



News and Stories - Fall 2017

Join Us for the 2017 Pittsburgh Research Benefit—October 27

The Amyloidosis Foundation is proud to announce the 2017 Amyloidosis Research Benefit in Pittsburgh, PA on Friday, October 27.

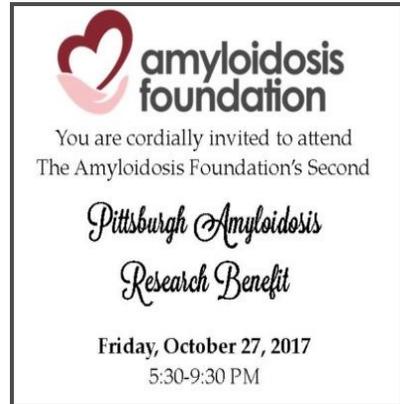
Our goal is to raise donations for the AF Research Grant Program. Since 2005, the foundation has awarded over \$1.4 million to young researchers pursuing a cure for amyloidosis.

Dr. Darcy Tannehill, amyloidosis patient, Pittsburgh resident and member of the Amyloidosis Foundation Board of Directors, is the Chairwoman for our fundraiser.

The event will be at the Montour Heights Country Club starting at 5:30pm. The evening will include strolling appetizers, dinner, live music, cash bar and a silent auction. Proceeds from this event will allow us to continue our support for ground-breaking medical research.

Join us on this special night as we raise funds for research and celebrate our amyloidosis community.

Tickets are \$175 each and tables of eight are available for \$1400. You can purchase tickets on our website,



www.amyloidosis.org.

We look forward to seeing everyone in Pittsburgh on this special night!

Thank you to our generous sponsors below for their support. **AF**



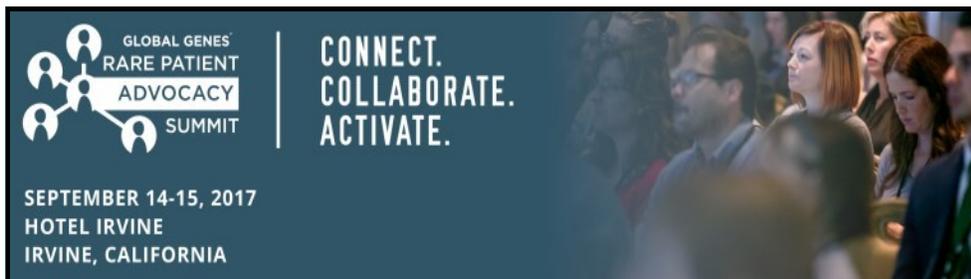
Amyloidosis Foundation Attends Global Genes Summit

The Amyloidosis Foundation attended the 2017 RARE Patient Advocacy Summit in California in September. This important event brings rare advocates from across the globe together to Connect, Collaborate, and Activate.

This educational conference created a space for members of the rare disease community to share best practices, create important introductions, and help catalyze powerful collaborations.

Attendees shared their experience, knowledge, and expertise as conference presenters and connected with patients from around the world.

Spreading amyloidosis awareness was our key goal and it was a pleasure meeting others who share a passion for rare disease patients. **AF**



Education • Awareness • Support • Research

www.amyloidosis.org



We Need YOU to Share Your Patient Story

How did it feel when you or a family member were first diagnosed with amyloidosis? What did you most want to hear about from another patient who was going through the same thing?

On our website and in past newsletters, we've shared many patient stories, about various types of amyloidosis.

Now we are asking you to be brave and show how you are managing your disease, what tips you have, how you keep track of symptoms, doctor appointments and more.

Show your support for others who are fighting this rare disease by writing your story, providing hope,

encouragement and empathy.

Send your story and a few photos to us at: info@amyloidosis.org. Feel free to call us with any questions—we look forward to hearing from you and know that other patients are waiting to read your story. **AF**

New Facebook Page

We have a **NEW** Facebook page ([@amyloidosisfdn](https://www.facebook.com/amyloidosisfdn)) and need YOU (plus your friends & family) to **follow** and **like** our new page. Communicating on social platforms like Facebook and Twitter bring conversations and events into **real time**. Make sure you stay connected and follow us today!

