The Fall Issue - 2026

amyloidosis foundation

Newsletter



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Navigating Insurance Denials

To successfully navigate an insurance denial, you must treat the rejection as a negotiation rather than a final decision. Begin by reviewing your Explanation of Benefits (EOB) or calling your insurer to find the exact reason or administrative error behind the denial. You can often bypass the formal appeals process entirely by asking your doctor to conduct a quick "peer-to-peer" phone review with the insurance company's medical director to clarify medical necessity.

If immediate tactics fail, you have the legal right to escalate through formal appeals. Start with a Level 1 internal appeal by submitting a formal challenge alongside a physician-signed Letter of Medical Necessity and supporting medical records. If the insurer upholds the denial, you can request an independent external review by a third party, or file a formal consumer complaint with your state's Department of Insurance to enforce your policy rights.

Our friends at Patient Advocate Foundation have shared a guide on how to begin the appeals process with advice on submitting a successful health insurance appeal after receiving a health insurance denial. View it here: **https://bit.ly/4iU9ziE**

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 out more here:
https://somebodytotalkto.com/session-calendar

Study Highlights: CAEL-101 and AL Amyloidosis

A clinical study evaluating CAEL-101, also known as anselamimab, offers encouraging early findings for people living with light-chain (AL) amyloidosis. The Phase 2 study examined the safety and tolerability of this investigational treatment, which is being studied for its potential to help address amyloid deposits in affected organs.

Overall, investigators found that anselamimab was well tolerated in this small study. The adverse events reported were generally consistent with those expected in people with AL amyloidosis or those receiving accompanying anti-plasma-cell treatments. These findings provide useful information about the treatment's safety as research continues.



The study also reported exploratory findings related to organ responses. Among participants who could be evaluated, the best reported cardiac response rate was 47.4% at Week 50. The best reported renal response rate was 85.7% at Weeks 62 and 98. These results offer insight into potential changes in heart and kidney involvement during treatment, two important areas of concern for people living with AL amyloidosis.

However, the findings should be interpreted with caution. The study included a small number of participants, was open-label and non-randomized, did not include a placebo group, and allowed other treatments alongside anselamimab. As a result, the organ-response findings cannot establish that anselamimab alone caused the observed responses or demonstrate how it compares with other treatments.

Why this matters: Research into treatments that target amyloid deposits remains an important area of progress in AL amyloidosis. While these Phase 2 findings are preliminary, they contribute to the growing understanding of anselamimab's safety and potential effects on affected organs. Larger, controlled clinical trials are needed to clarify its benefits and role in future treatment strategies.

You can read more here: *clinicaltrials.gov: https://clinicaltrials.gov/study/NCT04304144*

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.

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Clinical Trial Spotlight: The ALANIS Study – Exploring New Treatment Options for AL Amyloidosis

At our October 2, 2026, support group meeting, we were pleased to welcome Dr. Naing, who shared information about an exciting clinical research study known as the ALANIS Trial. This study represents another important step in exploring new treatment approaches for patients living with AL (light chain) amyloidosis.

The ALANIS trial is a Phase 2 clinical study designed for adults with newly diagnosed AL amyloidosis. Researchers are investigating whether adding an investigational medication called belantamab mafodotin to the current treatment combination of cyclophosphamide, bortezomib (Velcade), and dexamethasone (CyBorD) can improve treatment responses. Belantamab mafodotin is a targeted therapy designed to seek out plasma cells responsible for producing the abnormal light chains associated with AL amyloidosis. The goal is to determine whether this additional medication can help achieve deeper treatment responses while identifying the safest and most effective dosing approach. Because belantamab mafodotin can cause changes in vision and eye health, participants will also receive regular eye examinations and careful monitoring.

As with all clinical trials, the ALANIS study is investigational. Researchers are working to better understand its potential benefits, risks, and safety, and it is not yet known whether this combination will be more effective than existing treatments. We are grateful to Dr. Naing for helping our support group better understand this developing area of research. Clinical trials are an important part of advancing treatment options and bringing hope to the amyloidosis community.

Interested in learning more? If you or someone you know has newly diagnosed AL amyloidosis, ask your treating physician whether the ALANIS trial or other clinical trials may be appropriate. Participation requirements apply, and a clinical trial specialist can help determine eligibility.

To learn more, visit **ClinicalTrials.gov** and search for NCT07224672 (ALANIS).

