

ANNUAL REPORT

2020



amyloidosis
foundation

About Us

It is a joy for us to share with you about the Amyloidosis Foundation's accomplishments in 2020. We are proud that we continue to remain steadfast to our founding vision—supporting patients and families while promoting research, education and awareness. With your support, we expanded our reach in 2020 via virtual events and embarked on new social ventures while meeting the needs of patients, caregivers and families.

Our key priorities are:

- Provide research grants for all types of systemic amyloidosis
- Raising awareness in the medical field for an earlier diagnosis.
- Educating medical professionals through our Grand Rounds program and attendance at medical conferences.
- Empowering patients through our comprehensive range of services, including accurate up to date information.

We're proud to use GuideStar Platinum to share our full and complete story with the world. To reach the Platinum level, we have 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

What a year!! On March 16, 2020 the State of Michigan, for all intents and purposes, shut down due to Covid-19. At the foundation, we immediately started working remotely from the office. Fortunately, we already had systems in place to accomplish this, so the work of the foundation continued helping patients and caregivers understand amyloidosis, it's diagnosis and treatment.

There were many challenges and surprises along the way, many that affected everyone; how to safely shop for groceries, how to get support from our physicians, how to safely see family members that don't reside in our houses. We here at the foundation had to make many changes. All of the medical conferences that we normally attend to spread awareness of amyloidosis were either cancelled, or converted to virtual meetings. The support groups that we support had to be cancelled. We were unable to schedule any Grand Rounds, so educating physicians on amyloidosis was on hold. Many of these activities will continue to be on hold for the indefinite future.



Some positive things that have occurred in 2020;

- The generosity of our donors has continued throughout the pandemic
- We were able to support two research grants
- Zoom support group meetings started in December
- We continued to distribute informational pamphlets
- We had over 100 buildings around the world light up for 'Light the Night for Amyloidosis' in March, along with, and most exciting, we are able to support 2 Cardiac Amyloidosis Fellowships to educated young physicians

We can't begin to thank you enough for your support and generosity. None of our accomplishments could be achieved without you, your support and generosity. As we continue to battle through the Covid-19 pandemic, please take care of yourself.

Be Safe,

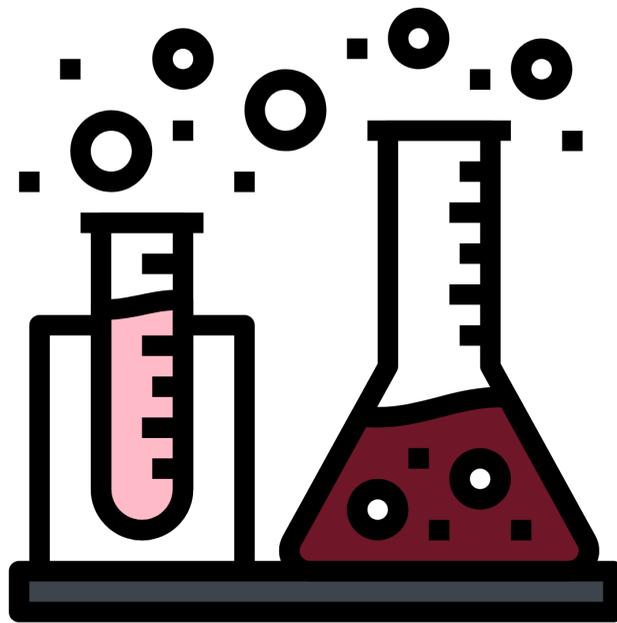
A handwritten signature in cursive script that reads "Mary".

Mary E O'Donnell

Research For Tomorrow

Advancing TODAY.

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



This is a pivotal time in the history of amyloidosis, with the approval of three drugs for ATTR in 2019 and a number of new therapies on the horizon. Increasing the level of support is essential for research in these underserved diseases. This creative and systematic work has been undertaken to increase the stock of knowledge that we currently have regarding amyloidosis. It involves the collection, organization, and analysis of information to increase understanding of amyloidosis.

