amyloidosis foundation

2022

ANNUAL REPORT

ABOUT US

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.

PRESIDENT'S MESSAGE

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

RESEARCH

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.

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"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

GRANT RECIPIENTS

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

REMEMBRANCE

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

3
Research Grant Awardees

$21K
Raised on GivingTuesday

273,008
Website Visitors

5.3K
Facebook Followers

4
FDA-Approved Drugs since 2018

48.29%
People using a mobile device to access our website

1,792
Instagram Followers

28
Legislative Priorities

HIGHLIGHTS

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

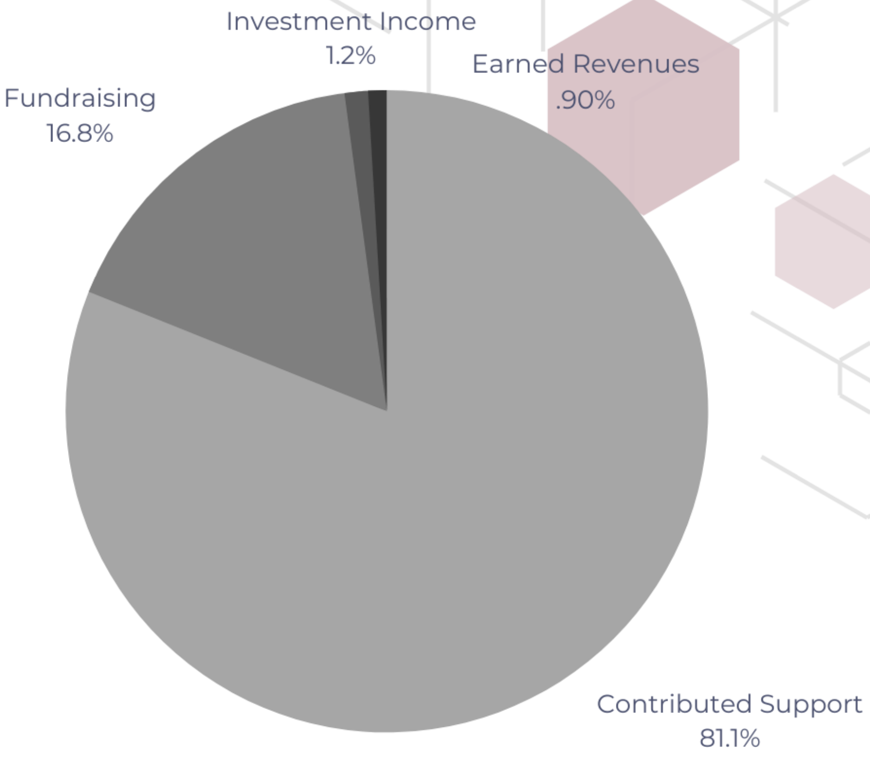
Frederick L. Ruberg, MD, Omar K. Siddiqi, MD, K. H. Vincent Lau, and Michelle Kaku, MD Boston Medical Center/Boston University – Boston, MA

