

Message

Every day I feel gratitude: for our donors, researchers, volunteers, Board of Directors, patients, caregivers, physicians and the staff here at the Amyloidosis Foundation. You all empower me, and the foundation as a whole, to reach higher—continuing to stay true to our mission; supporting patients and families while promoting research, education and awareness.



Together, we are making a remarkable difference. For over a decade, the Amyloidosis Foundation grant program has supported

research in all forms of systemic amyloidosis. Your fundraising efforts in 2017 enabled us to award six research grants, which target the challenges in the field of amyloidosis.

In 2018, we celebrate our 15th anniversary. It is hard to believe the foundation has come so far. What began as a small idea has become an international resource. We look forward to the next few years with hope for a cure. With your help, I know we can achieve it. Thank you for your support.

Sincerely,



Mary E. O'Donnell

President

Amyloidosis Foundation

“The Amyloidosis Foundation is an absolutely critical warrior in our collective battle against this often difficult and frequently under diagnosed condition. The foundation has been instrumental in raising awareness, improving education, and providing support both emotionally and physically for so many people.

Even more importantly, many active members of the foundation continuously push doctors and regulators to improve the care provided and to always explore new and improved treatment options.

I am lucky to say that I am an active member and I run forward into this battle with such wonderful people”.



Daniel J. Lenihan, MD, FACC

Professor of Medicine

**Director, Cardio-Oncology Center
Washington University, St. Louis, MO**

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

Since 2003, we have been able to support the efforts of over 36 researchers, seeking the cause of amyloidosis, seeking the effects of investigational treatments on various types of amyloidosis and trying to determine the underlying mechanisms of the disease.



Awareness

Impact

The Amyloidosis Foundation has awarded over \$1.7 million in research grants since 2005.



Support

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

www.amyloidosis.org



Research

Supporting patients and families while promoting research, education and awareness



2017 Highlights



Total Number of Donors-
Up 22%

2,626

\$116,395

Funds Raised through
Fundraising Events
in 2017



4

Our brochures
are available in
English,
Spanish, Polish
and Portuguese



9

Conferences Attended
by AF Staff and
Patient Volunteers

750+

Grand Rounds
Attendees-
Doctors
teaching Doctors



240%

Increase in
#GivingTuesday
Donations
from last year

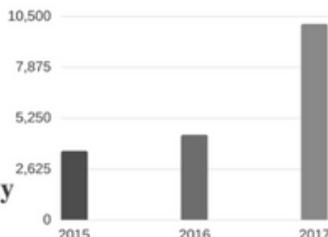


267,332

Page Views on our
website



#GivingTuesday
Results



6

Research Grant Awardees
-Up from 4 in 2016



Increasing Awareness

After my husband Tres passed away in 2015, the last thing I felt like doing was raising money for a disease that had turned my life upside down. A little over a year later, as my 50th birthday was quickly approaching in August, my close friends and family members were pressing me for ideas on how I wanted to celebrate. Celebrating was the last thing I wanted to do.

One day during a spin class a thought came to me - I no longer resented the disease that took my husband's life, I wanted to make a difference. I love to spin and asked my friends at Grit Cycle if they would host a ride as a fundraiser on my birthday for family and friends.

In lieu of birthday gifts, I requested that donations be made to the Amyloidosis Foundation. In 2016 we sold out the ride and raised over \$11,000. In 2017 we were able to raise over \$18,000!

I am committed to supporting the Amyloidosis Foundation and doing my part to raise awareness and funds for research to find a cure for this rare disease.

- **Kelli Heald**



Amyloidosis Foundation Board Member **Charlotte Haffner** (left) and **Sheryl Kernodle, RN** volunteering at our booth at the American Academy of Nurse Practitioners (AANP) conference in 2017.

I am honored to be a member of the Board of Directors of the Amyloidosis Foundation since 2014. We are proud of all our accomplishments and are making a real difference in research, education and awareness. This must continue so that we can support future patients as well.

I am fortunate to be a patient at Vanderbilt University Medical Center in Nashville, TN. As a founding member of the Vanderbilt Multi-disciplinary Program (VAMP), I have facilitated the AF amyloidosis support group meetings since 2011.

