



## News and Stories - Spring 2021

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### ***2nd Annual Virtual 'Run For Your Life!' starting May until July***

#### **WHAT IS A VIRTUAL RUN?**

A virtual run is a run that can be run (walked or rolled) from any location you choose. You can run, jog, walk or roll on the road, on the trail, on the treadmill, at the gym or on the track. You get to run safely on your own ,at your own pace, and time it yourself.

Once you have signed up for the run, either a 5K or 10K, then decide on the course you want to do, or you can do it on the treadmill. You time yourself. You can even get your friends and/or your

kids to run with you too. The run should be completed between May 1, 2021, and July 31, 2021.

Registration for the Virtual Run is currently open and includes a t-shirt!

5K Run – \$25.00

10K Run– \$35.00



Register at:

<https://bit.ly/afVirtualRun>

or call the office to register at **248-922-9610**. Don't forget to share the run with your friends and family!

Take Photos and Share Your Run with Us!

(Continued on page 2)

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### ***Why Should I Participate In A Clinical Trial?***

Clinical trials are part of clinical research and at the heart of all medical advances. Clinical trials look at new ways to prevent, detect, or treat disease.

The goal of clinical trials is to determine if a new test or treatment works and is safe.

Clinical trials can also look at other aspects of care, such as improving the quality of

life for people with chronic illnesses.

People participate in clinical trials for a variety of reasons. Healthy volunteers say they participate to help others and to contribute to moving science forward. Participants with an illness or disease also participate to help others, but also to possibly receive the

newest treatment and to have the additional care and attention from the clinical trial staff.

Clinical trials offer hope for many people and an opportunity to help researchers find better treatments for others in the future.

For more information, visit [clinicaltrials.gov](https://clinicaltrials.gov) **AF**

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**Education • Awareness • Support • Research**

[www.amyloidosis.org](http://www.amyloidosis.org)



## Virtual Run

(Continued from page 1)

Once you have completed your run, send photos to share to: [kathi@amyloidosis.org](mailto:kathi@amyloidosis.org).

We would love to hear about your run! Join our **Facebook page** (<https://www.facebook.com/amyloidosisfdn/>) and **Instagram page** (<https://www.instagram.com/amyloidosisfoundation/>).

#AFVirtualRun  
#AFVirtualRun2021  
#VirtualRun2021  
#RunforyourLife2021 **AF**

## From Our Instagram



## 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](mailto: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](http://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



Hello all,

As we enter into the second year of the pandemic, I hope this finds you all well. We have had to curtail many of our normal activities. Grand Rounds and Exhibition attendance are the two main awareness activities that were canceled last year and it appears we will have to cancel these activities again this year.

We continue to provide our patient support activities, distributing informational pamphlets, caregiver binders, and work to support individuals that are organizing awareness activities and fundraisers.

Please take care in this difficult time, stay safe.

*Mary*

## Miles For Meaning

**Thank you** to all of the runners, walkers and rollers who participated in the Kilter Rewards "Miles For Meaning" challenge, a FREE 31-Day running based challenge from March 1-31, 2021.



The Amyloidosis Foundation had so many participants that we had to start another team! In all, we had 107 members from our community participate!

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## Board of Directors

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Jonathan Wall, PhD

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**



## Lori Lawter, MPH Joins AF Board Of Directors

Lori has a history of working with patients in the non-profit space as well as the pharmaceutical industry. She spent 8 years as a Senior Manager of Patient Services for The Leukemia & Lymphoma Society based in Denver, CO.

Lori learned about amyloidosis as well as blood cancers and disorders through her work with LLS.

She later took a role with Alnylam Pharmaceuticals as a Senior Manager of Patient Advocacy and

Engagement where she was able to stay connected with amyloidosis patients, families, and patient support resources.

Lori lives in Colorado with her husband and blue heeler/cattle dog. She has three grown children, and she enjoys travel, reading, golf, and exploring new restaurants in the area.



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## Searching For Financial Assistance? Use FundFinder!

The PAN Foundation offers **FundFinder**, a free web app tool, to help patients

quickly find financial assistance across nine different charitable

organizations.

With FundFinder, you can easily track the status of more than 200 funds and sign up to receive text message or email alerts when funding for a specific disease becomes available.

Create your FREE account today!

<https://fundfinder.panfoundation.org/>



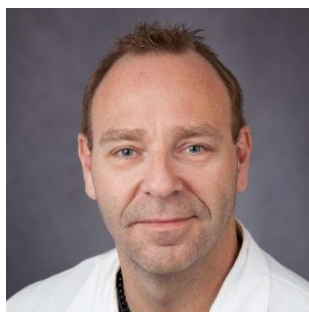
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## Jonathan Wall, PhD receives \$1.79 million to develop new amyloidosis treatment

The National Institute of Diabetes and Digestive and Kidney Diseases recently awarded Wall, professor in the University of Tennessee Health Science Center's Graduate School of Medicine in Knoxville, a \$1.79 million grant for his study titled "Developing a Theranostic Immunotherapy for Systemic Amyloidosis."

Current treatment focuses on limiting further production of amyloid protein in already diseased patients, but there is an urgent need to find a way to remove existing amyloid



deposits.

Lab studies involving amyloid-binding antibodies or antibody fragments designed to recruit cells capable of clearing amyloid, have been successful, however, none have yet been approved

for clinical use.

