



News and Stories - Winter 2021

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!

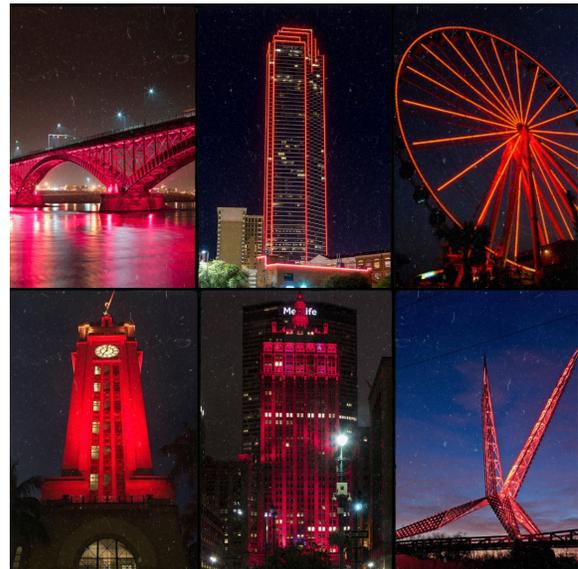
Since ‘Amyloidosis Awareness Month’ occurs in March, we are asking everyone to light up their porch / entryway with red bulbs for the month of March.

We have also contacted many worldwide landmarks and businesses to do the same in March 2021. On pages 6-7 is a list of the approved requests, along

with the date the lighting will occur.

In 2020, our inaugural year for the campaign, we had over 100 sites in five different countries light for our cause.

Some of those that lit up for amyloidosis are Niagara Falls, LAX Airport, Little Caesar’s Arena, JL Tower, Zakim Bridge, Wells



Fargo’s Duke Energy Center , Detroit Ford Field, and Bank of America Plaza.

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First Drug For AL Amyloidosis Approved By FDA

On January 15, 2021, DARZALEX FASPRO®, the subcutaneous formulation of DARZALEX, was approved for use in patients with newly diagnosed light chain (AL) amyloidosis.

The approval is based on the Phase 3 ANDROMEDA study. This approval makes DARZALEX FASPRO the first and only FDA-approved

treatment for new AL amyloidosis patients.

“There is an urgent need for awareness and treatment options to help in the fight against this serious blood cell disorder,” said Raymond L. Comenzo, M.D., Director, John C. Davis Myeloma and Amyloid Program, Tufts Medical Center, and

ANDROMEDA study investigator.



For information on Janssen’s CarePath Savings Program, enroll by phone (844-553-2792) or by creating an online account at: MyJanssenCarePath.com.

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Education • Awareness • Support • Research

www.amyloidosis.org



ATTRwt Journey

Written by Howard Covell

Where will this ATTRwt amyloidosis journey take me? I like to travel; however, this trip was not planned or wanted! I wonder a lot about the journey I am starting, so far it has been OK.

In 2017 I had an angiogram that my cardiologist described as being a little weird and she said she would keep watching it. Yearly visits and EKG's were done, but nothing showed any abnormality.

In the Spring of 2019, as I was trying to spread fertilizer on our lawn, I could only walk a few minutes before becoming very tired. At about that same time, I was

experiencing shortness of breath on little exertion.



My wife made my appointment with my PCP as I insisted it was nothing and it would go away. The doctor ordered an ECHO, then an angiogram, nuclear stress, and other tests. At that point, I was diagnosed with Wild-type amyloidosis and I asked "What in the world is

amyloidosis?" The answer was a very rare and fatal heart disease. WOW, that shook me and my mind went crazy as I thought of all the what-ifs ahead. Where did this come from? When did it start? How long do I have to live? On and on my mind went. Friends tell me that they knew it was the wild type as I am the wild type, not true. I was 78 when diagnosed, so how wild could I be?

When I had a follow-up appointment with my cardiologist she said, "I know nothing about this disease, you will have to go someplace else". Doctors need a lot

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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
- 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
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 Instagram: [@amyloidosisfoundation](https://www.instagram.com/amyloidosisfoundation)





President's Corner

Mary E. O'Donnell



So, 2020 was certainly a challenging year!

We spent several months working remotely from our homes as did the majority of the population. We are still in a semi shutdown phase in our state. With that said, we were still able to award two research grants, and we have added a new sponsorship– 2 Cardiac Amyloidosis Fellowships.

We continue to support patients and their families with knowledge and accurate information. None of these activities would be possible without the generosity of our supporters. Even in the midst of the pandemic, your support continues. We can't begin to thank you enough.

For 2021, we wish you a Happy New Year! Please take care and stay safe.

Mary

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#GivingTuesday 2020

This was a very strange year for all of us. Although we didn't meet our goal, we are ecstatic for what we were able to accomplish together.

