



## News and Stories - Spring 2022

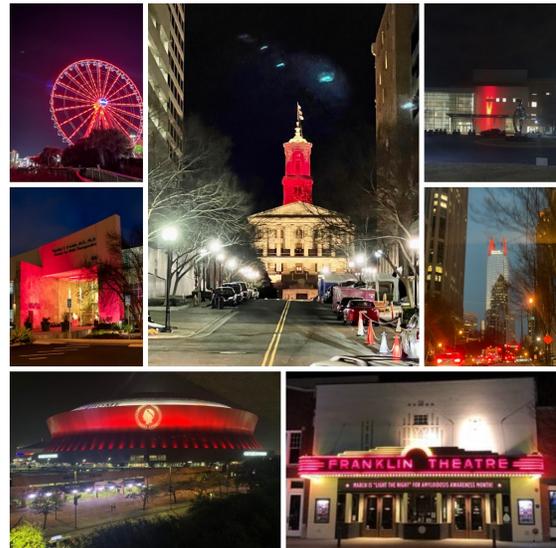
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### 3rd Annual 'Light The Night For Amyloidosis' Was A Hit!

Throughout March, locations around the globe lit for our 'Light The Night For Amyloidosis' awareness campaign. Over 100 locations in 5 different countries participated. There were also many patients, caregivers and families that supported the event by lighting up their homes.

The countries that took part were the United States, Australia, Canada, New Zealand and the United Kingdom. This year was a little different with many date changes so sites could light in yellow/blue to support Ukraine.

This campaign was created to draw attention to amyloidosis symptoms, diagnosis, treatment, and hopefully a cure! 'Amyloidosis Awareness Month' also occurs in March. To see full list of the illuminations, check pages four and five.



(Continued on page 4)

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### Rare Disease Week on Capitol Hill



We were busy during the month of March with legislative conferences, a Rare Disease Caucus Briefing, and Zoom meetings with advocates throughout the country. For two days, we met with legislators to advocate for amyloidosis patients. The main topics were the STAT Act (Speeding Therapy Access Today Act), The BENEFIT Act (Better Empowerment Now to Enhance Framework and

Improve Treatments) and we asked legislators to Cosponsor the Access to Genetic Counselor Services Act. We also asked for support of the Orphan Drug Tax Credit, a tax credit equal to 25 percent of the cost of qualified clinical testing expenses associated with developing orphan drugs — that is, a drug used to treat, prevent, or diagnose a rare (or "orphan") disease.

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**Education • Awareness • Support • Research**

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



## Find us on Facebook



We have a large community on Facebook. We share stories, articles, webinars, events and the latest news. We try to share something new every single day!

In 2018 we were approved as an official charity on Facebook. This means that if you have an account, you can fundraise on our behalf. It's free and easy!

<https://www.facebook.com/fund/amyloidosisfdn/>

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## 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)



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



## President's Corner

Mary E. O'Donnell



Hello to all!

Our activities over the past 2 years have definitely been affected. We have been unable to do any face to face interaction, therefore our efforts to inform the medical community has been greatly reduced. Fortunately, we have been able to continue our assistance to the amyloidosis patient/caregiver community. These activities include:

- ✓ Webinars (all available on our website (<https://amyloidosis.org/resources/#websites-and-support-groups>))
- ✓ Provide Patient/Caregiver Binders to help organize information, appointments, medications, etc.
- ✓ Distribute informational pamphlets regarding AL Amyloidosis, ATTR both hereditary and wild type
- ✓ Help patients find knowledgeable physicians

We hope to start our face to face activities, but in abundance of caution, we are aiming for the 2nd half of 2022.

As spring is arising, outdoor activities are being planned by various people as fundraisers for the foundation. We greatly appreciate these efforts, as we appreciate ALL of our supporters

Regards,

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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**



