



News and Stories - Summer 2020

****NEW** AF Cardiac Amyloidosis Fellowship**

The Amyloidosis Foundation is proud to announce the Cardiac Amyloidosis Fellowship for 2021.

The Amyloidosis Foundation was established in 2003 to support research for systemic amyloidosis by Junior Investigators.

As the prognosis for late diagnosed amyloidosis patients is poor, the foundation has decided to support a 1-year advanced cardiac amyloidosis fellowship.

This will be open to an accredited US based

academic institution, not an individual. The Institution fellowship program must include independent research, a strong mentoring program and clinical training.

cardiologists that have a focus on clinical practice, research and education to further understand all types of amyloidosis.

Grant funding is available to support one fellow for up



It is the foundations intent to support institutions with fellowship programs for

to one year. Funding will be awarded to an institution.

AF

Is Amyloidosis A Cancer? The Answer is NO

Amyloidosis may be localized to organs, such as the lung, skin, bladder, or bowel, or it can be systemic.

“Systemic” means that the deposits may be found throughout the body. Systemic amyloidosis is the most common. Although **AMYLOIDOSIS IS NOT A CANCER**, it may be associated with certain blood

cancers like multiple myeloma. Approximately 15-17% of those with AL amyloidosis also have multiple myeloma. AL stands for “amyloid light chains,” which is the type of protein responsible for the condition.

There's no known cause, but it happens when your bone marrow makes

abnormal antibodies that can't be broken down. It can affect your kidneys, skin, heart, liver, intestines, and nerves. AL may be treated with a combination therapy that could include a chemotherapy agent.

In short, amyloidosis is a rare and serious protein deposition disease, but it is not a cancer. **AF**

Education • Awareness • Support • Research

www.amyloidosis.org



AF Virtual Walk/Run Was A Great Success

The Amyloidosis Foundation held its first-ever VIRTUAL Walk/Run as a continuation of the 'Run For Your Life!' event. Participants were asked to run, jog, or walk on the road, on the trail, on the treadmill, at the gym, or on the track. They were able to run their own race, at their own pace, and time it any way they chose.

This was a fantastic way to raise funds where people from around the globe could participate. Runners (walkers) could run alone, during the pandemic, even if they were quarantined, yet still feel a part of a larger group.



The race began on May 25, 2020 and went until July 6, 2020. Once signed up for the race, they could choose either a 5K or 10K, then decide on the course they wanted to do. They then submitted their time, and received a t-shirt and/or medal for their efforts.

It's always fun to be a part of something bigger than yourself! Because of its inaugural success, this event will be continued year after year.

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
- Treatment Centers (US / International)
- Support Groups
- Exercises
- Webinars and Videos
- 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://www.facebook.com/amyloidosisfdn)
 Instagram: [@amyloidosisfoundation](https://www.instagram.com/amyloidosisfoundation)





President's Corner

Mary E. O'Donnell

Here we are, still in the middle of the Covid-19 pandemic, and activities definitely have changed. Our awareness activities at medical conferences are still on hold for the indefinite future. We are hoping that these will resume in 2021 and when they do restart we will be working with a vengeance to restart our awareness activities with the medical community.



Rest assured though, here at the office we are open and all staff are back from working remotely. We are here to answer phones, respond to emails, answer questions, find answers and help patients and their families journey the path through the diagnosis and treatment of amyloidosis. We are here to help!

Board of Directors

President

Mary E. O'Donnell

Treasurer

Dante Burchi

Charlotte Haffner

Daniel J. Lenihan, MD, FACC

Adrienne Molteni, RN

Mark Sutherland



Scientific Advisors

Merrill Benson, MD

Raymond Comenzo, MD

Lawreen Connors, MD

Rodney H. Falk, MD

Morie Gertz, MD

Mathew Maurer, MD

Giampaolo Merlini, MD

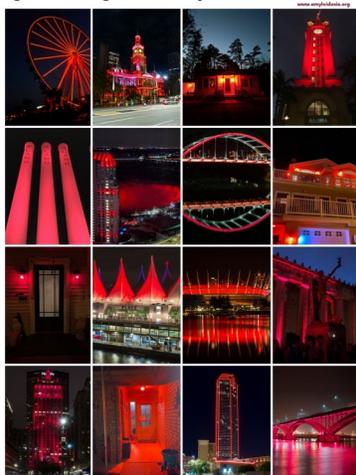
Vaishali Sanchorawala, MD

Douglas Sawyer, MD, PhD

Jonathan Wall, PhD

NEW Light The Night For Amyloidosis Poster!

