The Winter Issue - 2026

amyloidosis foundation

Newsletter

INSIDE, WE ALSO TALK ABOUT:

A Fresh New Look For The New Year!

As we welcome the New Year, we're excited to share a refreshed newsletter design—cleaner, more engaging, and easier to read. It reflects our mission and helps you stay connected to news, research, patient support, and community stories.

You'll notice a modern layout with clearer sections for updates, resources, and foundation news, plus simplified navigation and a renewed color palette inspired by hope, resilience, and progress.

We hope this makes your reading experience smoother and more meaningful. We'd love your feedback as we move into a bright year of discovery, connection, and support for everyone affected by amyloidosis.

— The Amyloidosis Foundation Team

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

#GivingTuesday Wrap-Up

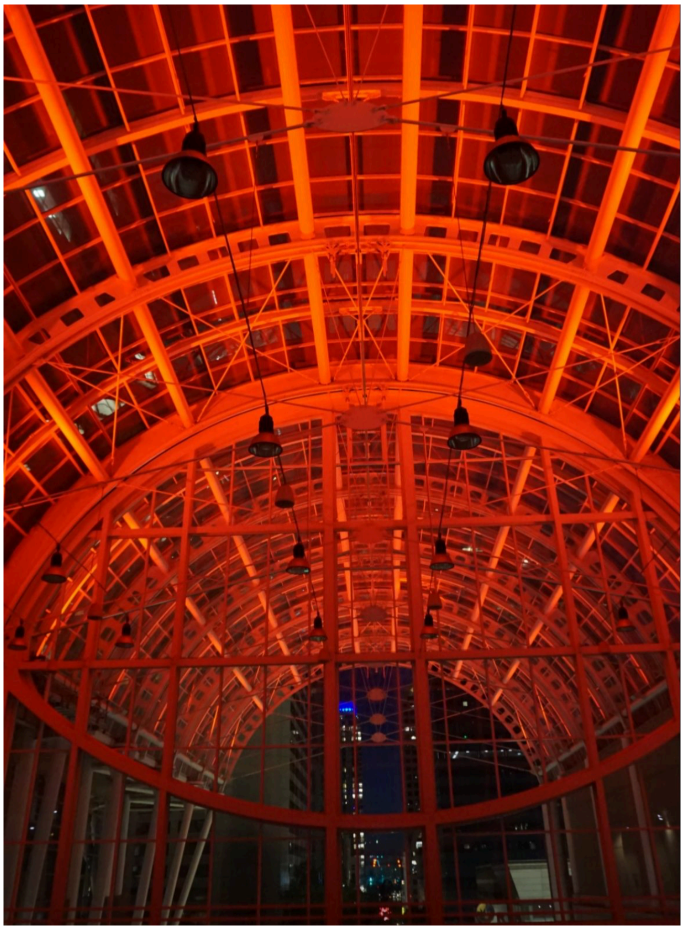
This year's #GivingTuesday was an incredible reminder of the strength and generosity of our amyloidosis community. Thanks to supporters like you, we raised nearly $52,000 to advance research, patient education, and support services.

Each donation—large or small—helps bring us closer to earlier diagnoses, better treatments, and improved quality of life for those living with amyloidosis. From first-time donors to longtime advocates, your participation made a real difference.

We also saw amazing creativity this year—supporters shared personal stories online, and encouraged friends to give in honor of loved ones affected by amyloidosis. Every act of kindness amplified our mission and raised awareness worldwide.

As we wrap up this year's campaign, we want to say **thank you!** Your generosity fuels hope and progress every single day. Together, we're shining a brighter light on amyloidosis and empowering patients and families everywhere.

If you missed #GivingTuesday, it's not too late to make an impact—your gift at any time helps sustain our work year-round. Donate here or scan the QR code:
https://secure.qgiv.com/for/?key=amyfound



Spotlight on Awareness: Light the Night for Amyloidosis

This March, landmarks around the world will glow red to honor Amyloidosis Awareness Month.

"Light the Night for Amyloidosis" is an awareness campaign designed to raise awareness about the symptoms, diagnosis, treatment, and potential cure for amyloidosis. In honor of 'Amyloidosis Awareness Month', we're encouraging everyone to light up their porch or entryway with red bulbs throughout the month. You can purchase the bulbs in our shop here: **https://amyloidosis.org/shop/**

If you'd like to reach out on our behalf to a site near you, we provide a toolkit here: https://bit.ly/LTN26

#LTN4Amyloidosis
#LightTheNightForAmyloidosis
#RedIsForAmyloidosis

2026 Research Grant Awardees

The Amyloidosis Foundation is committed to serving patient needs by supporting research and providing annual grants for junior research scientists whose research targets the challenges in the field of amyloidosis.

