



News and Stories - Fall 2025

'Run For Your Life' Recap



The Amyloidosis Foundation is thrilled to share the success of another year of Run For Your Life! Thanks to the incredible support of 268 participants—runners, walkers, bikers, and rollers—our community came together to raise awareness of amyloidosis in a fun and meaningful way.



Together, we raised \$7300 to support vital research, education, and awareness initiatives. We are truly grateful for the enthusiasm and generosity shown by everyone who joined us in making a difference!

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Finding Help

Living with amyloidosis can be challenging, and the cost of treatment often adds stress. The Amyloidosis Foundation website offers resources to help patients manage medication expenses.

In the *Patient Resources* section at **amyloidosis.org**, you'll find links to financial assistance programs, insurance tools, and advocacy organizations. These can guide you in reducing out-of-pocket costs for treatment.

A valuable tool is the *PAN Foundation FundFinder*, which tracks disease-specific assistance programs and notifies you when funding opens. Signing up ensures you don't miss support opportunities.

Exploring these resources can ease financial pressure and let you focus on your health.

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Education • Awareness • Support • Research

www.amyloidosis.org



Wednesday Webinars

Webinar Sessions are on Wednesdays from 6:00 PM - 6:45 PM Eastern Time Zone.

Join us for our LIVE webinars on all things about amyloidosis!

We've teamed up with One Amyloidosis Voice and Somebody To Talk To (STTT) to bring you relevant amyloidosis content!

*These sessions cannot be recorded due to patient involvement and HIPAA laws.

To Register:

<https://bit.ly/47t5aMd>

OR scan the QR code with your mobile phone



Join Us for a Webinar

**To protect patient privacy and comply with HIPAA, these sessions will not be recorded.*



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
- 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](https://twitter.com/Amyloidosisfdn)

Facebook: [@amyloidosisfdn](https://facebook.com/amyloidosisfdn)

Instagram: [@amyloidosisfoundation](https://instagram.com/amyloidosisfoundation)





SAVE THE DATE!!!

Save the Date: #GivingTuesday

#GivingTuesday is a worldwide movement dedicated to generosity and making a lasting impact. This year, we are thrilled to join forces with our incredible community to reach an ambitious goal of \$20,000 in support of #AmyloidosisResearch.

Mark your calendars and be part of this global day of giving! Your support helps drive progress, fuel hope, and change the lives of those affected by amyloidosis. Together, we can accelerate research, raise awareness, and bring hope to countless patients and families.

Will you be part of it? Every gift matters—and every act of kindness makes a difference.

Make your #GivingTuesday donation here:
<https://bit.ly/AFgive2025>

OR scan the QR code with your mobile phone



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Our newsletter is published quarterly (Spring, Summer, Fall and Winter) by the **Amyloidosis Foundation**. We welcome letters, articles and suggestions.

Please contact us anytime at: **info@amyloidosis.org**, (248) 922-9610
or 7151 N. Main Street, Ste. 2, Clarkston, MI 48346

If you wish to receive an electronic version, please send us an email:

info@amyloidosis.org

www.amyloidosis.org



♥ Become a Monthly Hero for Amyloidosis ♥

Want to make a lasting impact all year long? Set up a recurring gift and help us fund critical research, patient support, and awareness efforts—every single month.

Even a small monthly donation adds up to BIG change.

