

Annual Report  
2018



amyloidosis  
foundation



# 15 Years of Success

*One accomplishment  
at a time*

# An Outstanding Year. Thanks to YOU.

We appreciate the trust you place in us to be excellent stewards of your donations. It's why we work tirelessly to promote research, education and awareness.

Our commitment extends beyond our patients and families. We are proud to be good non-profit citizens in the communities we serve through grants and volunteerism. To continue to enhance the quality of life throughout our rare community, we are committed to producing a consistent, long-term culture that allows us to remain a strong institution, as we have the last 15 years.

Our objective is not simply to get bigger. Our growth is an outcome of doing all of the right things for our patients, families and donors. Our top priority is to constantly get better at how we serve you. Our key priorities have remained the same:

- Supporting medical and scientific research.
- 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 will never lose sight of where we came from and what we have nurtured since 2003. We are grateful for the patients, families and donors who are responsible for the success the Amyloidosis Foundation enjoys today.



Sincerely,

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

**Mary E. O'Donnell**  
**President**

Technology continues to be an area of focus. Ongoing work to enhance our rare communities experience gives the Amyloidosis Foundation a competitive advantage. Our digital strategy is fully integrated across all of the foundations media platforms. Our team takes great care to focus on how YOU use our technology to enhance your experience.

Using social media to share news and events, we are able to reach patients, volunteers and our community in numerous ways we haven't before, building stronger relationships with donors.

Technology is changing the communication plan, to include sharing patient stories, industry news and more. Technology can maximize success in achieving our mission, while streamlining operations and effectively managing resources.

It has enabled the expansion of fundraising efforts over the last several years, opening multiple fundraising channels and eliminating the need to focus solely on large, resource-heavy events or expensive direct mail campaigns. With these tech tools in place, you can contribute easily from your computer or mobile device at the time most convenient to you, through the channels that you most frequently engage with. In addition, our online presence has boosted advocacy and awareness of our mission.



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](http://www.guidestar.org)



# Growing and Giving

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



## 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 needs by supporting research and providing annual grants for junior research scientists 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 Matters

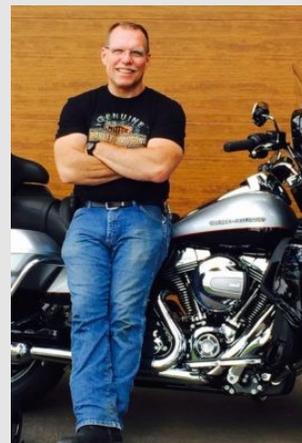
**Ralph Payne** ~ Taken from an account by Debra Payne, Wife and Caregiver

On Valentine's Day, 2013, Ralph received a call from his nephrologist. A week earlier they had no idea what a nephrologist was. And doctors don't typically call with biopsy results the next day. Something wasn't right. It began when their new family doctor ran a comprehensive series of tests on all his new patients. Ralph turned out to have an extremely high protein count in his urine. He was referred to a nephrologist to discover why, not for a minute imagining anything seriously wrong with him. He had been diagnosed with an extremely rare blood disorder called amyloidosis, AL amyloidosis in particular. The doctor wanted to send samples to Mayo Clinic for verification and referred them for immediate treatment to a local oncologist at Rocky Mountain Cancer Center in Longmont, Colorado.

In shock, they tried to learn everything they could about amyloidosis. One of the first things they read was that patients had a 12 to 15-month survival rate. That was devastating. The organ most impacted were his kidneys. The doctor explained treatment: low dose chemotherapy to disrupt the production of the folded proteins and an autologous stem cell transplant at Presbyterian Saint Luke's in Denver, Colorado, to hopefully reset the body's protein producing systems.

The scope of concerns was unending. They worried about insurance and paychecks and prescription costs. They worried about disability and qualifying for experimental studies. They worried about doctors and their success rates with this disease and survival of the treatment and side effects. They worried about bills, medical-caused bankruptcy, and charges for required tests not covered by insurance. They worried about jobs and taking time off and driving back and forth to hospitals while maintaining a household. And overall the most pressing concern: about whether he was going to survive this illness and the treatment.

