



Annual Report

2025



From Two Visions To One Mission

The Amyloidosis Foundation was formed in 2007 through the merger of two pioneering organizations: the Amyloidosis Research Foundation (ARF) and the Amyloidosis Support Network (ASN). This strategic union brought together complementary strengths—scientific advancement and patient-centered support—creating a unified and powerful force dedicated to research, awareness, and care for those affected by amyloidosis.

The Amyloidosis Research Foundation was established in 2003 by Don Brockman and Mary O'Donnell with a clear and ambitious mission: to advance medical and scientific research aimed at understanding amyloidosis and ultimately finding cures. ARF focused on funding innovative studies that could lead to meaningful breakthroughs in diagnosis and treatment for this rare and often misunderstood disease.

The Amyloidosis Support Network traces its origins to 1999, when Terry O'Malley, driven by a deeply personal connection to amyloidosis, began helping patients and raising awareness. He created an early online resource dedicated to providing information, support, and community for individuals and families navigating the disease. Although Terry tragically passed away in 2000 due to complications from amyloidosis, his vision endured. Dennis Krysmalski, who had collaborated with Terry on the website, carried the mission forward and formally established the Amyloidosis Support Network in 2004. Under Dennis's leadership, ASN focused on making a tangible difference in patients' lives while expanding awareness of amyloidosis within the medical community.

Today, the Amyloidosis Foundation proudly carries forward the legacies of both organizations. Our mission is rooted in hope, empowerment, and action. We are committed to ensuring that individuals living with amyloidosis have access to knowledgeable healthcare providers, accurate and timely diagnoses, effective treatment options, and strong support systems.

Through continued investment in research, education, advocacy, and patient support, the Foundation works to improve outcomes and elevate awareness of amyloidosis. Our ultimate goal is for every person affected by this disease to live a full and meaningful life, supported by a well-informed medical community and a compassionate network of care. Together, we strive to create a brighter future for the amyloidosis community.



Dennis Krysmalski
Founder



Don Brockman
Founder



From Then To Now: A Message Of Gratitude And Hope

In FY2025, the Amyloidosis Foundation continued to serve as a trusted resource for patients, families, and healthcare professionals navigating the complexities of amyloidosis. We remain deeply grateful for the generosity of donors, volunteers, researchers, and advocates who make our work possible.

Our priorities this year focused on expanding educational initiatives, funding promising research projects, and enhancing patient support programs. As the scientific and medical communities make important strides in understanding amyloidosis, we remain committed to ensuring that patients and caregivers have access to accurate information, expert guidance, and compassionate support.

Together, we are making meaningful progress toward earlier diagnosis, improved treatments, and ultimately a cure.

Mary



We're proud to use Candid Platinum to share our full and complete story with the world. The Platinum Seal of Transparency is the highest level of recognition offered by Candid, 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.candid.org





Supporting Every Step Of The Amyloidosis Journey

Program Highlights - FY2025

Education and Awareness

The Foundation continued to provide evidence-based educational materials, webinars, and resources for patients, caregivers, and healthcare professionals. Educational outreach efforts aimed to improve awareness of amyloidosis, promote early detection, and support informed decision-making.

Key initiatives included:

- Development and distribution of educational publications and digital resources
- Webinars and virtual events featuring medical experts
- Outreach to healthcare providers and medical institutions

Research Funding & Fellowship Support

Supporting research remains a cornerstone of the Foundation's mission. In 2025, the Foundation funded research projects focused on improving the understanding of amyloidosis mechanisms, advancing diagnostics, and exploring novel therapies.

Research priorities included:

- Two Clinical Fellowships in Hematology and Cardiology
- Basic and translational science studies
- Clinical research and treatment optimization
- Early-career investigator support

Patient and Caregiver Support

The Foundation provided direct support services to patients and caregivers through informational resources, peer connections, and referrals to specialized treatment centers.

Support activities included:

- Patient engagement and resource referrals
- Support group facilitation and peer connections
- Guidance on navigating diagnosis, treatment, and care
- Advocacy and Community Engagement

The Amyloidosis Foundation continued to advocate for increased awareness, improved access to care, and funding for amyloidosis research. Community engagement included collaborations with clinicians, researchers, legislators, and other advocacy organizations.

Join Us In Making A Difference



Memorial/Honorarium



Estate/Property



Planned Giving



Facebook Fundraiser



Host An Event



Matching Employer Gifts



Recurring Gifts



Charitable Gift Annuities



DONATE TODAY!

Strengthening Advocacy Efforts

Advocacy remains a core pillar of the Amyloidosis Foundation's mission to improve outcomes for patients and families affected by amyloidosis. This year, we strengthened our advocacy efforts to raise awareness, support patients and caregivers, and advance research and policy priorities.