Grant Awardees

Marcel A. Chuecos Rincon, PhD
Towards Precision Therapies for ApoA1 Amyloidosis: Model Development and Genome Editing Approaches
Amyloidosis Foundation Research Grant, 2026
Baylor College of Medicine, Houston, TX

Aaron Feinstein, PhD
Elucidating the Structural and Dynamic Basis of IgG Light Chain Fibrillogeniesis in Silico
Amyloidosis Foundation Research Grant, 2026
Tufts Medical Center, Boston, MA

Shabatun Islam, MD
Muscle Mass, Frailty and Self Reported Physical Activity Behaviors in Older Patients with Transthyretin Cardiac Amyloidosis
Amyloidosis Foundation Research Grant, 2026
Boston University Medical Center, Boston, MA

Living Well With Amyloidosis: Managing Fatigue

To manage fatigue from amyloidosis, prioritize rest and energy conservation by pacing activities, taking frequent short breaks, and sitting for chores. Incorporate gentle, regular exercise like walking or yoga, as it can increase energy. It is also crucial to maintain a good diet, get enough sleep, and work with your medical team to address underlying issues like anemia and organ involvement that may contribute to fatigue.

Lifestyle adjustments

- Rest and pacing: Prioritize rest, establish a sleep routine, and take short naps when needed. Pace yourself by spreading tasks out and sit for activities like cooking or cleaning instead of standing.
- Gentle exercise: Engage in light physical activity, such as walking, swimming, or yoga, as it can help improve energy levels and appetite.
- Diet: Ensure a balanced and nutritious diet and stay hydrated. Your doctor can advise you on specific nutritional needs.
- Manage stress: Maintain a positive outlook and avoid excessive alcohol or tobacco.

Medical and therapeutic support

- Talk to your doctor: Discuss your fatigue with your healthcare team, as it can be a side effect of treatments.
- Consider physical therapy: A physical therapist can help improve your balance and coordination.
- Explore complementary therapies: Therapies like aromatherapy, reflexology, and relaxation techniques may help reduce fatigue.
- Manage fluid retention: If you have edema, talk to your doctor about managing fluid intake, salt intake, and potential diuretics, and try elevating your legs to help with fluid buildup.

Important considerations

- Avoid overexertion: Pushing yourself too hard can make fatigue worse.
- Stay hydrated: Drink plenty of water throughout the day.
- Accept help: Don't hesitate to accept offers of help from family and friends to manage daily tasks.

Using AI to Find Cardiac Amyloidosis Earlier

By: Timothy Poterucha, MD (Mayo Clinic) and Pierre Elias, MD (Columbia University)

Cardiac amyloidosis can be difficult to diagnose. Its symptoms often resemble those of more common heart conditions, and many people live with shortness of breath, swelling, or fatigue for years before the correct cause is identified. Early diagnosis matters because today's treatments can slow disease progression and help patients feel better sooner. One of the greatest challenges in amyloidosis care has been identifying patients early enough to make a meaningful difference.

Our team recently explored a new approach to this problem by using artificial intelligence, or AI, as a supportive tool for clinicians. This work, published in JAMA Cardiology in November 2025, examined whether AI could help identify patients with transthyretin cardiac amyloidosis (ATTR-CM) earlier than is possible through routine clinical care alone.

At its core, the study asked a straightforward question: can an AI system review routine heart tests and detect subtle patterns that suggest ATTR-CM before the disease is recognized clinically? The system analyzes the same electrocardiograms and echocardiograms patients already receive as part of everyday care. The goal was simple: to help clinicians identify patients who might otherwise be overlooked and ensure they are considered for appropriate testing sooner.

We developed an AI tool called ATTRACTnet, which looks for patterns in these heart tests that are often difficult for humans to detect. Importantly, the AI does not make diagnoses on its own. Instead, it alerts a patient's physician that amyloidosis may be worth considering, allowing the care team to decide on next steps. To understand whether this approach could help real patients, we launched the Cardiac Amyloidosis Discovery Trial, a multisite clinical program within the NewYork-Presbyterian Hospital system. We ran this AI system on every ECG and echocardiogram in the system for about one year. When the AI flagged patients who had not previously been evaluated for amyloidosis, their physicians were notified and, when appropriate, testing was offered. Among the patients who completed amyloidosis testing, nearly half were diagnosed with ATTR-CM. This rate was almost three times higher than what is typically seen in routine clinical practice, highlighting the ability of the AI system to identify patients who otherwise might not have been found.

