It is an honor for us to share with you about the Amyloidosis Foundation’s accomplishments and key priorities in 2022. We are proud of our continued success in providing resources to patients, caregivers, family members and friends in the amyloidosis community. Our founding vision is supporting patients and families while promoting research, education, and awareness, and we don’t take those words lightly. We have given almost $4 million towards research since our inception in 2003. Our website has countless resources including webinars, newsletters, videos and a Patient/Caregiver Binder to empower the patient toward a better outcome.

We have grown and expanded our reach in many ways. Our staff advocates for you, whether it be legislatively or through our physician resources. We have compiled a list of financial resources for those based on need for medications. Our social platforms have grown as well. Thanks to your generosity, we have been able to support countless junior researchers targeting the challenges in the field of amyloidosis. We won’t reach the end of the road until a cure is found, and even then our work will not be done.

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.
As we proceed through 2023, we are quickly approaching the foundation’s 20th anniversary in October. It has been an exciting and interesting 20 years. We have awarded nearly $4 million in research grants to help understand the mechanism of all types of amyloidosis. We have provided information and moral support to hundreds of patients and caregivers as they travel through the amyloidosis journey. We have watched the medical community’s knowledge of amyloidosis is growing by leaps and bounds. Alas, there is still a long way to go in raising awareness, and that also is one of the main efforts of the foundation.

We thank you for your continued support,

Mary

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

This is a pivotal time in the history of amyloidosis, with the approval of four drugs for amyloidosis since 2018, one of which was approved for AL in 2021, and a number of new therapies on the horizon. Increasing the level of support is essential for research in these underserved diseases. 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.

**Grant Programs**

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. On request, a second year of funding will be considered, pending review of the research progress and as foundation funding permits.

**Travel Grants—ISA Symposium 2022**

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.
DONATE

Memorial/ Honorarium

Estate/ Property

Matching Employer Gifts

Facebook Fundraiser

Host an Event

Planned Giving

Recurring Gifts

Charitable Gift Annuities

Awareness Ambassador

“Never doubt that a small group of thoughtful committed citizens can change the world: indeed, it’s the only thing that ever has”

Margaret Mead
PATIENT STORY

David Zarzour

ATTR-CM Diagnosis

In 2018, I had what I thought was a particularly bad case of bronchitis. As I regularly get sick in the winter, I didn’t think too much about it, except I was unusually weak, and tired. I also started sleeping in a chair, as I couldn’t breathe lying down.

When I finally saw my Internist after 3 months, she noted the fluid in my legs and brought in a cardiologist. After my EKG, he immediately suspected ATTR-CM and referred me to a specialist at the Cleveland Clinic.

Like most people, I had never heard of amyloidosis, so like many, I googled it and the first thing I read was “amyloidosis is a fatal disease with a life expectancy of 2-3 years after diagnosis” YIKES!

When I saw the amyloidosis specialist a week later, and after a complete series of tests including ECHO, MRI, bloodwork, and genetic counseling, he made the diagnosis of ATTR-CM (ATTR-Cardiomyopathy). He reassured me that while there are no cures, there are several medicines on the horizon, Tafamidis (Vyndaqel™ or Vyndamax™), being one of them. He started me on Diflunisal. In November 2018, I started Tafamidis as part of an extended trial. I am now taking Vyndamax. I am also in a blind trial Helios-B.

Today, I’m doing OK. It mostly affects my stamina/energy although I can still do just about everything, just not like I used to. I am so grateful to the Cleveland Clinic for my quick diagnosis and ongoing treatment.

Read more patient stories at: https://amyloidosis.org/category/stories
K. H. Vincent Lau, MD
Evaluating Plasma Neurofilament Light Chain as an Early Biomarker for Polyneuropathy in V122I Hereditary Transthyretin Amyloidosis
Amyloidosis Foundation Research Grant, 2022
Boston University, MA

Zainul S. Hasanali, MD, PhD
Targeting amyloidosis through study of calcium dependent endoplasmic reticulum resident protein folding chaperones and their effect on antibody production in plasma cells
Amyloidosis Foundation Research Grant, 2022
University of Pennsylvania, PA

Taxiarchis Kouelis, MD
Characterizing the Role of the Tissue Immunome in the Pathogenesis of Renal AL Amyloidosis
Amyloidosis Foundation Research Grant, 2022

It is with a sad heart we report that our friend and board member, Charlotte Haffner, passed away after courageously and passionately battling AL amyloidosis. Just a few of her accomplishments include:

