



amyloidosis
foundation

WE ARE ON A MISSION

ANNUAL REPORT

MARCH
2017

On behalf of the foundation I would like to thank all of our generous donors and volunteers in supporting our mission. The importance of every donation is immeasurable.

Since 2002, we have been able to support the efforts of over 30 researchers, some seeking the cause of AL amyloidosis, some seeking the effects of investigational treatments on various types of amyloidosis and some just trying to determine the underlying mechanisms of the disease.

Although no miracle breakthroughs have been found, all of this research is important in the overall understanding of amyloidosis and future breakthroughs.

Your generosity also allows us to help patients and their families to better understand amyloidosis and raise awareness of this rare disease.



Again, your generosity is greatly appreciated.

Sincerely,

A handwritten signature in blue ink that reads "Mary".

Mary E. O'Donnell

President

Amyloidosis Foundation



"Upon my diagnosis of AL amyloidosis in 2012, I was so pleased to find the Amyloidosis Foundation, an organization dedicated to discovering a cure through supporting research and increasing awareness in the medical and general populations.

The information and support they provide to patients and families impacted by this rare disease is comforting and powerful. All of these things together give us a fighting chance to survive.

I am extremely grateful for all of their accomplishments."

Darcy Tannehill, PhD

Our Focus

Supporting amyloidosis patients and families while promoting research, education and awareness.

Patient Support

Our services are available to people with amyloidosis, families, and caregivers.

- Toll Free Phone Line
- Webinars with Physicians
- Accurate Information & Publications
- Treatment Center Locations
- Clinical Trial Information

Research

The Amyloidosis Foundation has a grant program targeting young researchers and has awarded over \$1.4 million since 2005.

The AF is also dedicated to encouraging scientists by providing travel grants. These grants enable participation in the bi-annual International Amyloidosis Symposium.

Medical Community

One of the foundations objectives is to increase awareness of the disease in the medical community. We accomplish this by:

- Providing Grand Rounds Speakers
- Exhibiting at Medical Conferences
- Publishing/Distributing Brochures

Making Progress

The Amyloidosis Foundation was founded by a patient, for all patients.

We are determined to continue making a difference. With your help we can.

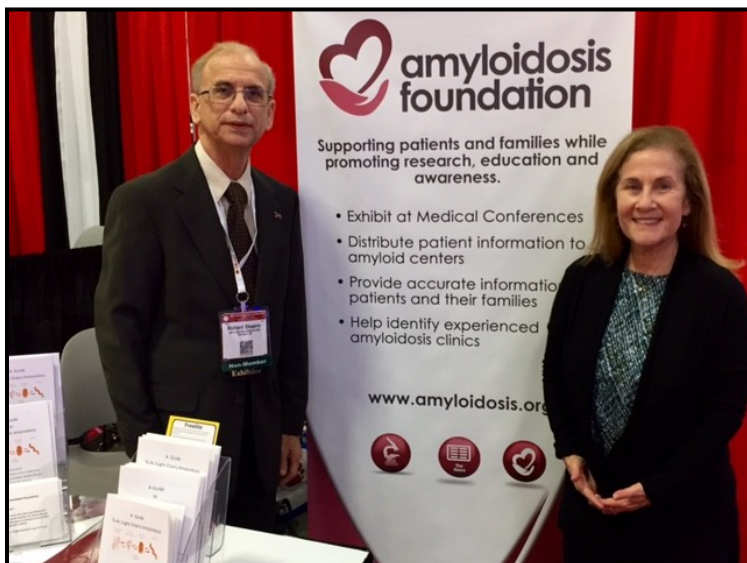
"The Amyloidosis Foundation has provided a haven for patients with support and information regarding new treatment options and updates on cutting edge research. This empowers patients following the diagnosis of amyloidosis. This function of the foundation is immeasurably important.

Their research grants support young investigators from around the world, striving for solutions to benefit patients.

Members of the AF are dedicated, driven and an inspiration to us all."

Jonathan Wall, PhD

University of Tennessee, Graduate School of Medicine



Richard and Ruth Shapiro, longtime Amyloidosis Foundation volunteers, spreading awareness at our booth at the 58th American Society of Hematology (ASH) annual meeting in San Francisco in December 2016.

