News and Stories - Spring 2020

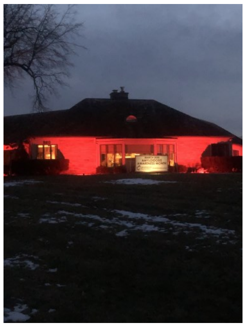
‘Light The Night For Amyloidosis’ Was A Huge Success!

Throughout March, locations around the globe lit for our inaugural “Light The Night For Amyloidosis’ awareness campaign. We had 108 locations in 5 different countries participate.

The countries that took part were United States, Australia, Canada, New Zealand and United Kingdom.

This campaign was created to draw attention to amyloidosis symptoms, diagnosis, treatment and hopefully a cure! Since ‘Amyloidosis Awareness Month’ occurs in March, we also asked our amyloidosis warriors to light their home porch/entryway with a red bulb.

Our community came together and showed their support in a big way. We thank you from the bottom of our hearts for getting the word ‘amyloidosis’ out there! **AF**



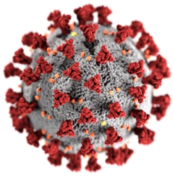
Are you on Facebook?

We have a large community on Facebook with our account and our business page. We have found that we reach more people by sharing stories, articles, webinars, events and news. We try to share something new every day!

In 2018, we were approved as an official charity through Facebook. This means that anyone who has an account can start a Facebook Fundraiser on our behalf. The funds raised are dispersed to us twice a month and Facebook doesn't charge fees on fundraisers for nonprofits.

Starting is easy. They’ll help you get started and give you tips to reach your goal. **Share with friends.** Connect friends to our cause and gain supporters across Facebook. **Get donations.** People can donate to your fundraiser in just a few clicks without leaving Facebook. For more info, find us on Facebook! **AF**

Coronavirus Changes Life As We Know It



The COVID-19 pandemic can be scary and uncertain for anyone, but for the amyloidosis patient, the fears are compounded because of weakened immune systems.

For weeks, the news about coronavirus has filled most of us with dread. Amyloidosis patients have been watching the spread of this pandemic with concern. The high rate of infection puts many patients at extreme risk.

Many are concerned about not only their own welfare, but access to their team of physicians, being able to keep medical appointments or treatments, access to medical supplies, being able to see family members, and financial hardship, which for many was already a stressful subject.

According to health experts, there are things that can be done to reduce the risk of this or any infection. Social distancing, hand washing and avoiding those who are ill are among the top pieces of advice given.

For those with compromised immune systems, there are additional steps to be taken. One of those is wearing a facemask when in a public space. Also recommended is to minimize time spent in public places and touching surfaces that could be contaminated.

Should you become sick, contact your amyloidosis physician immediately. It's important not to flood emergency departments, as immunocompromised patients can be at a higher risk of exposing themselves to more illness.

Keep up-to-date with the latest information from the CDC and your local health authorities and if you have any questions, your amyloidosis team should be your first choice of contact. **AF**

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**

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

- Treatment Centers (US / International)
- Support Groups
- Exercises
- Webinars and Videos
- 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

One of our very important efforts is to raise awareness of amyloidosis among the medical community. We do this in a great way by exhibiting at several medical conferences throughout the year.

Unfortunately with the current Covid-19 environment, the first two conferences of the year have been cancelled, and one coming up in June very well may be cancelled also. Rest assured that we will resume these activities with a vengeance once this settles down. Please take care of yourselves.

Mary

March was Amyloidosis Awareness Month.

We began in 2019/2020 by passing state resolutions and proclamations to recognize Amyloidosis Awareness Month in Tennessee, Michigan, Indiana, Florida, Louisiana, Washington and a city in Kansas. We have advocates working on similar legislation in the following states for 2020: AL, AR, CA, GA, KY, MA, NC, NY, OH, PA, TX, UT, VA and WI. If you're interested in helping to pass this legislation in your state, please contact **kathi@amyloidosis.org** **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**, **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

Rare Disease Week on Capitol Hill

In February, one of our staff members traveled to Washington DC for Rare Disease Week on Capitol Hill.

While there, she took part in different events such as advocating for amyloidosis patients, and giving them a voice on Capitol Hill.

Rare Disease Week kicked off on Monday, February 24, 2020 with FDA's Rare Disease Day Public Meeting. This meeting focused on supporting the future of Rare Disease Product Development.

