



News and Stories - Summer 2017

University of Utah Amyloidosis Symposium a Big Success

On Friday, June 9 the following groups hosted the first Amyloidosis Symposium in Utah: the Huntsman Cancer Institute, the University of Utah Healthcare and the Amyloidosis Foundation.

The keynote speakers were Daniel Lenihan, MD (*back row, left*) from Vanderbilt University and Raymond Comenzo, MD (*front row, right*) from Tufts University.

Jose Nativi, MD from the University of Utah (*far right*) spoke about TTR amyloidosis and coordinated the event, which included four other physicians from Utah.

Over 120 people attended the symposium: faculty, nurses, medical students, residents, patients and caregivers.

A patient panel was moderated by our Board Member, Charlotte Haffner (*far left*). Thanks to everyone in Utah for your support. **AF**



Annual AF Golf Outing was Fun for All, Raising Funds for Research

Our annual golf outing was held at The Fountains in Clarkston, MI on May 13th. We had great weather and wonderful friends to support the Amyloidosis Foundation — plus many prizes to win!

Over 60 people participated in the event which raised just over \$8,000. Proceeds will support the Amyloidosis Foundation research grant program.



We appreciate our sponsors (special thanks to Prothena), volunteers and most of all the golfers for playing – see you next year! **AF**



More photos on page 8

Education • Awareness • Support • Research

www.amyloidosis.org



Untangling Amyloidosis — Patient Webinar

One of the barriers patients and caregivers face in confronting this disease is confusion about how to diagnose and treat the different forms amyloidosis takes.

On June 1st, we were honored to host a webinar that featured two physicians - **Vaishali Sanchorawala, MD**, a hematologist and Director of the Boston University/Boston Medical Center Amyloidosis Center, and **Frederick L. Ruberg, MD**, the senior cardiologist with the group.



The overall objective was to provide a clear and concise summary of amyloidosis and to empower patients and their families so that they can confront, adapt to, and hopefully defeat this debilitating disease. They discussed AL and ATTR amyloidosis, gave updates on current clinical trials and answered many questions from patients and caregivers. The feedback was strong and people were thrilled to connect with these amyloidosis experts.



Here is a link to view this important presentation:

<http://bit.ly/2r6Ala3>. You can also find this link on our website, www.amyloidosis.org.

This program was supported by an independent grant from Alnylam. **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
- Newsletters
- Webinars
- Fundraising Toolkits

Follow Us



Stay connected for all the latest information on Amyloidosis:

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President's Corner

Finally, the days are warmer, the nights are longer—Summer is finally here!

Special thanks to Vaishali Sanchorawala, MD and Frederick L. Ruberg, MD for presenting our webinar in June. Patients and family members were happy to have their questions answered in a live format. Important and updated information was shared along with details of current clinical trials. We value the physicians time and they also appreciated interacting with patients and care givers in this webinar.

Please stay in touch and let us know how we can support you and your family dealing with this rare disease. Visit us online for the latest information here: www.amyloidosis.org or send us an email anytime at info@amyloidosis.com. We are here for you.

Enjoy the sun and be well,
Mary E. O'Donnell

Save the Date! Pittsburgh Benefit is October 27!

The Amyloidosis Foundation is proud to announce the **2017 Amyloidosis Research Benefit** in Pittsburgh, PA on **Friday, October 27** at the **Montour Heights Country Club**. Our goal is to raise donations for the AF Research Grant Program.

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

Purchase your tickets now online: <http://bit.ly/2aKNzTB> and visit our website for details on reserving your hotel room. **AF**



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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, 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 OR if you wish to receive a printed version, please send us an email:

info@amyloidosis.org

www.amyloidosis.org



Spreading Awareness and Providing Support

by Darcy Tannehill, Ed. D., member of the Amyloidosis Foundation Board of Directors

I was diagnosed with light chain amyloidosis (AL) on May 29, 2012. It's been quite a journey—one that has included chemotherapy (2012), a stem cell transplant (2012), more chemotherapy, (2015), and yet another series of chemotherapy beginning on July 6, 2017. It took over six years and visits to eight physicians to get diagnosed. Even after all those years, I only have some slight heart damage—fortunately. Unfortunately, I still have significant plasma cells in my bone marrow so my light chains are constantly trying to produce at too high a level. Hence, the need for frequent treatments.

