News and Stories - Spring 2024

Nashville Caregiver Support Group Meeting

The Amyloidosis Caregiver Support Group Meeting was held on April 13 from 1-3pm at St Stephens Catholic Church in Old Hickory, TN. The speaker was Joy McDaniel w/MASA Transportation Services (Emergency Transport Coverage). Joy's first question was, "Is your insurance enough?". She educated our group on emergency transport insurance coverage gaps and potential OOP expense w/ambulance and air transport domestically and abroad. An "emergency" is determined by insurance companies based on patient status "after the fact", so what we think constitutes an emergency, may not be what our insurance constitutes an emergency. Also, other expenses related to emergency transport can exist, such as family transport to the hospital, family housing, companion animal care during hospitalization, RV transport from a vacation spot when the driver is not able to bring it home, etc. It was a bit of an eye opener. Thank you Joy for bringing this information to our attention. Stay tuned for more caregiver support options!

APRIL WEBINAR

April 29, 2024
Mon 3:00 PM EDT
You can view the recording using the link below

What's new and exciting in ATTR cardiac amyloidosis in 2024

Join Dr. Fredrick Ruberg and Dr. Omar Siddiqi as they discuss the general overview of ATTR treatment with new developments over the past year (APOLLO-B, ATTRibute-CM), currently enrolled trials (HELIOS-B, CARDIO-TTRansform), and future trials (DepleTTR-CM, MAGNITUDE). They will also cover current heart failure therapy updates (SGLT2i) and imaging (evuzamitide). Following the presentation, there is a Q & A session.

https://bit.ly/AFSpringWebinar2024 **AF**

Recurring Donations

A recurring gift is made by a donor on a repeating basis, that could be monthly, quarterly, yearly etc. YOU get to decide what works best for you. The donor picks the amount they want to give each period, and the donation schedule.

You get to decide how much you'd like to give, when you'd like to give, and for how long you'd like to give. You can put an end date to it or give indefinitely. It's very easy! Our donors can pick whether they'd like to give monthly, quarterly or yearly. Having the option of sustained giving is a win for donors and a win for us!

Your lives are already designed around monthly recurring payments, such as for cell phones, internet, movies, music, etc. Being able to support your favorite cause with a small recurring gift is convenient and affordable. Amyloidosis won't stop and neither will we! Help us give hope to the many who have been diagnosed with amyloidosis and their family members. We truly appreciate your support!

For more information: **https://secure.qgiv.com/for/?key=amyfound** **AF**

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**
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Instagram: **@amyloidosisfoundation**
YouTube: **@amyloidosisfoundation4994**

SAVE THE DATE!

SAVE THE DATE for the 'Run for Your Life' Run-Walk-Roll-Bike!!!

Encourage your family and friends to register and participate!

Participate in this annual (and virtual) event at your leisure to help raise awareness of amyloidosis!

Run/walk/bike/roll anytime between May 15, 2024 and August 15, 2024. REGISTRATION INCLUDES A T-SHIRT!

REGISTRATION OPENS MAY 15, 2024

REGISTER HERE: https://bit.ly/RunWalkRollBike2024 AF

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

Light the Night for Amyloidosis was a success!

The Amyloidosis Foundation started our ‘Light the Night for Amyloidosis’ initiative in 2020 to coincide with ‘Amyloidosis Awareness Month’, which occurs in March. Every year, we ask sites to bring light to the darkness of amyloidosis. For patients and loved ones, the Amyloidosis Foundation’s Light the Night for Amyloidosis campaign offers hope instead of helplessness, connection instead of loneliness, and life-saving research and support every step of the way. When we come together as a community through awareness, we bring more people out of the dark.

This year was such a success, with just under 100 illuminations across the globe. The countries that participated were the United States, Canada, New Zealand, Australia and the United Kingdom. We had many that had participated in previous years and many new ones that we hope will shine a light on amyloidosis awareness for years to come as we gather as a community to celebrate, honor, and remember those touched by amyloidosis.