Light The Night For Amyloidosis 



Order your very own awareness poster from the March 'Light The Night For Amyloidosis' event. Over 100 sites from around the world as well as countless homes were lit in red for amyloidosis awareness.

Order yours here:

<https://bit.ly/afPoster>

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



Where will this ATTRwt amyloidosis journey take me?

By Howard Covell

Where will this ATTRwt amyloidosis journey take me? I like to travel; however, this trip was not planned or wanted! I wonder a lot about the journey I am starting, so far it has been OK.

In 2017 I had an angiogram that my cardiologist described as being a little weird and she said she would keep watching it. Yearly visits and EKG's were done, but nothing showed any abnormality. In the Spring of 2019, as I was trying to spread fertilizer on our lawn, I could only walk

a few minutes before becoming very tired. At about that same time, I was experiencing shortness of breath on little exertion. My wife made my appointment with my PCP as I insisted it was nothing and it would go away. The doctor ordered an ECHO, then an angiogram, nuclear stress, and other tests.

At that point, I was diagnosed with Wild-type amyloidosis and I asked, "what in the world is amyloidosis?". The answer was a very rare and fatal

heart disease.

WOW, that shook me and my mind went crazy as I thought of all the what-ifs ahead. Where did this come from? When did it start? How long do I have to live? On and on my mind went. Friends tell me that they knew it was the wild type as I am the wild type, not true. I was 78 when diagnosed, so how wild could I be?

When I had a follow-up appointment with my cardiologist she said,

(Continued on page 5)

Recurring Donations

A recurring gift or recurring donation 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 then the donation schedule is recorded in our system in order to complete the donation requests on the correct timeframe.

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!

Your lives are already designed around monthly recurring payments, such as for cell phones, internet, movies, music, "box of the month" clubs, etc. Being able to support your favorite cause with a smaller 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. If you've already set up recurring donations, THANK YOU from the bottom of our hearts! We truly appreciate your support!

For more information:
<https://secure.qgiv.com/?key=amyfound>
AF





(Continued from page 4)

"I know nothing about this disease, you will have to go someplace else". Doctors need a lot more education on this disease as few have much knowledge of it.

I researched online and chose the Cleveland Clinic in Ohio due to the distance from our home, insurance, and their reputation in the research and care of patients with this disease. I have severe amyloidosis, but the good news is that there is now a medication called Vyndamax that can slow down the progression of the disease. It was approved in May of 2019 and I started taking it in October. Is it working? I won't know that until my next visit in October 2020, I have more tests and get the results. I did have bilateral carpal tunnel surgery about 20 years ago. I think about if this disease could have been starting way back then.

I take diuretics to keep fluid from building up around my organs. Salt is a no-no, but we have found lots of good no salt foods, even no salt potato chips. No salt in cooking, at the table plus NO processed foods allowed in our home. We now find food at restaurants or family gatherings too salty for us.

Surprising how quickly we got used to no-salt, except that found naturally in foods.

I walk about 20-30 minutes a day and wish I could walk more. I have

osteoporosis that prevents the long walks I would prefer. I stay active caring for our home in Florida in the winter and in New York in the summer months, where I enjoy fishing. Church activities and volunteering at a hospital are important to my wife and myself, and puzzles are a fun pastime.

My doctors at the Clinic in Ohio and in Weston, Florida agree that if the Vyndamax works I could have 5 years left to enjoy, however, if it doesn't work I may have another 11 months to 2 years. The amyloidosis disease is compounded by the fact that I have Type 2 diabetes.



Currently, my diabetes is very well controlled. I understand that there are many medical conditions that could take my life other than amyloidosis. I don't waste a lot of time stressing about it. In the meantime, I feel good except that I tire easily and welcome an afternoon nap. The journey may get rough in the future, but for now I am thankful for each day and I try to live it to the fullest. I pray that researchers will find a medication to stop or reverse the disease progression for future patients. Life is good. **AF**

www.amyloidosis.org



Amyloidosis Symposium

By Charlotte Haffner



Dr. Mathew Maurer, head of the Amyloidosis program at Columbia Presbyterian Medical Center in New York City, lectured on treatment of TTR, both Hereditary (hATTR) and Wild

Doctors are becoming aware of the need for early diagnosis. This awareness can ultimately change the course for a disease that is challenging for everyone.

