

GOALS ■ **PROGRESS** ■ **IMPACT**

SHAPING OUR FUTURE

About Us

We are the **Amyloidosis Foundation**, the world's leading community for people with amyloidosis, their loved ones, and those who are working to find a cure. The 200,000 living with amyloidosis deserve the promise of a better life today. We have all of the resources you need to live your best life with amyloidosis.



We're proud to use GuideStar Platinum to share our full and complete story with the world. To reach the Platinum level, we added extensive information to our Nonprofit Profile: basic contact and organizational information; in-depth financial information; quantitative information about goals, strategies, and progress toward our mission.

For more information: www.guidestar.org



A Message From The President



As we are midway through our second decade here at the foundation, we take pride in the accomplishments we have achieved to date. Through the generous donations from our donors we have been able award over 30 young investigator research grants investigating the diagnosis and treatment of all types of systemic amyloidosis.

The AF has also been able to support over 60 young investigators attending the bi-annual International Symposium on Amyloidosis since 2004. By supporting these young investigators, they are encouraged to continue to work in the amyloid field helping to determine the underlying cause and potential treatments.

None of these accomplishments would have been attained without the generosity of our donors. We cannot begin to express our sincere thanks and look forward to your continued support to help to continue our efforts in supporting patients and their families while supporting research, education and awareness.

Mary

For Tomorrow

Advancing Research TODAY.

We invest in outstanding scientific research and innovative research models to expedite promising therapies to patients.



The Amyloidosis Foundation invests in research to explore what causes amyloidosis, how to treat it and how to find a cure. From financing studies on the immune microenvironment of AL, dissecting the role of ATTRv, to proteostasis (protein homeostasis) with cardiac amyloidosis, we are forever changing the future of amyloidosis.

Living with amyloidosis starts with a better understanding of the disease and how to properly manage it.

Research Grants

This is a pivotal time in the history of amyloidosis, with a number of new drugs being approved and new therapies on the horizon. Increasing the level of support is essential for research in this underserved disease. Researchers, clinicians and partners in the biotech and pharmaceutical industries are working on the development of therapies that are changing the landscape and improving the outlook for patients.

The Amyloidosis Foundation is committed to serving patient's needs by supporting research and providing annual grants for junior investigators whose research targets the challenges in the field of amyloidosis.

Grand Rounds

The Amyloidosis Foundation has a very successful Grand Rounds program, as part of our commitment to raise awareness of the amyloidosis diseases. We will sponsor an expert in amyloidosis to speak to doctors and medical staff regarding the diagnostic tools, clinical protocols and treatment therapies that are currently available.

Our speakers are among the most knowledgeable specialists and are involved in amyloidosis research and patient care. The Amyloidosis Foundation will arrange for the speaker and will cover all travel expenses and honoraria.

Travel Grants

The foundation is dedicated to encouraging young investigators that show an interest in amyloidosis research, by providing travel grants to physicians and researchers who have completed their medical doctorate or fellowship within the past 10 years. These grants enable participation in the bi-annual International Amyloidosis Symposium.

Awareness Highlights

Cocktails 4 A Cause

The 2nd Annual Cocktails 4 A Cause was an afternoon of fun, music, friendship, and charity as they gathered at this family friendly event to raise funds for the Amyloidosis Foundation and The Northwestern Memorial Hospital Stem Cell Transplant Program.

Lifelong Chesterton resident and Duneland School teacher Jason Conway has been courageously battling the rare and incurable disease Amyloidosis for four years. Jason and his family have been blessed beyond measure and the 2nd Annual Cocktails 4 A Cause is Jason's work to ensure continued progress in research and development of treatments to find a cure for this dreaded disease.