PROGRESS IN AMYLOIDOSIS: 2022

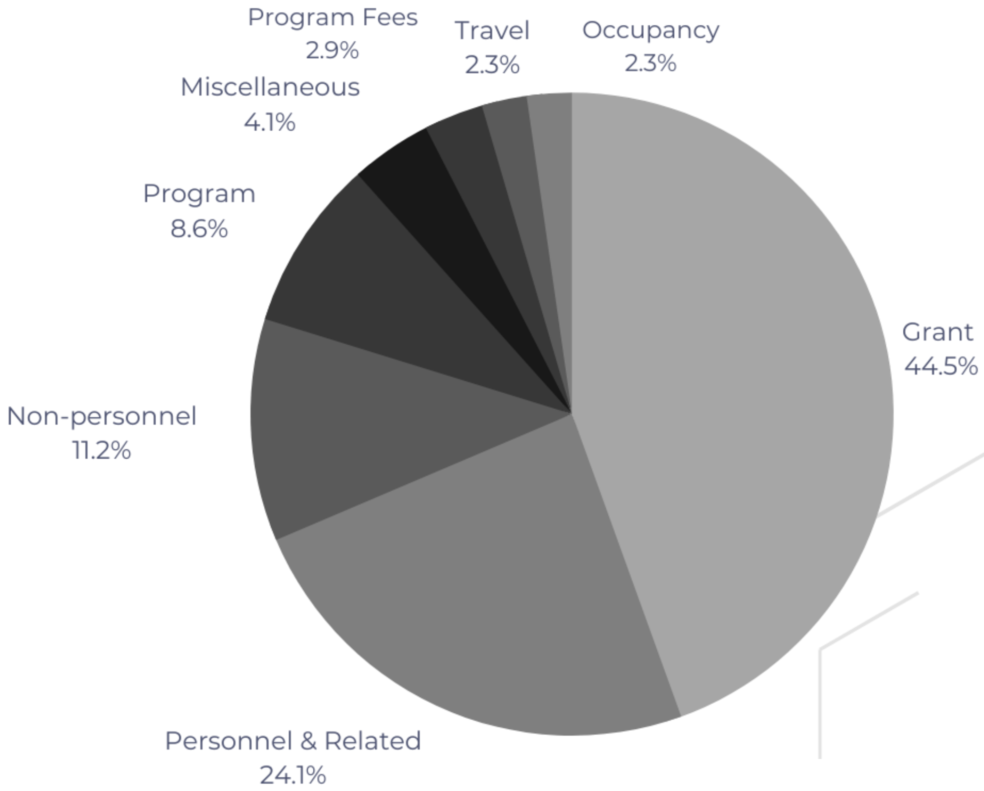
Jeffrey Zonder, MD – Barbara Ann Karmanos Cancer Institute and Wayne State University School of Medicine— Detroit, MI

FINANCIALS

REVENUE



EXPENSES



Statements of Activities (Non-audited) - Year end December 31, 2022

Support & Revenue

Contributed Support	614,078
Investment Income	8,900
Fundraising	127,372
Earned Revenues	7,054
Total	**757,404**

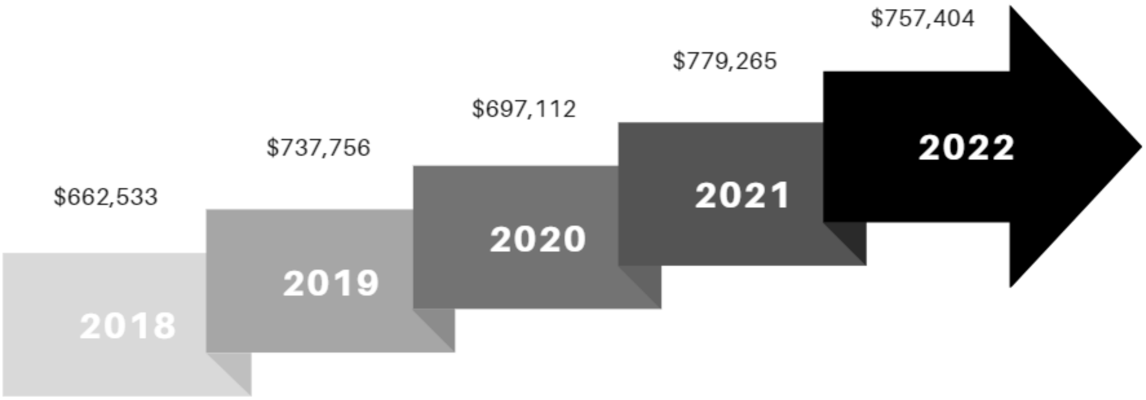
Expenses

Grant Expenses	315,866
Personnel & Related Expenses	171,203
Professional Fees	21,210
Program Services	61,127
Occupancy Expenses	16,058
Travel & Meeting Expenses	16,110
Non-personnel Expenses	79,414
Miscellaneous Expenses	29,053
Total	**710,041**

Net Income/Liability	**47,363**

Gross Income

5-year Snapshot



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

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