This new page will allow everyone to stay in touch with the Amyloidosis Foundation for the latest news and events in the amyloidosis community and much more. **Why wait? Get online today & follow us! 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

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

- Treatment Centers (US / International)
- Support Groups (CA, TN, WA)
- Newsletters
- Webinars
- Fundraising Toolkits

Follow Us



Stay connected for all the latest information on Amyloidosis:

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





President's Corner

As we change into our scarves and sweaters for Fall, we look forward to seeing everyone in Pittsburgh on Friday, October 27th for the 2nd Annual Amyloidosis Foundation Research Benefit. Special thanks to Board Member Darcy Tannehill, Ed. D. and her daughter Courtney Sullivan for organizing this wonderful event and gathering all the silent auction donations (*including over 75 bottles of wine!*). Last year was a huge success and we are confident this year's event will be even better.

Soon we will be reviewing the applications for our 2018 Research Grants. Your donations help fund these grants and we are thankful for your support. Awardees will be announced in December.

Take care and enjoy the beautiful colors this season brings.

Mary E. O'Donnell

**#GIVING
TUESDAY**

**November 28, 2017
Global Day of Giving**

#GivingTuesday is a day of giving, fueled by the power of social media and collaboration.

Celebrated on the Tuesday following Thanksgiving (in the U.S.) and the widely recognized shopping events Black Friday and Cyber Monday, **#GivingTuesday** kicks off the charitable season, when many focus on their holiday and end-of-year giving.

We ask you to donate to the AF on **#GivingTuesday**, follow us on social media and share our posts with your friends and family to create amyloidosis awareness in your community. **Thank you for your support!**

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Douglas Sawyer, MD, PhD

Jonathan Wall, PhD

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 North Main Street, Ste. 2, Clarkston, MI 48346**

If you no longer wish to receive this newsletter please send us an email:

info@amyloidosis.org



2018 International Symposium on Amyloidosis

The 16th International Symposium on Amyloidosis will be held March 26—29, 2018 in Kumamoto, Japan.

Since the 1st International Symposium on Amyloidosis in Holland in 1967, these gatherings have been *the* place for clinical discussions about new research and the latest achievements from the top investigators in the world.

The ISA has been acclaimed in the various fields of clinical and basic medicine.



The number of participants attending this bi-annual symposium has dramatically increased over the years.

The theme in 2018 will be "Amyloid Research, Winter to Blooming Spring". We look forward to hearing about new breakthroughs at this event and bringing those details to you in our newsletter and website. **AF**



ISA

The XVIth International Symposium on Amyloidosis

2018 KUMAMOTO

Amyloid Research Winter to Blooming Spring

We would like to thank all of our generous donors and volunteers in supporting our mission

Since 2005, we have been able to support the efforts of over 30 researchers, seeking the cause of AL amyloidosis, seeking the effects of investigational treatments on various types of amyloidosis and just trying to determine the underlying mechanisms of the disease.

Support

- Accurate information & Publications
- Treatment center locations
- Clinical Trial Information
- Toll Free Phonenumber
- Webinars with Physicians
- Providing Grand Rounds Speakers
- Exhibiting at Medical Conferences



amyloidosis
foundation



GUIDESTAR
PLATINUM

Awareness



Impact

The Amyloidosis Foundation has awarded over \$1.4 million in research grants since 2005.



Research

Supporting patients and families while promoting research, education and awareness



Birthday Spin a Smashing Success!

Thank you again to Kelli Heald, who chose to celebrate her birthday on August 18th doing what she loves – spinning with friends and family at GritCycle – and raising funds for amyloidosis research. This was the second year for this event and they raised over \$18,000 for

Kelli, her son Jack and daughter Lauren rode together—#4Tres.



#Ride4Tres – in memory of her husband, Tres.