On Tuesday, there was the Rare Disease Congressional Caucus Briefing. The main discussion was accelerating rare disease innovation across the pipeline, from discovery to access. This was followed by a Patient Advocacy listening session on Gene Therapy and Medical Ethics. The day finished with a documentary screening called 'Tin Soldiers' that shone a light on the victims of a debilitating disease, the hunt to find a cure, and the search for those still locked in darkness.

It's always amazing how each rare disease can emulate each other in so many ways. 95% of the rare diseases still have no treatments available.

On Wednesday, there was a Legislative Conference.

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Ways To Donate

- Memorial/ Honorarium
- Estate/ Property
- Matching Employer Gifts
- Recurring gifts
- Host an event
- Planned Giving
- Facebook Birthday Donation
- Charitable Gift Annuities
- Action Advocate

Rare Disease Week on Capitol Hill

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Since healthcare continues to be one of the most challenging issues, a health policy forecast was given, where Congressional staffers spoke about how Congress will impact healthcare policy in 2020, and how we (as an organizational group), can help to shape the trends.

There were several break-out sessions to elevate our policy expertise, to highlight our priorities, engage on a State level with advocacy and how a Rare Disease Center of Excellence within the FDA would bring rare disease understanding to a new level, removing barriers across centers and divisions to accelerate and improve therapy development.

As they prepared for successful meetings, the rest of the day was spent planning what they would ask of Members of Congress according to our specific community.

Thursday started out with 'Hill Day Breakfast' where our own, Kathi Luis, was the leader of all Michigan delegates. They joined each other to get fueled up for meetings on Capitol Hill, and to receive last minute updates and changes to schedules.

The meetings are based on where the advocate lives, so she met with Michigan legislators (Office of Senator Gary Peters [D-MI], Office of Senator Debbie Stabenow [D-MI], Office of Representative Elissa Slotkin [D-MI-8], and Office of Representative Fred Upton [R-MI-6]).

Friday was a busy day as Kathi traveled to Bethesda, Maryland for Rare Disease Day at the NIH (National Institute of Health). They were welcomed by leaders from NCATS (National Center for Advancing Translational Sciences), NIH and the CEO of the NIH Clinical Center.

NCATS Office of Rare Disease Research (ORDR), gave everyone an update along with resources to empower our patient community. Then were the specific sessions.

Kathi attended a session on Shortening The Diagnostic Odyssey. Amyloidosis patients often spend many years searching for answers before receiving a diagnosis. Diagnosis remains a challenge, but with current advances, we are making progress toward a quicker diagnosis.

Next on the list was genetic diseases. Advances in precision medicine has potential across-the-board implications for those that suffer from a rare genetic disease. They discussed individualized therapy, along with the challenges one could encounter with this approach.

Many rare stories were shared within our neglected communities and non-traditional methods to help gain and expand access were discussed.

They ended the day at NIH with a Town Hall. Many scientific, government and patient leaders were available for Q & A. We will continue to learn to serve you better!

AF

Cardiac Amyloidosis Needs to Be on the Decision Tree

Colonel Gary Supnick

For U.S. Marine Corps Colonel Gary Supnick (retired), the path to being diagnosed with transthyretin (TTR) cardiac amyloidosis was far from straight. Over a period of nearly five years, starting when his primary care doctor heard something "not quite right," Col. Supnick underwent more tests than he can recall only to be told that the cause of his enlarged left ventricle was idiopathic.

Then came cardiologist Eric Harrison, MD, who saw something on Col. Supnick's MRI and had a eureka moment. "Dr. Harrison told me, we need to check you for amyloidosis," Col. Supnick recalls.

The initial tests for amyloidosis came back negative, and Col. Supnick had his doubts. "All that was left was a heart biopsy, and I was close to refusing to do it," he says. "But we went ahead and, sure enough, the biopsy came back positive for wild-type TTR amyloidosis."

Once he had the diagnosis, everything changed for Col. Supnick. In short order, he was at the Mayo Clinic in Rochester, Minn., gaining insight into things that hadn't made sense in the past. For starters, why his workouts had gotten so much harder in the previous decade, so much so that he, a 30-year infantry officer accustomed to doing marathons, had found himself opting for a bike ride over a run.

