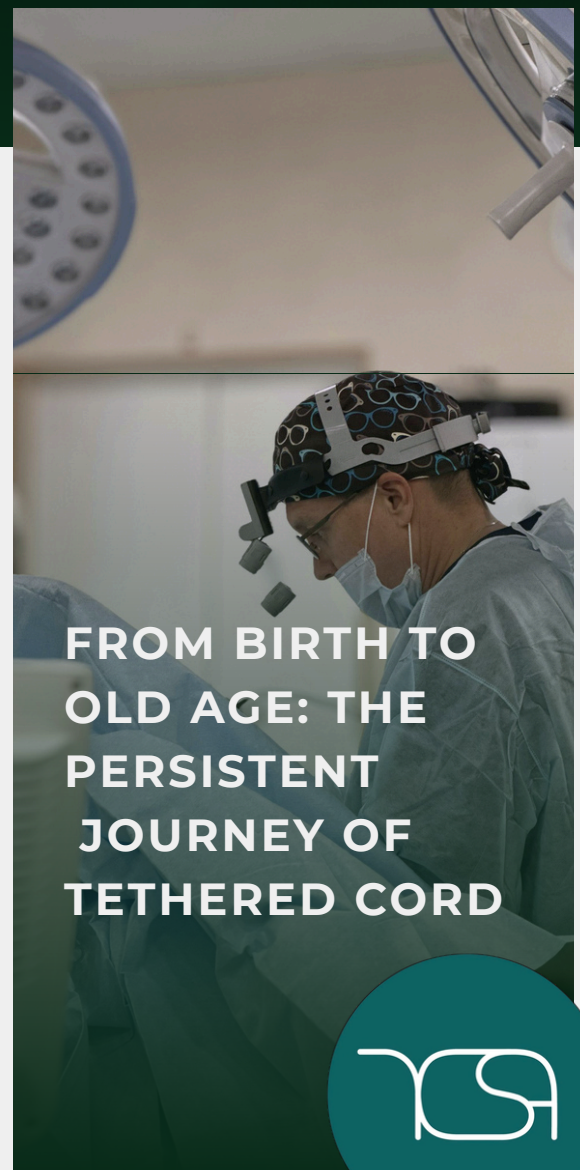
**ILLUMINATE PATHS TO  
COMMUNITY AND CONNECTION  
FOR THOSE WITH TETHERED  
CORD**

First and foremost, we extend our heartfelt gratitude to the donors and volunteers who continue to stand with us. Your generosity, time, and belief in this mission make our work possible and allow us to move forward with hope and purpose: advocating for greater awareness, earlier diagnosis, and improved outcomes for individuals and families navigating Tethered Cord Syndrome.

**We sincerely thank Lemons Charitable Fund, and Mr. Mark A. Lemons and Mrs. Lisa Kay Lemons, for their generous charitable fund grant given in honor of Noah Lachney.**

One of our most exciting recent milestones has been the successful launch of our educational webinar featuring Dr. Petra Klinge. We were encouraged to see over 500 people register, highlighting the tremendous need for accurate information, expert insight, and open conversation around this condition. The strong response reinforces why this work matters and motivates us to continue creating accessible, high-quality educational opportunities for patients, caregivers, and medical professionals alike.

This is just the beginning, and we're honored to have you alongside us as we continue to grow, learn, and work toward meaningful change.



**FROM BIRTH TO  
OLD AGE: THE  
PERSISTENT  
JOURNEY OF  
TETHERED CORD**





## Dr Petra Klinge, MD, PHD

### FROM BIRTH TO OLD AGE: THE PERSISTENT JOURNEY OF TETHERED CORD

#### Overview:

In “The Persistent Journey of Tethered Cord”, Dr. Petra Klinge, a leading neurosurgeon specializing in tethered cord syndrome (TCS) and related cerebrospinal fluid (CSF) disorders, outlines how tethered cord affects individuals across the lifespan - infancy, adulthood, and old age. The talk focuses on the continuum of symptoms, the challenges in diagnosis, and implications for treatment.

The nuances of tethered cord often begin in childhood, but how it presents itself changes as the nervous system matures. Early signs may be subtle, yet as symptoms advance, tethered cord becomes increasingly neurological in nature.

