



**amyloidosis  
foundation**



## News and Stories - Summer 2018

### Amyloidosis Brought My Family Together

My name is Jason Conway and I am a husband, father, teacher, and coach. I am 48 years old and have lived a pretty normal, healthy life. I have always been active and have taken care of myself. I am also an amyloidosis patient.

My life changed drastically in January of 2015. I was with my daughter at my son's basketball game and I started having cardiac problems. Being a guy, I just wanted to ignore the racing heart and the difficulty of

walking up the bleachers. My daughter didn't ignore the symptoms and made sure to tell my wife when we got home.

In hindsight, I'm glad she did because the next day I was admitted into the hospital with cardiac related concerns. The doctors diagnosed me with cardiomyopathy. My wife, Libbi, disagreed with this diagnosis because cardio-



myopathy is hereditary and there is no one in my family who suffers from it. Libbi pushed to have a cardiac MRI done.

*(Continued on page 7)*

### FDA Approves Treatment for Hereditary (hATTR) Amyloidosis

Alnylam Pharmaceuticals, Inc. received approval for ONPATTRO™ (patisiran) from the U.S. FDA in August for the first-ever treatment for patients suffering from hereditary (hATTR) amyloidosis.

This is exciting news for the entire amyloidosis community, as other companies are getting closer to having

other treatments become available soon. European regulators have also recommended approval, with a final decision coming shortly.

ONPATTRO™ was shown to improve polyneuropathy (numbness, pain, weakness in hands and feet) in patients and allow them to sustain activities of daily living. This drug is based on a natural cellular process of gene silencing that

represents one of most rapidly advancing aspects in today's biology and pharmaceutical development. By silencing the messenger (RNA), this treatment will prevent the problematic protein from being made.

For more details on this product and to see if you qualify for treatment, please visit their website: [www.alnylamassist.com](http://www.alnylamassist.com).

**AF**



**Education • Awareness • Support • Research**

[www.amyloidosis.org](http://www.amyloidosis.org)



## News from the Amyloidosis Foundation

### Website Update

Have you visited the “**Newsroom**” page on our website? Here you will find the latest updates on research and industry news in



the amyloidosis community. We've added links to this page on our social media channels to keep everyone informed about any future treatments, clinical trials, etc. Please follow us on social media (*details below*) and bookmark our website on your laptop or tablet.

### Fall Webinar

**AMYLOIDOSIS 2030:  
A Syfy Special**

**October 15, 11am (EST)**

A look 12 years into the future at how the risks of AL and ATTR will be managed and the diseases treated.

Hosted by Raymond Comenzo, MD, Professor of Medicine and Pathology at Tufts University School of Medicine.



Please share with your family & friends. Register today online: [www.amyloidosis.org](http://www.amyloidosis.org)



**Anniversary Open House**  
**September 20, 2018**  
**3:30pm—7pm**

**Fountains Golf & Banquet**  
**Clarkston, MI**

Join us to celebrate this special occasion. Our AF board members will attend, plus patients, donors, volunteers, friends, family and members of our local community. See you there! **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
- Toll Free Number **1-877-AMYLOID**
- Listing of experienced physicians that specialize in amyloidosis. Email us anytime with questions: [info@amyloidosis.org](mailto:info@amyloidosis.org)
- Our comprehensive website has information for patients, caregivers and physicians featuring:
  - Treatment Centers (US / International)
  - Support Groups
  - Newsletters
  - Webinars
  - Fundraising Toolkits

## Follow Us



Stay connected for all the latest information on Amyloidosis:

Web: [www.amyloidosis.org](http://www.amyloidosis.org)  
Twitter: [@Amyloidosisfdn](https://twitter.com/Amyloidosisfdn)  
Facebook: [@amyloidosisfdn](https://www.facebook.com/amyloidosisfdn)





## President's Corner

We are so thrilled with the news that the FDA has approved a drug for hATTR patients. Years of research and development, including many patients in clinical trials, have led to this opportunity. Hopefully more new treatments will follow soon, we know you share in our excitement.

Make sure to register for our next webinar on **October 15, AMYLOIDOSIS 2030: A SyFy Special**, hosted by Dr. Comenzo. You won't want to miss this topic, plus we have plenty of time scheduled for your questions.

Fall is coming soon which means it's time for the **2nd annual AF Run/Walk in Michigan on October 13th** and the **3rd annual Pittsburgh Amyloidosis Research Benefit on October 26**. You can find all the details and links to register online on our website, [www.amyloidosis.org](http://www.amyloidosis.org). Thanks as always for your support!