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 needs by supporting research and providing annual grants for junior research scientists whose research targets the challenges in the field of amyloidosis.

The Amyloidosis Foundation was established in 2003 to support research for systemic amyloidosis by Junior Investigators. As the prognosis for late diagnosed amyloidosis patients is poor, the foundation has decided to support two 1-year advanced Cardiac Amyloidosis Fellowship II in 2021.

hATTR Diagnosis



My older sister, Barbara Kaplan, started having shortness of breath in October of 2019. She went to her internist in Miami, Florida, and a chest x-ray which showed fluid in her lungs. Her internist immediately referred her to a cardiologist who suspected amyloidosis. She was diagnosed a few days later and was started on Vyndamax shortly after. Her 3 siblings were advised to get tested for the gene. Our two brothers were quickly tested and both were deemed negative. Our mother was tested and is negative as well. Our dad is deceased.

My testing was a little more complicated due to the fact that I had a bone marrow transplant in 2010. After submitting a buccal swab that came back inconclusive, it was determined that they needed to do a skin biopsy to test for the gene. That was about the time the coronavirus ramped up and the test was postponed. Finally, I had the biopsy in May of 2020, and it came back positive for the gene. I started at Boston Medical Center and was diagnosed on June 22, 2020. We have the T60 (80) variant. I have since transferred to Cleveland Clinic/Dr. Hanna due to insurance. I have been on Vyndamax since Aug. 1.

My numbers indicate early onset of the disease with cardiac involvement, but no neuropathy. I did have carpal tunnel surgery in November of 2018. I had a procedure on my thumb in October 2020 and the doctor did a tissue biopsy to see if the problem is due to amyloid. I have no symptoms and continue to do life as normal except for being extra, extra cautious during this pandemic. I bike 30 minutes every morning and walk for 30 minutes every afternoon. I play golf at least once a week and continue to work full time.

Bio:

Jaime Kaplan was born and raised in Macon, Georgia. She started playing tennis at the age of nine and went on to hold junior rankings as high as first in the state, second in the south, and 18th in the United States. At Stratford Academy, she produced an undefeated record of 156-0 in singles and doubles along with 5 state titles. She also was an all-state basketball player, playing on 3 state championship basketball teams. After playing collegiate tennis at UGA then FSU, Jaime competed on the WTA Tour for six years, achieving world rankings as high as 91 in doubles and 252 in singles. She played in Wimbledon five times, the US Open four times, the French Open four times, and the Australian Open once.

Jaime has been inducted into the Stratford Academy Athletic Hall of Fame, the Macon Sports Hall of Fame, the Georgia Tennis Hall of Fame, the Georgia Sports Hall of Fame, and the Southern Tennis Hall of Fame. A knee injury at Wimbledon forced Jaime to retire in 1989 and she settled in back home in Macon where she has been very involved in the community, raising over \$12,000,000 for various charities, mainly the Rescue Mission of Middle Georgia and United Way of Central Georgia, over the past 33 years. She serves or has served on over a dozen non-profit boards and in 2011 filled an unexpired term for six months on Macon's City Council.