The blur of hospital tests, treatments, and frantic phone calls are as raw today as five years ago. But the doctors refer to Ralph as a "rock star". His protein count went from uncountable at one point to well within normal range, kidney function returned to normal range, and no sign of amyloidosis today.



On September 27, 2018, the family and friends of Kevin Sullivan came together to hold a fundraiser in his memory and raise amyloidosis awareness. The event was held at Venue3Two, a beautifully restored home in Grand Rapids, MI. It was a beautiful night. Everyone mingled inside and out while enjoying hors d'oeuvres and drinks, and bidding on the unique items in the silent auction.

Nancy Sullivan, her children, Keenan, Kelsie and Connor all shared stories and memories of Kevin throughout the evening, along with lots of family photos of trips and holiday celebrations. Dr. David

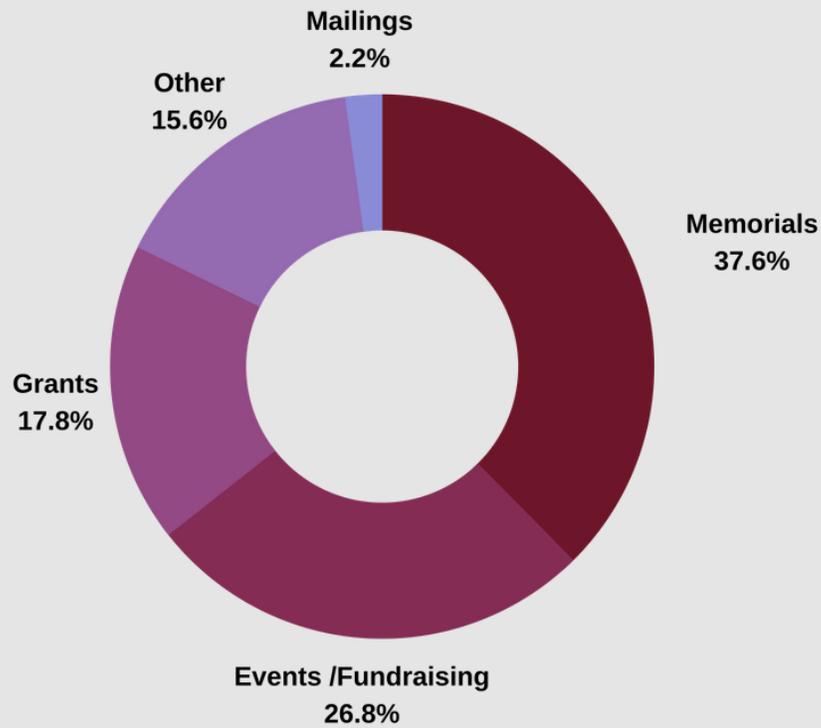
Fermin, Kevin's cardiologist from Spectrum Health in Grand Rapids, spoke about Kevin's strength and spirit, plus gave a short presentation of amyloidosis.

Over 70 people came out to support the family and the Amyloidosis Foundation. Monies raised helped to fund the annual Research Grant Program at the foundation. Thank you to everyone who attended the event and donated in honor of Kevin, a special event for an extra special man.

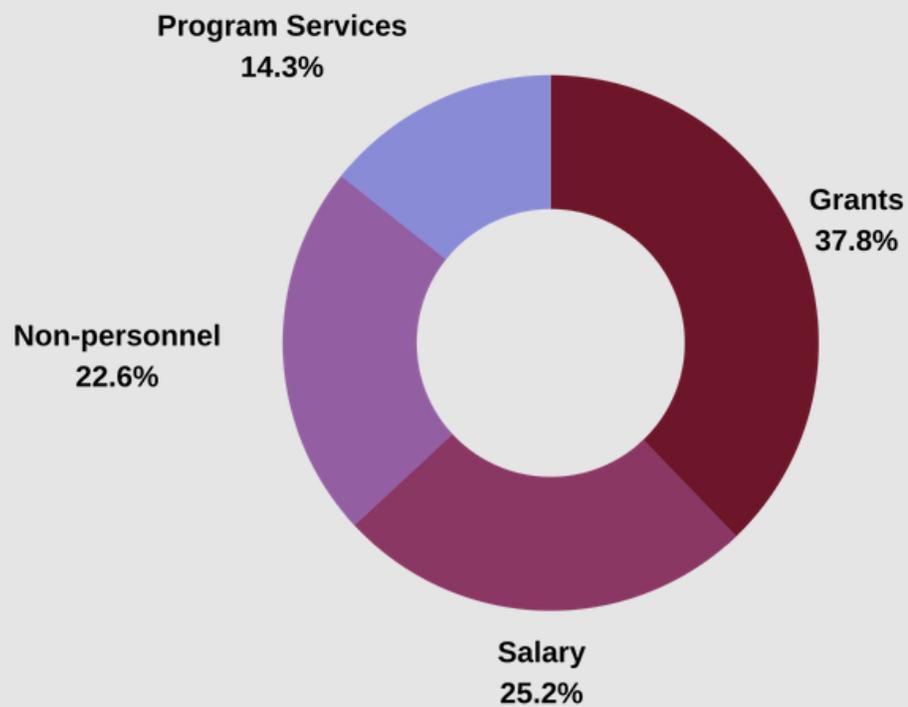
*(Pictured left to right; Connor Sullivan, Nancy Sullivan, Kesie Sullivan, Keenan Sullivan)*