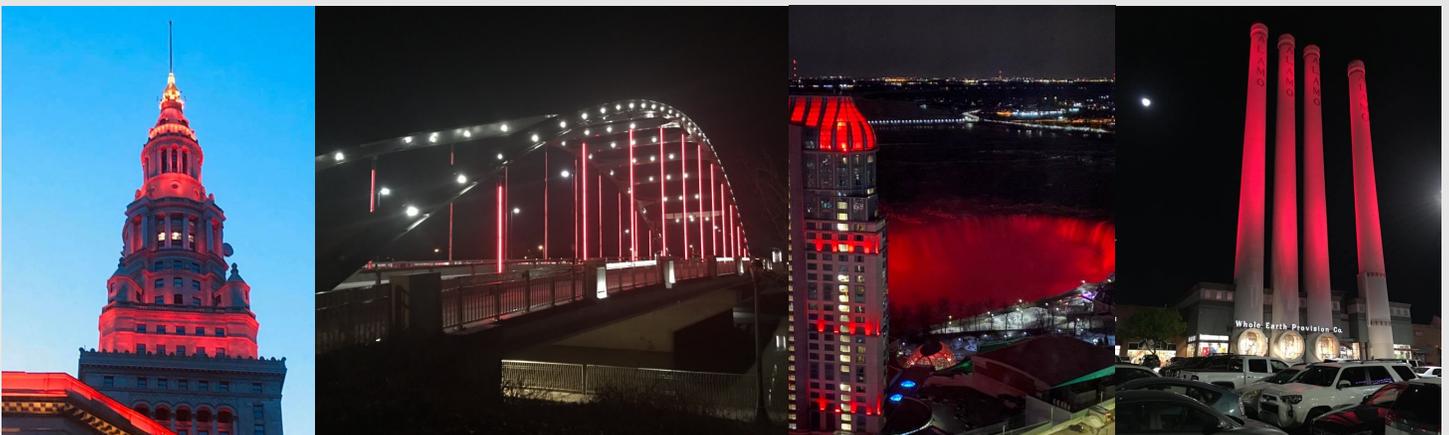


Ticket price provided a day of musical entertainment from Ally & Joe Christian, Angelo Cicco, and Delta Straight! --All while attendees relaxed with their drinks in a one of kind take home glass. Their bellies were sure to be full with the awesome culinary delights of Brisket/Pulled Pork Waffle Sliders, Bavarian Pretzel Bites with Cheddar Ale Sauce, Flatbread with Roasted Veggies and Gorgonzola Cheese, and the grand finale of Brownie Waffle with Chocolate Stout Fudge Sauce.

Light The Night For Amyloidosis

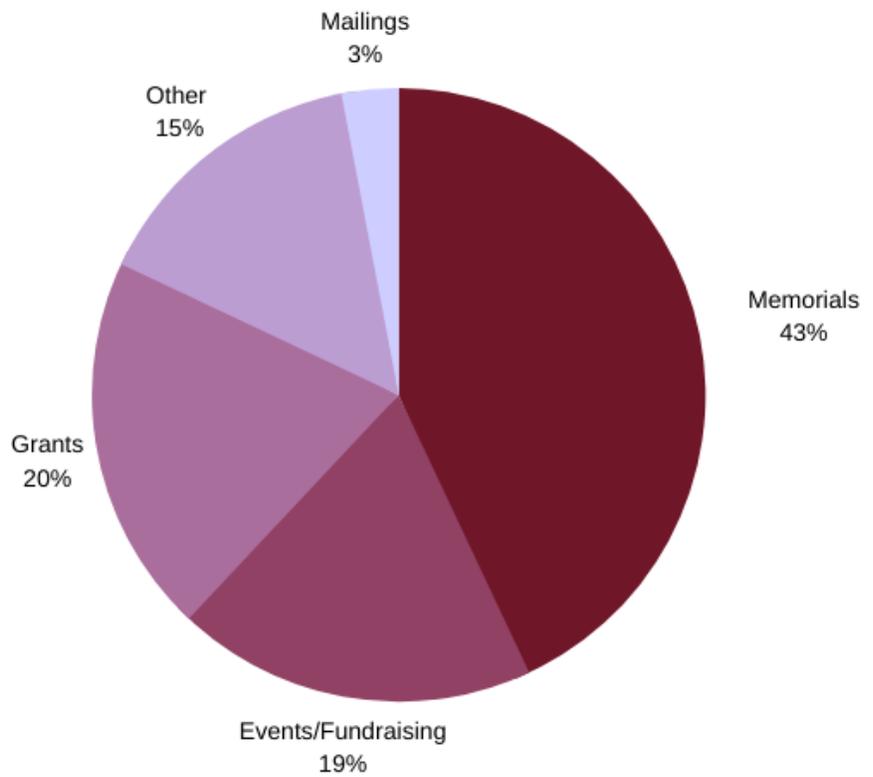
The First Annual "Light the Night for Amyloidosis" is an awareness campaign created to draw attention to amyloidosis symptoms, diagnosis, treatment and hopefully a cure! Since 'Amyloidosis Awareness Month' occurs in March, we asked everyone to light up their porch / entryway with red bulbs for the month of March. We hope this will continue every year.