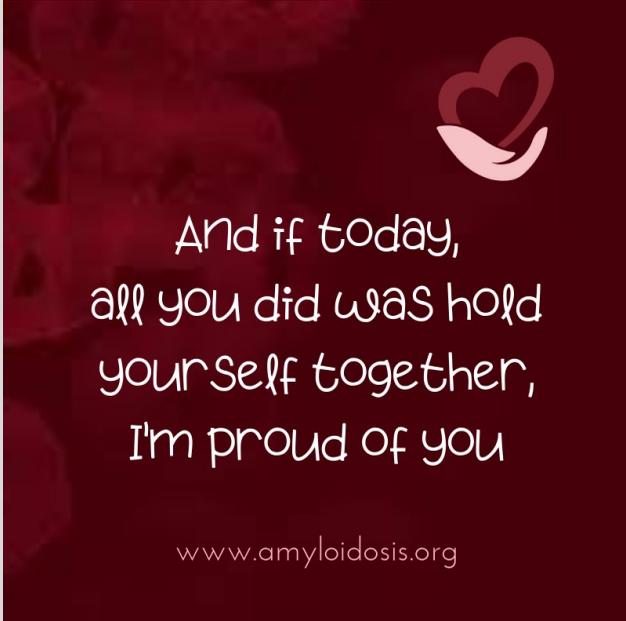
Jaime was diagnosed with a rare form of acute myeloid leukemia on April 23, 2010. She underwent a bone marrow transplant on August 27 of 2010. On June 22, 2020, Jaime was diagnosed with hATTR Amyloidosis, a rare disease of which currently there is a treatment, but no cure. Jaime is the Director of Philanthropy at United Way of Central Georgia, Event Manager of the Five Star Kevin Brown Russell Henley Celebrity Classic and Head Coach of the Stratford boys and girls varsity tennis teams. Jaime's individuals and teams have won 45 region titles and 16 state titles since she started coaching in 2005. If you ask Jaime her greatest accomplishment, she will tell you that it's not being inducted into halls of fame. She will tell you that it's the many lives she has touched through her charity work and her journey with cancer and amyloidosis.

Instagram Inspiration

If it doesn't nourish
the soul,
let it go



I admire people who choose
to shine even after all of the
storms they've been
through.



And if today,
all you did was hold
yourself together,
I'm proud of you

www.amyloidosis.org



Amyloidosis may
be **RARE**
but **HOPE**
should not be



Think **BIG**
thoughts,
but
appreciate
small
successes.



BE STRONG
when you are weak

BE BRAVE
when you are scared

BE HUMBLE
when you are victorious

BE A WARRIOR
everyday



“Those who are happiest are those that do the most for others.”