## Light The Night... (Continued from page 1)

AL- Birmingham- Regions Field  
 AL- Tuscaloosa- City Hall  
 AL- Tuscaloosa- Intermodal Facility (Downtown Parking Deck)  
 AL- Tuscaloosa- Fountain at Alberta Park  
 AR- Little Rock- Union Plaza Building  
 AU/NSW-Sydney- Town Hall  
 AZ- Gilbert- Gilbert Water Tower  
 AU/SA- Adelaide- Adelaide Oval  
 AU/QLD- Brisbane- City Hall and King George Square  
 AU- Brisbane- Sandgate Town Hall  
 CA- Carlsbad- Ionis Pharmaceuticals (2855 Gazelle Court)  
 CA- Moreno Valley- "M" on Box Springs Mountain  
 CA- South San Francisco- Prothena Biosciences (331 Oyster Point Boulevard)  
 CAN/AB- Calgary- TELUS Spark  
 CAN/AB- Edmonton- High Level Bridge  
 CAN/BC- Surrey- Surrey Civic Plaza  
 CAN/BC- Maple Ridge- City Hall  
 CAN/BC- Whistler- Fitzsimmons Creek Bridge  
 CAN/ON- Fort Erie- Peace Bridge  
 CAN/ON- London- City of London City Hall  
 CAN/ON- London- Dufferin Building (195 Dufferin)  
 CAN/ON- London- JA Taylor Building  
 CAN/ON- London- RBC Place  
 CAN/ON- Toronto- 3D TORONTO Sign  
 CAN/ON- Toronto- CN Tower  
 CAN/ON/USA- Niagara- Niagara Falls  
 CT- New Britain- Beehive Bridge  
 DE- Sussex County- Indian River Inlet Bridge  
 DE- Wilmington- AstraZeneca - US Headquarters  
 FL- Panama City Beach- Skywheel  
 GA- Atlanta- 1180 Peachtree  
 GA- Atlanta- Georgia World Congress Center Authority  
 GA- Atlanta- King & Queen Buildings  
 GA- Cumming- GA 400 Water Tower  
 KS- Lawrence- LIED Center of Kansas  
 KS- Manhattan- Flint Hills Discovery Center  
 KS- Shawnee- City Hall  
 KS- Shawnee- Clear Creek Bridge  
 LA- Baton Rouge- APTIM Building  
 LA- Baton Rouge- Springfield High School Sign  
 LA- Baton Rouge- State Capitol Building  
 LA- Denham Springs- James Drug Store Sign  
 LA- New Orleans- Billboard at E/S Clearview Pkwy .2 mi N/O Jefferson  
 LA- New Orleans- Billboard at Poydras St. at South Claiborne Ave Westbound  
 LA- New Orleans- Billboard at Poydras St. at South Claiborne Ave Eastbound  
 LA- New Orleans- Billboard at Tulane Ave at Bolivar  
 LA- New Orleans- Billboard at Tulane Ave at S. Johnson  
 LA- New Orleans- Mercedes-Benz Superdome  
 MA- Boston - Longfellow Bridge- 3/12/2022  
 MA- Boston - Rose Kennedy Greenway Conservancy  
 MA- Boston - Zakim Bridge  
 MA- Foxborough- Gillette Stadium





MA- Quincy- Fore River Bridge  
MA- Worcester- Kenneth F. Burns Memorial Bridge  
MD- Baltimore- City Hall Dome  
MI- Detroit- Ford Field  
MI- Grand Rapids- The Blue Bridge & Gallery Ramp  
MI- Warren- City Hall  
MN- Eagan- Sperry Tower  
MN- Minneapolis- I-35 W Bridge  
MN- Minneapolis- Lowry Avenue Bridge  
NC- Charlotte- NASCAR Hall of Fame  
NC- Charlotte- Romare Bearden Park  
NC- Charlotte- 550 S Tryon (Wells Fargo's Duke Energy Center)  
NY- Binghamton- Home Security Mutual Life Insurance Building  
NY- Buffalo- Kosciuszko Bridge  
NY- Buffalo- Peace Bridge- 3/5/2022  
NY- New York- 230 Park Avenue (Helmsley Bldg)  
NY- New York- Gotham Hall  
NY- New York- Mid-Hudson Bridge  
NY- New York- Pier 17 (Lightband)  
NY- Rochester- Central Library of Rochester and Monroe  
NY- Rochester- Xerox Tower  
New Zealand- Wellington- Michael Fowler Centre  
OH- Cleveland- Rock and Roll Hall of Fame  
OH- Cleveland- Terminal Tower  
OH- Columbus- Hilton Columbus Hotel Downtown Skybridge  
OK- Oklahoma City- Skydance Bridge  
OR- Salem- Union St. Railroad Pedestrian Bridge  
PA- Bethlehem- Wind Creek Bethlehem Blast Furnace  
PA- Philadelphia- Pennsylvania Convention Center  
PA- Philadelphia- PECO Energy Building (display "March is Amyloidosis Awareness Month!")  
PA- Philadelphia- Boathouse Row  
PA- Pittsburgh- Fifth Avenue Place (Highmark)  
PA- Pittsburgh- One Liberty Place  
PA- Pittsburgh- Two Liberty Place  
RI- Portsmouth- Sakonnet River Bridge  
TN- Franklin- The Franklin Theatre Marquee  
TN- Nashville- State Capitol Building  
TX- Dallas- Bank of America Plaza  
TX- San Antonio- Alamo Quarry Smokestacks  
UK/ENG- Bradford- City Hall Clock Tower  
UK/ENG- Bradford- Forster Square Railway Arches  
UK/ENG- Bradford- Margaret McMillan Tower  
UK/ENG- Bradford- Mirror Pool, City Park  
UK/ENG- Portsmouth- Emirates Spinnaker Tower  
UK/WAL- Bangor- Ards Town Hall- 3/5/2022  
UK/WAL- Bangor- McKee Clock Tower- 3/5/2022  
UT- Salt Lake City- Huntsman Cancer Institute  
UT- Salt Lake City- Salt Palace Convention Center  
VA- Virginia Beach- Virginia Aquarium & Marine Science Center  
WA- Seattle - Columbia Center  
WA- Seattle- SR 520 Floating Bridge  
WA- Seattle- Washington State Convention Center  
WI- Milwaukee- Gas Light Building  
WI- Milwaukee- The Pfister Hotel  
WI- Milwaukee- Wisconsin Center Crossover above Wells St.



