The Summer Issue - 2026

amyloidosis foundation

Newsletter

INSIDE, WE ALSO TALK ABOUT:

Alliance for Patient Access (AfPA) Amyloidosis Initiative

The Alliance for Patient Access hosted its annual meeting of the Amyloidosis Initiative of the Rare Diseases Working Group on April 17–18, 2026. The event convened clinicians, patient advocates, pharmaceutical representatives, and other stakeholders to discuss policies that impact people living with amyloidosis.

Topics discussed included reducing access barriers in amyloidosis care, access trends in commercial insurance, effective clinician advocacy, federal and state policy and advocacy updates, genetically targeted technologies, the emotional toll of amyloidosis, and more.

One important discussion assessed the needs of the amyloidosis community and how we can move forward to help patients with drug costs, travel to specialty centers, genetic counseling for hereditary amyloidosis, clear and accessible information, screening protocols for high-risk groups, and earlier detection initiatives. Attendees emphasized the importance of continued collaboration across sectors to drive meaningful change and ensure equitable access to care.

Patient Resources

The foundation has several programs that benefit patients and their families. All of these are provided free of charge.

· Webinar recordings posted on our website

· Updated informational pamphlets

· Listing of experienced physicians that specialize in amyloidosis. Email us anytime with questions: **info@amyloidosis.org**

Our comprehensive website has information for patients, caregivers and physicians featuring:

· Treatment Centers (US / International)

· Support Groups

· Newsletters

· Webinars

· Caregiver/Patient Binder

· Fundraising Toolkits

Follow Us!

Stay connected for all the latest information on Amyloidosis:

Web: www.amyloidosis.org
Twitter: @Amyloidosisfdn
Facebook: @amyloidosisfdn
Instagram: @amyloidosisfoundation

Partner Webinar Series

In collaboration with 'Somebody To Talk To', the Amyloidosis Foundation promotes sessions specializing in everything amyloidosis. These live Zoom webinar sessions are every Wednesday evening from 6:00 PM – 7:00 PM (America/New_York).

Provided are free, professionally-led group sessions covering emotional well-being, caregiving skills, disease information, support, and more. The sessions are available to every rare disease family — live via Zoom, on-demand, and at no cost.

The sessions are live and are not recorded due to patient involvement.

Find more information and register for sessions here:

https://somebodytotalkto.com/session-calendar

Understanding Transthyretin Amyloidosis (ATTR)

A recent study looked at 72 people diagnosed with transthyretin amyloidosis—a rare disorder where abnormal proteins build up in the body and can damage nerves, the heart, and other organs. The goal was to better understand differences between two main types of the disease: hereditary (ATTRv) and non-hereditary or "wild-type" (ATTRwt).

Who was affected?

Most patients in the study (61 out of 72) had the wild-type form, while 11 had the inherited version. One clear difference was age: people with ATTRwt were typically older, with a median age of 78, compared to 74 in those with ATTRv. The wild-type form also affected far more men—about 90%—while the hereditary type had a lower, though still majority, male percentage at 64%.

Genetics and background factors

Among those with the inherited form, most had a specific genetic change (called p.Val50Met), while a few had other rare variants. Only one person came from an area where the disease is more commonly seen, showing that it can appear even outside typical regions.

Other health conditions

Some patients in both groups also had diabetes (around 16–18%), which is important because it can cause nerve damage on its own. This made it harder for researchers to distinguish symptoms caused by amyloidosis vs. diabetes.

Differences in early symptoms

One of the most striking findings was how differently the disease showed up early on:

- In the hereditary group (ATTRv), nearly three-quarters of patients had already been diagnosed with nerve damage (polyneuropathy) before their amyloidosis diagnosis.
- In contrast, this was very rare in the wild-type group—only 3% had this prior diagnosis.

On the other hand, people with ATTRwt were more likely to have been diagnosed earlier with carpal tunnel syndrome (CTS), a condition that causes numbness and tingling in the hands.