* established patient support groups in Nashville and Knoxville, TN and St. Louis, MO
* provided individual support to dozens of fellow amyloid patients over the years, helping to advocate and facilitate their care
* Charlotte was the initial inspiration for the development of the Vanderbilt Multidisciplinary Program (VAMP)
* became an amazing resource for VAMP providing patient education materials
* represented the AF at dozens of medical conferences raising awareness of amyloidosis in the medical community
* was key to the establishment of March becoming Amyloidosis Awareness Month, helping with obtaining proclamations from numerous states
* organized a medical symposia attended by both medical professionals and patients
* organized a gala benefit supporting the AF

She will be greatly missed.
NUMBERS

154 Sites that lit for 'Light the Night for Amyloidosis'

302 Facebook Fundraisers

$21K Raised on GivingTuesday

273,008 Website Visitors

5.3K Facebook Followers

48.29% People using a mobile device to access our website

4 FDA-Approved Drugs since 2018

1,792 Instagram Followers

28 Legislative Priorities

3 Research Grant Awardees
504 Patient/Caregiver Binders have been sent out.
This binder was designed by the Amyloidosis Foundation staff, a team that strives 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 it in a 3 ring binder to take with you to doctor’s appointments, or one can be requested and we will mail it.

We had 556 participants for our Annual ‘Run for Your Life’ virtual event.
Participants around the world ran, walked, rolled or biked toward awareness in their own hometown. They were sent t-shirts to raise more awareness during their activity.

311 people participated in 2 webinars that we held.
The two webinars were:

*UPDATES IN ATTR CARDIAC AND NEUROLOGICAL AMYLOIDOSIS: What's new and exciting for 2022 and beyond*
Frederick L. Ruberg, MD, Omar K. Siddiqi, MD, K. H. Vincent Lau, and Michelle Kaku, MD
Boston Medical Center/Boston University – Boston, MA

*PROGRESS IN AMYLOIDOSIS: 2022*
Jeffrey Zonder, MD – Barbara Ann Karmanos Cancer Institute and Wayne State University School of Medicine— Detroit, MI
FINANCIALS

REVENUE

- Contributed Support: 81.1%
- Earned Revenues: 9.0%
- Investment Income: 1.2%
- Fundraising: 16.8%

EXPENSES

- Personnel & Related: 24.1%
- Non-personnel: 11.2%
- Program: 8.6%
- Miscellaneous: 4.1%
- Travel: 2.3%
- Grant: 44.5%
- Occupancy: 2.3%
- Program Fees: 2.9%
Statements of Activities (Non-audited) - Year end December 31, 2022

**Support & Revenue**

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributed Support</td>
<td>614,078</td>
</tr>
<tr>
<td>Investment Income</td>
<td>8,900</td>
</tr>
<tr>
<td>Fundraising</td>
<td>127,372</td>
</tr>
<tr>
<td>Earned Revenues</td>
<td>7,054</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>757,404</strong></td>
</tr>
</tbody>
</table>

**Expenses**

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grant Expenses</td>
<td>315,866</td>
</tr>
<tr>
<td>Personnel &amp; Related Expenses</td>
<td>171,203</td>
</tr>
<tr>
<td>Professional Fees</td>
<td>21,210</td>
</tr>
<tr>
<td>Program Services</td>
<td>61,127</td>
</tr>
<tr>
<td>Occupancy Expenses</td>
<td>16,058</td>
</tr>
<tr>
<td>Travel &amp; Meeting Expenses</td>
<td>16,110</td>
</tr>
<tr>
<td>Non-personnel Expenses</td>
<td>79,414</td>
</tr>
<tr>
<td>Miscellaneous Expenses</td>
<td>29,053</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>710,041</strong></td>
</tr>
</tbody>
</table>

**Net Income/Liability**

<table>
<thead>
<tr>
<th></th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Income/Liability</strong></td>
<td><strong>47,363</strong></td>
</tr>
</tbody>
</table>

**Gross Income**

5-year Snapshot
BOARD OF DIRECTORS

Mary O'Donnell, President  Dante Burchi, Treasurer  Stacey Goodman, MD

Lori Lawter, MPH  Daniel Lenihan, MD, FACC  Adrienne Molteni, RN  Mark Sutherland

SCIENTIFIC ADVISORS

Raymond Comenzo, MD  Morie Gertz, MD  Mathew Maurer, MD  Giampaolo Merlini, MD  Vaishali Sanchorawala, MD  Douglas Sawyer, MD, PhD  Jonathan Wall, PhD
THANKS TO YOU!