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## AF VIRTUAL Walk/Run/Roll/Bike Registration is OPEN!!!

AF VIRTUAL RUN!!!

May 1, 2022 and July 31, 2022

Walk or run or bike at your leisure to help raise awareness of amyloidosis, in your local park, or your neighborhood. Encourage your family and friends to register and participate.

5k- \$25  
10k- \$35

REGISTER TODAY for the 2022 AF Virtual Run!!!

You can do your run at your leisure anytime between May 1, 2022 and July 31, 2022.

Please tag us in your pics as we would LOVE to highlight YOU and your amyloidosis awareness!

REGISTER HERE <https://secure.qgiv.com/for/amyfound/event/815306/>

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## Louisiana Nurse Raises Awareness

Megan Alford, RN stopped by the FOX 44 studio to raise awareness about amyloidosis. She has been working with the Amyloidosis Foundation the last 2 years as an Awareness Ambassador to help with our "Light the Night Campaign" and is responsible for securing numerous sites to illuminate in Louisiana.



Megan, who has a personal connection to amyloidosis, had never heard of amyloidosis, along with her colleagues in the medical field. Her mother passed shortly after diagnosis. She had the telltale signs and it wasn't recognized in time. To view her interview, go to:

[https://www.youtube.com/watch?v=GTQZ9\\_kwEf4](https://www.youtube.com/watch?v=GTQZ9_kwEf4)

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## What is Peripheral Neuropathy?

Amyloid deposits can affect the nerves of the hands, feet and lower legs and may cause pain, numbness and tingling. A loss of sensitivity to temperature may also occur. This is called peripheral neuropathy. Nerves that control blood pressure, heart rate, bowel motility, erectile function, and other body functions can also be affected, causing a variety of symptoms including dizziness when standing too quickly, nausea and diarrhea. This is called autonomic neuropathy.

Peripheral neuropathy is a common manifestation of AL amyloidosis, and the incidence of peripheral neuropathy in AL amyloidosis varies from 9.6 to 35%. The typical pattern of amyloid neuropathy is symmetrical, lower-limb predominant, slowly progressing polyneuropathy, with severe pain. The involvement of small nerve fibers is more severe than that of large nerve fibers.



Over time, both motor and sensory fibers and both large and small fibers become involved. Autonomic neuropathy is a particularly severe complication that manifests with gastroparesis, diarrhea or constipation, impotence and severe postural hypotension. If you feel you have symptoms of peripheral neuropathy, speak to your physician. Treatments are available.

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## Mayors Present Resolution in Tennessee

Williamson County Mayor Rogers Anderson and Franklin Mayor Ken Moore recently presented a resolution to Charlotte Haffner proclaiming March as Amyloidosis Awareness Month in Williamson County and Franklin.

Haffner, an amyloidosis survivor diagnosed in 2006, was accompanied to both presentations by her friend, Faith (Mayton) Fairhope, whose husband, Pastor



Andrew Mayton Sr., died in 2007 from cerebral amyloidosis. Haffner created an amyloidosis support group and became active in the Amyloidosis Foundation, rising to a director's position. In 2018, her work led Tennessee to become the first state to recognize amyloidosis as a disease, and Gov. Bill Haslam signed Joint Resolution 711 declaring March Amyloidosis Awareness Month in Tennessee.



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