Immix Advances Plans to Bring NXC-201 to Patients with AL Amyloidosis

Following encouraging clinical trial results, Immix Biopharma is preparing for the potential commercialization of NXC-201, an investigational CAR-T cell therapy for people with relapsed or refractory AL amyloidosis. The company is focusing on CAR-T treatment centers as it plans for possible future access to this emerging therapy.

NXC-201 is designed to use a patient's own genetically modified T cells to target BCMA, a protein found on plasma cells responsible for producing the harmful light chains that cause amyloid buildup and organ damage. In a September 2026 clinical update, Immix reported an 89% complete response rate among 45 participants in its Phase 2 NEXICART-2 study. These preliminary findings are encouraging, particularly for patients whose disease has returned or has not responded adequately to previous treatments.



The company's strategy also highlights an important access challenge: CAR-T therapies require specialized facilities, trained medical teams, and coordinated patient care. Building relationships with treatment centers could help prepare for broader access if NXC-201 receives regulatory approval.

Although these results offer hope, NXC-201 remains investigational, and its safety and effectiveness require continued evaluation. The study's final results and regulatory review will be important next steps in determining whether this therapy can become a new treatment option for people living with AL amyloidosis.

Run, Walk, Bike, Roll: Making Every Step Count

What an incredible event for the amyloidosis community! The Amyloidosis Foundation's Run, Walk, Bike, Roll brought together 190 participants united by a shared commitment to raising awareness and supporting those affected by amyloidosis. Whether running, walking, biking, or rolling, everyone played a part in making this event a success!

Together, our amazing participants, supporters, and donors raised $6,700 to help advance the Amyloidosis Foundation's mission of providing education, raising awareness, and supporting the amyloidosis community. Every dollar raised and every participant who joined us helped make a meaningful difference.

Events like this remind us that we are stronger together. They bring families, friends, caregivers, patients, and advocates together to show that no one has to face amyloidosis alone.

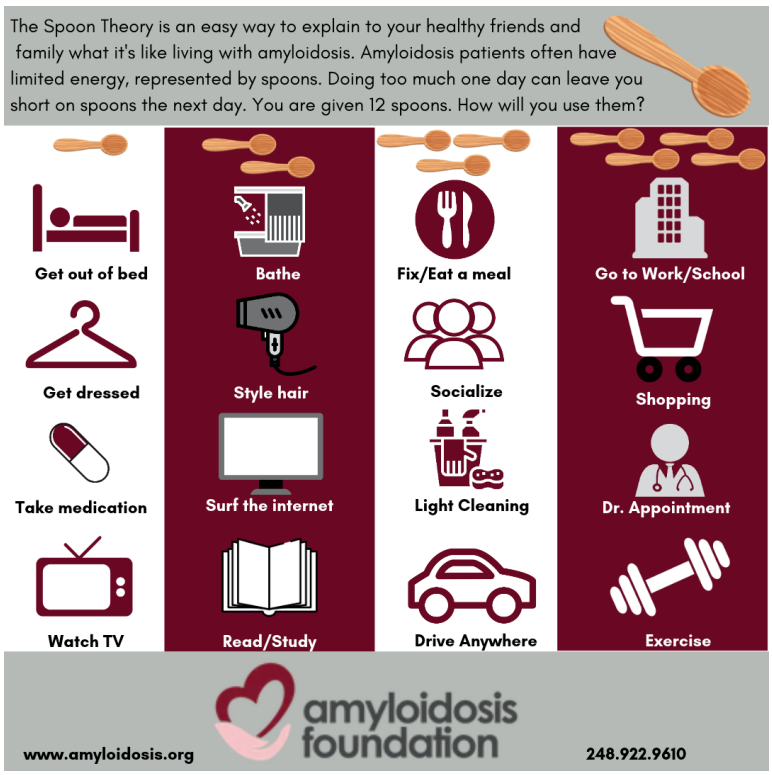
A heartfelt THANK YOU to everyone who participated, donated, and helped spread the word. Your enthusiasm, generosity, and support keep our mission moving forward—one step, one ride, and one person at a time. We are grateful to have you on this journey with us and look forward to doing it all again!

Together, we are raising awareness, building community, and making a difference for everyone affected by amyloidosis!



The Spoon Theory

The Spoon Theory is a visual metaphor used by people with amyloidosis—and other chronic illnesses—to explain the limited amount of mental and physical energy they have each day. Originally created by Christine Miserandino, the theory helps healthy individuals understand the calculated choices patients must make to manage fatigue, chronic pain, and organ dysfunction.



