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
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.
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

- Memoria\l\ls 43%
- Events/Fundraising 19%
- Grants 20%
- Other 15%
- Mailings 3%

Expenses

- Salary 24.5%
- Grants 32.7%
- Non-personnel 26.5%
- Program Services 16.3%
### Statements of Activities (Non-audited) - Year End December 31, 2019

#### Support & Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributed Support</td>
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</tr>
<tr>
<td>Investment Income</td>
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<tr>
<td>Fundraising</td>
<td>136,690</td>
</tr>
<tr>
<td>Earned Revenues</td>
<td>13,234</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>654,529</strong></td>
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</tbody>
</table>

#### Expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grant Expenses</td>
<td>210,000</td>
</tr>
<tr>
<td>Salaries &amp; Related Expenses</td>
<td>159,564</td>
</tr>
<tr>
<td>Other Personnel Expenses</td>
<td>15,976</td>
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<tr>
<td>Non-personnel Expenses</td>
<td>168,979</td>
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<tr>
<td>Occupancy Expenses</td>
<td>14,388</td>
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<tr>
<td>Travel &amp; Meeting Expenses</td>
<td>49,444</td>
</tr>
<tr>
<td>Miscellaneous Expenses</td>
<td>31,474</td>
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<tr>
<td>Business Expenses</td>
<td>3,046</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>652,871</strong></td>
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</tbody>
</table>

#### Net Income/Liability

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>1,658</strong></td>
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</tbody>
</table>

### Gross Income

#### Four-Year Snapshot

![Four-Year Snapshot Chart](chart.png)
Creation of the Patient & Caregiver Binder

This binder was designed by the Amyloidosis Foundation staff, a team who strive to make caregiving 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!
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 +
The Chip Miller Charitable Foundation
Rohan Nirody

$4000-$9999
Bridgewater Bank Tavern
Barbara Carney
Henry J. Kaiser Family Foundation
Liese Mayer

$2000-$3999
BrightStar Care of Central Dupage–Wheaton
Sarah Dodds-Brown
Avelina Ledford
Frances Mitchell
Ray Peaco
Southern Historical Showcase
Jane & Frances Stein Foundation
Adam & Courtney Sullivan
Nancy Sullivan

$1000-$1999
Mark Blackman
Henry Blaxter
Deb Boedicker
Clydene Bresee
Burton W Ruder Foundation
James Connell
Jason Conway
Sharmila Dorbala
Edwards Lifesciences Foundation
Enterprise Products
Sharon Gibson
Thomas Green
Harmony Fund
Galvin Financial LLC
Geoffrey Gibbs
Thomas Green
Harmony Fund
Katrina Jamison
John Marshall Family Foundation
Barbara Janney-Desanze
Sean Keller
Gregory Leech
Karen McDermott
Linda Perillo
Jeff Rosenberg
Amanda Ruecker
Martha Skinner, MD
Alexander Tayebati
The Ehret Family
The Garth Family Foundation
The Italian-American Women
Susan Toland
Jeannie Varney
Susan Wadsworth
Dorothy Watenmaker
Lloyd Wenning
Lisa Werkstell

$500-$999
Baird Foundation, Inc.
Benton Central Jr/Sr High School
Betsy Baron
Jon Baron
Ralph Battat
David Beisler
Chris Borman
Walt & Nancy Brockman
Victoria Cantu
Margaret Cassidy
Caterpillar Employee Political
Zachary Christopherson
Kristina Conner
Crowe LLP
Mike Devenport
Jerome Doucette
Peter Dolan
Ann Fletcher
Denise Fraser
GAMA-1 Technologies
Elaine Gambel
Roland Gilles
Angela Gray
Groveland Elementary School
Aaron Hamp
David Helman
Maggie Herrington
Jon Heyman
Greg Hjelm
Herb Hoyer
Insurance Agents & Brokers
Intouch Group LLC
Blair Jones
Hilary Jones
Tyrone Jones
Kaplan Rosenow Family Foundation
Kian Capital Partners LLC
Lake Erie Auxiliary No. 2875
Christine Leibel
Daniel Lenihan
Matthew Levenson
Gina Lewis
Lois Lieberman
Carolyn Lloyd
Katherine Lund
Annick Ma
Yen-Hwa Mar
Heather McCollum
Lynda Mitchell
Paula Mitchell
Paula Mitchell
Helen O’Donnell
Oskosh Corporation
Ronald Ostrowski
Patient Worthy
Pearl Hospitality
Sandra Pope
PPNPF
Bruce Raber
Stacy Rangel
Troy Schmidt
Ann Schuster
Rheta Smith
Star Group
Robert Stillman
The Noble Group
Charles Thornsvard
Tisma Inc.
TMLIRP
Kenneth Tong
Tonn’s Orchard Burlington
Michael VanderKieft
Amy Wright

$250-$499
Wendy Addessi
Alaska CHARR
James Albertine
Russell Anderson
Steven Altran
Barbara Barry
BASYS LLC
Rachel Bender
Albert Benjamin
Bertino C. Yen, DMD Inc.
Helen Boldy
Bill Boris-Schacter
Keith Butterfield
James Cannon
Emily Choy
John Christman
Jesse Cook
Cooley LLP
John Cooney
Eddie David
Linda Donahue
The Amyloidosis Foundation would like to acknowledge the following for their generous philanthropy:

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

THANK YOU FOR YOUR SUPPORT!
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
Board of Directors

Mary E. O’Donnell
President

Dante Burchi
Treasurer

Charlotte Haffner
Director

Daniel Lenihan, MD, FACC
Director

Adrienne Molteni, RN
Director

Mark Sutherland
Director

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Indiana University Medical Center

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Tufts Medical Center – Boston

Vaishali Sanchorawala, MD
Boston University School of Medicine
Amyloidosis Center

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Allan and Sandra Gerry Amyloid Research Laboratory – Boston University

Douglas Sawyer, MD, PhD
Maine Medical Center

Rodney H. Falk, MD
Brigham and Women’s Hospital – Boston

Jonathan Wall, PhD
University of Tennessee - Knoxville

Morie Gertz, MD
Mayo Clinic – Rochester, MN

Mathew Maurer, MD
Columbia University Medical Center, NY