# Financials

## Support & Revenue



## Expenses



Statements of Activities (Non-audited) - Year End December 31, 2018

**Support & Revenue**

Contributed Support	479,596
Investment Income	29,126
Fundraising	148,289
Earned Revenues	4,179
Realized Gain/Loss	(3,230)
Total	657,961

**Expenses**

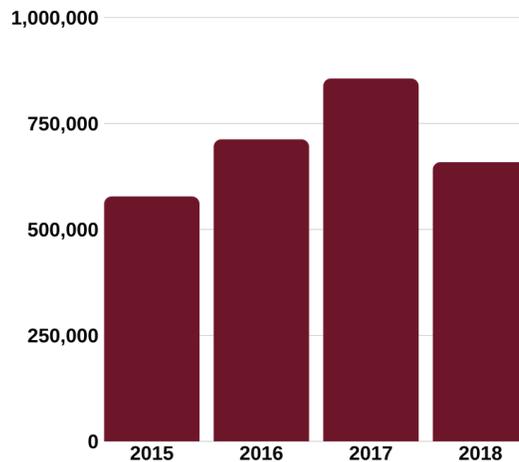
Grant Expenses	230,000
Salaries & Related Expenses	153,588
Other Personnel Expenses	15,677
Non-personnel Expenses	137,709
Occupancy Expenses	14,263
Travel & Meeting Expenses	28,312
Miscellaneous Expenses	24,396
Business Expenses	4,543
Total	608,488

**Net Income/Liability** **49,473**

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**Gross Income**

Four-Year Snapshot



# 15 Years of Accomplishments

From the beginning, the Amyloidosis Foundation began with a vision and a desire to support research, patients and increase awareness. While our name and logo have changed, we remain committed to that proud tradition.



The Amyloidosis Research Foundation was founded by Don Brockman (patient) and Mary O'Donnell in 2003. The ARF mission was to support medical and scientific research for amyloidosis.



2003



The Junior Researcher Travel Grant Program was started in 2006. The foundation is dedicated to encouraging young scientists 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.



2006

2004



In 2004, the first Research Grant was awarded. We invest in outstanding scientific research and innovative research models to expedite promising therapies to patients.





The AF surpassed \$1 Million in Research Grants awarded to researchers in 2014. 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.

Thank you for your support since 2003. What began as a small idea has become an international resource for amyloidosis patients, families, physicians and researchers. We are proud to share our 15th anniversary with all of you. Here is a snapshot of some of our accomplishments:

- The AF has funded over \$1.9 million in research grants
- Supported over 36 Grand Rounds (physician education programs) across the U.S.
- Attended over 45 major medical conferences, and hosted our awareness booth often with patient volunteers
- Distributed thousands of informational pamphlets to patients, family members, friends, physicians and medical students
- Assisted countless patients and family members in learning about amyloidosis: its symptoms, diagnosis and treatment facilities - via telephone, email, social media and on our website

**2007**

**2014**

**2015**

**2018**

The Amyloidosis Foundation is the result of the merging of the Amyloidosis Research Foundation and the Amyloidosis Support Network in 2007, so that the missions of both organizations could be brought together.