Why this matters

These findings highlight that the two forms of transthyretin amyloidosis can look quite different in real life. Hereditary cases often show up first as nerve problems, while the wild-type form may begin with more subtle issues like carpal tunnel syndrome. Recognizing these patterns could help doctors diagnose the disease earlier and more accurately.

Bottom line

Even though both forms share the same underlying disease process, who gets them—and how they first appear—can differ significantly. Better awareness of these differences may lead to faster diagnosis and improved care for patients.

Read the original article here: https://pmc.ncbi.nlm.nih.gov/articles/PMC12504723/

Stay informed on the latest developments in amyloidosis research, treatment options, and community initiatives by visiting Amyloidosis Foundation at amyloidosis.org. Our website offers up-to-date news, educational resources, and information on upcoming events, helping patients, caregivers, and healthcare professionals remain connected and informed.

CARES Phase III clinical program

CARES Phase III clinical program did not meet the primary endpoint in the overall light chain amyloidosis population; however, it demonstrated anselamimab as a potential first anti-fibril therapy in **kappa light chain amyloidosis**.

According to the AstraZeneca press release, distributed on May 29, 2026, "the global CARES Phase III clinical program showed that treatment with anselamimab, a potential first-in-class anti-fibril therapy, resulted in nominally statistically significant and highly clinically meaningful benefit in adults with advanced kappa light chain (AL) amyloidosis as first-line therapy added to standard of care plasma cell dyscrasia (PCD) treatments, compared to placebo. In the overall population of patients with AL amyloidosis, treatment with anselamimab did not meet the primary endpoint, defined as a hierarchical combination of time to all-cause mortality (ACM) and frequency of cardiovascular hospitalizations (CVH), as previously disclosed.

In a prespecified subgroup analysis of patients with kappa predominant light chain isotype, anselamimab improved survival by 62%, measured by ACM (hazard ratio 0.38; 95% confidence interval [CI] 0.17, 0.86; nominal p=0.012), and reduced the frequency of CVH by 71% (incidence risk ratio 0.29; 95% CI 0.10, 0.87; nominal p=0.028), compared to placebo in the subgroup with kappa AL amyloidosis.

The reduction in the risk of ACM in the kappa subgroup was also observed in both trials comprising the CARES Phase III clinical program among patients with kappa isotype with Mayo stage IIIa disease (75%) and Mayo stage IIIb disease (48%). No differences in ACM and CVH were observed among patients with lambda predominant light chain isotype.

The Cardiac Amyloid Reaching for Extended Survival (CARES) clinical program consists of two parallel global, Phase III, randomized, double-blind, placebo-controlled, multicenter trials evaluating the efficacy and safety of anselamimab plus standard of care (SoC) for underlying plasma cell dyscrasia in patients with light chain (AL) amyloidosis and cardiac involvement defined as European modification of Mayo 2004 stage IIIa and stage IIIb, respectively. The CARES clinical program is the largest prospective investigation in cardiac AL amyloidosis to date, with a total of 406 patients enrolled from 19 countries globally, including 281 patients with stage IIIa and 125 patients with stage IIIb disease per European modification of the Mayo 2004 staging system".

Read the press release in its entirety here:

https://bit.ly/AZprRl

Linvoseltamab yielded hematologic CR (Complete Response) in 18/20 patients

At the 2026 American Society of Clinical Oncology (ASCO) Annual Meeting, Dr. Hans C. Lee of the Sarah Cannon Research Institute presented promising early results from the phase 1/2 LINKER-AL2 study evaluating linvoseltamab for patients with relapsed or refractory AL amyloidosis. Currently, there are no FDA-approved treatments for patients whose disease returns after frontline therapy.