2016 Highlights



1,531

Grand Rounds
Attendees-
Doctors teaching
doctors

2,050

2016 Total
Number of
Donors



62,487

Facebook Likes-
Up 5.8%

48%

People using a
mobile device to
access our website



1,198

Twitter Followers-
Up from 853 in
2015

283,085

Page Views on
our Website



2017 Research Grant Recipients

We invest in outstanding scientific research and innovative research models to expedite promising therapies to patients. Through our research program we encourage, promote and invest in the medical study and exploration of the amyloidosis diseases.



Emily Martin - PhD
A Method to Predict Amyloid Risk in Patients

Amyloidosis Foundation Donald C. Brockman Memorial Research Grant

University of Tennessee Medical Center
Medicine Division: Amyloidosis



Lorena Saelices - PhD
A Novel Strategy for the Treatment of ATTR

Amyloidosis Foundation David Seldin, MD, PhD Memorial Research Grant

Regents of the University of California, Los Angeles



Petros Moustardas - PhD
Novel Therapy for Renal Amyloidosis

Amyloidosis Foundation Research Grant

Linköping University, Sweden
Medicine Division: Microbiology & Molecular Medicine

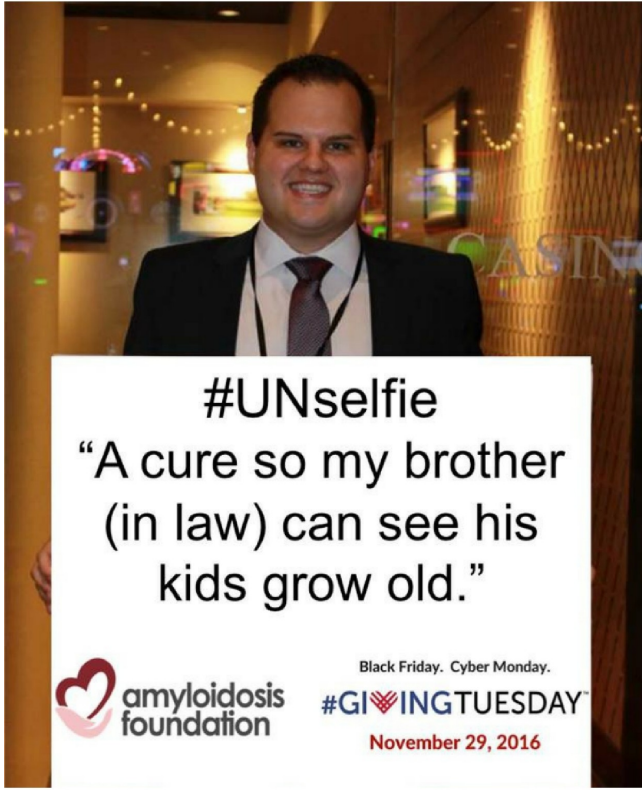


Carolina Lemos - PhD
New Biomarkers for FAP

Amyloidosis Foundation Research Grant

University of Porto, Portugal
Medicine Division: Molecular Biology

Awareness in Action



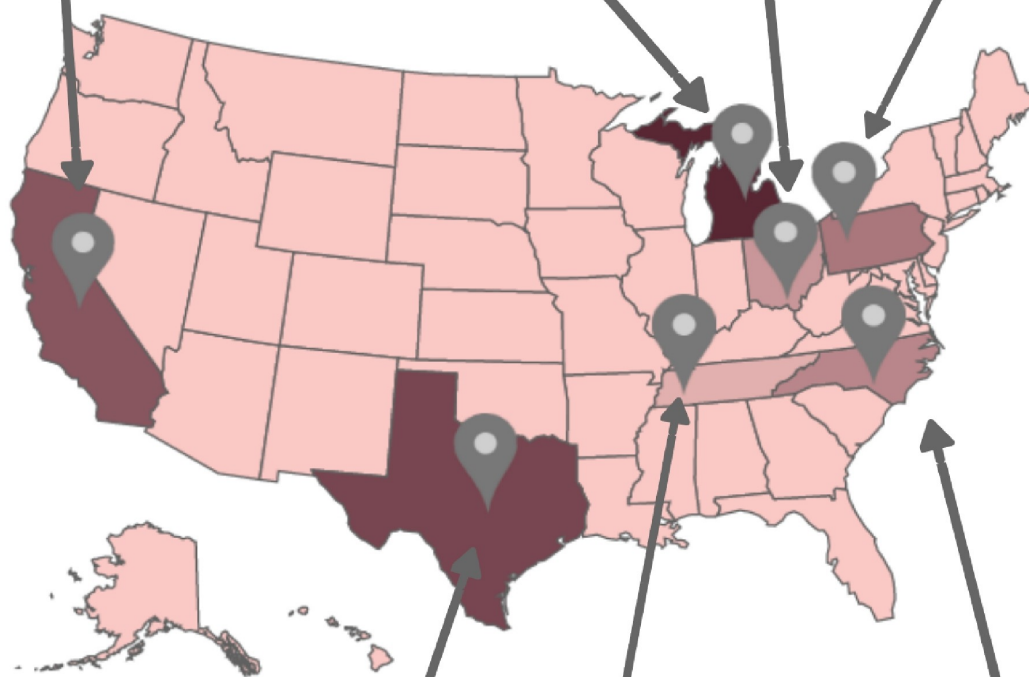
Events Held Around the U.S.