We raised over \$17,000!!! Those funds will go toward amyloidosis research. THANK YOU!



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



Amyloidosis Resources

The Amyloidosis Foundation has many resources at your disposal. Things that you may find include worldwide support groups, treatment centers, information on clinical trials, and brochures, broken down by type.

We also have our past newsletters, webinars, and videos available for your viewing, along with Rare Toolkits. These toolkits provide individuals with usable information on a variety of topics related to living with and/or advocating for rare disease patients.

Within the last couple of years, we have added to our list with resources for Vietnam Veterans, exercises, different travel



options to get you to your appointment, and resources for caregivers, including a downloadable binder chock-full of helpful information.

Our 'Additional Resources' tab has financial help, government agencies, organ foundations, insurance help, among many other links to help you gain knowledge about your or your loved one's condition.

To access this wealth of information, go to our website:

www.amyloidosis.org

and click on the resources tab at the top of the page in burgundy. On a mobile device, click  then Resources'.

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ATTRwt Journey (Continued from page 2)

more education on this disease as few have much knowledge of it. I researched online and chose the Cleveland Clinic in Ohio due to the distance from our home, insurance, and their reputation in the research and care of patients with this disease.

I have severe amyloidosis, but the good news is that there is now a medication called Vyndamax that can slow down the progression of the disease. It was approved in May of 2019 and I started taking it in October. Is it working? I won't know that until my

next visit in October 2020, I have more tests and get the results. I did have bilateral carpal tunnel surgery about 20 years ago. I think about if this disease could have been starting way back then. I take diuretics to keep fluid from building up around my organs.

Salt is a no-no, but we have found lots of good no salt foods even no salt potato chips. No salt in cooking, at the table plus NO processed foods allowed in our home. We now find food at restaurants or family gatherings too salty for us.

Surprising how quickly we got used to no-salt, except that found naturally in foods.

I walk about 20-30 minutes a day and wish I could walk more. I have osteoporosis that prevents the long walks I would prefer.



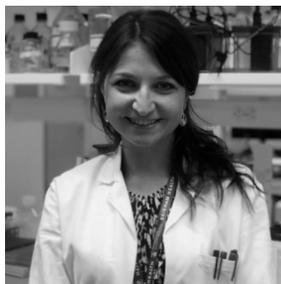
Read the rest of Harold's Journey at:
<https://amyloidosis.org/where-will-this-attrwt-amyloidosis-journey-take-me/>

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AF Announces 2021 Research Grant Recipients

Meet our grant awardees! We are proud to feature our grant recipients whose research targets the challenges in the field of amyloidosis.



Maria Moscvin, MD

Targeting Free Light Chain Secretion as a Novel Therapeutic Strategy in AL Amyloidosis

**Amyloidosis Foundation Donald C. Brockman Memorial Junior Research Grant, 2021
Brigham and Women's Hospital, Boston, MA**



Timothy Poterucha, MD

Prospective Identification of Transthyretin Cardiac Amyloidosis Using Deep Learning

Amyloidosis Foundation David C. Seldin Memorial Junior Research Grant, 2021

Shop with Gift cards while donating to AF!

The Amyloidosis Foundation is excited to offer an easy way to raise money for our organization.

Experience the right way to fundraise!

Gift card fundraising is the best way to raise money for our organization. Buy gift cards from your favorite brands to earn on your daily purchases.

It's never been easier to create opportunities for what matters most to you. No extra money spent. No extra time wasted.

How it works:

Raise money by purchasing gift cards at face value

Shop 750+ top brands and immediately earn up to 20% on every gift card you buy. You can easily raise \$1,000 or more every year.

Use gift cards at full value for your daily purchases

Earnings come from brands, not from your pocket, so gift cards are worth every penny. Raise money simply by doing everyday things—like grabbing your morning coffee or ordering dinner for the family.

How to get started:

Create an account on the RaiseRight app or at ShopWithScrip.com using our organization's enrollment code.

What is the enrollment code? This code is the Foundation's unique identifier. Please contact Nancy at 248-922-9610 or info@amyloidosis.org to request the enrollment code or for more information.



www.amyloidosis.org



Light The Night For Amyloidosis (Continued from page 1)