Empowering Patients and Caregivers

We expanded educational resources and support programs to help patients and caregivers navigate diagnosis, treatment, and care. Webinars, digital guides, and peer connections provided timely information and fostered a stronger, more connected community.

Educating Healthcare Professionals

To reduce diagnostic delays, we increased outreach to clinicians through educational programs, conference engagement, and awareness initiatives. These efforts promote earlier recognition, accurate diagnosis, and coordinated multidisciplinary care.

Policy and Research Advocacy

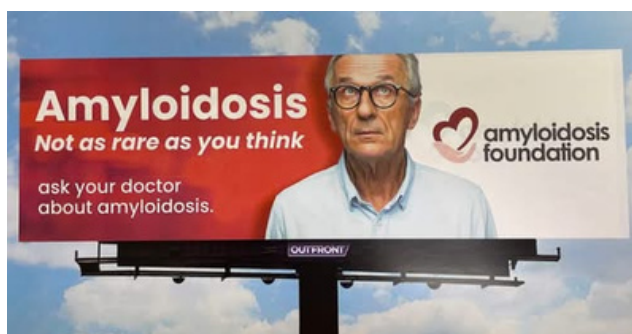
The Foundation continued to engage policymakers and research stakeholders to advance rare disease policy, increase research funding, and incorporate patient perspectives into research and regulatory discussions. Our research grant program remains a key driver of innovation in amyloidosis science.

Partnerships and Community Engagement

We strengthened collaborations with patient organizations, academic centers, and industry partners to amplify awareness and advocacy impact. Public awareness campaigns and community events further elevated understanding of amyloidosis and encouraged earlier conversations about symptoms and diagnosis.

Looking Ahead

We will continue to expand education, strengthen clinician outreach, advance policy and research advocacy, and engage diverse communities—ensuring that patient voices guide progress toward earlier diagnosis, better treatments, and a cure.



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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)

Researchers Supported By Our Grants



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



Research Impact

The Amyloidosis Foundation plays a critical role in advancing scientific discovery and accelerating new treatments for amyloidosis. Through its competitive grant program, the Foundation funds innovative research across all forms of systemic amyloidosis, supports early-career investigators, and promotes collaboration among clinicians, researchers, and industry partners. These investments have helped expand understanding of disease mechanisms, improve early diagnosis, and contribute to the development of emerging therapies that are changing the outlook for patients with these rare and underserved diseases.

Exceptional Philanthropic Support

Corporations and Foundations

Alnylam Pharmaceuticals
Astra Zeneca
Eidos Therapeutics
Prothena Biosciences
Chip Miller Charitable Foundation
Lloyd Family Foundation
Omaha Community Foundation
Jane & Frances Stein Foundation
Brian D. Stevens Foundation
The Benny DeRosa Foundation
The Barbara Silver Levin Foundation

Fundraisers

Advanced Radiology Services, PC
Crazy Crafts Fair (Karissa Dahnke)
Giving Tuesday
Pinboys at the Beach PGA
Podiatry Care Specialists
Run for Your Life 5K/10K
Seneca Valley Track Booster Club
Trinity High School NHS
Zebras In Motion

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Resources



Brochures



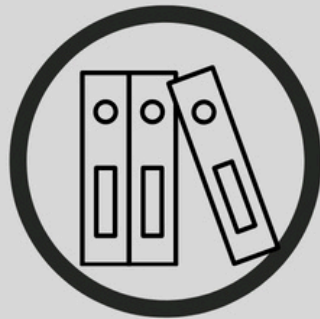
Newsletters



Webinars



Videos



Patient/Caregiver Binder



Exercises



Clinical Trials



Various Other Resources

Extraordinary Generosity From Our Donors

While space limitations prevent us from listing donor gifts below a certain amount, we are deeply grateful for the generosity and support of every donor.

\$10,000+

Lauren Osborne
James Parnell
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\$4,000 - \$9999