In this study, Dr. Wall and his team in the Amyloidosis and Cancer Theranostics Program in Knoxville aim to develop a new peptibody (a peptide-fused antibody fragment) capable of clearing amyloid deposits in tissue, that is also "readily labeled for imaging."

Dr. Wall has devoted 26 years to studying the pathogenesis of amyloid diseases.

**AF**

## Support The AF While You Shop!

There are many ways to support the Amyloidosis Foundation while you shop!

Every little bit adds up:

Amazon Smile-  
**<http://amzn.to/1pWN2E3>**

iGive.com-  
**[iGive.com/pSpIPJr](http://iGive.com/pSpIPJr)**

ShopWithScrip (RaiseRight) App- order online or call our office at **248.922.9610** for the access code.

Kroger Community Rewards-  
**Organization Number: HS565**

**amazon**smile  
You shop. Amazon gives.

iGive.com®

ShopWithScrip®





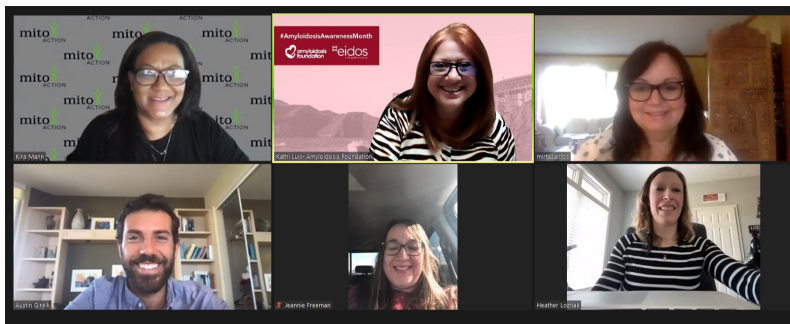
# Rare Disease Week 2021

The Amyloidosis Foundation participated in Rare Across America, meetings for rare disease advocates with their Members of Congress and/or the Member's staff.

This is one way that we make an impact on federal policy. We shared patient stories, the burden of amyloidosis, met with other rare disease advocates and let our voices be heard.

This year was a little different because of the worldwide pandemic, so we met via Zoom.

The Senate and House members we met with were Senator Gary Peters (D-MI), Senator Debbie Stabenow (MI), a Senior U.S. Senator and a member of Senate leadership, Congresswoman Slotkin (MI-8), and Congresswoman Brenda Lawrence



(MI-14).

One of the initiatives we spoke to legislators about was the STAT Act. The Speeding Therapy Access Today Act, H.R. 1730/S. 670 is a bipartisan bill that was created with the input of the rare disease community aimed at improving the development of and access to therapies for the rare disease community.

The centerpiece of the STAT Act is the creation of a Rare Disease Center of Excellence at the US Food

and Drug Administration. The STAT Act will:

- Accelerate rare disease therapy development,
- Optimize interagency coordination,
- Advance science-based regulatory policies, and
- Facilitate access to therapies.

Due to our efforts, The STAT Act of 2021 was officially introduced the week following our meetings by Senator Amy Klobuchar (D-MN), Senator Roger Wicker (R-MS), Rep. Gus Bilirakis (R-FL) and Congressman G. K. Butterfield (D-NC).

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## 'Light The Night For Amyloidosis' Recap

The Amyloidosis Foundation had great participation in its 'Light The Night For Amyloidosis' campaign, with 141 sites in 5 countries lighting for our cause, including two entire cities!

This campaign was created to draw attention to

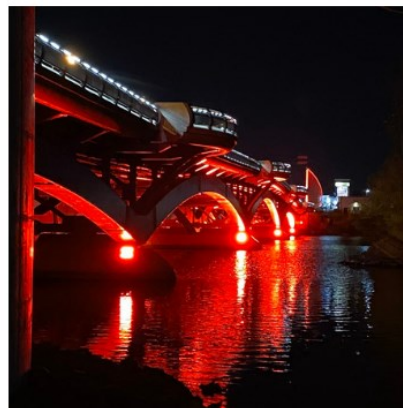
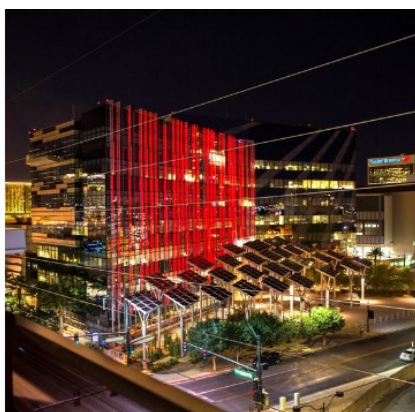
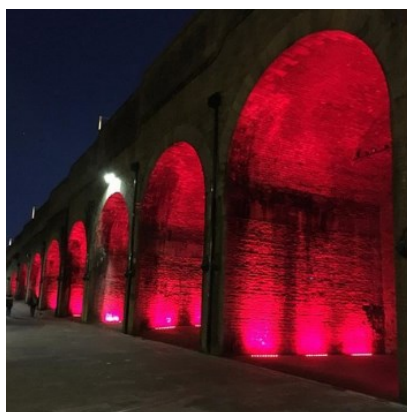
amyloidosis symptoms, diagnosis, treatment and hopefully a cure!

Since 'Amyloidosis Awareness Month' occurs in March, we thought it was befitting to have our awareness campaign in March.

Supporters of the foundation also bought red lights to light up their front porches and homes.

Thank you to all for a successful year of awareness!

**AF**





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One of the sites from the 'Light The Night For Amyloidosis' Awareness Campaign

