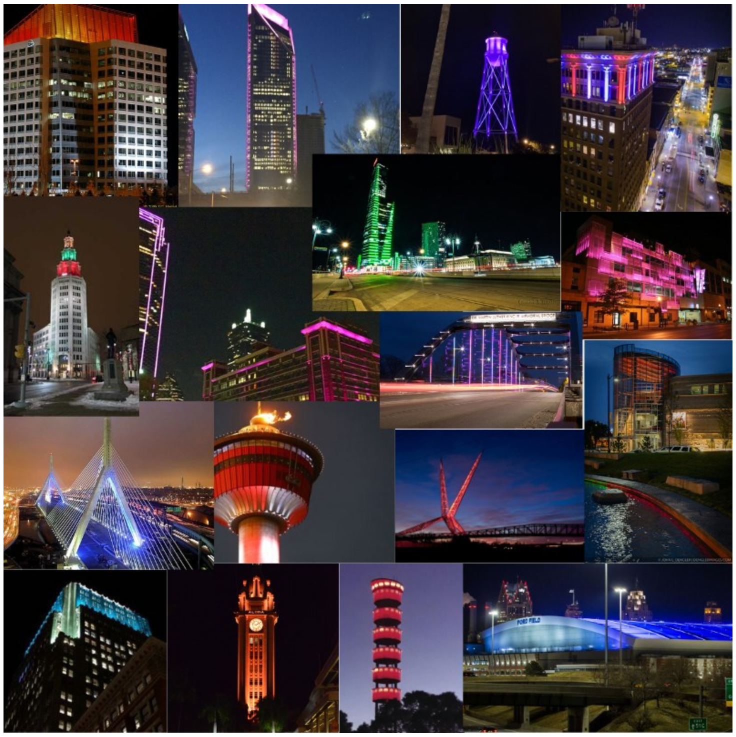
amyloidosis
foundation

News and Stories - Winter 2020

Light The Night For Amyloidosis

“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.



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****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.

RAREDISEASEDAY.ORG

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

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, aunties, 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

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

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

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

Follow Us

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Stay connected for all the latest information on Amyloidosis:

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

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 through out 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.

Mary

#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**

Board of Directors

Scientific Advisors

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

Amyloidosis Symposium at Washington University

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:
http://bit.ly/WUST2020

For more information:
http://bit.ly/WUST20AGENDA

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Aubrey's Journey

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much evidence of this. We believe that having this problem actually may have led him to be tested earlier as without the symptoms, the progression of the disease would have been a lot worse before being caught. His taste buds have somewhat improved, not completely, but at least he can eat without gagging. The cough is less but still there.

His condition got progressively worse with the protein depositing in his gastrointestinal tract, nerve (polyneuropathy) and unfortunately his heart. 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/** **AF**

AF Announces 2020 Research Grant Recipients

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.

Susan Bal, MBBS

Understanding the Immune Microenvironment of Light Chain (AL) Amyloidosis

Amyloidosis Foundation David Seldin, MD, PhD Memorial Research Grant, 2020
University of Alabama,

Birmingham, AL

Renato Polimanti, PhD

Dissecting the role of the genetically-determined TTR

Amyloidosis Foundation Research Grant, 2020

Yale University School of Medicine

Mark Ranek, PhD

Chip'n Away at Cardiac Amyloidosis with PKG

Amyloidosis Foundation Donald C. Brockman Memorial Research Grant, 2020

Johns Hopkins University, Baltimore, MD

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Contact us if you'd like more information at:

info@amyloidosis.org

Light The Night For Amyloidosis

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AK Anchorage- JL Tower- 3/1/2020

AZ Gilbert- Gilbert Water Tower- 3/6-3/8

CA San Diego- San Diego Convention Center- 3/7/2020 (From 7:00 PM- 11PM PT)

CA San Francisco- 140 New Montgomery St. (PACBell)- 3/6-3/8

CAN/AB- Calgary- Calgary Tower- 3/1/2020

CAN/AB- Calgary- Reconciliation Bridge- 3/1/2020

CAN/AB-Edmonton- High Level Bridge- 3/1/2020

CAN/BC- Vancouver- BC Place- 3/15/2020

CAN/BC- Vancouver- The Sails of Light- 3/1/2020

CAN/ON- London- Canada Life- 3/2-3/8

CAN/ON- London- City Hall-3/2-3/8

CAN/ON- London- JA Taylor Building- 3/2-3/8

CAN/ON- London- RBC Place- 3/2-3/5 and 3/7-3/8

CAN/US- Niagara- Niagara Falls- 3/1/2020 (From 10:00PM- 10:15PM ET)

FL St. Petersburg- Sunshine Skyway Bridge- 3/7/2020

GA Atlanta- King & Queen Buildings-3/27-3/29

HI Honolulu- Aloha Tower- 3/1/2020

IN Fort Wayne- MLK Jr Memorial Bridge- 3/6-3/8

IN Indianapolis- Monument Circle- Tentative

KS Manhattan- Flint Hills Discovery Center- 3/7/2020

KY Lexington- Helix Garage- Month of March

MA Boston - Rose Kennedy Greenway Conservancy- 3/1-3/7

MA Boston - Zakim Bridge- 3/1/2020

MD Annapolis- The Governor's House- 3/2/2020 (Red only)

ME Boothbay- Boothbay Brewery, Tavern & RV- 3/1/2020

MI Detroit- Greektown Casino & Hotel- Tentative

MI Detroit- Ford Field- Tentative 3/6-3/7

MI Warren- Warren City Hall- 3/1- 3/8

MN Eagan- Sperry Tower- 3/6/2020

MN Minneapolis- I-35 W Bridge- 3/1/2020

NC Charlotte- Wells Fargo's Duke Energy Center- 3/6/2020

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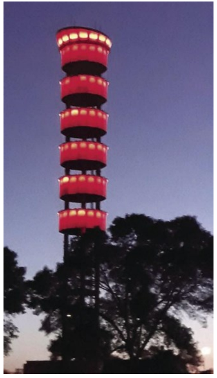
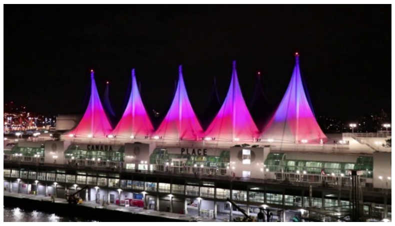


NY	Binghampton- Home Security Mutual Life Insurance Building- 3/1/2020
NY	Brooklyn- Electric Tower- 3/1/2020
NY	Buffalo- Peace Bridge- 3/1/2020
NY	New York- Mid-Hudson Bridge- 3/7 or Month of March
NY	New York- 230 Park Avenue (Helmsley Bldg.)- 3/1/2020
NY	Yonkers-City Clock Tower- Month of March
OK	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/

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