“Light the night for amyloidosis” is an awareness campaign created to draw attention to amyloidosis symptoms, diagnosis, treatment and hopefully a cure! Since ‘Amyloidosis Awareness Month’ occurs in March, we are asking everyone to light up their porch/entryway with red bulbs for the month of March.

We have also contacted many worldwide landmarks and businesses to do the same in March 2020. On pages 6-7 is a list of the approved requests, along with the date the lighting will occur.

***Save The Date: February 29, 2020***

Rare Disease Day takes place on the last day of February each year.

The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients’ lives.

Building awareness of rare diseases is so important because 1 in 20 people will live with a rare disease at some point in their life.

Despite this, there is no cure for the majority of rare diseases and many go undiagnosed.

AF
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
- Toll Free Number **1-877-AMYLOID**
- Listing of experienced physicians that specialize in amyloidosis. Email us anytime with questions: **info@amyloidosis.org**

### Patient Resources

The foundation has several programs that benefit patients and their families. All of these are provided free of charge.

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

### Aubrey’s Journey

Written by Jamie, Wife and Caregiver

Aubrey was diagnosed with hATTR. We had prayed that this disease that claimed the lives of his grandmother, father, brother, aunts, uncles and cousins would somehow skip him, but that was not to be. It started with a severe taste aversion.

Overnight, salt in his food gave an alkaline taste, sweet became bitter etc. He had also progressively developed a cough that seem to be triggered by consuming spicy foods (this had never affected him before), then any sort of food, and went on to having a cough for every time he starts to talk. As you can imagine, being a prolific corporate director in the field of Technology, with media presence here in New Zealand, this cough was becoming a big problem for him. This inability to now enjoy eating (or talking) led to his losing weight and with the cough, his doctor/general practitioner recommended that he see a gastroenterologist and interventional endoscopist. The endoscopist, Dr Ravinder Ogra, thankfully took a look at Aubrey’s family history with the disease, and when doing a biopsy of his gastrointestinal system, dared to investigate lower down the tract to remove a larger portion for biopsy. He then tested with the Congo red dye and this is how diagnosis was made.

Still today, we don’t know how this taste aversion came to be as I have tried to find out if this is part of the symptoms of having this disease, but there’s not

(Continued on page 4)
President’s Corner
Mary E. O’Donnell

As we enter into a new decade, we here at the foundation are so very thankful for all the support you have provided us over the years. We continue to work hard in trying to raise awareness of all types of amyloidosis by exhibiting at 6 annual medical conferences throughout the year.

We are proud of the fact that we can help patients and their families to better understand their disease and help them to find doctors experienced with amyloidosis. When my husband was diagnosed in 2003, there were not a lot of options as to where he could go for treatment, whereas now, there are dozens of multi-disciplinary clinics throughout the country.

We look forward to continued advances in the understanding of the disease, and improved treatments for all types of amyloidosis.

#GivingTuesday 2019

The Amyloidosis Foundation is thankful for the amazing generosity from our friends and donors on #GivingTuesday.

You helped us surpass our goal of raising $20,000 in 24 hours by soaring past that with close to $30,000 in online donations and Facebook fundraisers. 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, 1-877-AMYLOID (877-269-5643) 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
The Amyloidosis Foundation is proud to be a partner at this event, *Amyloidosis: A Disease Now at the Forefront of Practice Latest Diagnostic & Treatment Strategies* on February 22, 2020 at Washington University in St. Louis, MO, chaired by our Board of Director, Daniel Lenihan, MD.

This is a symposium for providers, patients and their families. Continuing Medical Education (CME) credits will be available.

Patients touched by amyloidosis and their families are invited to attend the lunch and afternoon session. The breakout sessions will allow attendees the opportunity to ask questions of various medical providers and network.

Guest faculty includes:

**Raymond L. Comenzo, MD**
Professor of Medicine, Tufts University School of Medicine, Director, John C Davis Myeloma and Amyloid Program, Tufts Medical Center, Boston, Massachusetts

**Mathew S. Maurer, MD**
Arnold and Arlene Goldstein Professor of Cardiology, Professor of Medicine, Columbia University Irving Medical Center, Director, Cardiac Amyloidosis Program, New York, New York

Registration for patients and families:
For more information:

Aubrey’s Journey

(Continued from page 2)

He has been diagnosed with cardiac amyloidosis (“stiff heart syndrome”) due to the amyloid deposits taking the place of normal heart muscle. It is the most typical type of restrictive cardiomyopathy.

On 9th Feb 2016, he underwent New Zealand’s first ever domino liver transplant at Auckland hospital. Since then, his donor liver is doing excellent in his body despite the fact that the other organs are compromised, especially his heart and nerves, as they continue in their unrelenting deterioration. Long story short, we are resolute that we must make a difference with whatever time we have with each other and are in the process of starting a non-profit charity that will advocate for awareness about the disease to the general public here in NZ, and within our medical practitioner’s network, while also championing the cause for other patients and their caregivers in this country.

Read the rest of Aubrey’s Journey at:
http://amyloidosis.org/aubreys-journey/
We are pleased to announce the funding of three new research projects. The Donald C. Brockman Memorial Research Grant has been awarded to Mark Rank, PhD of Johns Hopkins University. His study revolves around cardiac amyloidosis. The David Seldin, MD, PhD Memorial Research Grant recipient is Susan Bal, MBBS of the University of Alabama-Birmingham. Her study will focus on Light Chain (AL) amyloidosis. The third grant is awarded to Renato Polimanti, PhD of Yale University of Medicine. His research is geared towards wild-type ATTR.