~Booker T. Washington

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



Memorial/
Honorary



Estate/
Property



Matching
Employer Gifts



Facebook
Birthday
Donation



Host an
event



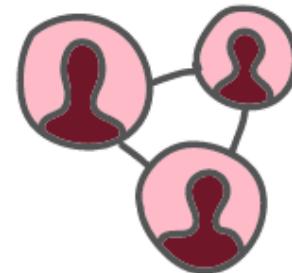
Planned
Giving



Recurring
gifts

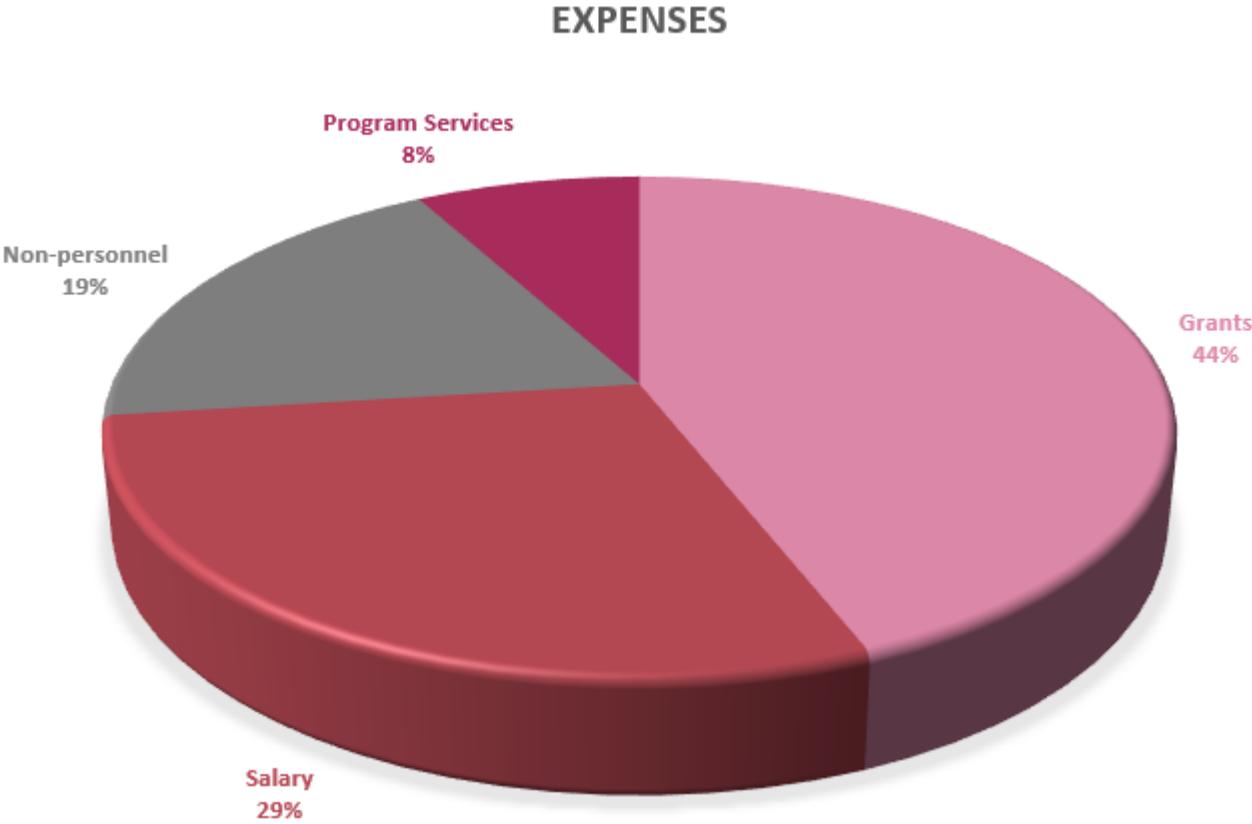
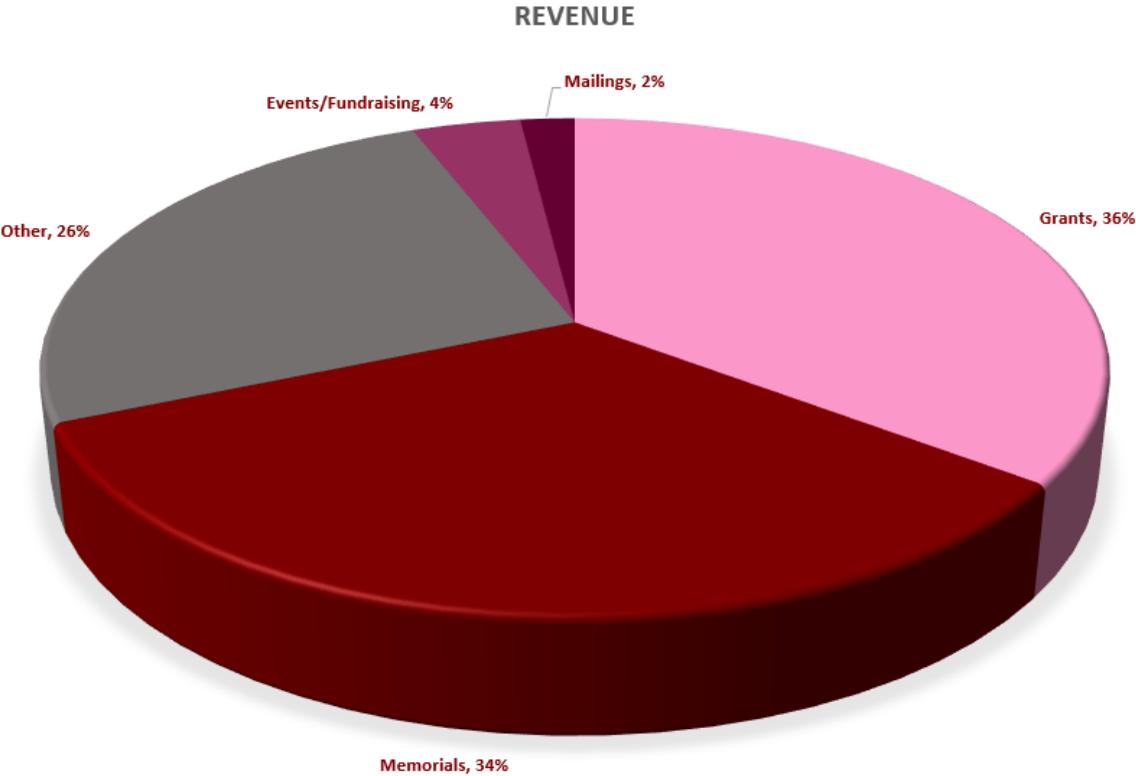