Linvoseltamab is a bispecific antibody that redirects T cells to attack abnormal plasma cells responsible for producing the harmful light chains that damage organs in AL amyloidosis. Among the first 20 patients treated, 90% achieved a hematologic complete response, while the remaining patients achieved very good partial responses. Responses occurred rapidly, with a median time to complete response of just 1.5 months and significant reductions in harmful light chain levels seen within 15 days.

Hans C. Lee, MD, presented early data for LINKER-AL2, showing linvoseltamab drives rapid and deep responses following relapse after frontline treatment for AL amyloidosis, which has no approved therapies.
Image Credit: © SCRI

The treatment demonstrated a manageable safety profile. Most cytokine release syndrome (CRS) events were mild (grade 1 or 2), and no dose-limiting toxicities were reported. Although two patients died during the study, investigators determined that neither death was related to linvoseltamab treatment.

These early findings suggest that linvoseltamab may offer a highly effective and accessible treatment option for patients with relapsed AL amyloidosis. Its ability to produce rapid, deep responses and its potential for outpatient administration make it a promising therapy that could help address a significant unmet need in this rare and life-threatening disease.

Run-Walk-Bike-Roll

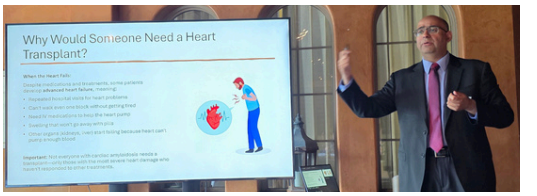
The Amyloidosis Foundation invites you to participate in the Run-Walk-Bike-Roll Virtual Challenge, taking place from June 1 through September 8. This virtual event allows participants to support the amyloidosis community while staying active on their own schedule. Whether you choose to run, walk, bike, or roll, you can take part from anywhere and participate at a pace that works for you.

This event is a great way to raise awareness of amyloidosis while supporting the Foundation's efforts to provide patient support, educational resources, and research funding. Participants can set personal goals, involve family and friends, and make every mile count in the fight against this rare disease. No matter your fitness level or preferred activity, everyone is welcome to join.

Registration is now open, and getting started is easy. Sign up today at: ***https://bit.ly/2026VirtualWalk*** and help us move our mission forward throughout the summer.

Together, we can increase awareness, inspire hope, and make a meaningful difference for individuals and families affected by amyloidosis.

Tennessee Amyloidosis Support Group Recap



The May 2 Nashville Area Amyloidosis Patient Support Group meeting was a tremendous success! We gathered at Giovanni's in Nashville for a delicious lunch, meaningful conversations, and valuable patient-centered education.

The event brought together patients, caregivers, healthcare providers, nursing staff, and several pharmaceutical representatives. Our featured provider speaker was Dr. Hasan Siddiqi, a cardiologist with the Vanderbilt Amyloidosis Multidisciplinary Team. We were also honored to hear from one of our patient advocates, who shared his personal journey to diagnosis and discussed some of the day-to-day challenges he and his wife navigate while living with amyloidosis.

Dr. Siddiqi's presentation, "Cardiac Amyloidosis: What You Need to Know," provided a clear and engaging overview of a complex disease. He covered the fundamentals of amyloidosis, its effects on the heart, the different disease subtypes, warning signs and symptoms, diagnostic approaches, treatment options, heart transplantation, and available resources and support services.

One of the highlights of the presentation was Dr. Siddiqi's ability to explain the science behind amyloidosis in an accessible way. He described how proteins can misfold, become "sticky," form long chains, and eventually clump together to create amyloid deposits. He also compared the two primary types of amyloidosis—AL and ATTR—explaining their differences in amyloid formation, genetic factors, risk profiles, disease progression, treatment approaches, and the organs most commonly affected. Dr. Siddiqi shared echocardiogram images that demonstrated how amyloid deposits can affect the heart muscle, helping attendees visualize the impact of the disease. Throughout the presentation, he transformed complex medical concepts into practical information that patients and caregivers could easily understand.