Managing amyloidosis is a daily event. Even when I am not in treatment, there are effects from the disease—fatigue, shortness of breath, edema, intestinal problems, and more. However, I decided at the time of diagnosis that I would not just accept it without finding a way to further research for a cure. While I still work full time as a college professor, own a small business, and have many personal activities, I decided that I had to make a much larger differ-

ence in the fight against amyloidosis. That includes: learning all that I can, raising funds for the Amyloidosis Foundation, spreading awareness, and providing support. This has been a huge focus of the past five years of my life.

To that end, my daughter and I held the first Amyloidosis Research Gala last October—we raised over \$40K for the Foundation. Its success made us decide to hold this event every year until a cure is found - October 27th is this year's date.



In addition to raising money, increasing awareness is imperative. There have been a number of smaller stories but I have also been privileged to have the major newspaper in Pittsburgh write an article on amyloidosis and my battle. This was also featured on the local evening



news. Several months later that same local television station asked me to do a guest spot on their morning show to discuss amyloidosis.

In May, I taped a podcast during which I talked about what it is like to live with amyloidosis: <http://bit.ly/2rlKTXZ>. We talked about the need to keep hope alive and never give up the fight!

In addition, I have joined Life Sciences PA, a patient advocacy group that works in my state capitol as well as in Washington, D.C. This will allow me to become more involved in the political side of this battle.

I subscribe to three medical journals to learn all that I can about my illness—I want to know every test result, every treatment detail, and any new research coming in the future. The more I know

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Shop Today and Together We Can Make a Difference

Wear these items proudly and show everyone you are an amyloidosis ambassador. form (<http://bit.ly/2toBXlv>) or call us directly at **1-877-AMYLOID** (1-877-269-5643).

T-shirts—\$25

Wristbands—\$5

Ribbon Lapel Pins—\$8

Note cards (set of 12)—\$15
(tax and shipping included)

You can place your order online, mail in an order



These items make great gifts and people purchase them to create awareness for amyloidosis at their fundraising events.

Show your spirit and shop today! **AF**

Spreading Awareness and Providing Support

Continued from page 4

the more powerful I can be in the fight. All of these things have resulted in contacts with other patients and care providers—a patient from Moscow, Russia found me through the podcast, and we are now connected via Facebook and email.

Several patients and care givers have contacted me from my local area and I am in the process of beginning a local support group.

This will allow us not only to share support but to spread



information about treatments and living with amyloidosis.

I would be less than truthful if I said having amyloidosis is okay—it's not. I hate it with everything in my being. But, I am determined to make the best of a bad situation.

I can do that by doing all that I can to help others beat this awful illness and enjoy their lives as much as possible while doing so. **AF**





His Legacy Makes Us Proud by Kathy Gonzalez

Amyloidosis. A name we had never heard of until the afternoon of August 22, 2016. It is a disease that forever changed our lives.

Our husband, father, grandpa, brother, uncle and friend was diagnosed that sunny afternoon. A team of skilled doctors, led by Dr. Nativi at the Huntsman Cancer Institute in Utah, gave us the news they had suspected for months.

Hans Nievaard was born in Holland in 1942. He immigrated to the United States at the age of 8. During his life, he lived briefly in California, but called Utah home. He lived a very healthy life. Several years earlier he overcame the trial of open heart surgery but he could not overcome the cruelty of this disease.

For about six months we watched him go downhill. He tackled each day with a smile and the determination to fight. He never lost his spirit or his dignity.

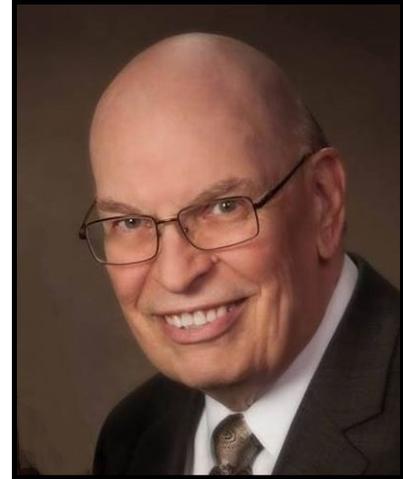
Just over a month after being diagnosed he passed away quickly and peacefully on September 16, 2016. He died in the loving arms of his wife of 50 years, his sweetheart Gerrie.