Starting in 2019, we contacted many worldwide landmarks and businesses to light for our cause in March 2020. We reached out to over 450 properties. We had an overwhelming response with over 100 lighting approvals in 5 different countries! The countries joining in our awareness efforts were United States, Canada, Australia, United Kingdom and New Zealand. We have received so many beautiful pictures from our supporters. These are shared on our social media platforms with the hashtags #LightTheNightForAmyloidosis #LTNFA and #AmyloidosisAwareness. Here are some of our favorites!

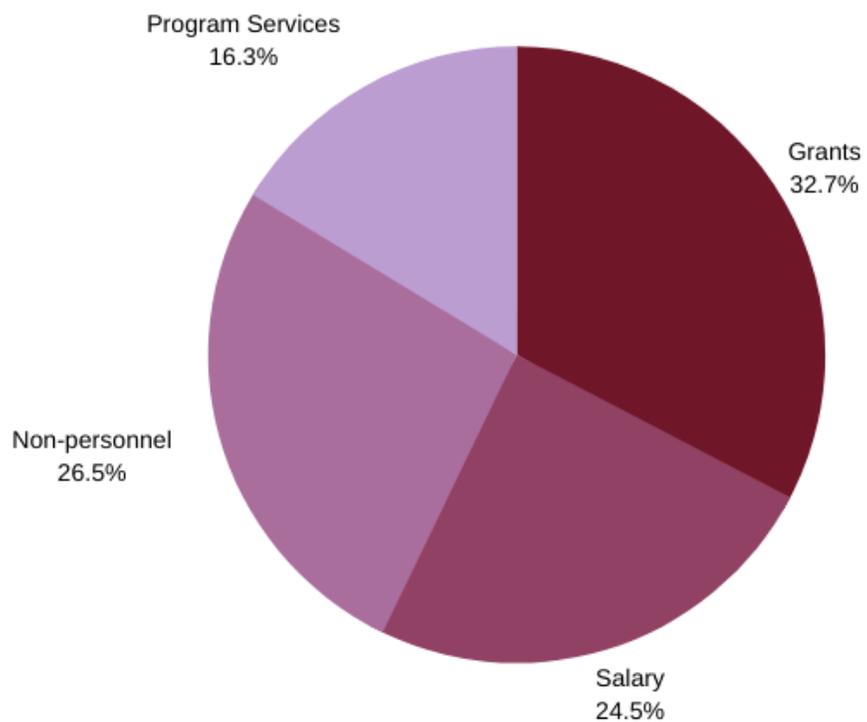


Financials

Support & Revenue



Expenses



Support & Revenue

Contributed Support	494,622
Investment Income	9,983
Fundraising	136,690
Earned Revenues	13,234
Total	654,529

Expenses

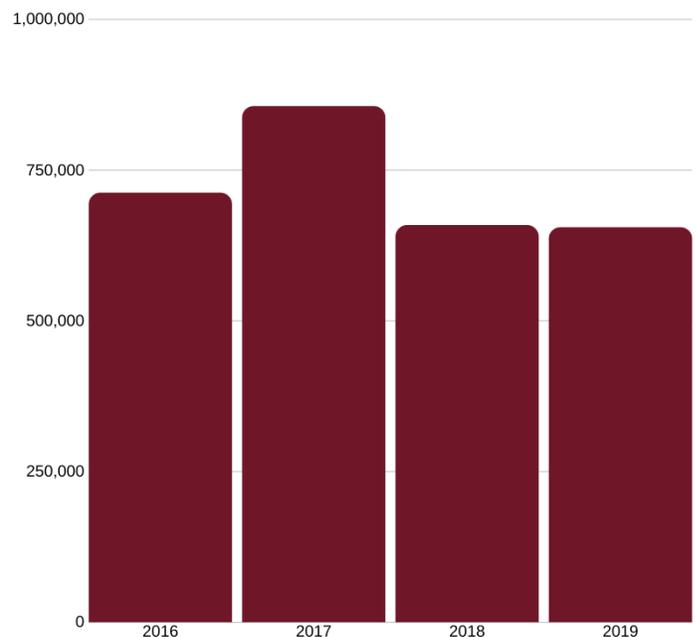
Grant Expenses	210,000
Salaries & Related Expenses	159,564
Other Personnel Expenses	15,976
Non-personnel Expenses	168,979
Occupancy Expenses	14,388
Travel & Meeting Expenses	49,444
Miscellaneous Expenses	31,474
Business Expenses	3,046
Total	652,871