Patient input is very helpful during this time. Doctors are learning more everyday and a patient attitude and honesty with their doctor goes a long way in understanding the disease.

On February 21, 2020 my good friends/associates, Adrienne Molteni and Beverly Murray and I, hit the road for St. Louis, Mo. Our destination was the amazing Amyloidosis Symposium which was at the Washington University Medical Center. The meeting was presented by the Washington University School of Medicine, Cardiovascular Division.

type (ATTRwt) Amyloidosis. Dr. Raymond Comenzo, head of the Amyloid program at Tufts University in Boston, Ma., focused his lecture on AL Amyloidosis. There were approximately 200 doctors and patients attending.

I believe it takes a dedicated team of doctors to treat Amyloidosis patients. The multidisciplinary approach is your best chance of getting the treatment and results you ultimately hope for.

We had an easy trip to St. Louis and beautiful weather for traveling. At dinner, the food was excellent and we met some new friends as well as got to catch up with some old ones we had not seen in awhile.

One of the best features of these symposiums is the support of the Doctors affiliated with the Medical Center, and the way they pull together for a collective understanding of this terrible disease. Washington University physicians from each discipline spoke on their specialties.

Dr. Daniel Lenihan has these symposiums every year. They are well attended by the top Amyloidosis specialists in the country. This year was no exception.

During the past year there have been many improvements in therapies that have shown to improve the outcomes for patients.



(Continued on page 7)



(Continued from page 6)

Learn as much as you can each time you see your doctor. He or she is there for you. Never be afraid to ask them anything. You will help them as much as yourself.

I learned so much at this symposium, and met so many wonderful patients

LightChain
immunoglobulin
AL^{cat2}
Amyloidosis
serum amyloid
Symposium
kappa
protocol
protein
transferrin
misfolded

and doctors. I hope you all will try to attend one whenever you can.

Charlotte Haffner
Patient, AL Amyloidosis.
12 years out.
Heart Transplant, Stem Cell
Transplant, PTLD.
BOD member Amyloidosis
Foundation.

AF

Neuropathy: What is it?

The Nervous System:

The term neuropathy means nerve damage.

Peripheral Neuropathy-

The following ATTR symptoms are caused by a condition known as peripheral neuropathy. Peripheral neuropathy (PN) can be caused by inflammation of, or damage to, the nerves.

It can result in tingling, numbness and burning pain in any part of the body, but commonly is felt in the hands, feet and lower legs. Some patients may experience an increased sensitivity to pain. A loss of sensitivity to temperature may also occur.

Sensorimotor impairment means the loss of a combination of sensory and motor activities. This can decrease a patient's ability to move and feel (sensation)

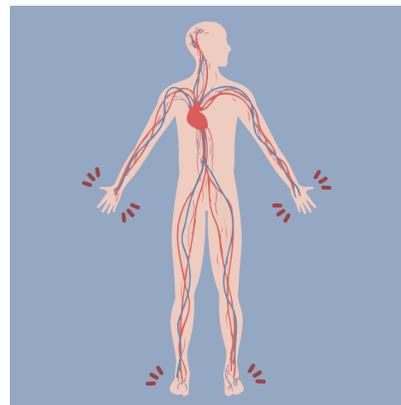
because of nerve damage. Restless leg syndrome (RLS) is also considered a sensorimotor disorder.

Autonomic Neuropathy- Autonomic neuropathy (AN) is a condition that results from damage to nerves that assist in organ and organ system functioning. Autonomic nerves control the functions of our internal organs such as the heart, stomach and intestines, as well as the glands.

Nerves affected by ATTR amyloid deposits may cause the inability to control the muscles that expand or contract blood vessels, which affects the heart rate (irregular heart beats) and blood pressure.

If a patient has a sudden drop in blood pressure (such as when moving from a seated to a standing position), then dizziness,

fainting, or lightheadedness may occur. Other body functions may also be affected, including perspiration patterns, poor digestion, bowel motility and erectile function.



We have exercises for peripheral neuropathy on our website at:

<http://www.amyloidosis.org/wp-content/uploads/2017/08/ExercisesPeripheralNeuropathy.pdf>

AF