All of our donors are greatly appreciated, and we wish we had room to list all of them.

**Corporations and Foundations**

Alnylam Pharmaceuticals  
Baird Foundation Inc.  
Chip Miller Charitable Foundation  
Eidos– BridgeBio Inc.  
Omaha Community Foundation  
Prothena Biosciences  
The Benny DeRosa Foundation  
The Tudor Foundation, Inc.

**Fundraisers**

Steve Penland Golf Outing  
Dale Gallaway Memorial Concert  
Beer and Brats  
Jeff Brennan Golf Outing  
Dan Groff Fundraiser  
Gunther Memorial Golf Tournament

<table>
<thead>
<tr>
<th>Amount Range</th>
<th>Donors</th>
</tr>
</thead>
<tbody>
<tr>
<td>$10,000+</td>
<td>Nicole Carey, Lauren Osbourne</td>
</tr>
<tr>
<td>$2000-$3999</td>
<td>Amanda Campbell, Barbara Carney, CFF Holdings</td>
</tr>
<tr>
<td>$1000-$1999</td>
<td>Christopher &amp; Nancy Bright, Kathleen Cannon, Robert Castrignano, James &amp; Susan Childs, Elizabeth Eicher, Elizabeth Deegan &amp; Family, John Forch, Jay &amp; Jennifer Godfrey, Robin Graiff, Ruth Gunn, Barbara Hemenez, Steve &amp; Glenna Johnson, Mandy Lacey, Mary Ann Landis, Avelina Ledford, James Lee, Mark Lloyd</td>
</tr>
</tbody>
</table>
THANKS TO YOU!

$1000-$1999 (continued)
John Menard
Doug Meyer
Paula Mitchell
Shigeyoshi Moroi
Ray Peaco
Veronica Poon
Mark & Loraine Schumacher
Stephen Smith
Jackie Solondz
Gloria Starr
Martha Stone
Robert & Jill Strub
The Wonderful Company Foundation, Inc.
Tonn’s Orchard Burlington LLC
Tudor Investment Corporation
Patricia Vaccaro
Mark Volker
Shelagh Watson
Lisa Werkstell
Mike West

$500-$999
Sumaiya Andaleeb
Robin Appia
Betsy Baron
Susan Baxter
Richard Block
Lan Bowling
Michele Bradbury
Walt & Nancy Brockman
Olga Chekene
John Christman
Adam & Shannon Churchill
Richard & Carol Clark
Vann Cochran
Community Foundation of Middlesex County Mountain Laurel Fund
Aretha Denard
Mike Devenport
Ken DiBiasio
Robert Epstein
Richard & Karen Fahrenholz
Ann Flechter
Avron & Wendy Fogelman
Dick Fowler
Daisy Goecker
Jeffrey & Gwen Haas
Charlita Hearn
Jerome Helfant
Hill Health Enterprises
Laura Hutcheson
Blair & Gordon Jones
John Kiernan
Marie Knochenhauer
Stephanie Lennon
Matthew Levenson
Greg Lisiewski
LKQ 130
Carla McCool
James Millard
William Mintzer
Malia Nagle
Carol Nalty
Diane Papalia
Gary Parzych
Richard Paynton
Pinboy’s At The Beach
Thomas Pontano
Howard Powell
Daniel Prest
Richard G. Kline Family Fund
Joyce Rodak
Andrew & Amy Samett
Douglas Sawyer
Brian Schaezler
Kristie Schultz
Paul Sieracki
Richard & Michalene Sieving
Dorothy Sintas-Abeyta
Fred & Nancy Sloan
Bob & Susan Smith
John & Jean Snyder
Rush & Linda Snyder
Nancy Sullivan
The Barletta Family
The Dewars
The Rettie Family
The Wong Family
Theater Resources Unlimited/Board & Advisory Board
Thirty One Gifts - Natalie Stoner
Tamara Tittle
Sascha Tuchman
US Hydrations
Michael Van der Kieft
George Wolfe
Carl Zeppieri

$250-$499
Max Altschuler
Lorraine Armelin
Mary Balistreri
Barbara Barry
Albert Benjamin
Boathouse Ministry Family
Larry & Barbara Briggs
John Brodnax
Kiersten Brown