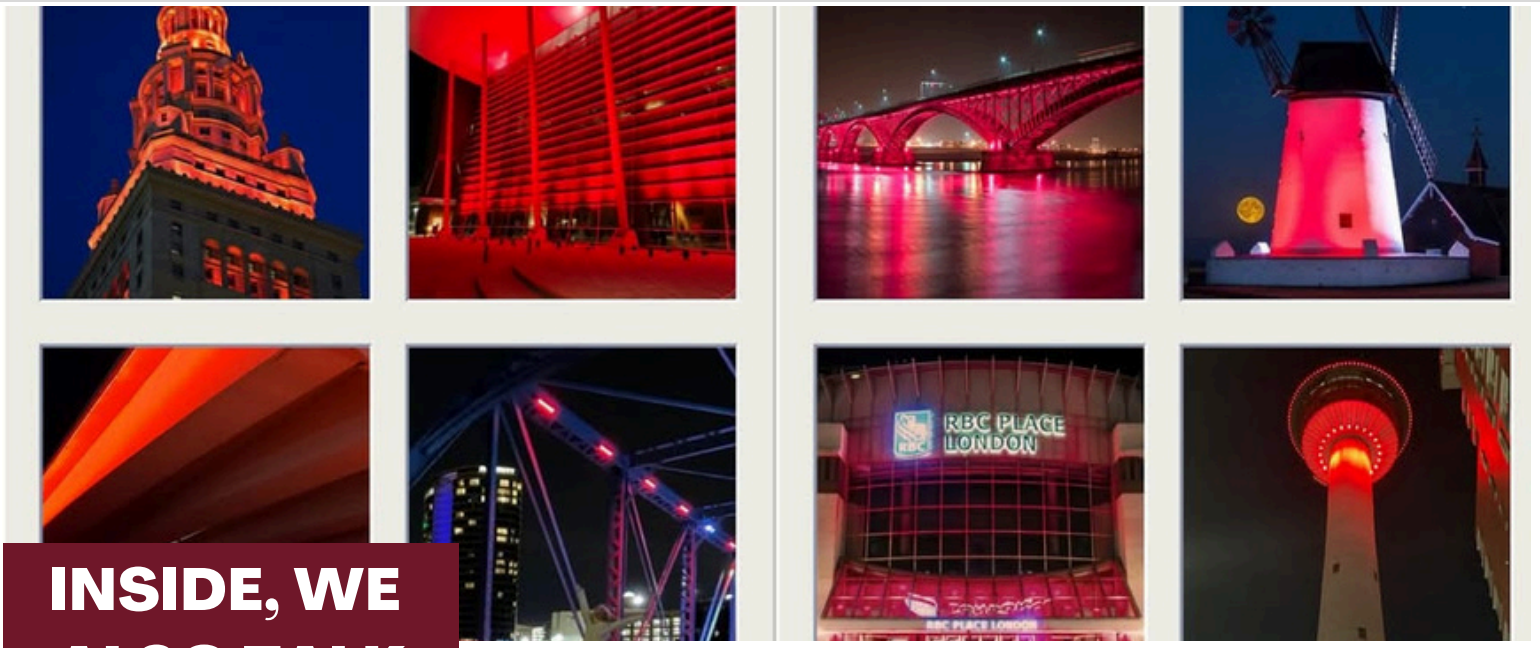
The Spring Issue - 2026

amyloidosis foundation

Newsletter



INSIDE, WE ALSO TALK ABOUT:

Lighting the Way Forward

The glow from this year's Light the Night for Amyloidosis event was more than symbolic—it was a powerful reminder that awareness, community, and hope can shine, even in the face of rare disease. As we reflect on the success of this inspiring initiative led by the Amyloidosis Foundation, we also look ahead to the work that remains.

Amyloidosis is still widely underdiagnosed, often mistaken for more common conditions. Events like Light the Night play a crucial role in changing that reality by bringing patients, families, caregivers, and advocates together under one shared mission: to increase understanding and accelerate early detection. Each light represents a story—of resilience, of loss, and of unwavering determination to improve outcomes.

The momentum built through Light the Night reminds us that every voice matters, every story counts, and every action brings us closer to a future where amyloidosis is diagnosed earlier and treated more effectively. The Amyloidosis Foundation invites everyone to stay engaged—through education, advocacy, and support—so we can keep the light shining long after the night is over.

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

Diagnoses Of ATTR Amyloidosis Increasing As Awareness And Testing Improve

Researchers report that diagnoses of transthyretin amyloidosis (ATTR) are rising across the United States, largely due to greater clinical awareness and advances in diagnostic tools. A recent analysis found that the number of people living with the condition grew by about 26% between 2019 and 2022, suggesting the disease may be more widespread than previously believed.

ATTR amyloidosis occurs when abnormal transthyretin proteins accumulate in tissues, damaging organs such as the heart and nerves. The heart-related form (ATTR-CM) was identified as the most common, while many patients showed signs of both cardiac and neurological involvement, indicating mixed disease presentations are more frequent than once assumed.

