



**amyloidosis
foundation**



News and Stories - Winter 2015

Nashville Gala was a Great Success!

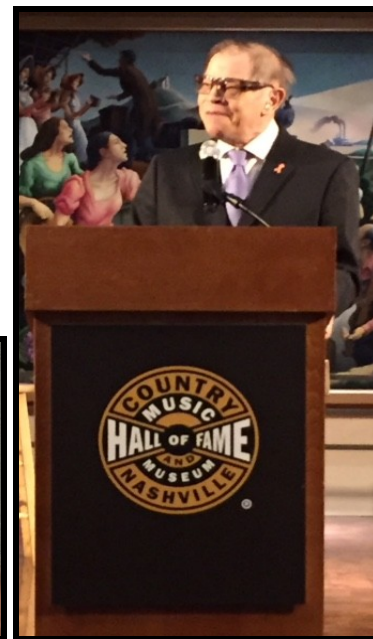
Thank you Nashville! What an amazing evening we all had on Friday, October 16, 2015 for our Nashville Gala, in the beautiful Country Music Hall of Fame. Patients, friends, families and physicians all came together for a night to celebrate and raise funds for our amyloidosis community. Actor Michael York spoke about his amyloidosis journey and gave an impromptu performance of Shakespeare!

Everyone enjoyed the beautiful dinner and wonderful live music from The Kentucky Linemen. The silent auction had many unique items which raised funds at the event. Proceeds will be donated to the Amyloidosis Foundation

and the Amyloid Research Fund at Vanderbilt University Medical Center.

Thank you again to everyone that attended the gala, plus those who donated or volunteered and took the time to be a part of this special night. Big thanks to our Gala Chairmen Charlotte Haffner, Rosanne Johnson and Daniel Lenihan, MD, Vanderbilt University School of Medicine.

Thank you to our sponsors Alnylam, Prothena and Takeda Oncology. We appreciate your continued support. **AF**



2015 Amyloidosis Foundation Patient Day

The Amyloidosis Foundation hosted a team of highly-regarded medical specialists in Nashville on October 17th, to join patients and their families for a day of amyloidosis information and discussion titled "Raising Awareness, Improving Care and Enhancing New Treatments."

The agenda included medical presentations representing the following institutions: Vanderbilt University School of

Medicine, Memorial Sloan Kettering Cancer Center, Boston Medical Center, The University of Tennessee Graduate School of Medicine and Tufts University School of Medicine.

Our day concluded with an open patient forum discussion with speakers Allen Freytag, Leslie Schumacher-McKee, Darcy Tannehill plus Michael York.

They shared their personal stories of triumph and it was empowering to listen to them speak about their struggles, strengths and faith.

Thank you again to our sponsors Alnylam, Prothena and Takeda Oncology for your support at both of our Nashville events. A special thank you to the Vanderbilt University Medical Center and Charlotte Haffner for assisting with the coordination of this event. **AF**

Education • Awareness • Support • Research

www.amyloidosis.org



ARC Hosts Patient Forum with the FDA



On November 16th, the Amyloidosis Research Consortium (ARC) hosted an historic event. Over 220 people from all over the nation came to Silver Spring, MD to participate in a patient forum with the U.S. Food and Drug Administration (FDA). The meeting was simultaneously webcast with another 500 people watching it live, while still more are viewing the meeting daily on the ARC website. The webcast and more information about the meeting is available at: <http://www.arci.org/fda-page>

The day was structured around successful patient focused drug development meetings previously held at the FDA.



There were patients, caregivers and advocates who covered the whole spectrum of the disease; from newly diagnosed to those that have lived with it for years. Patients talked openly and honestly about their experience of living with AL and ATTR amyloidosis; discussing quality of life, the burden of the disease, existing treatments, clinical trials and the unmet need of patients.

These discussions and the report that will be generated out of this meeting will be an important resource for the FDA and industry to refer to when they design and evaluate therapies for our patients.



Isabelle Lousada,
ARC President & CEO

Among the many FDA members who attended were regulators from the different divisions who



are responsible for evaluating amyloidosis therapies. We were very fortunate to have Dr. Woodcock in attendance, the director of the Center for Drug Evaluation and Research.