Net Income/Liability

1,658

Gross Income

Four-Year Snapshot



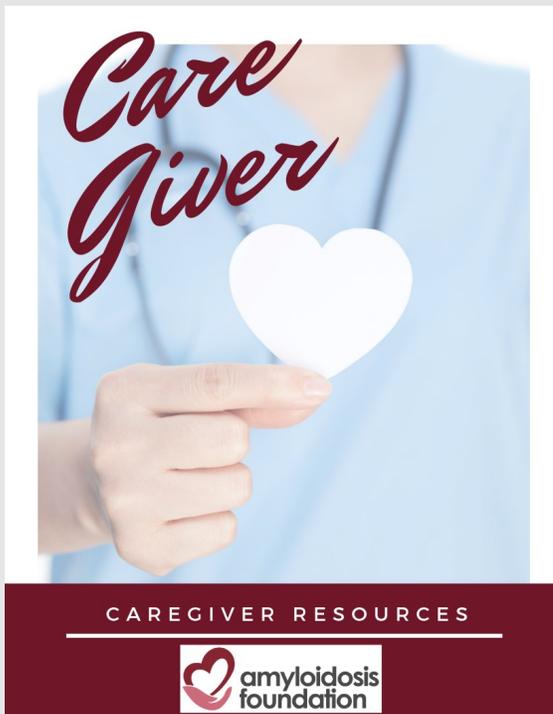
Creation of the Patient & Caregiver Binder

This binder was designed by the Amyloidosis Foundation staff, a team who strive to make care giving easier for caregivers and patients. Each section has links to PDF files that are designed so that you can print your own copy and keep in a 3 ring binder to take with you to doctor's appointments. If you do not have access to a printer, we will mail you an assembled binder. Just

email your request for a binder to info@amyloidosis.org.

This Binder will help you to Keep documents in one location:

- Medical Records
- Medication Information
- Medical History
- Lab Results
- Appointments
- Your Questions
- Notes from the doctor
- Information, business cards and handouts



Take It, Share It, Use It. Take it with you to doctor's appointments. Share it with other caregivers and loved ones. Use it to make caregiving easier and more effective.

Suggestions From Other Caregivers:

- Move pages and sections to fit your needs
- Use pockets in the 'Medications' section for information you receive from the pharmacy
- Use the calendar to keep track of appointments and when to order medications and medical supplies
- Use a plastic business card sleeve to hold business cards. You may also write notes on the front/back of the cards
- Buy a small blank notebook to keep a daily journal of important events, milestones, and issues you and the patient may encounter. Keep it with the binder or slide it in a pocket.

“Selfless giving is the art of living.”

~Frederick Lenz

It is our mission to support patients and families while promoting research, education and awareness. Help us to do that. **Donate today!**



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Matching
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gifts



Host an
event



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Awareness Through Your Eyes



Grant Recipients

Meet our grant awardees! We are proud to feature our grant recipients whose research targets the challenges in the field of amyloidosis.



Renato Polimanti, PhD

Dissecting the role of genetically-determined TTR

Amyloidosis Foundation Research Grant, 2020

Yale University School of Medicine



Susan Bal, MBBS

Understanding the Immune Microenvironment of Light-Chain (AL) Amyloidosis

Amyloidosis Foundation David Seldin, MD, PhD Memorial Research Grant, 2020

University of Alabama, Birmingham, AL



Mark Ranek, PhD

Amyloidosis Foundation Donald C. Brockman Memorial Research Grant, 2020

Johns Hopkins University, Baltimore, MD



Donor Honor Roll

\$10,000 +

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Rohan Nirody

\$4000-\$9999

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\$500-\$999

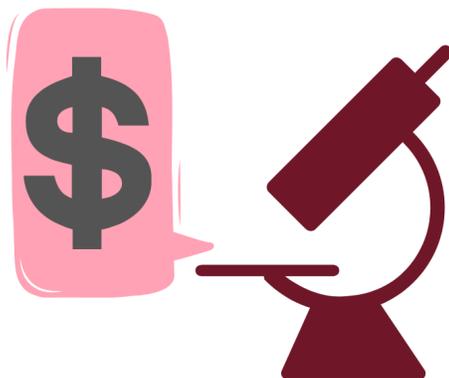
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**THANK YOU
FOR YOUR
SUPPORT!**



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

- **Akcea Therapeutics**
- **Alnylam US, Inc.**
- **Harmony Fund**

2019 By The Numbers

59.5%

of users access our
website via mobile

3

Research Grant
Awardees

12

Conferences attended
by AF staff or
volunteers

323

Facebook
Fundraisers

5

Grand Rounds

\$30K

Raised on
#GivingTuesday

618

Instagram Followers
in our first year

130,500

New Users
on our Website

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