- ☒ Easy to set up
- ☒ Hassle-free
- ☒ Makes a difference every month

Whether it's \$5, \$50, or \$100/month or year, your ongoing support helps us get closer to better treatments—and one day, a cure. ✨

Become a recurring donor today and be a part of something powerful:
<https://bit.ly/3PLhyQ3>

Instructions:

After you go to our donate page at: <https://bit.ly/3PLhyQ3>

1. Choose “Ongoing”
(circled in red)

The screenshot shows the Amyloidosis Foundation website's donation page. At the top, there's a navigation bar with links for Log In, AL, AA, Hereditary, Wild-type, Other, Search, and a Donate button. Below this, the 'Choose Your Gift' section is visible. It has two tabs: 'One Time' and 'Ongoing'. The 'Ongoing' tab is selected and circled in red. Below the tabs, there's a 'Give Monthly' dropdown menu. Underneath, there are buttons for \$50, \$100, \$250, and \$500. There's also an 'Other' field. Below these options, there's a section titled 'Greatest Impact' with text about the benefits of monthly donations and a 'Customize Dates' link. At the bottom, there are two checkboxes: 'This donation is made in dedication to an individual.' and 'Add a little extra to help with fees.'.

2. Click the dropdown menu where it says “Give Monthly”, and choose the frequency you'd like to give. (circled in red)

This screenshot shows the same donation page as the previous one, but with the 'Give Monthly' dropdown menu open. The dropdown menu is circled in red, and the 'Monthly' option is selected. The other options visible are 'Quarterly', 'Semiannually', and 'Annually'. The rest of the page, including the 'Greatest Impact' section and the checkboxes at the bottom, remains the same.

(Continued on next page)



Monthly Hero, Continued

Instructions (continued):

3. Click the box with the dollar sign (\$) if you'd like to choose your own amount (circled in red).

The screenshot shows the 'Choose Your Gift' page on the Amyloidosis Foundation website. The 'Give Monthly' dropdown is selected. The '\$' box is circled in red. The 'Greatest Impact' section is visible below the donation options.

4. Click the dropdown box circled in red if you'd like to dedicate your donation in honor/memory to an individual.

The screenshot shows the 'Choose Your Gift' page on the Amyloidosis Foundation website. The 'Other' dropdown box is circled in red. The 'Greatest Impact' section is visible below the donation options.

Double Your Impact with Matching Gifts!

Did you know your donation could be matched by your employer—at no extra cost to you?

It's easy:

- 1□. Donate to your favorite amyloidosis nonprofit
- 2□. Check if your employer offers a matching gift program
- 3□. Submit a quick form (usually online)
- 4□. Your employer matches your donation — sometimes even 2:1!

That means your \$50 could turn into \$100...or more!

Many companies offer this—even for retirees and part-time employees!

Ask your Human Resources Team!

Make your gift go further. Double the impact. Same donation.

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15-Year AL Analysis Study

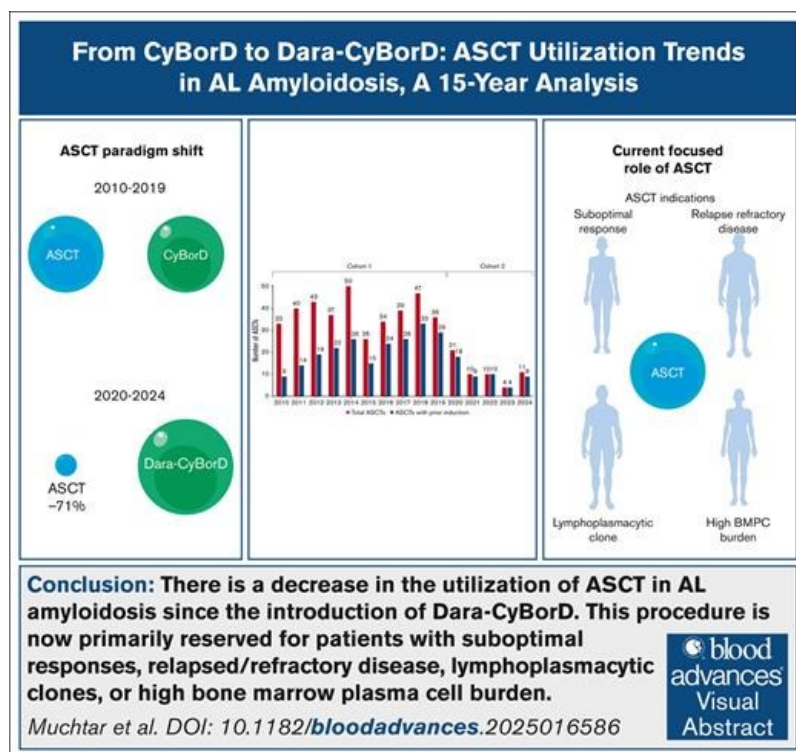
Over the past decade, novel therapies (particularly regimens including bortezomib and daratumumab) have improved response rates. This study aimed to see how these newer treatments have changed how often ASCT is used, who gets it, and with what outcomes.