The ARC was established earlier this year to bring together all those in the amyloidosis field to collaborate and expedite the evaluation of treatments for amyloidosis.

Together with the AF programs that support patients, education and awareness, we look forward to a bright future. **AF**

Follow Us

Stay connected for all the latest information on Amyloidosis:

Web: www.amyloidosis.org
Facebook: [Amyloidosis Foundation](#)
Twitter: [@Amyloidosisfdn](#)
LinkedIn: [Amyloidosis Foundation](#)



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
- Accurate informational pamphlets
- New & comprehensive website with information for patients, caregivers and physicians
- Toll Free Number **1-877-AMYLOID**
- Listing of experienced physicians that specialize in amyloidosis, it's diagnosis and treatment. Email us anytime with questions: info@amyloidosis.org



President's Corner

The holidays are here and we at the Amyloidosis Foundation are thankful for your continued support this year. The amyloidosis community is a family, even though we are all spread across the United States and beyond, we stay connected and push toward a cure.

It was wonderful to see so many familiar faces in Nashville in October at our Gala and Patient Day events, plus lots of new faces who we have communicated with this year via email and social media. At the ARC Patient Forum, it was powerful to listen to the many patient voices tell their stories and share the amyloidosis journey of their own family as well.

Remember **#GivingTuesday** is **December 1st**, we appreciate your donations on this day of philanthropy.

Everyone at the foundation wishes you and your family happy holidays and a joyful new year.

- Mary O'Donnell



RARE DISEASE DAY USA

Save the date for **Monday, Feb. 29, 2016** (the rarest day of the year) to celebrate **#RDD2016!** If you are interested in planning an event, we would love to hear from you. The amyloidosis community participates in events nationwide on this important day.

You can also contact the National Organization for Rare Disorders (NORD) at rdd-us@rarediseases.org. See more at: www.rarediseaseday.us.

Join others in your community to raise awareness. Be an advocate in your own state to make your voice heard!



Board of Directors:

Board Chairman
Isabelle Lousada

President
Mary O'Donnell

Treasurer
Dante Burchi

Secretary
Uria Espinoza-Leopold
Raymond Comenzo, MD

Charlotte Haffner

Dena Heath

Robert A. Kyle, MD

Giampaolo Merlini, MD

Martha Skinner, MD

Scientific Advisors:

Raymond Comenzo, MD

Rodney H. Falk, MD

Morie Gertz, MD

Giampaolo Merlini, MD

Vaishali Sanchorawala, MD

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

info@amyloidosis.org

www.amyloidosis.org



You've Seem Them Care, Now Show You Care About Them

November was National Caregivers Month, here are some ideas to give thanks

Reprinted from October 2015 AARP.org by Amy Goyer. Copyright 2015 AARP. All rights reserved.