Just as importantly, most patients who were diagnosed were able to begin treatment quickly. In many cases, the AI identified patterns consistent with amyloidosis an average of one year before the diagnosis was ultimately made. For a disease where every month matters, this earlier recognition can be meaningful.

The program also reached patients who have historically experienced the greatest delays in diagnosis. About half of the patients diagnosed through the AI program were Black or Hispanic, groups known to have higher rates of ATTR-CM but lower rates of timely diagnosis. These findings suggest that tools like this may help reduce long-standing disparities in care.

While these results are encouraging, this work represents an early step. AI is not a replacement for physicians, nor is it a standalone diagnostic tool. Rather, it is one more way to support clinicians, raise awareness, and ensure that patients receive the right testing at the right time. Larger studies are planned, and we hope they will move us closer to a future in which every patient with amyloidosis is identified earlier, treated sooner, and given the best possible chance for improved outcomes.

This work was made possible through an extraordinary level of support, including a research grant from the Amyloidosis Foundation. We are deeply grateful to the patient community for inspiring this effort. Your stories, persistence, and trust continue to guide us toward better, earlier, and more equitable care for all people living with amyloidosis.

Disclosures: This study was funded by the Amyloidosis Foundation, the American Heart Association, the New York Academy of Medicine, Pfizer, and Eidos/BridgeBio.

Joining forces in amyloidosis care: a multidisciplinary treatment approach

Amyloidosis is a rare condition that can affect many parts of the body at the same time. Because it is complicated, people with amyloidosis usually do best when their care is handled in a special center where many types of health professionals work together and have experience with this disease.

A recent scholarly article outlines the requirements for these specialized amyloidosis centers. It describes which doctors and health specialists should be involved and how teams can be organized to ensure patients receive comprehensive care.

When many specialties work together, it helps:

- find the disease earlier and more accurately
- choose the right treatments
- support patients and families better
- improve how people feel and how long they live

Strong amyloidosis programs are built around several main ideas:

- a team made up of different specialty health professionals who communicate closely
- ongoing learning and quality improvement
- research and new treatment development
- access to the right medicines and therapies
- advanced testing to confirm the diagnosis
- working with national and international groups and patient organizations

The paper also explains that not all centers are the same. Some may mainly focus on heart-related amyloidosis, while others handle many kinds of amyloidosis and the most complex cases. A “tiered” system helps patients and doctors understand what level of services each center can provide, from basic care to highly specialized centers of excellence.

Overall message: patients benefit most when amyloidosis care is organized, team-based, and provided in centers with real experience in this condition.

For a list of vetted amyloidosis centers, reach out to kathi@amyloidosis.org, or copy/paste the following link into your browser: ***https://amyloidosis.org/resources/#treatment-centers***

Life with AL Amyloidosis and Multiple Myeloma

By: Denelle Belle Isle

It was Memorial Day weekend 2023 and our annual family vacation in Myrtle Beach, SC. The perfect time to hit the beach, play in the waves and pools, build sandcastles, and reunite with my children, their spouses, and my grandchildren. I wasn't feeling 100%, but thought the fatigue was due to seasonal allergies. The shortness of breath had been something I noticed for some time but chalked it up to being out of shape. My stomach had also been a little wonky and I never quite knew how food would sit, but having an empty stomach made me feel even more nauseous. I was on vacation, and it was time to have fun and forget about all of that.

I had also developed a dry cough that was keeping my family up at night. Again, my thoughts were allergies. Cough drops and sips of water didn't work. I had heaviness in my chest. Then things worsened. I found myself unable to catch my breath walking at a normal pace down to the beach. My heart felt like it was going to explode from within my chest and the fatigue was like none I had ever experienced. At that time, my daughter insisted I go to urgent care, and I was diagnosed with an allergy-induced asthma flare-up and I was given nebulizer treatments and put on a methyl/prednisolone pack. The problem was I felt a little better but honestly not good. We flew home to Minnesota and then drove back to Wisconsin the next day.

> ***" I remind myself -***
> ***Faith over Fear***
> ***-***
> ***and chin up - keep moving forward!"***

Once settled at home, I couldn't sleep and had a nasty cough, chest tightness, and shortness of breath. I woke up early morning experiencing shortness of breath and noticed my ankles were swollen. I went to the E.R. and my oxygen was 90%, and my blood pressure was very high. They ran tests and my lab work was not normal. The E.R. physician recommended I see a cardiologist. Dr. Glenn Nickele, a cardiologist at St. Croix Health ordered several tests and scans, and he mentioned the diagnosis of amyloidosis.

Read Denelle's complete story at:
https://amyloidosis.org/patient-story/life-with-al-amyloidosis-and-multiple-myeloma/

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Wishing you a prosperous and healthy New Year!
May all your dreams come true.

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