With over 45 riders and lots of community support in Monarch Beach, CA, everyone came out on this important day to raise amyloidosis awareness.

Thanks to all of the donors, riders, sponsors and employees at GritCycle for sharing her passion to find a cure for amyloidosis. **AF**

Marisa (instructor) and Lauren, all smiles...



WWW.GRITCYCLE.COM

The GritCycle crew!



2017 Amyloidosis Foundation Fundraising Events

- October 21: Penny’s Ride for a Cure Bike Race (TN)
- October 21: AF “Run for Your Life” 5K (MI)
- October 27: 2nd Annual Pittsburgh Research Benefit
- November 11: Hills & Hollers Half Marathon/5K (TN)
- November 28: #GivingTuesday—Global Day of Giving

Details & online registration links on our website:

www.amyloidosis.org



Northern Michigan Community Supports “I Ran for Joann”

The Amyloidosis Foundation hosted a 5k run and 2 mile walk on Saturday, July 22, 2017 in honor of Joann Waldo, who passed away from amyloidosis in 2016.

Joann's best friend Shari Tollefson and her daughter Alicia (*in the photo below, Joann was Alicia's God-mother*) organized this fundraiser with lots of help from the community in the beautiful Upper Peninsula of Michigan, during Crystal Fall's Summer Fest.

Thanks to over 150 participants, \$12,000+ was raised which will be used by the foundation for patient support, education, awareness and research leading to a cure for amyloidosis.



Everyone enjoyed snacks and refreshments after the run/walk and they bid on the



We appreciate all the runners, walkers and many volunteers who made this day so special.

basket raffles donated by local companies and friends of Joann.

Plans are being made to make this an annual event. See you next year! **AF**



2017 Chicago Multiple Myeloma/Amyloidosis Rounds

The Amyloidosis Foundation was a partner at the 2017 Multiple Myeloma Rounds in Chicago in August.

Two cases detailing amyloidosis were presented. The first was about the diagnosis and management of amyloidosis in a

patient who is a transplant candidate and the second included the management of a cardiac amyloidosis (non-transplant) patient.

We were proud to be a part of this program that has grown to include a committee of 36

specialists from 24 institutions, providing rounds in 5 cities this year.

This is a unique forum for healthcare professionals to learn the latest information on Multiple Myeloma and amyloidosis. **AF**



AF Attends American Association of Nurse Practitioners Conference

The Amyloidosis Foundation hosted a booth in June at the 2017 American Association of Nurse Practitioners conference in Philadelphia, spreading amyloidosis awareness to their attendees.

Thank you to our Board Members Charlotte Haffner and Sheryl Kernodle, RN (*pictured right*) from Vanderbilt University Medical Center, for volunteering at our booth. Over 4,500 NP's attended the event, and Charlotte and Sheryl were thrilled to speak with everyone and pass out amyloidosis brochures, discuss details about amyloidosis symptoms, diagnosis and treatment options.

One of the foundations objectives is to increase awareness of this disease in



the medical community.

We also have booths at these annual conferences: the American College of Cardiology, American

Society of Hematology, American Society of Nephrology and the Heart Failure Society of America. **AF**

Amyloidosis Foundation Run for Your Life! 5k/10k

Save the Date!

October 21, 2017

Independence Oaks County Park
Clarkston, MI



We cordially invite you to participate in the **Amyloidosis Foundation Run for Your Life! 5k/10k Walk/Run**. This event will raise money to provide medical research and will help fund programs that benefit amyloidosis patients and their families.

The event will be held **Saturday, October 21, 2017** 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. Race includes food, drinks, tech race shirt and custom medal at the finish line.

Join us & register online today!

Photos from Kelli's Birthday Spin #4Tres



The Amyloidosis Foundation appreciates your continued support.

If you would like to become more involved in the foundation, interested in starting a fundraiser or becoming an amyloidosis ambassador—we would enjoy speaking with you and helping in any way we can.

Please call our office today **1-877-AMYLOID** (877-269-5643) or send us an email at info@amyloidosis.org.

Thank you!