1 Bring her a low-maintenance houseplant

2 Take in his mail

3 Shovel snow from her driveway and walkway

4 Grab his grocery list and go shopping

5 Arrange a play-date for her kids



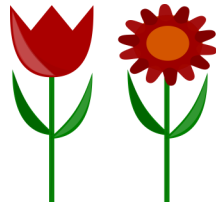
6 Gas up his car

7 Encourage her to relax with a gift of bubble bath

8 Do a load of his laundry

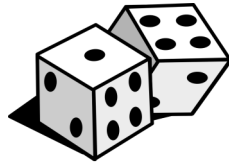
9 Take her kids or grandkids to a movie

10 Do some holiday shopping for him



11 Send her flowers

12 Bring over a guitar and sing familiar songs



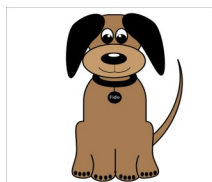
13 Stop by with a board game to play



14 Take him out for coffee

15 Teach her a skill she admires you for

16 Visit him with a pet that has a sweet disposition



17 Send her to a day spa for some pampering



18 Buy him a coupon for exercise classes

19 Take her dog on a hike

20 Drop off his packages at the post office



21 Give her a foot massage



22 Water his flowers

23 Do her dishes

24 Bring a favorite movie and watch it together

25 Return his library books

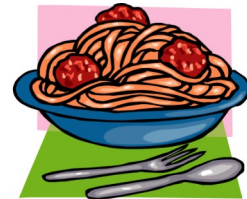


26 Mow her lawn

27 Wash his car

28 Arrange for a housecleaning service to visit

29 Cook and deliver a meal he likes



30 Clean her gutters

31 Replenish his coffee or tea supply



32 Bring ingredients and cook a meal with her



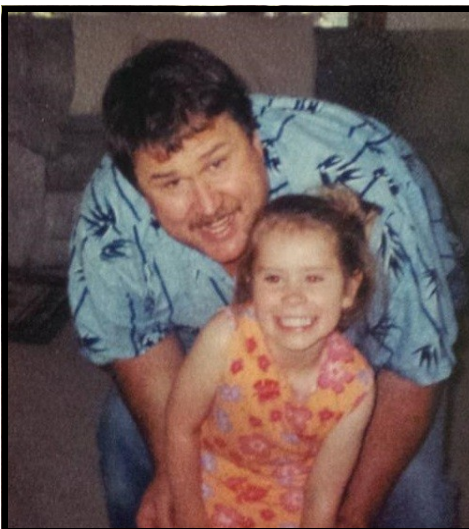
Running to Support Amyloidosis Research

In August of 2014, Cari Archer lost her father, Corey Shaw, to amyloidosis.

Doctors stressed the importance of optimism, but the family still felt as if they were facing the fight blindfolded. For her father, a copious amount of amyloid protein collected in his nervous system, kidneys, liver, stomach and heart. He had to navigate every day with neuropathy, zero appetite and crippling weakness.

They were told by his physicians that there is no cure for amyloidosis, but that treatments, such as chemotherapy and a stem cell transplant, could help to limit further production of the protein.

Corey agreed to throw everything modern medicine had at his disease; however, his organs were unable to keep up the fight with him. He passed away on August 17, 2014.



In his memory, Cari is dedicated to increasing awareness and raising funds for medical research to help others who suffer from amyloidosis. Her goal is to do everything she can to save another family from the terrible pain she and her family had to endure at the hands of this disease.

On October 11, 2015 Cari ran the Bank of America Chicago Marathon in honor of her father.

She says she ran because her dad and others like him are no longer able to.

Every step of every mile was dedicated to those who have suffered through this debilitating disease. Her goal was to raise funds needed to advance research and treatment to save lives.



The Amyloidosis Foundation set up an electronic fundraising page that Cari was able to share with friends and family. Her goal was to raise \$2,000 and she surpassed that, in the end raising \$2370 for amyloidosis research.

We are so thankful for Cari and her many supporters who chose to donate and make a difference. **AF**

Contact us if you would like more information to start **your** own fundraiser!

Join the AF team TODAY!!

1-877-AMYLOID or

info@amyloidosis.org



Our Amyloidosis Journey Ends with a Miracle

by Jayne Pike

My husband George has cardiac Amyloidosis.

Our journey with amyloidosis began when George was diagnosed in November of 2005 and given six months to live. That was not part of our life plan...through prayer, modern medicine and a wonderful support team, George underwent extensive treatment and clinical trials and is still here today.

Let me tell you a little bit about George. He obsesses over home projects, the tiniest detail has to be drawn and planned before a hammer hits the nail. When it came to Amyloid, however, his approach to keeping positive was to mentally distance himself - George didn't want to know any potential risks or side effects - if you told him that an upset stomach during stem cell replacement might occur, it would have turned into an ulcer.

George abdicated his health choices to me - a major responsibility, a burden and an honor. Some wives say "he couldn't live without me". However, in my case, it's actually true.

George was diagnosed at Boston Medical Center by the incredible Dr. David Seldin. George's medical team, led by Dr. Seldin and Dr. Sanchorawala, have taken us on a journey - starting with high dosage Melphalan and autologous stem cell transplant in January of 2006. George received a partial response and we watched anxiously over the next year as his free light chains began to increase.