Run #4Tres **\$10,700**
Kelli Heald's birthday
spin party
\$11,500

#GivingTuesday **\$4,600**
Prieber Open **\$4,900**
AF Golf Outing **\$7,300**

Cincinnati Spin
Fundraiser
\$760

Pittsburgh Benefit
for Amyloidosis
Research
\$34,600



Addison Lacy
sold bracelets
at school to
benefit AF **\$410**

Hills & Hollers Half
Marathon/5K
\$3,000 to AF

Golf Tournament
to benefit John
Lindley and AF
\$500

Events Up Close



\$34,600

The Amyloidosis Foundation hosted a benefit at the Montour Heights Country Club in Pittsburgh, PA on Friday, October 28, 2016 and what an amazing night it was! Over 120 people attended this event to raise funds for our AF Research Grant Program. Darcy Tannehill, Ed.D., and her daughter Courtney Sullivan were Chair and Co-Chairs.



\$4900

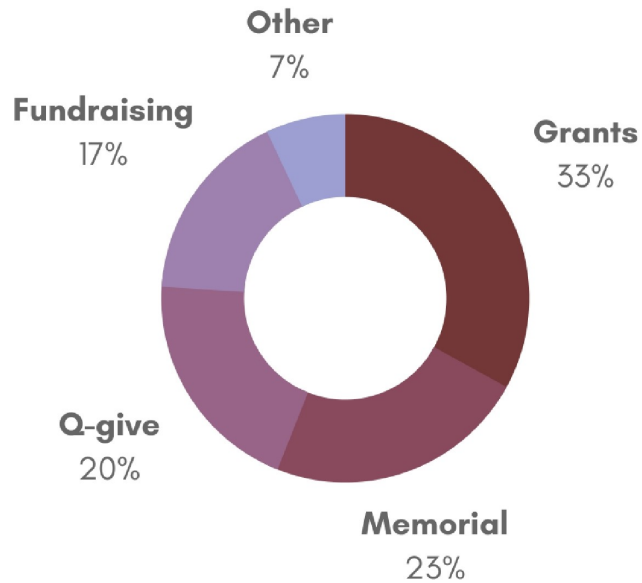
On August 13, 2016, over 300 golfers took to the links in The Prieber Open, to honor the memory of Christopher Priebe and raise awareness. He was diagnosed in October 2015 and passed in February 2016. His wife Johna wanted to share his spirit for life and raise funds for others struggling with this rare disease.