The Amyloidosis Foundation has awarded over $2 million to research since the inception of the grant program in 2005.
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<thead>
<tr>
<th>State/Province</th>
<th>City/Location</th>
<th>Details</th>
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<tbody>
<tr>
<td>AK</td>
<td>Anchorage- JL Tower</td>
<td>3/1/2020</td>
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<td>AZ</td>
<td>Gilbert- Gilbert Water Tower</td>
<td>3/6-3/8</td>
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<tr>
<td>CA</td>
<td>San Diego- San Diego Convention Center</td>
<td>3/7/2020 (From 7:00 PM- 11PM PT)</td>
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<tr>
<td>CA</td>
<td>San Francisco- 140 New Montgomery St. (PACBell)</td>
<td>3/6-3/8</td>
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<td>CAN/AB</td>
<td>Calgary- Calgary Tower</td>
<td>3/1/2020</td>
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<tr>
<td>CAN/AB</td>
<td>Calgary- Reconciliation Bridge</td>
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<td>Edmonton- High Level Bridge</td>
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<td>Vancouver- BC Place</td>
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<td>Vancouver- The Sails of Light</td>
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<td>CAN/ON</td>
<td>London- Canada Life</td>
<td>3/2-3/8</td>
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<td>London- City Hall</td>
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<td>London- JA Taylor Building</td>
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<td>CAN/ON</td>
<td>London- RBC Place</td>
<td>3/2-3/5 and 3/7-3/8</td>
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<td>CAN/US</td>
<td>Niagara- Niagara Falls</td>
<td>3/1/2020 (From 10:00PM- 10:15PM ET)</td>
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<td>St. Petersburg- Sunshine Skyway Bridge</td>
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<tr>
<td>GA</td>
<td>Atlanta- King &amp; Queen Buildings</td>
<td>3/27-3/29</td>
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<td>HI</td>
<td>Honolulu- Aloha Tower</td>
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<tr>
<td>IN</td>
<td>Fort Wayne- MLK Jr Memorial Bridge</td>
<td>3/6-3/8</td>
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<tr>
<td>IN</td>
<td>Indianapolis- Monument Circle</td>
<td>Tentative</td>
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<tr>
<td>KS</td>
<td>Manhattan- Flint Hills Discovery Center</td>
<td>3/7/2020</td>
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<tr>
<td>KY</td>
<td>Lexington- Helix Garage</td>
<td>Month of March</td>
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<tr>
<td>MA</td>
<td>Boston - Rose Kennedy Greenway Conservancy</td>
<td>3/1-3/7</td>
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<tr>
<td>MA</td>
<td>Boston - Zakim Bridge</td>
<td>3/1/2020</td>
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<tr>
<td>MD</td>
<td>Annapolis- The Governor's House</td>
<td>3/2/2020 (Red only)</td>
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<tr>
<td>ME</td>
<td>Boothbay- Boothbay Brewery, Tavern &amp; RV</td>
<td>3/1/2020</td>
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<tr>
<td>MI</td>
<td>Detroit- Greektown Casino &amp; Hotel</td>
<td>Tentative</td>
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<tr>
<td>MI</td>
<td>Detroit- Ford Field</td>
<td>Tentative 3/6-3/7</td>
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<td>MI</td>
<td>Warren- Warren City Hall</td>
<td>3/1-3/8</td>
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<tr>
<td>MN</td>
<td>Eagan- Sperry Tower</td>
<td>3/6/2020</td>
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<tr>
<td>MN</td>
<td>Minneapolis- I-35 W Bridge</td>
<td>3/1/2020</td>
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<tr>
<td>NC</td>
<td>Charlotte- Wells Fargo's Duke Energy Center</td>
<td>3/6/2020</td>
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Light The Night For Amyloidosis (Continued from page 6)

NY  Brooklyn- Electric Tower- 3/1/2020
NY  Buffalo- Peace Bridge- 3/1/2020
NY  New York- Mid-Hudson Bridge- 3/7 or Month of March
NY  New York- 230 Park Avenue (Helmsley Bldg.)- 3/1/2020
NY  Yonkers-City Clock Tower- Month of March
OK  Oklahoma City- Crystal Bridge Tropical Conservatory- Tentative
OK  Oklahoma City- Skydance Bridge- 3/1/2020
OR  Portland- Oregon Convention Center- Tentative
OR  Woodburn- Woodburn Bridge- 3/2-3/7
PA  Philadelphia- Benjamin Franklin Bridge- 3/1/2020
PA  Philadelphia- Cira Centre- 3/7-3/9
PA  Philadelphia- FMC Tower at Cira Centre- 3/7-3/9
PA  Philadelphia- Cira Garage- 3/7-3/9
RI  Portsmouth- Sakonnet River Bridge- 3/1/2020
TX  Dallas- Bank of America Plaza- 3/7/2020
TX  Houston- Montrose Bridges & City Hall- 3/6-3/7
UT  Salt Lake City- Huntsman Cancer Institute- Tentative 3/6-3/8
VA  Virginia Beach Virginia Aquarium & Marine Science Center 3/6-3/8
WA  Seattle- Columbia Center- 3/6/2020 (Red only)
WA  Seattle- SR 520 Floating Bridge- 3/2-3/9
WA  Seattle- Washington State Convention Center- 3/6-3/9
WI  Milwaukee- Gas Light Building- 3/1-3/5
WV  Huntington- The WV Building- 3/1 or Month of March

PLEASE NOTE: We have only heard back from about 1/3 of the requests made. Above are the approvals, some have been denials. We have made requests in every state in the US along with many other countries. For an updated list, visit:
http://amyloidosis.org/light-the-night-for-amyloidosis-awareness-campaign/

We have red light bulbs available for purchase!

Please join us in our “Light the night for amyloidosis” awareness campaign.
Order yours today here=> http://amyloidosis.org/products/
Happy NEW YEAR 2020