Charitable Gift
Annuities



Action Advocate

Financials



Statements of Activities (Non-audited) - Year End December 31, 2020

Support & Revenue

Contributed Support	656,009
Investment Income	8,716
Fundraising	26,534
Earned Revenues	5,853
Total	697,112

Expenses

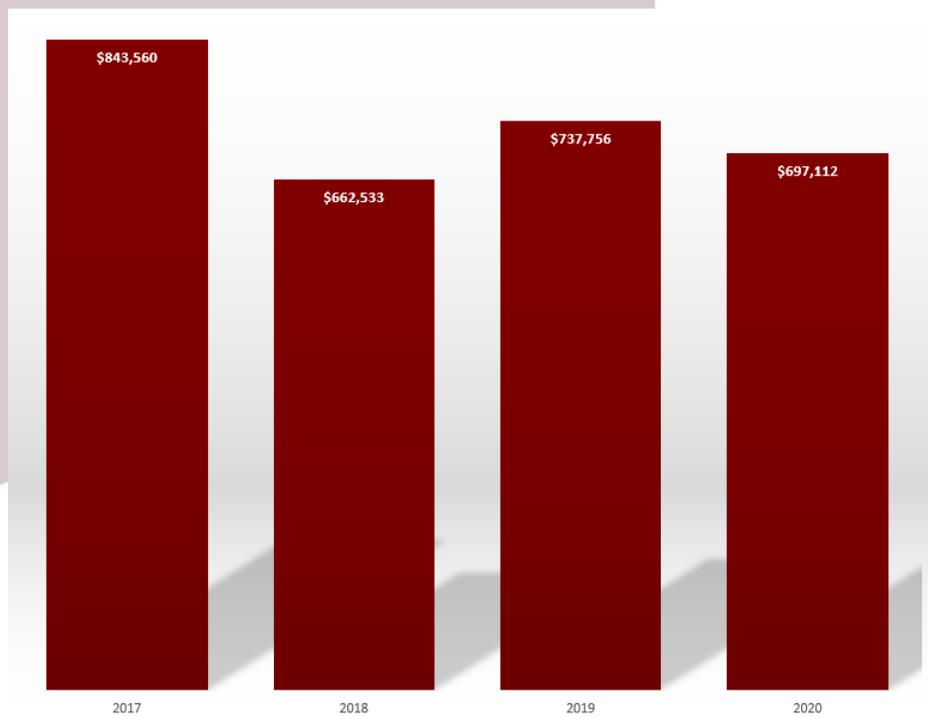
Grant Expenses	263,273
Personnel & Related Expenses	174,564
Other Personnel Expenses	16,803
Program Services	46,801
Occupancy Expenses	14,073
Travel & Meeting Expenses	5,972
Non personnel Expenses	45,275
Miscellaneous Expenses	30,553
Total	597,314