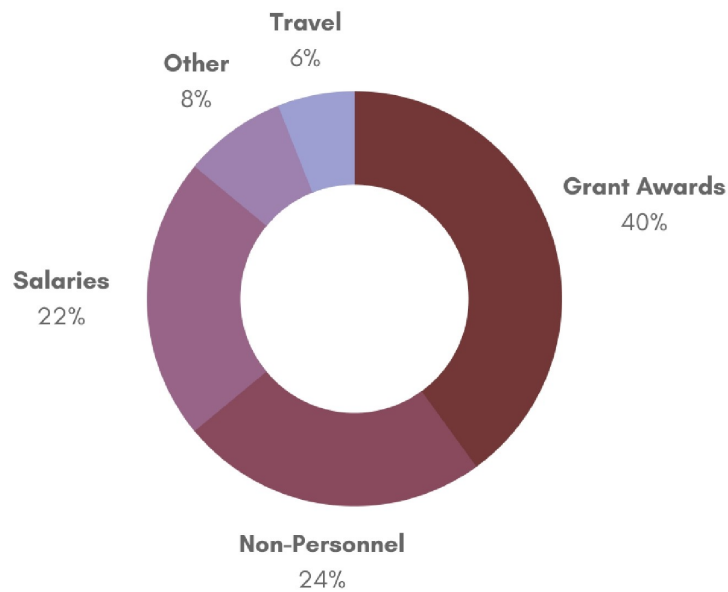
\$7300

The annual AF golf outing was held at The Fountains in Clarkston, MI on Friday, September 30, 2016. A great day was had by all – our raffle had over 40 baskets and gift certificates for our participants, including many families affected by amyloidosis. Special thanks to Prothena for being a sponsor as well.

Support & Revenue



Expenses



Financials

Statements of Activities (Non-audited) - Year End December 31, 2016

Support & Revenue

Contributed Support	576,381.69
Investment Income	2,995.37
Fundraising	132,494.22
Earned Revenues	2,621.50
Realized Gain/Loss	-2,729.49
	<hr/> <hr/>
	711,763.29

Expenses

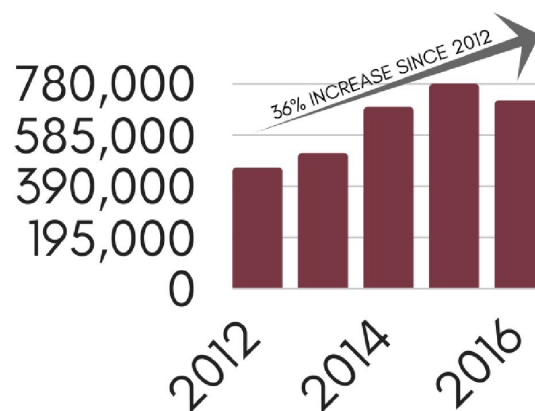
Grant Expense	255,486.08
Salaries & Related Expenses	140,426.77
Other Personnel Expenses	14,825.00
Non-personnel Expenses	154,262.42
Occupancy	13,260.04
Travel & Meeting	39,267.98
Miscellaneous Expenses	17,950.43
Business Expenses	3,885.00
	<hr/> <hr/>
	-639,363.72

Net Income/Liability

72,399.57

Gross Income

Five-Year Snapshot



We thank the following individuals and families who have donated to the Amyloidosis Foundation. Our work is made possible by your generosity. It is through these donations that we are able to continue to support research.

\$4000-\$9999

Barbara Carney
Gail Craddock
Roland Gilles
Eleanor Laughlin
Sandy Pope

\$2000-\$3999

Doreen Finnerty
Sharon Gibson
Joseph Hardy
Eric Heald
Otis Heald
Present Troubles Racing
Quattro
Southern Historical Showcase
Lisa Werkstell

\$1000-\$1999

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Kyle Roberts
Jeanne Rosenthal
Paul Ryan
Owen Saddler
The Salem Country Club, Inc.

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TCF Bank
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Gus Varon
Michael Walch
James Ward
Carolyn Williams
Gary Wrigley
YMCA of Greater Flint

\$250-\$499

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Ansel Van Zandt
Joseph Vaughn
David Vesole
Visible Communication
Kristin Warbasse
George Watchko
James Weiss
West Side Beer Distributing
Kent Woodward
Darby Yohman
Roslyn Zankic

The Amyloidosis Foundation would like to acknowledge the following for their generous gifts:

- Chip Miller Charitable Foundation
- Henry J. Kaiser Family Foundation
- IGD Solutions Corp.
- IONIS Pharmaceutical

- Prothena Biosciences
- The Rueter Foundation
- Jane and Frances Stein Foundation
- Phyllis & Perry Schwartz Foundation
- Takeda Oncology

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Donations

Our vision is to help amyloidosis patients and families who need us and fund research for a cure.

Help make this happen by donating today:

www.amyloidosis.org



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Action
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Together We Can Make A Difference

You are the reason we can keep providing vital support for people living with Amyloidosis.

Give online:

www.amyloidosis.org

Give by phone:

1-877-AMYLOID

Give by mail:

Amyloidosis Foundation
7151 N. Main St., Suite 2
Clarkston, MI 48346

Visit our website for upcoming 2017 events.



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