"I'd attributed the decline in physical performance to aging, but now I think it was the early signs of my cardiac amyloidosis," says Col. Supnick. His Mayo Clinic cardiologist, Martha Grogan, MD, told him that his overall physical fitness and lean body mass had helped mask the symptoms. "She showed me my tests compared to those of a typical 60-year-old man, and said, 'Make no mistake, this is a very sick heart,'" Col. Supnick remembers. "She's been spot on about everything from day one."

Dr. Grogan helped him modify his workouts to avoid extra exertion on his heart, had him adjust his diet to low-sodium and limited fluid intake, and got him into a tafamadis clinical trial. "Until they come up with a way to pull the amyloid crap out of my heart, my plan is staying active, staying lean and tafamadis," he says. It's working so far. "I'm still active. I can't sprint or run 5Ks like I used to, but my wife and I hiked Diamondhead in Hawaii this year. Last year, we went to Yosemite and the Grand Tetons, where the air is thinner. I had to take breaks, but I made it."

Besides following his doctors' recommendations to the letter, Col. Supnick is committed to learning everything he can about cardiac amyloidosis. When Dr. Harrison mentioned that ASNC was hosting a cardiac amyloidosis workshop in Florida last March, Col. Supnick attended. Calling on the concepts he learned as a health/physical education major, he wasn't daunted by a course designed for physicians. "It never

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hurts to get smarter on aspects of your condition and what's being done about it," he says. Among the new things he learned is that there's a noninvasive imaging option, Tc-99m-PYP, that makes it possible for some patients to be accurately diagnosed without undergoing a cardiac biopsy. For Col. Supnick, the most important message from ASNC's workshop—and the one he wants more medical professionals to learn—is that doctors need to get cardiac amyloidosis on their radar and into their diagnostic algorithms. "They've found it's a bigger, more widespread problem than they thought," he says. "So, once a doctor has ruled out other signs and symptoms, they should automatically check for amyloidosis. It should be on the decision tree. It shouldn't be a eureka moment." **AF**

Orthostatic Hypotension: What is it?

Orthostatic hypotension is defined as a decrease in systolic blood pressure of 20 mm Hg or a decrease in diastolic blood pressure of 10 mm Hg within three minutes of standing when compared with blood pressure from the sitting or lying down.

Common symptoms include dizziness, light-headedness, blurred vision, weakness, fatigue, nausea, palpitations, and headache.

Other symptoms include fainting, shortness of breath, chest pain, and neck and "shoulder pad" symptom; where the patient notices an enlargement of the shoulders, causing restriction in the joint due to swelling and/or amyloid deposits in the surrounding tissues.

OH may be a feature of autonomic neuropathy and/or cardiac involvement but is also a feature of volume depletion, which may occur as a result of diuretic treatment.

While low blood pressure isn't necessarily a problem for healthy people, in an amyloidosis patient, blood pressure drop rate could be meaningful. Your amyloidosis physician or team should be made aware of all symptoms. It may even be an easy fix like an adjustment of medications.

User-friendly home BP (blood pressure) monitors are helpful for patients and their healthcare practitioners to be able to keep track of the ups and downs.

If you have low blood pressure, fainting, dizziness upon standing or shortness of breath, contact your amyloidosis physician to see if it could be OH associated with your type of amyloidosis. **AF**

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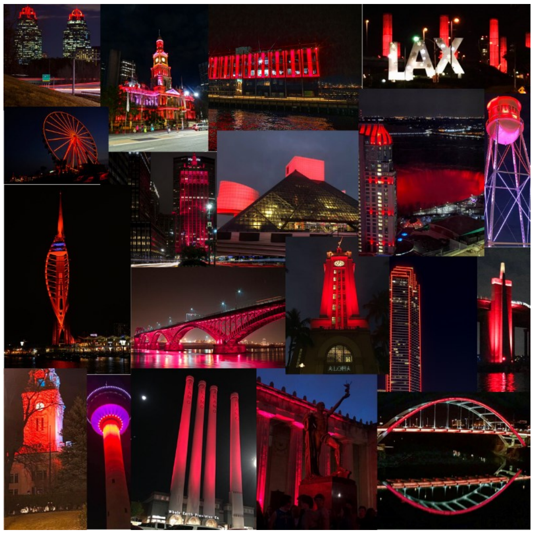

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Thank you to all that participated around the globe and for getting the word out about amyloidosis!