Amyloidosis warriors and supporters united globally shining a red light outside of their homes, businesses and municipal properties. Many helped by asking local sites to light for us. The goal of lighting up the buildings, landmarks, bridges, monuments, billboards and falls in red throughout the world is to get people wondering why they are lit and look it up, which will, of course, lead them to information about amyloidosis. Our goal is simple, to give light and hope to those affiliated with amyloidosis. With more awareness comes knowledge, and more people achieving an earlier diagnosis.

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Understanding ATTR: The Challenges of Amyloidosis

By: AstraZeneca published March 11, 2024

my ATTR roadmap

Transthyretin amyloidosis (ATTR) is a complex medical condition that happens when a protein called transthyretin (TTR) does something different than what it's supposed to do in the body. Normally, TTR is a four-piece protein produced mostly in the liver that helps carry important substances, like thyroxine (thyroid hormones) and vitamin A, throughout the body. When someone has ATTR, the pieces of TTR fall apart, misfold, and change shape. These pieces bind together to form larger structures called amyloid fibrils, which do not break down normally. These amyloids can then build up in different parts of the body, including nerves, the heart and other organs. When this happens, it can cause problems because the amyloids interfere with the normal functioning of those body parts.

Living With ATTR

"ATTR isn't something a lot of people are talking about, which makes it harder for doctors to diagnose and for patients to understand. We need people to recognize that this condition exists, and we need more information out there for doctors and patients. Right now, patients need to be their own advocates because their lives are at stake. With more information and awareness, diagnosis could happen faster, and patients would feel more supported and seen," said Mike, an ATTR patient.

To help provide people who have been diagnosed with ATTR and their loved ones with more information, AstraZeneca has launched www.MyATTRroadmap.com. This website was developed to provide resources and information for people living with ATTR so you can better understand your condition and find support from the amyloidosis community. After what was likely a long road to diagnosis, it's important to have the information you need to continue on your ATTR journey.

To help increase awareness of ATTR among the healthcare community, AstraZeneca has launched a comprehensive disease education site for healthcare practitioners (www.seethepattrns.com) about the symptom patterns associated with ATTR to facilitate diagnosis. Our hope is that by increasing awareness and knowledge of these disorders, we can help empower health care providers to quickly and accurately diagnose ATTR to ensure patients are appropriately treated in a timely manner.

Why Is ATTR a Challenge to Diagnose?

To read why and the article in its entirety, go to https://bit.ly/UnderstandingATTR

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Life with AL Amyloidosis and Multiple Myeloma

By: Denelle Belle Isle

I am grateful beyond measure!

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.

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. After many tests, scans, ultrasounds, and biopsies I was referred to Dr. Valmiki Maharaj at the University of Minnesota Clinic and Hospital, who then connected me with my hematologist/oncologist Dr. Sean Tracy. I also consulted with a bone marrow transplant physician, Dr. Daniel O'Leary, after many weeks of tests/scans.

Read the rest of Denelle's story here: **https://amyloidosis.org/category/stories/**

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Rare Disease Week on Capitol Hill

Last month, one of our staff members was in Washington DC to advocate for amyloidosis patients. While there, Kathi attended a legislative conference, the Rare Disease DEIA discussion and caucus briefing, met with Congressional and Senate leaders, and was invited to the White House for the first-ever White House Rare Disease Forum. Only 10 advocates out of 800 were chosen to attend.

She was able to speak to leaders in health outcomes and science and technology. Those in attendance were the assistant to the President for Science & Technology, FDA, NIH, NORD, pharmaceutical, researchers, and patient advocacy organizations. Addressing amyloidosis, and supporting patients and caregivers who face the disease, requires all of us to work together to improve health outcomes. Progress is made when others know how patients are affected on a personal level.

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foundation
7151 N. Main St.
Ste. 2
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