2024 ANNUAL REPORT

amyloidosis

[am-uh-loi-**doh**-sis] ● Phonetic (Standard) ○ IPA

noun

Pathology.

Plural **amyloidoses** [am-, uh, -loi-, d

1 a deposit of amyloid in tissues

2 the diseased state resulting

amyloidosis foundation

☎ 248.922.9610 www.amyloidosis.org 7151 N Main St, Suite 2, Clarkston MI 48346

GET TO KNOW US

The Amyloidosis Foundation was established in 2007 through the merger of the Amyloidosis Research Foundation (ARF) and the Amyloidosis Support Network (ASN). This union combined the strengths and missions of both organizations, creating a powerful force for advancing research, increasing awareness, and offering support for those affected by amyloidosis.

The Amyloidosis Research Foundation was founded in 2003 by Don Brockman and Mary O'Donnell, with the mission of supporting medical and scientific research aimed at understanding and finding cures for amyloidosis. Their vision was to fund innovative studies and create meaningful advancements in the diagnosis and treatment of this rare and often misunderstood disease.

On the other hand, the roots of the Amyloidosis Support Network date back to 1999, when Terry O'Malley, motivated by a personal connection to amyloidosis, began helping patients and working to raise awareness. Terry's dedication led him to create a website focused on providing support, information, and a sense of community for individuals affected by amyloidosis. Tragically, Terry passed away in 2000 due to complications from the disease. However, Dennis Krysmalski, who had worked alongside Terry on the website, took up the mantle and continued the mission. In 2004, Dennis formally established the Amyloidosis Support Network, with a clear goal: to make a tangible difference in the lives of patients and their families, while also increasing awareness of amyloidosis within the medical community.

Today, the Amyloidosis Foundation continues the work that began with these two pioneering organizations, with an overarching mission to support those affected by amyloidosis. Our vision is one of hope and empowerment. The Foundation is dedicated to ensuring that individuals living with amyloidosis have access to knowledgeable healthcare professionals, accurate and timely diagnoses, effective treatment options, and robust support systems. Our ultimate aim is for all individuals impacted by amyloidosis to be able to lead fulfilling lives, despite the challenges posed by the disease. Through ongoing research, advocacy, and educational efforts, the Foundation strives to provide a brighter future for the amyloidosis community, helping to improve outcomes and bring greater awareness to this often-overlooked condition.

AMYLOIDOSIS.
LOOK IT UP.

amyloidosis foundation

PRESIDENT'S PERSPECTIVE

A Heartfelt Thank You for Your Ongoing Support

Hello,

I've been deeply involved in the amyloid world for over 20 years, starting in 2002 when my husband, Don Brockman, was diagnosed with AL amyloidosis. It was a challenging journey, with limited treatment options not only for AL but also for ATTR. How far we've come since then! Today, we have an FDA-approved drug for AL, two treatments for cardiac ATTR, three for neuropathy-related ATTR, and one for a combination of poly-neuropathy and cardiac involvement, with many more in the pipeline.

Even with these significant advancements, there's still much work to be done. With your continued support, we're able to provide research grants, sponsor fellowships, and raise awareness about amyloidosis within the medical community by attending conferences and engaging with experts.

We also remain committed to helping and supporting patients by providing information about amyloid centers, the disease, and available treatments. Our team is always here to assist, whether it's answering questions or simply offering a compassionate ear.

Thank you sincerely for your unwavering support.

Warm regards,

Mary

We're proud to use GuideStar Platinum to share our full and complete story with the world. The Platinum Seal of Transparency is the highest level of recognition offered by GuideStar, the world's largest source of nonprofit information. 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

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Candid.

EXPLORATION

We, at the Amyloidosis Foundation, are investing in important scientific research to find better treatments for amyloidosis, a disease that affects the organs. We are helping speed up the process of discovering new therapies that could help patients.

Recently, there have been some big advancements, like the approval of three new drugs for ATTR amyloidosis in 2019, and there are more treatments being developed. To keep this momentum going, it's crucial to support research into diseases like amyloidosis, which are often overlooked. The foundation helps by offering funding and grants to young researchers working on these diseases, encouraging them to focus on new and innovative treatments.

Investing in rare disease research is crucial for several important reasons:

Improving Patient Outcomes: Many rare diseases, like amyloidosis, are often overlooked because they affect smaller populations. Research helps identify better diagnostic tools, treatments, and therapies, which can drastically improve the quality of life for those who suffer from these conditions.

Advancing Medical Knowledge: Research in rare diseases often leads to breakthroughs that can help in the treatment of more common diseases. Understanding the mechanisms of rare diseases can uncover new approaches to medicine and contribute to overall advancements in healthcare.