From infancy through the late teen years, the pattern shifts:

- Infancy & early childhood: changes in leg tone, frequent unexplained discomfort or “colicky” behavior, and recurrent urinary tract infections
- School-age years: increasing leg stiffness, fatigue, coordination issues, and early neurologic signs
- Adolescence: progression to spasticity, bladder and bowel incontinence, mental strain, and social or emotional challenges related to chronic symptoms

Spasticity is a key biomarker of tethered cord syndrome.

When the spinal cord remains abnormally stretched, nerve bundles are placed under constant strain, disrupting normal nerve signaling. On neurological examination, this may be seen as increased muscle tone, hyperreflexia, clonus in the feet, and weakness or coordination deficits, particularly in adolescents and adults. These findings reflect ongoing neurological stress rather than simple muscle tightness or orthopedic issues.

A common misconception about tethered cord, especially when a fatty filum has been present since birth is that symptoms should have appeared in childhood. When adults begin to experience symptoms, it can be difficult to reconcile how something congenital could suddenly cause problems decades later. The tethered cord has, in fact, been present all along ; what has changed is the cumulative stress placed on the spinal cord over time. Throughout life, we use our bodies. We twist, bend, stretch, carry, overuse, and experience both minor and major physical stressors. Over years and decades, these repetitive movements and mechanical forces place increasing tension on a spinal cord that is already tethered. While the body may compensate for a long time, there often comes a point where the nervous system can no longer adapt. At that stage, symptoms emerge or accelerate, not because the tethered cord is new, but because the strain has reached a critical threshold.

This helps explain why adults with a fatty filum may experience a delayed onset of neurological symptoms and why those symptoms can worsen over time.

Watch the webinar here!

[FULL WEBINAR](#)

# Upcoming Events

## MARCH 2026

**March 3 @ 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

**March 17 @ 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

**March 10 @ 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.

**March 24 @ 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

## Volunteer Spotlight

**MARI YENTZER RAINS**  
VOLUNTEER COORDINATOR

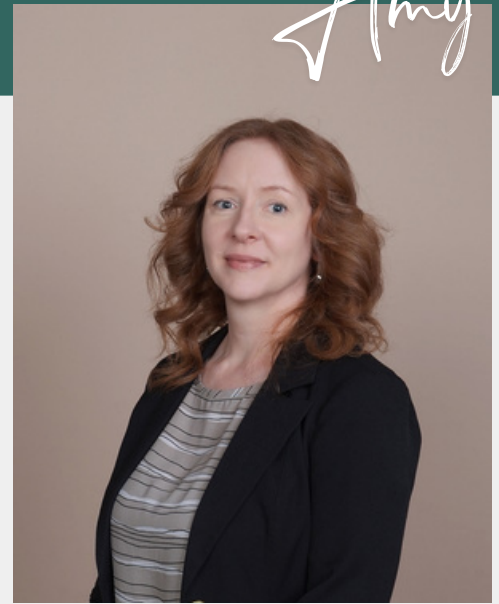
MARI YENTZER RAINS GAINED HER TRIPLE-RARE DISEASE PATIENT BADGE WITH HER RECENT RARE DISEASE DIAGNOSIS OF TETHERED CORD SYNDROME. HER BODY MAY SEEM LIKE A "LEMON" BUT SHE'S TURNING LEMONS INTO LEMONADE, FOR HERSELF AND OTHERS!

[LEARN MORE](#)



# COMMUNITY STORIES

Amy



When I was born, my parents were told that I'd likely never be able to walk. Never afraid to take on a challenge, it was only nine months later when I proved the doctor wrong. My parents were relieved but still concerned about my fussiness, choosing to nap on the floor by the warm air vent and not sleeping at night. The doctor attributed those issues to behavioral problems and poor parenting.

Throughout my childhood, I was prone to tripping and falling. I often sprained my knees and ankles. When I mentioned to my family that my ears were ringing, they assured me that it meant someone was talking about me. Severe nausea caused me to be underweight. Falling asleep during class was a daily occurrence and I barely slept at night. In addition, I was plagued with anxiety.

The adults in my life scolded me for not being more careful, being a picky eater, and not paying attention in class. My mother suspiciously questioned me about my pupils being dilated. Every couple of months, I would run a low-grade fever which was accompanied by aches and chills. Those episodes usually resolved after a day or so.