Amyloidosis is a difficult disease to diagnose. Ten years ago when I began treatment, there was little hope. Today we have many more options, and lives are being saved every day.

Thanks to all who support the foundation and have faith that one day we will have a cure.

- **Charlotte Haffner**

Grant Recipients



Celia Torres Arancivia - PhD

Age-Related Cardiac Amyloid Disease (ATTRwt)
David Seldin, MD, PhD Memorial Research Grant, 2018
Boston University Amyloidosis Center

Matteo de Rosa - PhD

A New Route to the Development of Therapeutics
Amyloidosis Foundation Research Grant, 2018
National Research Council, Italy, Medicine Division: X-Ray Crystallography & Structure-Based Drug Design



Luke Berchowitz - PhD

A New Platform to Discover the Genes Involved in
Amyloid Formation
Donald C. Brockman Memorial Research Grant, 2018
Columbia University Medical Center, New York



Mario Nuvolone - MD, PhD

Investigating New Therapies to Treat AL Amyloidosis
Amyloidosis Foundation Research Grant, 2018
University of Pavia, Italy, Medicine Division: Amyloidosis
Research and Treatment Center



Surbhi Sidana - MBBS

Understanding the Composition and Mechanism of
Amyloidogenesis in Light Chain Amyloidosis
Amyloidosis Foundation Research Grant, 2018
Mayo Clinic, Medicine Division: Hematology



Alexandra Silva - B.S, Chemistry, PhD

Assessing Efficiencies in Machado-Joseph Disease (MJD)
Therapies
Amyloidosis Foundation Research Grant, 2018
Instituto de Biologia Celular e Molecular, Portugal, Medicine
Division: Biomolecular Structure and Function Group



All Thanks To YOU...



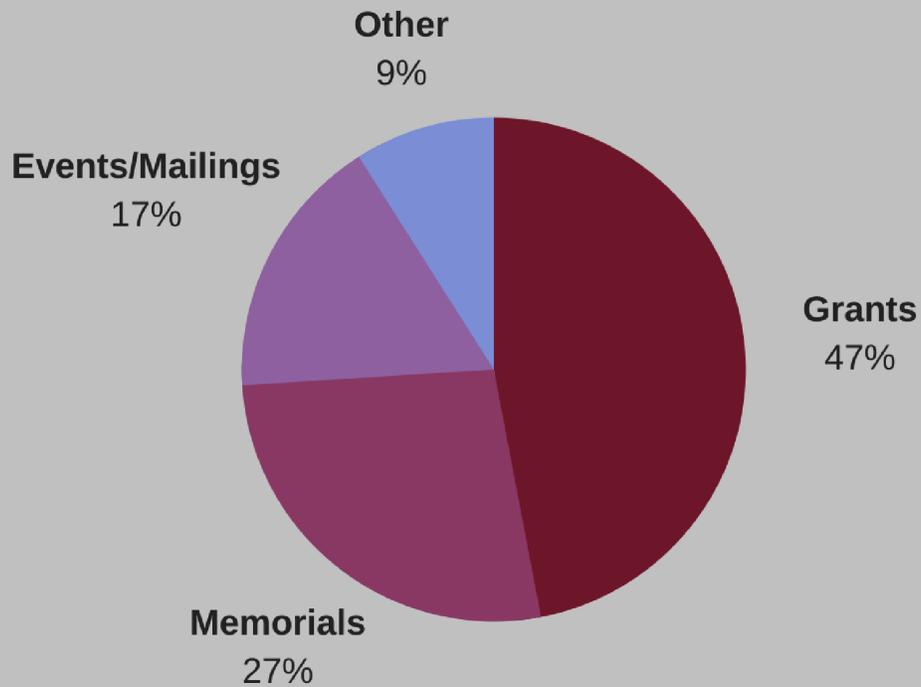
Together, over **\$116,000** was raised
in 2017 through fundraising events