Sincerely,

Mary E. O'Donnell

### *Save the date!*

**3rd Annual Pittsburgh Amyloidosis Research Benefit**

**Friday, October 26, 2018**

**Join us and enjoy a gourmet dinner, live music, wine raffle, silent auction, and more—all in the name of raising funds for amyloidosis research.**

**Montour Heights Country Club**

**Tickets \$175**

***Buy your tickets today: [www.amyloidosis.org](http://www.amyloidosis.org)***

## Board of Directors

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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](mailto:info@amyloidosis.org), **1-877-AMYLOID** (877-269-5643) or **7151 N. Main Street, Ste. 2, Clarkston, MI 48346**

*If you wish to receive a printed newsletter, please send us an email:*

**[info@amyloidosis.org](mailto:info@amyloidosis.org)**



## Four Infrequently Asked Questions, by Raymond Comenzo, MD



**Don Brockman, co-founder of the Amyloidosis Foundation**

### 1. Who is this man?

This is Don Brockman, the patient with AL amyloidosis whose vision for finding a cure for amyloidosis led him and his wife, Mary O'Donnell, to form the Amyloidosis Research Foundation in 2003.

### 2. What happened to Mr. Brockman?

Mr. Brockman sought treatment for AL amyloidosis at all the major centers and with all of the key AL investigators of that day. He bravely enrolled in a clinical trial for a new drug and died while on the trial. Patients who enroll in clinical trials are brave by definition and give substantial meaning to their lives and deaths.

### 3. What happened to the Amyloidosis Research Foundation?

Under the leadership of Don's widow, Mary, the ARF became the Amyloidosis Foundation. Now, 15 years later, the AF has an unparalleled record of achievement—they have distributed over \$1.7 million in grants for global research into all forms of amyloidosis.

### 4. How close are we to achieving Don's vision for a cure?

We are closer to achieving a cure for AL amyloidosis than ever before, and many pharmaceutical companies are developing novel agents that will move us even closer. Many—but not all—AL patients are living for 10 or more years after being diagnosed and treated. The other major type of systemic amyloidosis, ATTR, is the current focus of scientific research. As new drugs come into clinical development, the pace of their success depends on the bravery of patients and caregivers willing to participate in clinical trials as Don Brockman did. The AF has been the major driving force over the past 15 years in pursuit of cures for both AL and ATTR.

### Thank you, Don Brockman

Please show your support for the AF by donating \$15 for 15 years—to raise funds for research, patient education and help to spread awareness for this rare disease.



**\$15 for 15 years**

HELP US CELEBRATE OUR 15TH ANNIVERSARY BY DONATING \$15

DONATE AT: [WWW.AMYLOIDOSIS.ORG](http://WWW.AMYLOIDOSIS.ORG)





The Amyloidosis Foundation is proud to announce that we will be participating in the National Organization for Rare Disorders, Inc. (NORD) Rare Summit in October in Washington, D.C.

During the 2018 NORD Rare Summit, over 700 leaders from FDA, NIH, industry, patient groups, payers and research institutions will address the New Era of Patient-Focused Innovation. Together, NORD Rare Summit

October 15-16, 2018  
Washington, D.C.

**a new era of patient-focused innovation**

**RARE DISEASES & ORPHAN PRODUCTS BREAKTHROUGH SUMMIT™**

[nordsummit.org](http://nordsummit.org)

attendees will explore the new and innovative ways in which patients and caregivers are helping drive progress for the rare

disease community. We look forward to making new connections and learning from this event. **AF**

## Fundraising on Facebook is Easy, Give it a Try!

Have you ever donated online to a fundraiser? For a cause or group that you feel strongly about supporting? Maybe a friend or family member has sent you a donation link, to share details for an event or asked you to help? Well, here is your chance to make a difference.

Since 2017, the Amyloidosis Foundation has had great online support from friends and family members — starting fundraisers in honor or memory of a loved one or their own birthday or anniversary. So far we have raised over \$63,000—with

each fundraiser averaging just over \$400! Crowd funding has grown dramatically over the years, and we are thankful for our generous donors.

Next time you are on FB, use the details below to start your own fundraiser! **AF**

### Support A Cause You Care About! Create a fundraiser to raise money for the Amyloidosis Foundation on Facebook.



**Starting is easy**

We'll help you get started and give you tips to reach your goal.



**Share with friends**

Connect friends to your cause and gain supporters across Facebook.



**Get donations**

People can donate to your fundraiser in just a few clicks without leaving Facebook.



**Did you know?**

**You can create a Facebook Fundraiser!**

Starting is easy. Share with your friends.  
Get donations!

<https://www.facebook.com/fundraisers/>



## Daughter Raises Donations for Amyloidosis Research

In 2015, Addi Lacy had just started the third grade. She decided to start a bracelet fundraiser to support the Amyloidosis Foundation as part of a school project. Her father, Josh, was celebrating his second "birthday", receiving a stem cell transplant in 2013. She wanted to honor him and start a fundraiser as a birthday gift for him on this special day.

Addi is now 11 years old and in the sixth grade. She has sold her bracelets at church, school sports games, to family members and online

with the help of her mom's Facebook page.



on a family cruise and even swam with the dolphins!