As I grew, I developed terrible allergies and food intolerances. Over the summers, I was congested with allergies. Through the winters, I was sick with every virus that went around the school. Still, none of my symptoms were alarming to anyone. When I began having fainting spells, I was more embarrassed than anything else. My mother was glad that I hadn't hurt myself when I fell. Doctor visits revealed only that I tended to be anemic and needed iron supplements.

By the time I reached adulthood, I sought treatment for my allergies. Headaches and heart palpitations became a nuisance. Sharp, pinching pains in my abdomen frightened me. Doctors couldn't find any significant cause for these symptoms. The remedies that they suggested were never effective and often came with awful side effects. Low blood pressure and low hemoglobin were the only findings. Not even IV Venofer made a difference. When my fatigue was at its worst, I fell asleep behind the wheel while driving on the freeway. It was terrifying!

My health also affected my career. Nodding off during meetings is unprofessional. My muscles became so stiff while sitting at the office that I could hardly walk when I stood up. The leg pain began to affect my hips and low back as well. Sometimes it felt like the front of my hips were cramping and my legs would give out. I would throw out my low back, hips, or neck from time to time. As symptoms continued to progress, my calves would swell while I was standing or sitting. By the time I was in my early thirties, I started keeping my feet up on an ottoman under my desk at work. At that time, I became aware that I was intolerant of too much light or heat and was prone to excessive sweating. The pinching abdominal pains evolved into episodes of laying incapacitated on the bathroom floor. Brief black out spells continued with no traceable cause. Over the years, I tried several medications, supplements, allergy treatments, dietary changes, exercises, and stress management techniques. Some things helped a bit, but nothing resolved all of my issues. In fact, I found it difficult to specify symptoms to my doctors because most of them were my "normal". Most people found me either comical or annoying. I became adept at masking my symptoms and avoiding people.

They say that everything goes downhill after forty. In my case, it was an icy hill. After an especially horrific flare-up of abdominal pain and blacking out, I made an appointment with a gynecologist who I hadn't seen before. Carefully navigating the mental health quiz and interrogation about opioid use, I won a physical exam which revealed that I had endometriosis. It was life-changing to finally have a valid diagnosis. I wanted to shout it from the rooftops. Two surgeries and a few years later, I was well on my way to having it in remission. Encouraged by my newfound success working with medical professionals, I went on to ask about the leg and back pain. That resulted in a diagnosis of arthritis in my knees. It wasn't a surprise, but helped to restore my faith in doctors.

Late in my forties, I had built enough trust with my primary doctor to confess that my tailbone in particular was bothering me. This prompted an x-ray which not only confirmed arthritis in my spine, but also showed spina bifida occulta. That was shocking news since I thought I had been cleared of spina bifida during my first year of life. The only knowledge I had about it was that one of my childhood neighbors was born with spina bifida and had always walked with braces. I certainly did not have the same issue.

With modern medical information at my fingertips, I looked up everything I could. The Spina Bifida Association's website included details about related conditions. Their description of tethered spinal cord rang all the bells for me. The spine specialist that I had been referred to tag-teamed with an "associate" to discredit every symptom and question I mentioned. They were confident that spina bifida occulta is completely asymptomatic and there is no value in confirming or denying it. They were sure that all of my problems were related to arthritis. It wasn't until I pointed out some false assumptions that they had made and specifically asked about tethered cord that they decided to humor me by ordering an MRI. It was a couple of weeks later when tethered cord was confirmed.

The SBA's website saved me a second time with their list of local neurosurgeons. Since the spine specialist had failed to impress me, I asked my primary doctor to refer me to a clinic that the SBA site mentioned. The neurosurgeon there was wonderful. He explained the difference between spina bifida occulta and tethered cord, taking time to address all of my questions. My whole life finally made sense. He recommended detethering surgery to prevent further damage although there was no guarantee that my existing symptoms would resolve. Recovering from neurosurgery at the age of forty-nine was difficult in every way, but nothing has ever been easy for me. It was a rollercoaster of symptoms and physical therapy for several months. My only regret was that I didn't do it sooner. While the damage is permanent and I'll likely always be symptomatic, everything is much more manageable now. Just understanding what is happening to my body is therapeutic all by itself. Now I can allow myself grace, even when others don't.

I'll be forever grateful to the Tethered Cord Support Alliance for the knowledge and compassion they offer. For everyone on the tethered cord journey, I wish you all of the peace and comfort you can get! - Amy

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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