Filling the Treatment Gap: Rare diseases often don’t get the attention they need from larger pharmaceutical companies because they affect fewer people. Without investment in research, many of these diseases would remain under-researched with limited treatment options.

Empowering Affected Communities: Patients with rare diseases and their families can often feel isolated or forgotten. Research provides hope by actively working to improve their situation, creating new therapies and bringing attention to their needs.

Economic and Societal Benefits: Investing in rare disease research can lead to better treatments, which can lower healthcare costs in the long run by preventing complications, reducing hospital visits, and improving overall productivity and quality of life.

In short, investing in rare disease research not only improves the lives of those directly affected but also drives innovation in medicine and contributes to the betterment of healthcare for everyone.

HOW YOU CAN ASSIST

Memorial/Honorarium

Estate/Property

Planned Giving

Facebook Fundraiser

Host an Event

1 You donate + 2 They match = 3 Double your impact

Matching Employer Gifts

Recurring Gifts

Charitable Gift Annuities

Donate Now!

ADVANCING ADVOCACY

The Amyloidosis Foundation makes life better for people with amyloidosis by advancing research toward a cure. In everything we do, we build on the advocacy, experience and passion of our global amyloidosis community.

Advancing Advocacy for Amyloidosis on the Global Stage

Throughout this period of transition and growth for, our mission to improve the lives of individuals living with rare diseases—particularly those affected by amyloidosis—remains at the core of our work. We continue to be a strong, unified voice for amyloidosis patients worldwide, advocating for their needs in a collaborative and inclusive manner. Our commitment to promoting equity, pushing for policy reforms, and seeking innovative solutions to systemic challenges—such as access to early diagnosis, specialized treatment, and comprehensive care—has shaped our activities in 2024 and will continue to guide our future efforts.

Amyloidosis Advocacy: A Policy Priority in 2024

In 2024, our advocacy efforts centered on advancing equity and improving access to care for individuals with amyloidosis and other rare diseases. In February, we attended Rare Disease Week urging that Members of Senate and Congress ensure that no one is left behind—particularly those with complex and often overlooked conditions like amyloidosis. We successfully advocated for the inclusion of rare diseases POLICY emphasizing the need for timely diagnosis, multidisciplinary care, and innovative therapies.

Elevating Patient Voices and Research for Amyloidosis

At the heart of our advocacy is the lived experience of amyloidosis patients, who often face years of misdiagnosis and limited treatment options. By amplifying their voices, we continue to stress the urgent need for:

Faster diagnostic pathways: Many amyloidosis patients endure years of misdiagnosis due to the disease's rarity and complexity. We continue to push for increased awareness among healthcare professionals and expanded genetic and biomarker testing.

Access to innovative treatments: With the development of groundbreaking RNA-targeted therapies, monoclonal antibodies, and gene-silencing treatments, we advocate for access to these life-saving innovations.

Comprehensive and specialized care: Amyloidosis requires a multidisciplinary approach, yet access to centers of excellence remains limited. We are working to establish global care networks that connect patients to specialized providers.

These milestones reflect our unwavering dedication to ensuring that individuals with amyloidosis receive the recognition, support, and medical advancements they deserve on a global scale.

BOARD OF DIRECTORS


Mary O’Donnell, President


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Gareth Morgan, PhD *(*Boston University- Gerry Amyloid Research Laboratory, MA)

Vaishali Sanchorawala, MD *(*Boston University School of Medicine- Amyloidosis Center, MA)

GRANT BENEFICIARIES

We are proud to feature our annual grant recipients, whose research targets the challenges in the field of amyloidosis.

Michael S. Hughes, MD
Preclinical Efficacy and Activity of the 11-1F4 CAR Macrophage in AL Amyloidosis

Amyloidosis Foundation Research Grant, 2025
Columbia University New York, NY

Emre Karayol, MD
Identification of Novel Therapeutic Targets within the Proteostasis Network in AL Amyloidosis - Follow Up Grant Award

Amyloidosis Foundation Research Grant, 2025
Brigham and Womens Hospital, Boston, MA

Taxiarchia Kourelis, MD
Development and validation of a human organoid model for renal AL Amyloidosis

Amyloidosis Foundation Research Grant, 2025
Mayo Clinic, Rochester, NY

NUMBERS THAT TELL THE STORY

Top Languages Used To Visit Our Website In 2024

Spanish	1.1 K
German	493
French	475
Italian	289
Korean	240 K
Arabic	238

OUTPOURING OF GENEROSITY

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

Corporations and Foundations

Alnylam

Astra Zeneca

Chip Miller Charitable Foundation

Jane & Frances Stein Foundation

Omaha Community Foundation

Prothena

The Cotswold Foundation

The Benny DeRosa Foundation

Fundraisers

2nd Annual Crusaders Walk

Pinboys at the Beach

PGA Metropolitan Section

Seneca Valley Track Booster Club

Trinity High School NHS

(Continued on Page 10)

English	92 K
Portuguese	400
Dutch	216

BIGHEARTED SUPPORTERS

Space constraints prevent us from listing the donor gifts under $250, however, we sincerely appreciate the generosity and support of those many donors.