How the Spoon Theory Works

- The Spoon Value: Every activity costs a "spoon." A person with amyloidosis starts the day with a fixed, limited number of spoons (e.g., 12 spoons), whereas a healthy person has an seemingly endless supply.
- No Replenishing: Once a spoon is used, it is gone for the day. Rest or sleep does not automatically restore them.
- The Energy Deficit: Going "into debt" by using tomorrow's spoons results in severe crashes, heightened symptoms, or flares the following day.

The Cost of Daily Tasks with Amyloidosis

Because amyloidosis involves abnormal protein deposits that can damage organs like the heart, kidneys, and nervous system, routine tasks require significantly more energy.

Why It Matters for Amyloidosis Patients

- Invisible Fatigue: Amyloidosis is often an "invisible illness." Patients may look completely healthy on the outside while operating on their very last spoon on the inside.
- Forced Prioritization: A patient may have to choose between showering or making dinner, as they do not have enough spoons to do both in the same day.
- Social Sacrifices: Canceling plans at the last minute is rarely a matter of desire; it is almost always because the patient ran out of spoons unexpectedly.

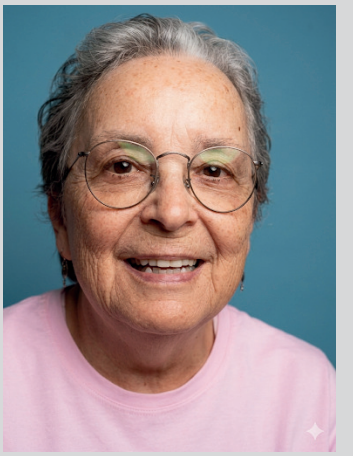


The Amyloidosis Foundation offers a vast collection of resources for patients and caregivers. We're here to help every step of the journey.

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

Patient Story- My AL Saga

By: Susan MacMillan



In 2003 at age 51, my ECG showed enough of a change to indicate having a stress/echo exercise test. During the course of the test, my ECG became very abnormal, with deeply inverted T-waves. The cardiologist diagnosed restrictive cardiomyopathy. He was very perplexed about why a 51 year old female would develop this. What he did not consider was amyloidosis.

By 2004 I became progressively weaker and had lost my appetite. It took some physician shopping to find one who took this with much seriousness. Finally, a urine dip was “off the charts”, which was followed by a 24 hour urine sampling. The next step was a kidney biopsy which showed the amyloidosis, which of course I had never heard of, and was also clearly the cause of my mysterious restrictive cardiomyopathy.

This diagnosis was also checked by having a bone biopsy, and in 2005 I began taking an oral regimen of Dexamethasone and Thalidomide. This treatment was new at that time. I got the steroid “apple face” and was even more tired feeling, but I managed to get into a routine. I was able to return to my job part time.

I took those two drugs faithfully for 6 whole years. Finally, my wonderful hematologist declared me in remission in 2011.

I began a routine of and ECG and echocardiogram, and blood test for kappa/lambda every six months.

When I was first diagnosed, my kidney GFR was in the 40s. Now, 20 years later it is in the high 20s. So, I’m trying to keep my diet kidney friendly. I have also developed atrial fibrillation, and take amiodarone to keep me from going into rapid A Fib.
Early in this medical saga, I didn’t think I’d see age 60. I’m 73 now, and have gotten to see all those milestones that we all treasure. Just don’t ask me to walk up a steep hill with any speed!

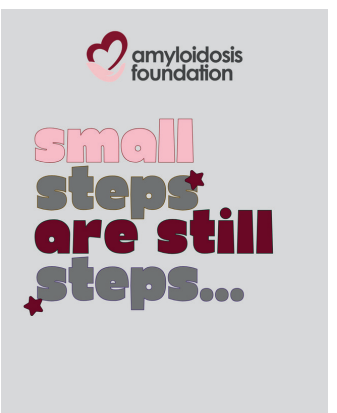
I would think that with all the medical advances in the past 20 years, there will be many more success stories like mine. Do your best, and keep the faith.

Share Your Amyloidosis Journey

Every amyloidosis journey is unique, and every story has the power to make a difference. By sharing your experiences, challenges, milestones, and moments of hope, you can help others feel less alone, raise awareness, and build a stronger, more connected amyloidosis community. Whether you are a patient, caregiver, or family member, your voice matters! We invite you to share your story with the Amyloidosis Foundation and inspire others who may be navigating a similar journey.
Ready to share? Email your story to ***kathi@amyloidosis.org****. Your experience could be the encouragement someone else needs today!*

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