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.

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.

(Continued on page 4)
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

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/

Patient Resources

Our comprehensive website has information for patients, caregivers and physicians featuring:

- Treatment Centers (US / International)
- Support Groups
- Newsletters
- Webinars
- Caregiver/Patient Binder
- Fundraising Toolkits

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!

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Follow Us!

Stay connected for all the latest information on Amyloidosis:

Web: www.amyloidosis.org
Twitter: @Amyloidosisfdn
Facebook: @amyloidosisfdn
Instagram: @amyloidosisfoundation

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,

Mary

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
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

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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- Binghampton- 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.

www.amyloidosis.org
AF VIRTUAL Walk/Run/Roll/Bike Registration is OPEN!!!

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/

AF

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

AF

www.amyloidosis.org
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.

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.