The introduction and widespread use of Dara-CyBorD has corresponded with a sharp decline in ASCT utilization in AL amyloidosis. Rather than ASCT being default frontline for many, it is now more often reserved for patients who did not achieve deep responses with induction, those with relapsed/refractory disease, or those with higher tumor burden or certain disease subtypes (lymphoplasmacytic / IgM).

The deeper responses achieved with the newer therapies reduce the need for transplant in some patients. When transplant is performed, outcomes (in terms of hematologic responses) are better in recent years.

However, long-term data are still limited for newer treatments; ASCT has decades of follow-up, so there remains value in ASCT for those who are eligible or in whom induction response is suboptimal.

The shift implies more personalized treatment: assessing who truly benefits from transplant vs who may be adequately managed with non-transplant regimens.



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ATTR Approved Therapies & What's In The Pipeline

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ATTRwt, ATTRv **Polyneuropathy** treatment & development of additional therapies

FDA Approved



Pipeline/ Clinical Trial

TTR Stabilizer
Vyndamax (tafamidis)
* Vyndaqel (tafamidis)

TTR depleter
Wainua (eplotersen)

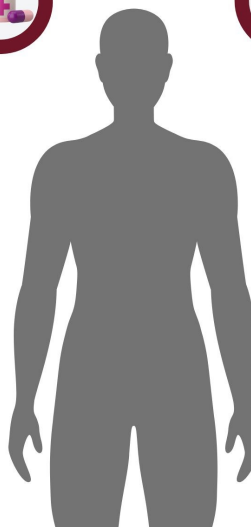
TTR Silencer-RNA interference (RNAi)
OnPattro (patisiran)
Amvuttra (vutrisiran)

Antisense oligonucleotide-RNA-targeting
* Tegsedi (inotersen)

* Not available in the US

TTR Stabilizer
Attruby (acoramidis)

Gene Editing
CRISPR-Cas9- YOLT-201
CRISPR-Cas9-NTLA-2001 (nexiguran ziclumeran- nex-z)



ATTRwt, ATTRv **Cardiac** treatment & development of additional therapies

FDA Approved



Pipeline/ Clinical Trial

TTR stabilizer
Vyndamax (tafamidis)
Attruby (acoramidis)
* Vyndaqel (tafamidis)

TTR Silencer-RNA interference (RNAi)
Amvuttra (vutrisiran)

Diuretics

RNA interference (RNAi)
Nucresiran (ALN-TTRsc04)

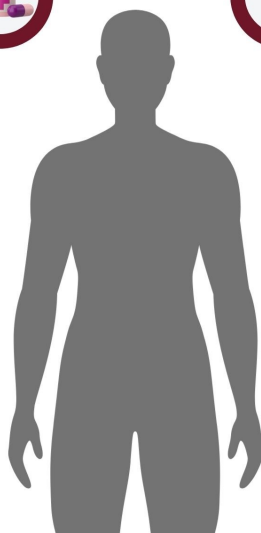
TTR depleter
ALX-ALXN 2220
Wainua (eplotersen)

Gene Editing
CRISPR-Cas9

Anti-amyloid antibody
NW6019
CORAMITUG (PRX004)

Pan-amyloid removal (PAR)
AT-02

* Not available in the US



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