$10000 +

Estate of Cynthia Trauernicht
Lauren Osbourne

$4000– $9999

Lars Frieberg
Kaye O’Riordan
Richard Lewin
The ERS Fund

$2000- $3999

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$1000-$1999

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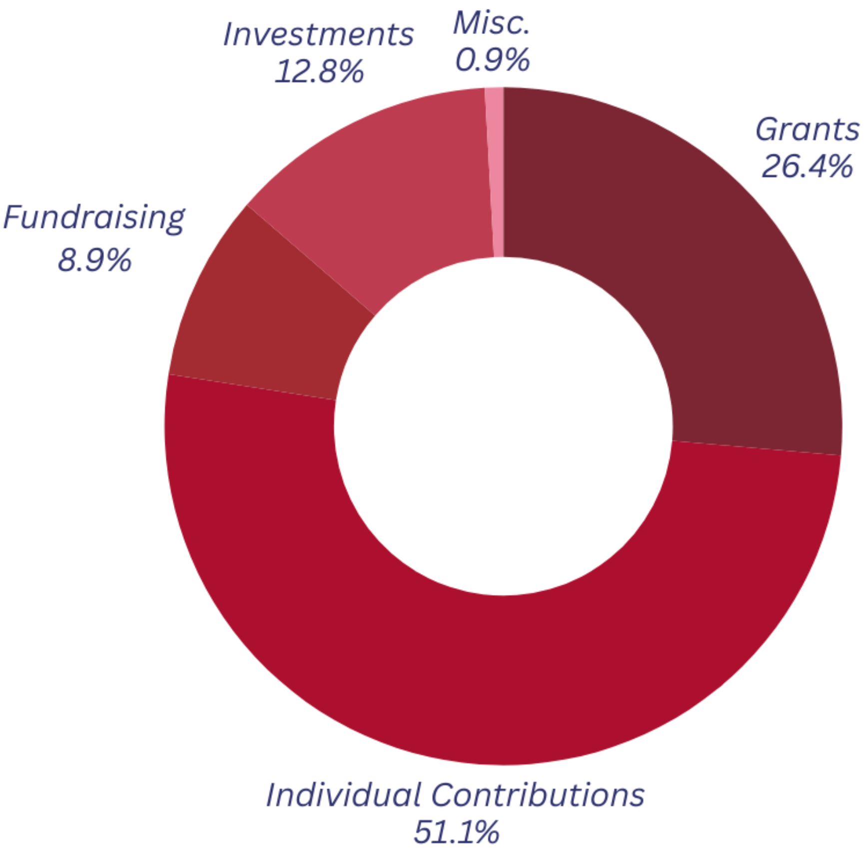
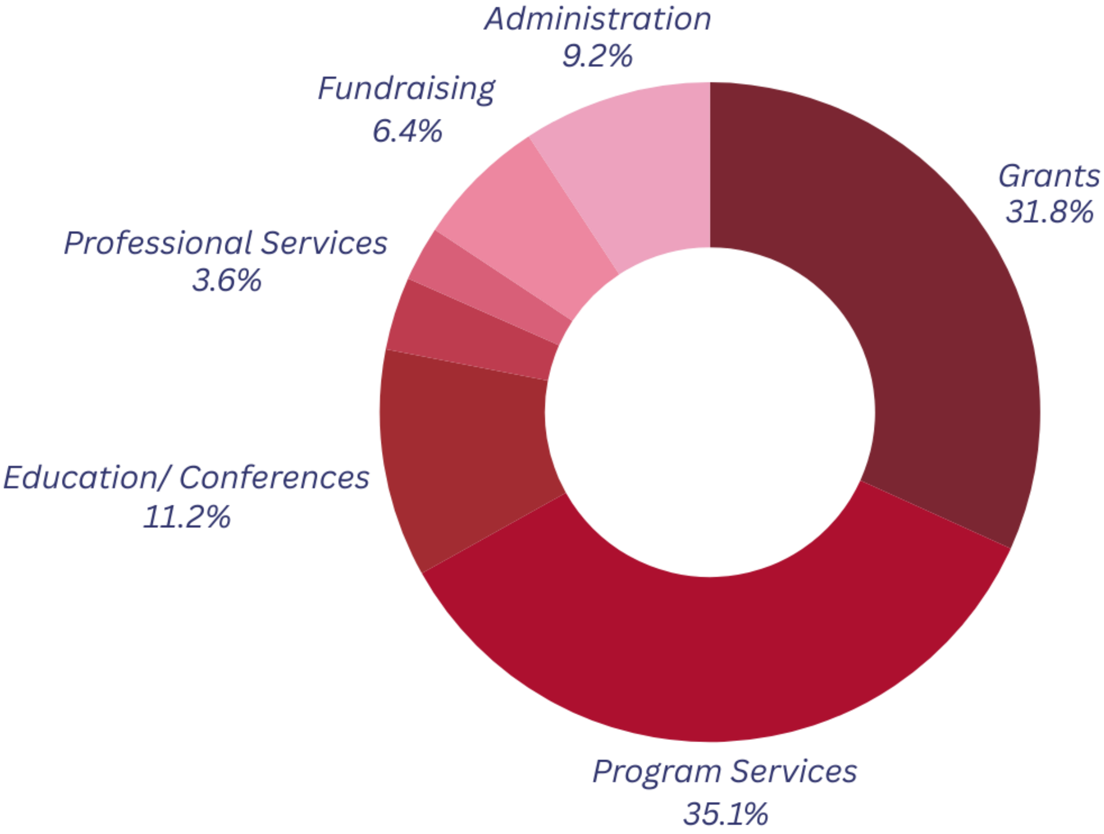
ECONOMIC SUMMARY