Action

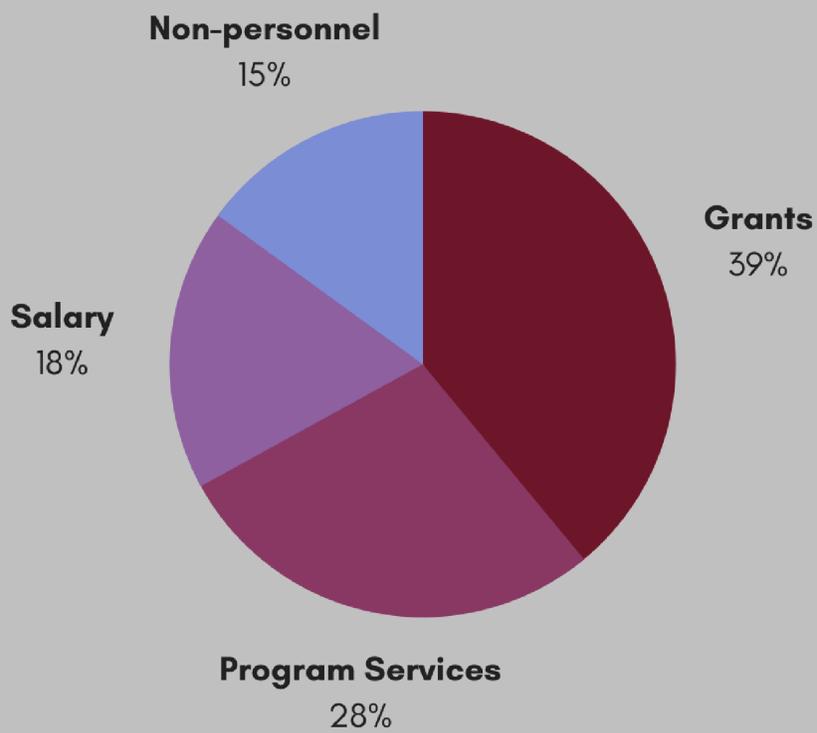


Stats

Support & Revenue



Expenses



Financial Report

Statements of Activities (Non-audited) - Year End December 31, 2017

Support & Revenue

Contributed Support	705,612.35
Investment Income	7,219.40
Fundraising	116,395.36
Earned Revenues	4,260.27
Realized Gain/Loss	21,932.77
	855,420.15

Expenses

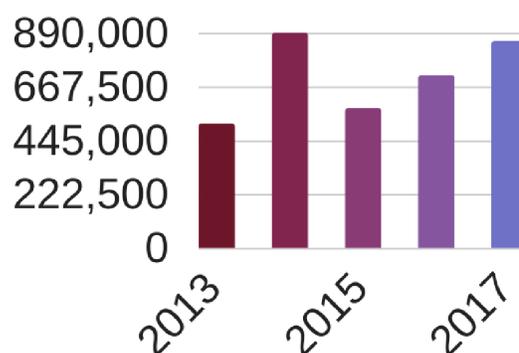
Grant Expenses	413,000.00
Salaries & Related Expenses	148,025.65
Other Personnel Expenses	14,865.00
Non-personnel Expenses	127,499.28
Occupancy Expenses	15,261.00
Travel & Meeting Expenses	52,814.24
Miscellaneous Expenses	27,367.99
Business Expenses	4,250.90
Returned Checks	1,000.00
	804,084.06

Net Income/Liability

51,336.09



**A 40% INCREASE
SINCE 2013!**



2017 Donors

\$10,000 +

The Chip Miller Amyloidosis Foundation

\$4000-\$9999

Present Troubles Racing

UPMC Mercy

Barbara Carney

\$2000-\$3999

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Grit Phamily, LLC

Henry J. Kaiser Family Foundation

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Linda Heald

Duane Sobaski

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\$1000-\$1999

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\$500-\$999

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Kevin Brockman

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William Clark

Pat Collins

Garrett D'Alessandro

Mike Devenport

Leslie Ellis

Robert Epstein

Peter Faix

Rick Flatt

Larry Gauchman

Jennifer Graham

William Gorman

Aaron Hamp

Nicholas Hamp

Kevin Hauri

Maeve Heald

Peter Heald

Marvin Heyman

David Hoffman

Katrina Jamison

Tuleda Johnson

John Kiernan

Kathi LaPointe

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Sascha Tuchman

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THANK YOU!

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

- **Alnylam US, Inc.**
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- **Ionis Pharmaceuticals**
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