15 Years of Success
One accomplishment at a time
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,

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
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

- Memoriais: 37.6%
- Events/Fundraising: 26.8%
- Mailings: 2.2%
- Other: 15.6%
- Grants: 17.8%

Expenses

- Grants: 37.8%
- Non-personnel: 22.6%
- Salary: 25.2%
- Program Services: 14.3%
**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

![Bar chart showing gross income from 2015 to 2018](chart.png)
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.

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.

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

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.

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
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

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

$2000-$3999
John Beale
Sharron L. Gibson
Jay Godfrey
Joseph Hardy
Leslie Marquart
Dan Pompei
Geri Potter
Present Trouble Racing
Sony DADC
Southern Historical Showcase
Renee Steinike
Nancy Sullivan

$1000-$1999
Jillian Belbin
Gordon Beyerlein
Robert Bingham
Mark Blackman
Henry Blaxter
Bo Tkach Foundation
Stuart Brown
Cline Davis & Mann LLC
Jason Conway
Frank Diassi
Sarah Dodds-Brown
Sharmila Dorbala
Galvin Financial LLC
Geoffrey Gibbs
Thomas Green
Harmony Fund
Katrina Jamison
Barbara Janney-Desanzo
Eleanor Laughlin
Lavonne Horowitz Charitable Foundation
Daniel Lenihan, MD
Annick Ma
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Diane Papalia
Louise Scanlon
Stephanie Sherman
Martha Skinner, MD
Daniel Solomon
Susan Toland
USA Pro Shoreline Tech
Lisa Werkstell

$500-$999
John Arena
Kitty Bradley
John Brinks
Walt & Nancy Brockman
Michelle Burke
Diane Cadesky
Ted Chapman
Mike Devenport
Jerome Doucette
Enterprise Products
Robert Epstein
Express Employment Professionals
Robert Ferguson
Teresa Flatt
Patrick Gibbons
Melissa Goldman
Barbara Gullickson
Charlotte Haffner
Greg Henn
Jon Heyman
James Higgs
Jay Merchant Builders Inc
Douglas Jones
Joseph Junewick
Kappa Alpha Psi
Karmanos Cancer Institute
Jim Leeds
Carolyn Lloyd
Cherie Loustauau
Katherine Lund
Preston Maguire
Yen-Hwa Mar
Bill Mathis
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Geoffrey McGrane
Janiece McNichols
Stephen Mettler
Brian Miller
Lynda Mitchell
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Robert Smith
Spectrum Health
Martha Sproule
Robert Stafford
Jonathan Stein
Stephen B. Strum, MD, PC
The Noble Group
Chris Theodoropoulos
Michael Trahan
Sascha Tuchman
Michael VanderKieft
VECA Professional Services
Dorothy Watermaker
James Weldon
Margaret Yelland
Edward Yoon
Sally Young

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1954
55 Club c/o Paul Morgan
Marianne Aalbue
Charles Alcorn
Michael Alter
Linda Anderson
Armenta Collection
Valerie Armstrong
Nancy Arnosti
Arica Atkins
Steven Atran
John Bailey
Dana Balkin
Bank of Oklahoma
Barbara Barry
David Batdorf
Ralph Battat
Kristin Bender
Albert Benjamin
Bernard W. Abrams Family Fdn
Bishop-Broden Associates Inc.
Shelley Blumenthal
John Bouma
Daina Bowman
Carey Brakebush
Scott Branvold
Vanessa Bridges
James Brock
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

993 Webinar Participants

2 FDA drugs approved for hATTR polyneuropathy

12,310 Total Page views on social media
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