Income



Expense



Statements of Activities (Non-audited) - Year end December 31, 2024

Income

Grants	*26.4%*	*$182,500*
Individual Contributions	*51.1%*	*$353,550*
Fundraising	*8.9%*	*$61,438*
Investments	*12.8%*	*$88,509*
Miscellaneous	*0.9%*	*$6,078*
		$692,076

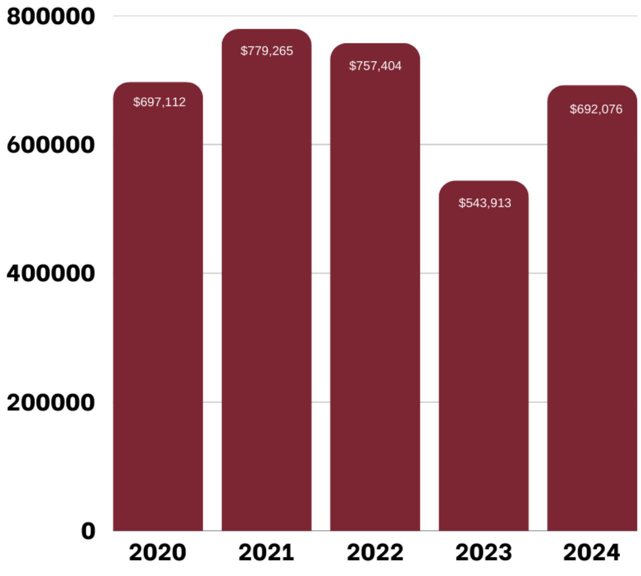
Expense

Grants	*31.8%*	*$195,318*
Program Services	*35.1%*	*$215,755*
Education/Conferences	*11.2%*	*$68,702*
Professional Services	*3.6%*	*$22,048*
Occupancy	*2.7%*	*$16,559*
Fundraising	*6.4%*	*$39,452*
Administration	*9.2%*	*$56,822*
		$614,656

Net Income/ Liability ***+$77,420***

Gross Income

5-year Overview



INSPIRATION

“So grateful for the information you have shared throughout the years! It has been invaluable as we walk this journey”

- Leigh

“[The Amyloidosis Foundation] has been a wonderful source of information for patients and families affected by this devastating disease “

- Louise

“Education of this rare disease has helped those around me understand its effects and physicians to more quickly diagnose it in the future “

- Susan

“Thank you for providing this [the Patient/Caregiver Binder] for our caregivers. Being a caregiver is an important, but difficult responsibility. I know that without [my wife], my amyloidosis life would be much different. Keep being wonderful, Amyloidosis Fdn!”

- Jason

"I have it [amyloidosis], it doesn't have me!"