One of his most important messages was that many signs and symptoms of amyloidosis—particularly ATTR amyloidosis—overlap with common conditions associated with aging. As a result, the disease is often overlooked or diagnosed later than it should be.

We are incredibly grateful to Dr. Siddiqi and our patient speaker for sharing their expertise and experiences with our group. Before leaving the restaurant, several attendees commented on how much they had learned from the presentations.

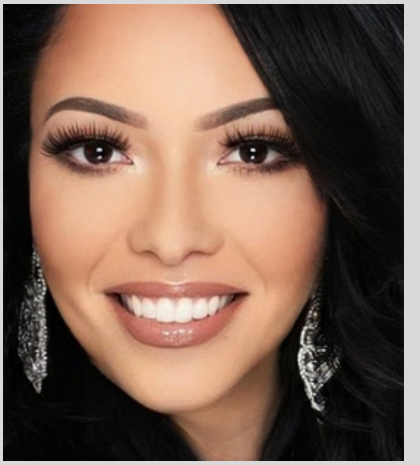
If you were unable to attend, we encourage you to view Dr. Siddiqi's presentation slides, which are available on our website. Go to 'Webinars' on our website landing page.

The Amyloidosis Foundation offers a vast collection of resources for patients and caregivers. We're here to help every step of the journey.

Scan the QR code to access additional resources, tools, and information about our services and programs.

Patient Story

By: Tisha Downing



About a year ago, my health took a sudden and frightening turn. I had been living with Ehlers-Danlos Syndrome (EDS) and POTS, so I was no stranger to chronic illness. But this felt different. My symptoms quickly escalated beyond anything I had experienced before. I fainted in my bathroom, resulting in a minor concussion. My shortness of breath became so severe that asthma was considered. The fatigue was overwhelming—I was forcing myself just to get out of bed each day. My POTS symptoms intensified, and treatments that once helped, including IV therapy, no longer provided relief. Simple daily tasks became impossible. I couldn't wash my hair, walk up the stairs without assistance, or take care of my home. Cooking and cleaning were out of the question. I lost nearly 30 pounds in less than three months and was dealing with nausea, loss of appetite, and increasing weakness.

As my condition worsened, I was forced to take a medical leave of absence. That was incredibly difficult for me. I am deeply passionate about helping others through my work with Connected Warriors, where I provide trauma-conscious yoga to veterans, active-duty military, and their families. Not being able to show up for my community in the way I was used to felt like losing a part of myself. Despite everything, my family stood behind me every step of the way, offering unwavering support during one of the most challenging times of my life. Even with all of this, answers were hard to find.

At different points, I was told it could be depression, a POTS flare, low potassium, or part of my existing conditions. Bloodwork showed anemia, but that wasn't unusual for me, given my history. But deep down, I knew something more was wrong. I remember crying to my husband, telling him I felt like something was being missed—something bigger than what we were seeing.
Determined to find answers, I pursued additional genetic testing. A previous test had shown a variant of unknown significance (VUS) in my TNXB gene, but it didn't explain my symptoms.
The additional testing changed everything.

I learned that I carry the TTR gene mutation associated with hereditary transthyretin amyloidosis and was diagnosed with hATTR-PN (hereditary transthyretin amyloidosis with polyneuropathy). At the time, I had never even heard of amyloidosis. I turned to online communities for support and was able to quickly connect with a specialist, which was a blessing. After extensive testing and a second genetic confirmation, I finally had answers.
After months of uncertainty and misdirection, I finally understood what was happening in my body. Receiving my diagnosis was life-changing—but it also gave me something I desperately needed: clarity.

Today, I am learning how to navigate life with hATTR-PN while continuing to advocate for awareness. My journey has reinforced the importance of listening to your body, trusting your instincts, and pushing for answers—even when it's hard. If sharing my story helps even one person feel less alone or leads them to the diagnosis they've been searching for, then it's worth it.

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JUNE 1 – SEPT 8

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