Using insurance claims and electronic health records, researchers estimated that prevalence ranges widely depending on diagnostic criteria—from roughly 60 cases per million under strict definitions to more than 250 per million under broader criteria—underscoring likely underdiagnosis and inconsistent medical coding. Most patients were older adults, with a higher proportion of men and frequent coexisting health conditions.

The study suggests the increase in cases reflects improved detection and longer survival rather than a true surge in disease risk. Experts call for standardized diagnostic criteria and coding practices to better track ATTR amyloidosis and improve patient management.

FDA Clears Anumana's ECG-AI Algorithm for Cardiac Amyloidosis

Cardiovascular AI company Anumana has received clearance from the U.S. Food and Drug Administration for its ECG-based artificial intelligence tool designed to help detect cardiac amyloidosis (CA). The software is the first of its kind to use standard 12-lead electrocardiograms for this purpose.

The algorithm is intended to assist clinicians in identifying patients who may be at risk for CA during routine care. By analyzing subtle patterns in ECG data—signals that are often difficult for the human eye to detect—it can flag cases that might otherwise go unrecognized.

Originally developed at Mayo Clinic, the model was validated in a large multi-center study involving more than 25,000 patients across U.S. health systems. It demonstrated strong accuracy, with high sensitivity and specificity in detecting the condition among patients with relevant symptoms or risk factors.

Because the tool works with ECGs already collected in clinical settings, it can be incorporated into existing workflows without requiring additional testing. Experts say innovations like this could help improve early detection of cardiac amyloidosis, which is often missed due to overlapping symptoms with other heart conditions.

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.

Immix Biopharma Receives U.S. FDA Breakthrough Therapy Designation for NXC-201

The FDA has granted Breakthrough Therapy Designation to NXC-201 for patients with relapsed/refractory AL Amyloidosis, a serious disease with no approved therapies, on January 28, 2026. The decision is based on promising Phase 2 interim results from the NEXICART-2 clinical trial, recently presented at ASH 2025.

This designation helps speed development and review, bringing Immix one step closer to delivering a potential new CAR-T therapy to patients in need.
READ MORE HERE: https://bit.ly/IMMIX128

Golf legend Jack Nicklaus diagnosed with Cardiac Amyloidosis

A recent announcement that golf legend Jack Nicklaus, 86, has been diagnosed with ATTR-CM is bringing new attention to a condition many people have never heard of.

ATTR-CM (transthyretin amyloid cardiomyopathy) is a progressive and often underdiagnosed disease that affects the heart. Increased awareness can lead to earlier diagnosis, better care, and improved outcomes for patients and families.

Jack Nicklaus absolutely shanked his ceremonial tee shot at The Masters on April 9th, leading the Golden Bear to explain he hasn't been playing due to a recent surgery.

Nicklaus told reporters in Augusta he underwent carpal tunnel surgery, which prevented him from hitting the links leading up to his annual tournament opener. In fact, he later admitted, he only played once all of last year and followed that with a single round in February.

If you or a loved one is experiencing unexplained heart symptoms, don't ignore them. Learning more about amyloidosis could make a life-changing difference.

Learn more at:
amyloidosis.org

"If you recognize any of these red flags, ask your doctor about ATTR-CM"

- Jack, a real patient with ATTR-CM

Take Charge of Your Care: Becoming Your Own Health Advocate

Talking with your doctor about changing your amyloidosis treatment can feel overwhelming, especially if you're unsure how to begin or concerned about how the conversation will be received. Those feelings are completely normal. However, speaking openly is an important part of your care.

When you communicate clearly and confidently, you give your doctor the information they need to better understand your experience and adjust your treatment plan in a way that supports your symptoms and overall well-being.

Strong communication plays a key role in managing amyloidosis effectively. Your doctor relies not only on medical tests but also on what you share about your daily life, symptoms, and any side effects you may be experiencing.

Preparing ahead of your appointment can make these discussions easier. Keeping notes about changes in your condition, identifying your personal health goals, and focusing on a few main concerns can help guide a more productive conversation and ensure your priorities are addressed.

If you feel hesitant to speak up, remember that asking questions and sharing concerns is a normal and valuable part of healthcare. Many patients worry about taking up too much time or saying the wrong thing, but doctors generally appreciate engaged and informed patients.

Practicing what you want to say beforehand or writing down key points can help build confidence. Over time, these conversations can become more comfortable, helping you take an active role in your care and work collaboratively with your doctor to make the best decisions for your health.

Patient Advocate Foundation (formerly PAN) Introduces TotalAssist Program

We're excited to introduce TotalAssist, Patient Advocate Foundation's new unified financial assistance program launching July 1, 2026. This program will offer more than 130 disease-specific and health equity funds to support people living with rare, chronic, and complex conditions.