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Nandan Associates
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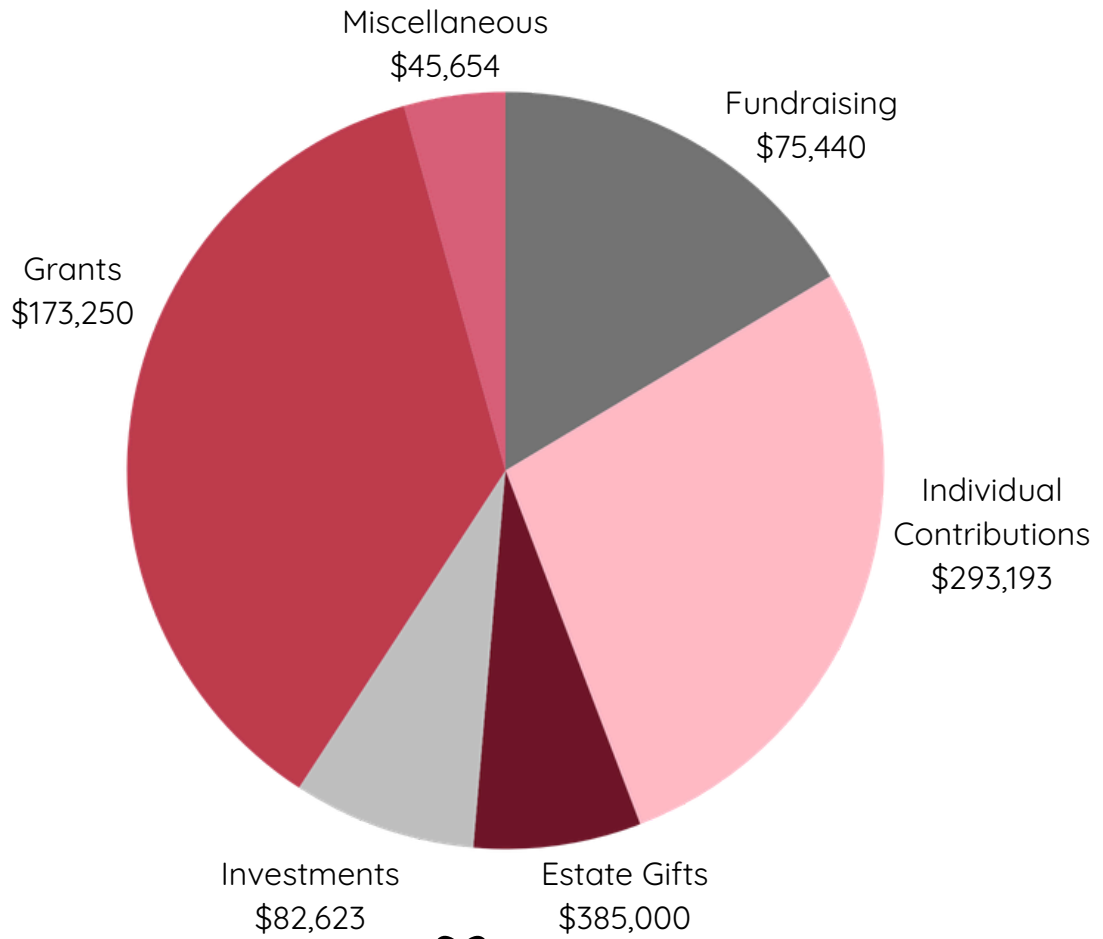


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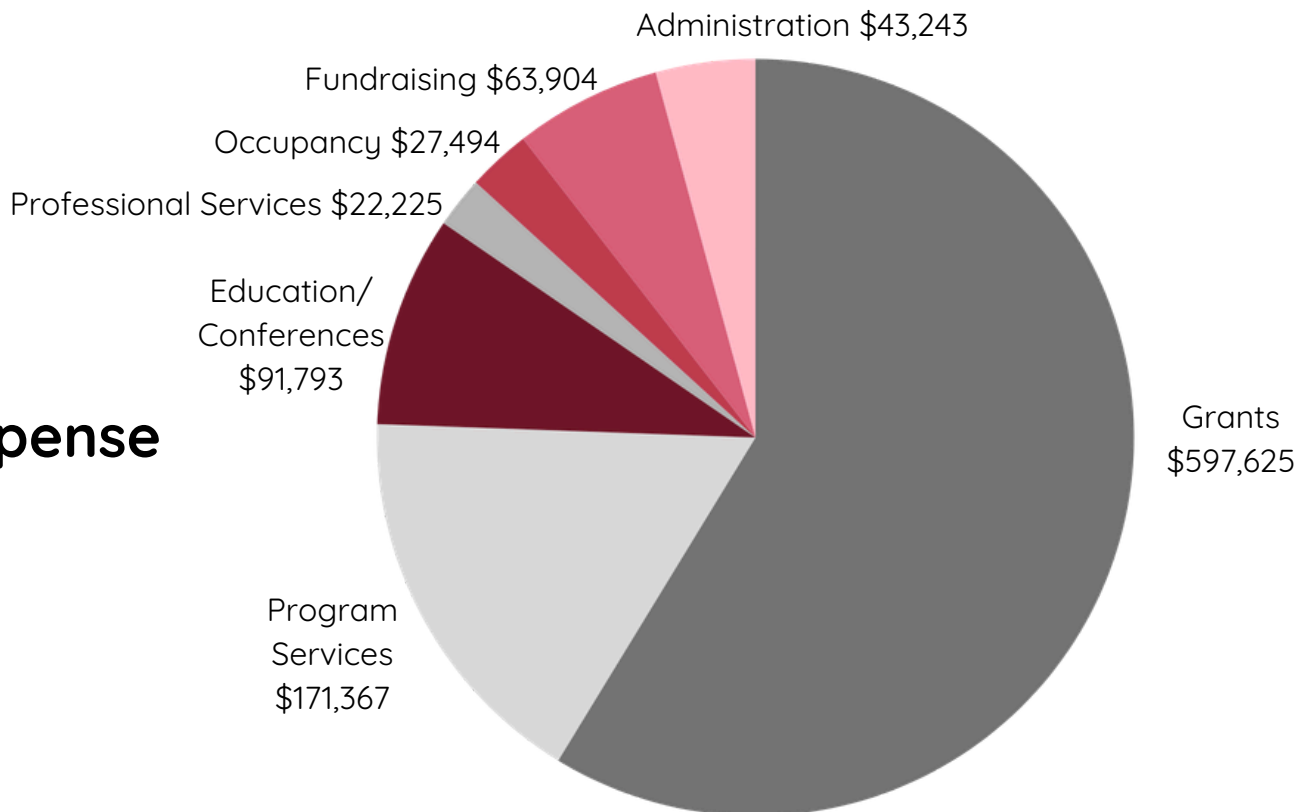
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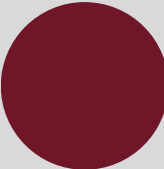
Financial Highlights