Net Income/Liability

99,798

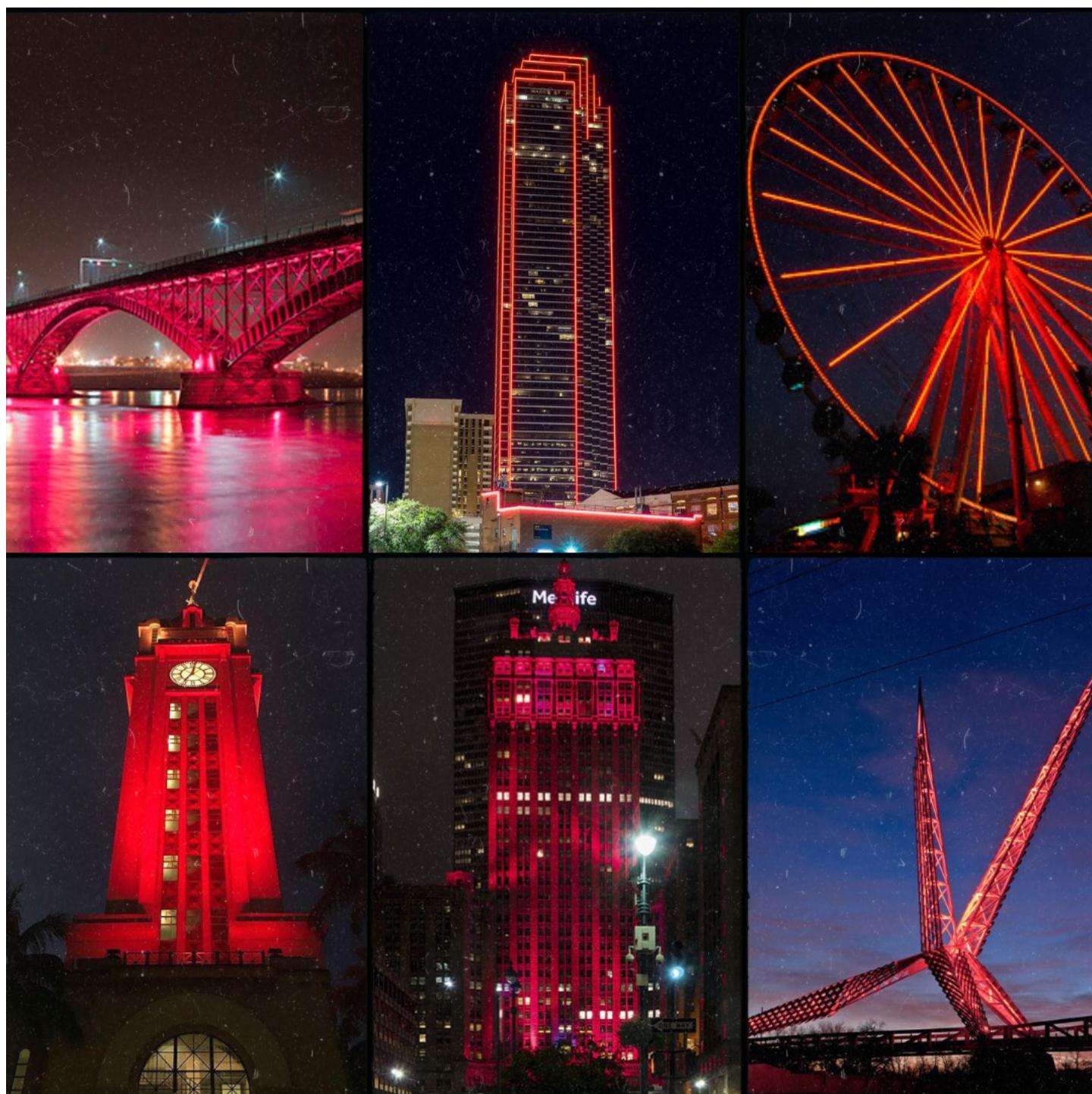
Gross Income

Four-Year Snapshot



Awareness

The Amyloidosis Foundation had great participation in its inaugural 'Light The Night For Amyloidosis' campaign in 2020, with over 100 sites in 5 countries lighting for our cause. Some of those that lit up for amyloidosis were Niagara Falls, Aloha Tower, LAX Airport, Little Caesar's Arena, JL Tower, Zakim Bridge, Wells Fargo's Duke Energy Center, Detroit Ford Field, MLK Jr Memorial Bridge, Bank of America Plaza, The PA Capitol Building, Emirates Spinnaker Tower, Calgary Tower and many other notable locations across the globe. Supporters of the foundation also bought red lights to light up their front porches and homes. Thank you to all for a successful year of awareness!