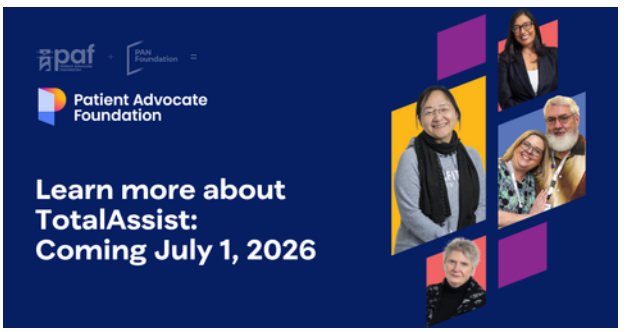
Patients can use grants to cover a wide range of healthcare costs, including medication expenses, insurance premiums, office visits, and treatment-related fees—helping reduce barriers to care.

TotalAssist also brings several improvements for eligible patients, such as guaranteed grant amounts with potential additional support, six-month retroactive coverage for qualifying expenses, and no waitlists—funds will be available on a first-come, first-served basis. Patients can also sign up for real-time notifications when funds open and access simple online portals designed for patients, providers, and caregivers.

Starting July 1, existing users will transition to the new TotalAssist system, including updated portals and support services. To learn more, join the free webinar series beginning ***May 12 at 1 pm ET***, where they'll cover program details, benefits, and what the launch means for patients.

Registration is encouraged, even if you can't attend live, to receive a recording and additional resources.

Register here:
https://bit.ly/PAFwebinar



Clinical Trial Update: MAGNITUDE-2 (ATTRv-PN)

Intellia Therapeutics has announced that the FDA has lifted the clinical hold on the MAGNITUDE-2 Phase 3 clinical trial evaluating nexiguran ziclumeran (nex-z) for people living with hereditary transthyretin amyloidosis with polyneuropathy (ATTRv-PN).

Patient enrollment and dosing are expected to resume as soon as possible. Additional liver safety monitoring measures have been put in place. The trial is now planning to enroll approximately 60 patients.

The clinical hold on the related MAGNITUDE Phase 3 trial for ATTR with cardiomyopathy (ATTR-CM) remains in place, and discussions with the FDA are ongoing. Updates will be shared as more information becomes available. Nex-z is being studied as a potential one-time CRISPR-based gene-editing treatment designed to reduce transthyretin (TTR) protein production.

As always, we encourage patients and families to talk with their healthcare team about clinical trial options and what may be right for them.

Read the news release here: https://bit.ly/4Release

American Society of Hematology (ASH) Conference 2026

At the American Society of Hematology (ASH) Annual Meeting, the Amyloidosis Foundation's booth served as a key point for education and awareness.

Attendees learned about amyloidosis through accessible resources and conversations with knowledgeable representatives, helping bring greater attention to this often underrecognized disease.

The booth also fostered meaningful connections among clinicians, researchers, and advocates. By maintaining a visible presence in the exhibit hall, the Foundation helped keep amyloidosis part of the broader hematology conversation while supporting collaboration and progress in patient care.

Patient Story

By: Nicole Emery

I was just 15-years-old when my mother was diagnosed with Amyloidosis, a word no one in my family, or anyone else in our life for that matter, had ever heard before. What was it? What did it mean? For me, all I knew was that my mom was very sick and eventually, that she wasn't going to get better. That is a heavy thing for anyone to process, let alone a 15-year-old high school girl whose biggest worry up until that point was what to wear to the mall that weekend. So what do we do when faced with this harsh reality? How do we stay present and cherish the time with our sick family members? Good question.

Grief looks different for everyone, and at 15, I wasn't ready to face it at all and that's okay. It was my body's way of protecting me from something I just didn't have the bandwidth for yet. But pain demands to be felt, and we can either choose to steward and honor its experience or it will appear in other ways, whether we like it or not.

So as a 34-year-old woman, who has come out the other side, through many years of healing, counseling, and growth, here are my two cents on what would have helped me immensely during that very difficult time in life, and perhaps it can lend a hand to others:

> ***"pain demands to be felt, and we can either choose to steward and honor its experience or it will appear in other ways..."***

Having your people, those you know you can rely on and rest in, to just be there. They don't have to have all the right words, just their presence is enough to be reassured that you are not alone.

Not being told how to grieve, while often meant with good intentions, people need to grieve at their own pace and in their own way. A better approach, inviting them back into life and holding space for them to share when they are ready.

Sharing our loved ones, honors them. Often people were afraid to bring up my mom after she passed, even today it seems to be a subject people tip-toe around but the greatest medicine for me has been to share and celebrate the incredible woman my mother was. Respect if someone would prefer not to share, but don't be afraid to remember the good times with someone who is grieving!

Lastly, **connecting with the Amyloidosis Foundation, and others walking this path,** is an incredible way to honor those who have fought their greatest fights, and bring light to their stories so that others may be helped.

With Greatest Gratitude, for "Mimi" - Nicole

amyloidosis foundation
7151 N. Main St.
Ste. 2
Clarkston, MI 48346

NONPROFIT ORG
U.S. POSTAGE
PAID
ROYAL OAK, MI
PERMIT NO 964

Scan this code with the camera on your mobile device to get directed to our webpage!