He spent nearly 50 years running his own CPA practice. His work was more of a hobby. His clients were considered friends. His repu-



tation for being honest and fair was known by his colleagues.

His greatest pride and joy was his family. He dedicated his life to providing family adventures and incredible memories to cherish. He loved to explore this world and travel. Regardless of where he was, he left an impression



on those he met.

Has was a life-long member of the LDS faith. A Mormon. A man who devoted his life to serving others. He was very generous and would help anyone in need. His shoes will not be easy to fill.

Our wish is to spread information and raise awareness of this disease. Diagnosis comes too late and for most people it is already terminal.

His legacy makes us proud. We love and miss this great man. He will never be forgotten. **AF**

2017 Amyloidosis Foundation Fundraising Events

- **July 22:** "I Ran for Joann" (MI)
- **October 19:** Bike Race/Fun Ride (TN)
- **October 21:** AF "Run for Your Life" 5K (MI)
- **October 27:** Annual Pittsburgh Research Benefit (PA)

Details & online registration on our website below:

www.amyloidosis.org



Updates on AF Fundraisers Held in Spring 2017

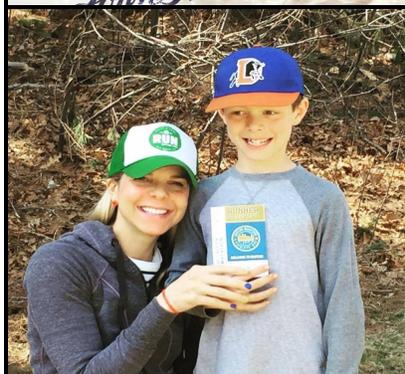


Amy Menard ran the Boston Marathon on April 17 and raised over \$2905! Her event was dedicated to the memory of her Mother-in-Law, Joyce Menard, a loving daughter, sister, Mother and Grandmother.

Alicia Conrad raised over \$1840 by participating in her first Half Ironman Triathlon on May 21st in Chattanooga, TN.

For those unfamiliar with a Half Ironman race, it consists of a 1/2 mile swim, a 56 mile bike ride and a 13.1 mile run.

Alicia ran in memory of her friend, Melanie Gretzinger, who died at the age of 53 from complications from amyloidosis. She was a young, vibrant woman who is deeply missed.



On May 7 Brian Rossetti participated in the Pittsburgh Half Marathon and raised \$1200 for the Amyloidosis Foundation.

He ran in memory of his Aunt Nancy, who passed from AL amyloidosis in 2016. He is hopeful that this donation will help fund future research for better treatments and ultimately a cure for this devastating disease. **AF**

Researcher Jonathan Wall, PhD Receives \$1 Million Grant from NIH

Reprinted with permission from the University of Tennessee Health Science Center

Congratulations to the University of Tennessee Health Science Center's Jonathan Wall, PhD, professor in the Graduate School of Medicine and director of the Amyloidosis and Cancer Theranostics Program in Knoxville, on receiving a new three-year grant totaling \$1,050,000 from the National Institutes of Health to study "Pre-targeting Immunotherapy for Light Chain (AL) Amyloidosis."

Dr. Wall has been with UTHSC since January 1995, and has received continual funding to study amyloidosis for almost 10 years (in the back row, with glasses).

The Knoxville research program has been working on



amyloidosis for over 50 years, developing new diagnostic techniques and drugs for this rare disease. **AF**

Annual AF Golf Outing was Fun for All, Raising Funds for Research

AF BOD Dante Burchi (left) & his golf partner looking good!



Aaron Hamp (right) and his friend enjoy the day!



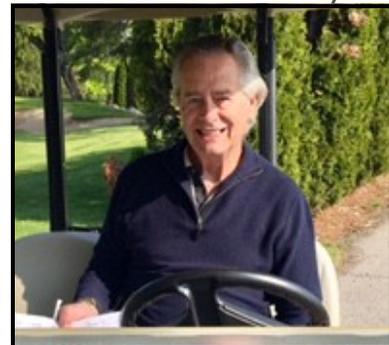
Nick Hamp & friend ready to tee off!



Cooper & Kovach foursome causing trouble!



Former Development Director, Boris Sellers, came back to celebrate his birthday!



Great raffle prizes!



Thanks to our volunteers!



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!