- AK Anchorage- JL Tower- 3/6/2021
- AL Birmingham- Regions Field- 3/1-3/7 (Birmingham sign)
- AR Little Rock- Union Plaza Building- 3/6, 3/13 and 3/27
- AU/NSW-Sydney- Town Hall- 3/15/2020 (Annually)
- AU/SA Adelaide- Adelaide Oval - 3/7/2021
- CA Moreno Valley- "M" on Box Springs Mountain- 3/6/2021
- CAN/AB- Calgary- Calgary Tower- 3/6/2021
- CAN/AB- Calgary- TELUS Spark- 3/6/2021
- CAN/AB- Edmonton- High Level Bridge- 3/6/2021
- CAN/BC- Maple Ridge- City Hall- 3/6/2021
- CAN/BC- Vancouver- The Sails of Light- 3/6/2021
- CAN/NS- Charlottetown City Hall- 3/6/2021
- CAN/NS- Halifax- City Hall- TBD
- CAN/ON- Burlington- Brant Street Pier- 3/6/2021
- CAN/ON- London- Canada Life (255 Dufferin)- 3/5-3/7
- CAN/ON- London- City of London City Hall- 3/5-3/7
- CAN/ON- London- Dufferin Building (195 Dufferin)- 3/5-3/7
- CAN/ON- London- Fountain at the Forks- 3/5-3/7
- CAN/ON- London- JA Taylor Building- 3/5-3/7
- CAN/ON- London- RBC Place- 3/5- 3/
- CAN/ON- Toronto- Canada Life (330 University)- 3/5-3/7
- CAN/ON- Toronto- City Hall Towers- 3/6/2021
- CAN/ON- Toronto- CN Tower -3/5/2021
- CAN/ON/USA- Niagara- Niagara Falls- 3/13/2020 (From 10:00PM- 10:15PM ET)
- CO Denver- Hyatt Regency at Denver CO Convention Center- 3/6/2021
- FL Fort Lauderdale- B of A Plaza at las Olas City Centre- 3/6/2021
- FL Panama City Beach- Skywheel- 3/6/2021
- IL Chicago - BOMA/ ILLUMINATE CHICAGO (City Skyline)- 3/1-3/7
- IL Chicago - One South Dearborn- 3/1-3/7
- IL Chicago- The Mart- 3/1-3/7
- KS Lawrence- LIED Center of Kansas- 3/6/2021
- KS Manhattan- Flint Hills Discovery Center- 3/6/2021
- KS Shawnee- City Hall- 3/5-3/8 KS Shawnee- Clear Creek Parkway over K-7 Hwy.- 3/5-3/8
- MA Boston - Rose Kennedy Greenway Conservancy- 3/6/2021
- MN Eagan- Sperry Tower- 3/6/2021
- MN Minneapolis- I-35 W Bridge- 3/6/2021
- NC Charlotte - Wells Fargo's Duke Energy Center- 3/6/2021



Light The Night For Amyloidosis *(Continued from page 6)*

NC Greensboro- Greene St. Parking Deck- 3/6/2021
NJ Camden- Benjamin Franklin Bridge- 3/6/2021
NY Brooklyn- Electric Tower- 3/6/2021
NY New York- 230 Park Avenue (Helmsley Bldg.)- 3/6/2021
NY New York- Mid-Hudson Bridge- 3/6/2021
NY New York- Pier 17 (Lightband)- 3/6/2021
NY Yonkers-City Clock Tower- 3/6/2021
New Zealand- Christchurch- Airport Terminal and Airways Tower- TBD
OH Cleveland- Rock and Roll Hall of Fame- TBD
OK Oklahoma City- Crystal Bridge Tropical Conservatory- 3/6/2021
OK Oklahoma City- Skydance Bridge- 3/6/2021
OR Portland- Oregon Convention Center- 3/6/2021
OR Portland- Oregon Convention Center- 3/6/2021
OR Salem- Union St. Railroad Pedestrian Bridge- 3/3- 3/10
OR Woodburn- Woodburn Bridge- 3/7-3/13
PA Bethlehem- Wind Creek Bethlehem- TBD
PA Philadelphia- Benjamin Franklin Bridge- 3/6/2021
PA Philadelphia- Cira Centre- 3/6/2021
PA Philadelphia- FMC Tower at Cira Centre- 3/6/2021
PA Philadelphia- Cira Garage- 3/6/2021
PA Philadelphia- ONE Liberty Place- 3/6/2021
PA Philadelphia- TWO Liberty Place- 3/6/2021
SD Rapid City- Main Street Square- 3/6/2021
TX Dallas- Bank of America Plaza- 3/6/2021
TX San Antonio- Alamo Quarry Smokestacks- TBD
UK/ENG- Bradford-City Hall Clock Tower- 3/11/2021
UK/ENG- Bradford- Forster Square Railway Arches- 3/11/2021
UK/ENG- Bradford- Margaret McMillan Tower- 3/11/2021
UK/WAL- Bangor- Ards Town Hall- 3/6/2021
UK/WAL- Bangor- McKee Clock- 3/6/2021
VA Virginia Beach- Virginia Aquarium & Marine Science Center- 3/8-3/14



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:

<https://amyloidosis.org/2021-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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