Income



Expense





Income

Grants	\$173,250
Individual Contributions	\$293,193
Fundraising	\$75,440
Investments	\$82,623
Estate Gifts	\$385,000
Miscellaneous	\$45,654
	\$1,055,160

Expense

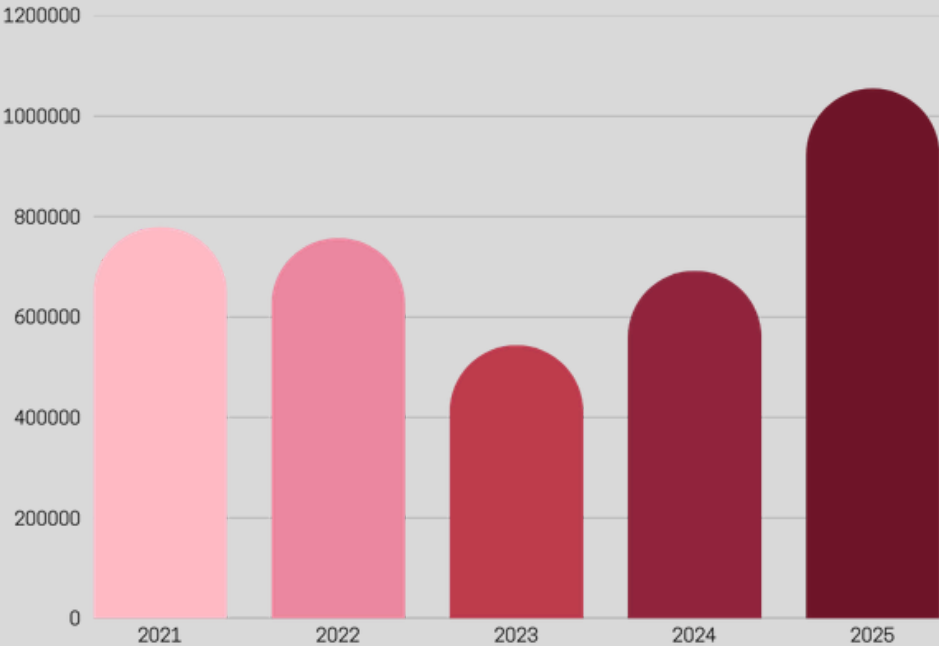
Grants	\$597,625
Program Services	\$171,367
Education/Conferences	\$91,793
Professional Services	\$22,225
Occupancy	\$27,494
Fundraising	\$63,904
Administration	\$43,243
	\$1,017,652

Net Income/ Liability **+\$37,509**



Gross Income

5-Year Snapshot



Community Connection



LIVE WEBINAR

*These sessions cannot be recorded due to patient participation and HIPAA laws



Somebody
To Talk To

oneAMYLOIDOSISvoice

Media Snapshot



Facebook

400 K Views
113% increase in
interactions
6,872 followers



Instagram

38.4 K Views
34% increase in
profile visits
2,828 followers



X

3,250 followers
X only provides insight
data for a paid account.
We believe our money is
more helpful in other
areas.



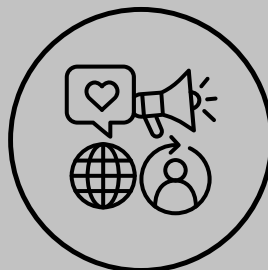
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239 K Views
Top view by country:
US, China, UK, Canada
& Singapore



Our YouTube Channel

3.9 K Views
839 Subscribers
509.7 hours watched





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