Grant Recipients

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

For over a decade, the Amyloidosis Foundation grant program has supported outstanding research in all forms of systemic amyloidosis. Through our research program we encourage, promote and invest in the medical study and exploration of the amyloidosis diseases.

Candidates will have completed their doctoral studies or clinical fellowship within ten years prior to application. Grants are awarded for one year according to the award conditions and reporting guidelines.

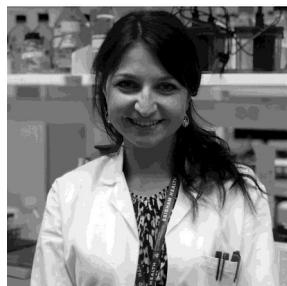


Timothy Poterucha, MD

Prospective Identification of Transthyretin Cardiac Amyloidosis Using Deep Learning

Amyloidosis Foundation David C. Seldin Memorial Junior Research Grant, 2021

Milstein Hospital, Columbia University, New York, NY



Maria Moscvin, MD

Targeting Free Light Chain Secretion as a Novel Therapeutic Strategy in AL Amyloidosis

Amyloidosis Foundation Donald C. Brockman Memorial Junior Research Grant, 2021

Brigham and Women's Hospital, Boston, MA

*“Research is to see what everybody else has seen,
and to think what nobody else has thought”*

~Albert Szent-Gyorgyi

Generous Contributors

\$4000-\$9999

Barbara Carney
John Childs
Eli Dickinson
Veronica Gilles
Wiebren Jonkman

\$2000-\$3999

Portia Bamiduro
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Cecil Loyd
Nikki Menard
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Alexandra Grulke
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Kieran Hanrahan
Linda Heald
Ruth Heyman
Pia Jala
Ruben Johnson
Blair Jones
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Jennifer Nakata
Andrea Nemit
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Mary O'Donnell
Ronald Ostrowski
Podiatry Care Specialists
Howard Powell
Daniel Preast
Jordan Renner
The Rettie Family
Derek Riddle
Owen Saddler
Brian Schaezler
Mark Scher
Michael Sodaro
Mary Sundvold
Sandra Roberts-Taylor
Susan Toland
Celina Valenzuela
Nicolas Ziebarth

\$250-\$499

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John Arlotta
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Rachel Bain
Barbara Barry
Albert Benjamin
Kathleen Bilek
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Thomas Brockley
Richard Brooks
Barry Broussard
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 Jodi Urquhart
 David Vesole
 Alison Waring
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 Dan Weinzimmer
 Marylou Weinzimmer
 Rachel Welch
 Joanne Wright

Fundraisers

The Zebra Dazzle– Zebras in Motion
 Cecilia Polcyn– Jewelry Fundraiser

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 Eidos Therapeutics
 Alexion Pharmaceuticals
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 Janssen: Pharmaceutical Companies of
 Johnson & Johnson
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 that created Facebook
 Fundraisers. Your generosity
 is boundless!**



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Check out our website or make an online donation at **www.amyloidosis.org**



Follow us on Instagram at **instagram.com/amyloidosisfoundation/**



Email us at **info@amyloidosis.org**

2020 By The Numbers

59.5%

of users access our
website via mobile

2

Research Grant
Awardees

297

Facebook
Fundraisers

\$17K

Raised on
#GivingTuesday

100+

Sites that lit for 'Light
The Night for
Amyloidosis'

964

Instagram Followers

3,820

Facebook Likes

130,500

New Users
on our Website

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