Their son, Chet, just turned seven and they all give thanks everyday for Josh's health.

What a special girl Addi is, with such a big heart. We are in awe of her spirit, kindness and creativity. Thank you for your support and the donations you continue to send the AF. **AF**



Addi and her family recently moved from Texas to Wisconsin to be closer to family. They celebrated Josh's fifth birthday

## Don't Miss Out - Make Plans to Join Us in October!

We cordially invite you to participate in our **2nd Annual Amyloidosis Foundation Zombie Run for Your Life!**

**5k/10k Walk/Run.** This event will raise money for our research grant program. The event will be held **Saturday, October 13, 2018 at Independence Oaks County Park in Clarkston, MI.** The 10k will kick off at 9:30 a.m.,

followed by the 5k at 9:45 a.m. Awards will be given for top qualifiers as well as best costume.

**This year is special as we celebrate our 15th anniversary!**

Registration includes: Run for Your Life! Long sleeve tech shirt, medal, prizes plus food & drink.

We still have sponsorships available! All the details are online at our website, [www.amyloidosis.org](http://www.amyloidosis.org). **AF**





## Amyloidosis Brought My Family Together

(Continued from page 1)

I think the doctors agreed just to appease Libbi. That cardiac MRI was crucial to my amyloidosis diagnosis.

Amyloidosis quite often gets misdiagnosed. However, that was not the case for me. Dr. Wheat, a cardiologist in Valparaiso, Indiana read my MRI and diagnosed me with amyloidosis. I can still vividly remember the day that this occurred. Libbi and I sat in Dr. Wheat's office. I knew something was really wrong with my heart, but I figured my diagnosis would include a change in lifestyle and medicine. I was not prepared for the onslaught of new words and phrases that included amyloidosis and oncologist.

Since my diagnosis I have received 16 weeks of chemotherapy and a stem cell transplant at Northwestern Memorial Hospital. This was in conjunction with multiple medications and very long hospital stays. Currently, I am in hematologic remission and receive maintenance chemotherapy once a month to maintain remission.

I would not wish amyloidosis on anyone. Amyloidosis is the hand that I have been dealt. I cannot change this, I can only carry it. The general consensus is that amyloidosis only takes. However, I believe that in some ways,

amyloidosis has given to me. Amyloidosis has brought my family closer together.

It has also given me reason to tell my children, Kelsey, Ethan, and Seth that I love them more frequently. The girls that I coached experienced my amyloidosis journey with me. They were given the opportunity to see that even though horrible things can happen, a strong person with a great support group can persevere. This is an incredibly valuable life lesson.



Although I don't open up too much to my students about my condition, I have had students confide in me that a parent is going through or is getting ready to go through chemotherapy. These students are scared and unnerved.

However, when I tell them that I am receiving chemotherapy, it brings a sense of calm to them.

I am of the opinion that my story is rather boring and insignificant. I am simply a guy who had the unfortunate luck of getting amyloidosis. That's really how I feel. However, out there in my world of supporters, I am sure there are many differing views. I suppose one thing that we can all agree upon is that bad things do happen and with the help of others we are able to carry what we have been given. **AF**

Libbi Conway wanted to give back and support amyloidosis patients and families, knowing first-hand what it feels like. She decided it was time to plan something fun – to help others facing this rare disease. "Cocktails 4 a Cause" was born!

The event in July included a great night of cocktails, live music and amazing food – celebrating with friends and family. The goal was to raise funds for the Amyloidosis Foundation and Northwest Memorial Hospital, where Jason was treated. We are so grateful for people like the Conway's, who want to give back and support others going through this same journey. **AF**

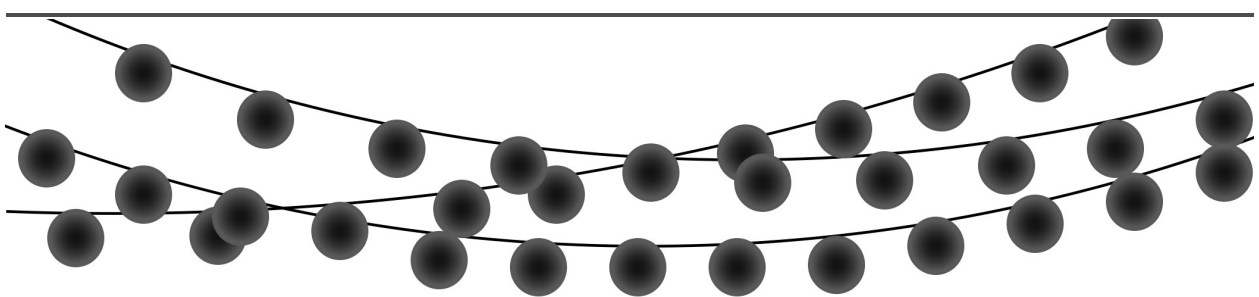






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*Cheers to*  
**15 YEARS**