- Connie

“The Amyloidosis Foundation has been an excellent resource in providing the most up to date research, clinical trials, medicine etc. We stand by their pursuit of increasing awareness, providing research grants and educating medical professionals”

- Nicole

Life doesn't get easier or more forgiving;

we get stronger and more resilient"

ENGAGEMENT HIGHLIGHTS

The Engagement Highlights Report offers a detailed summary of our audience's demographics, attendance, interests, and behaviors.

Social Media Engagement

11,692
New Followers

11,519
Social Media View

16,286
Social Media Reach

Website Visitors

Total Visitors

98,830

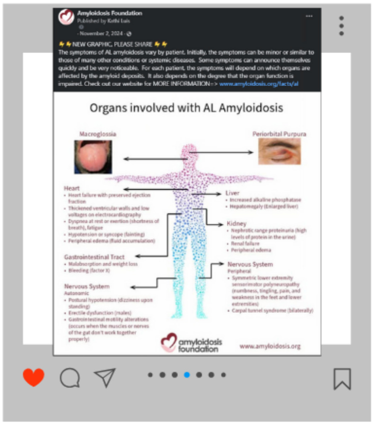
Total Views

233,859

Top Countries

United States	Australia
United Kingdom	India
Canada	Germany

Top Performing Content:



Amyloidosis Foundation
Published by Kathi Luis
· November 2, 2024 ·

⚡⚡NEW GRAPHIC, PLEASE SHARE ⚡⚡
The symptoms of AL amyloidosis vary by patient. Initially, the symptoms can be minor or similar to those of many other conditions or systemic diseases. Some symptoms can announce themselves quickly and be very noticeable. For each patient, the symptoms will depend on which organs are affected by the amyloid deposits. It also depends on the degree that the organ function is impaired. Check out our website for MORE INFORMATION=> www.amyloidosis.org/facts/al

Organs involved with AL Amyloidosis

Macroglossia

Periorbital Purpura

Heart
- Heart failure with preserved ejection fraction
- Thickened ventricular walls and low voltages on electrocardiography
- Dyspnea at rest or exertion (shortness of breath), fatigue
- Hypotension or syncope (fainting)
- Peripheral edema (fluid accumulation)

Liver
- Increased alkaline phosphatase
- Hepatomegaly (Enlarged liver)

Kidney
- Nephrotic range proteinuria (high levels of protein in the urine)
- Renal failure
- Peripheral edema

Gastrointestinal Tract
- Malabsorption and weight loss
- Bleeding (factor X)

Nervous System
Peripheral
- Symmetric lower extremity sensorimotor polyneuropathy (numbness, tingling, pain, and weakness in the feet and lower extremities)
- Carpal tunnel syndrome (bilaterally)

Nervous System
Autonomic
- Postural hypotension (dizziness upon standing)
- Erectile dysfunction (males)
- Gastrointestinal motility alterations (occurs when the muscles or nerves of the gut don't work together properly)

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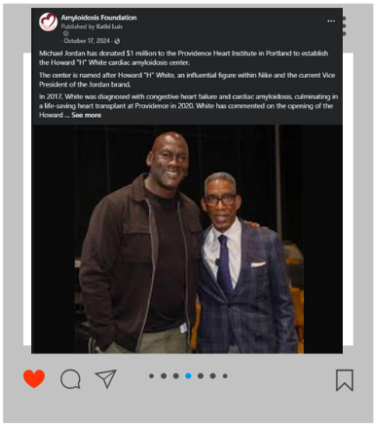
5351 Views



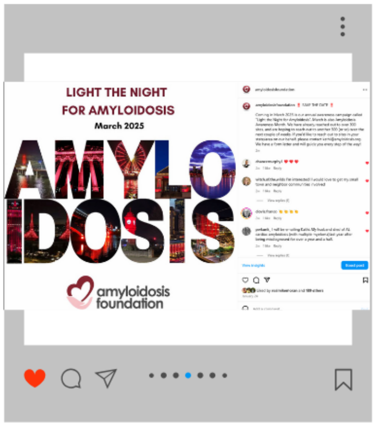
Amyloidosis Foundation
Published by Kathi Luis
· October 17, 2024 ·

Michael Jordan has donated $1 million to the Providence Heart Institute in Portland to establish the Howard "H" White cardiac amyloidosis center.

The center is named after Howard "H" White, an influential figure within Nike and the current Vice President of the Jordan brand.

In 2017, White was diagnosed with congestive heart failure and cardiac amyloidosis, culminating in a life-saving heart transplant at Providence in 2020. White has commented on the opening of the Howard ... **See more**

4104 Views



2846 Interactions

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