George participated in his first clinical trial for Open-Label Phase 1/2 Study of Velcade

Injection in September of 2007 but was prematurely stopped due to neuropathy. Again we watched his free light chains continue to increase over time.

George began his 2nd clinical trial of Phase 2 Revlimid with Dexamethasone from May of 2009 until May of 2011. I have to admit I liked the initial effects of George on steroids - always very frugal, George suddenly wanted to buy new furniture and remodel our kitchen. But the negative side of steroids on George's heart resulted in a heart attack in August of 2009. We decided to continue the trial with Revlimid only. George received a strong response to Revlimid.

George has quarterly check-ups at BMC - we are blessed to have such an amazing team! But Amyloid is a tricky disorder - within two years, George's light chains were again on the rise.

In October of 2014, George began a Phase 1/2 trial of Pomalidomide and Dexamethasone - designed specifically for patients with AL Amyloidosis who had been previously treated. I was nervous about the addition of Dex though I did want a new bedroom set - but my worries have now become joy. Just recently, BMC advised that George was in complete remission after a year of clinical trial treatment.

Another miracle for my husband, my family and for all patients with amyloidosis.



I have to admit that at the beginning of this journey, I would have said that Kappa and Lambda were fraternity houses. But after a decade of being a caregiver to someone who didn't want to admit weakness; who didn't want to admit he was even sick - I have to say that this is my legacy - my gift to my husband - along with a lot of help from Boston Medical Center.

Our gratitude towards BMC cannot be expressed in words - our treatment team, including the wonderful Anthony Shelton, has continued to push us in the direction of better health.

How can a decade pass without an approved treatment protocol for amyloidosis? My husband was diagnosed when our son, Tom, was only 11 years old - a student in the 5th grade. George has lived to watch Tom go to his senior prom, his high school graduation and enter his senior year of college.

Please help us in this journey - please help us find an approved treatment plan. **AF**

***Jayne kept a journal during George's treatments and is moving it into a blog:*
www.radiateharmony.com.



Shop for Friends and Family plus Support the Amyloidosis Foundation this Holiday Season!

All items make great gifts and are available for purchase online at our website: www.amyloidosis.org. You may also call the office if that is more convenient for you: **1-877-AMYLOID (877-269-5643)**. Tax and shipping are included. Shipped within 24 hours of order. **Thank you!**



Wristband—\$5.00

A great way to show your amyloidosis awareness spirit! **Available sizes:** Adult or child



Adult T-shirt—25.00

Perfect for fundraising events and more, show everyone you are an advocate for action.

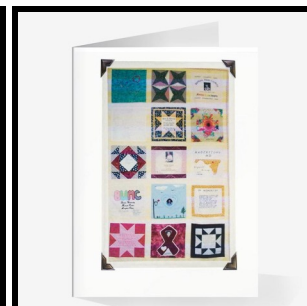
50% cotton/50% polyester.

Available sizes: S, M, L, XXL



Ribbon Awareness Pin—\$8.00

Wear your pin proudly and show everyone you are an amyloidosis ambassador.



Note cards—\$15.00

Unique, printed to order note cards. The image represents a quilt; each quilt block was beautifully created by someone living with amyloidosis. 12 note cards and envelopes.

#GIVINGTUESDAY™ on Dec 1, 2015

Since its inaugural year in 2012, **#GivingTuesday** has become a movement that celebrates and supports giving and philanthropy. Now in its fourth year, **#GivingTuesday** is a global day of giving fueled by the power of social media and collaboration.

Observed on the Tuesday following Thanksgiving 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.

The Amyloidosis Foundation is looking forward to connecting with our supporters on this special day. **Please save the date & start thinking NOW about how you can be a part of this.**

Encourage your friends and families to donate in honor of Amyloidosis.

We have a special **#GivingTuesday** donation page for everyone to use on our website: www.amyloidosis.org. Copy the link and send to your contacts to encourage philanthropy towards finding a cure for amyloidosis. **Thank you for your support.**



Thanks to all who attended our 2015 Nashville Gala!



**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 anyway we can.

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

Thank you!