The David Seldin, MD, PhD Memorial Research Grant, and the Donald C. Brockman Memorial Research Grant were established in 2015. "This grant from the Amyloidosis Foundation will allow us to perform the first large-scale characterization of the mutations and gene expression changes in AL amyloidosis by evaluating patient's plasma cells at diagnosis and following treatment. We expect such studies to allow us to identify genes that contribute to the development of disease, predict treatment responses, and identify new therapeutic targets. This study will play an important role in future development of a cure for amyloidosis."



~Heather Landau, MD



# Awareness in Action



# Grant Recipients



**Siyang Leng - MD**

*Quality of Care and Disparities in Myeloma Associated Amyloidosis*

Amyloidosis Foundation Donald C. Brockman Memorial Research Grant, 2019  
Columbia University Medical Center, New York



**Amandeep Godara - MD**

*Development of Antibodies for Elimination of Serum Free Light Chains*

Amyloidosis Foundation David Seldin, MD, PhD Memorial Research Grant, 2019  
Tufts Medical Center, Boston, MA

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## Remembrance

It is with deep regret that we lost our good friend Darcy B. Tannehill, Ed.D., who passed away on Saturday, April 21, 2018, after courageously and passionately battling amyloidosis.

Darcy was the Associate Professor of Education at Robert Morris University in Pittsburgh, PA. After her diagnosis in 2012, she became an advocate for researching a cure. Darcy had served as chairwoman for the annual Pittsburgh Amyloidosis Research Benefit since 2016. The event this year, on Friday, October 26, was chaired by her daughter, Courtney Sullivan and Courtney's husband, Adam Sullivan, PhD.

Darcy joined the Board of Directors of the Amyloidosis Foundation in 2017. She had hoped that her hard work in awareness would ultimately help to save many lives.



*(Pictured left to right; Courtney Sullivan, Alaina Sullivan, Darcy B. Tannehill, Ed.D)*

# Donors

## **\$10,000 +**

**The Chip Miller Charitable Foundation  
The Vance Family Foundation**

## **\$4000-\$9999**

Kevin Bassett  
Roland Brandel  
Brookfield HS NHS  
Barbara Carney  
Linda Heald  
Jane & Frances Stein Foundation  
Liese Mayer

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Joseph Hardy  
Leslie Marquart  
Dan Pompei  
Geri Potter  
Present Trouble Racing  
Sony DADC  
Southern Historical Showcase  
Renee Steinike  
Nancy Sullivan

## **\$1000-\$1999**

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John Brinks  
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Diane Cadesky  
Ted Chapman  
Mike Devenport  
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Geoffrey McGrane  
Janiece McNichols  
Stephen Mettler  
Brian Miller  
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Paula Mitchell  
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Chip Rennaker  
Robert Morris University  
Daniel Rohlf

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Owen Saddler  
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Rheta Smith  
Robert Smith  
Spectrum Health  
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Robert Stafford  
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James Weldon  
Margaret Yelland  
Edward Yoon  
Sally Young

## **\$250-\$499**

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55 Club c/o Paul Morgan  
Marianne Aalbeue  
Charles Alcorn  
Michael Alter  
Linda Anderson  
Armenta Collection  
Valerie Armstrong  
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Arica Atkins  
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Aaron Hamp  
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David Kunz  
Joshua Lacy  
Daniel Lee  
Harold Lefkoff  
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Julie Waddell  
Abigail Walbrook  
Richard Wellman  
West Walker Steel  
Dawn Willis  
Enid Woodward  
Kevin Woodward  
Amy Wright

**THANK YOU!**



**amyloidosis  
foundation**



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

- **Akcea Therapeutics**
- **Alnylam US, Inc.**
- **Eidos, Inc.**
- **Prothena Biosciences, Inc.**
- **Takeda Pharmaceuticals USA, Inc.**

# Highlights

6

AF Webinars from  
2015-2018

2175

Total number of  
donations in  
2018

\$108K

Raised through  
Facebook  
Fundraising

\$20K+

Raised on  
#GivingTuesday

2

FDA drugs approved  
for hATTR  
polyneuropathy

993

Webinar  
Participants

12,310

Total Page views  
on social  
media

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