2023

ANNUAL
REPORT

amyloidosis
foundation

ABOUT US

Our mission remains urgent — to help all people affected by amyloidosis feel engaged and empowered to live better lives. The core principles of our strategic plan are to focus on people with and affected by amyloidosis; collaborate with others to drive the field forward; ensure our work is evidence-based and evidence-generating; and aim for maximum impact, sustainability and measurability in all of our programs. 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. Our research vision is that new discoveries that are in the pipeline will prevent, control and ultimately cure the disease. We continue to invest in the most promising research ideas by funding junior research scientists whose research targets the challenges in the field of amyloidosis. As of 2023, we have dedicated nearly $4 million toward amyloidosis research.

Our vision is that all people with amyloidosis have access to equitable and quality care. Finally, our education and support vision is that all people affected by amyloidosis have the information and resources they need. In 2023, we have also marked the twenty-year anniversary of the foundations inception. We have come extremely far in helping to fund the development of treatments for amyloidosis and building an increasing level of awareness about the disease, with our awareness events including ‘Light the Night for Amyloidosis’, Amyloidosis Awareness Month (March), and Rare Disease Day. We have participated in and fought hard for our community legislatively to gain access to treatments, accelerate approval, promote clinical trial diversity, increase rare disease funding, and lower copays so that patients can afford their medications. It is an ongoing challenge that we strive daily to achieve. Thank you for helping us reach further to improve the lives of those around the globe living with amyloidosis.

PRESIDENT'S MESSAGE

Hello and Thank You for your generosity and support.

It is hard to believe that the foundation celebrated its 20th anniversary last fall. The beginnings were a discussion between my husband Don (a patient) and myself agreeing that something had to be done to improve the prognosis for patients. We agreed that to do this, more monies were needed in the research arena. Thereafter the Amyloidosis Foundation was born.

We began very grass roots, just the two of us asking friends and family for their support. After Don's passing in 2004, the board and I realized that we needed to grow the foundation, and we did. We went from awarding our first research grant of $25,000 to supporting close to $4 million in research grants and travel awards, helping young researchers attend amyloidosis meetings. We have supported patients through support groups, informational pamphlets, caregiver binders and answering questions we receive via the phone and/or email.

We could not have carried out any of these efforts without the support of all our generous donors. We extend our heartfelt condolences to the families and friends that lost loved ones over the years. We continue our efforts in supporting the important and necessary amyloidosis research and helping patients and their families.

Mary

GUIDESTAR

Gold
Transparency
2023
Candid.

We're proud to use GuideStar Gold to share our full and complete story with the world. To reach the Gold 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

Investing in research, focused on patients

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 the amyloidosis, with the approval of another drug for ATTR in 2023 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. In 2023, we have increased our funding to $75,000 per awardee. Research has proven to be fruitful with six drug approvals for amyloidosis since 2018. The remarkably successful period of amyloidosis drug development over the past years shows a potential for a bright future of drugs to control the course of amyloidosis.

HOW CAN YOU HELP?


Memorial/Honorarium


Estate/Property


Matching Employer Gifts


Facebook Fundraiser


Host an Event

Planned Giving


Recurring Gifts

Charitable Gift Annuities

Donate Now!

“The greatness of a community is most accurately measured by the compassionate actions of its members”

~Coretta Scott King

MEET SHALISE

Rising Above AL Amyloidosis: Shalise's Story of Hope

My name is Shalise Gorrell, and nothing could have prepared me for this diagnosis or the journey that was to come. I was only twenty-six years old when I received my diagnosis, but I had endured well over two years of gradual symptoms leading up to that moment. My symptoms started off small, with some swelling in the legs, and shortness of breath; things that were easy to overlook in the beginning. Yet, my symptoms persisted and became more impactful, such as consistent weight gain despite strict dieting, an inability to walk due to breathlessness, hardening and swelling in the abdomen, and consistently puffy eyes. Collectively, these symptoms didn't stand out as anything to worry over, but whenever I did begin to worry, the people closest to me insisted that I was overthinking. My primary physician at the time assumed that it was just my new job, that with time these symptoms would pass, and assured me that I was healthy. At the time, as a full-time graduate student, outside of school and full-time work I didn't have much free time to consider otherwise, and therefore things continued to fester.

For months I was dealing with worsening edema, severe constipation, abdominal pain, terrible fatigue, and reoccurring infections. I began to notice an abundance of foam in my urine, blood clots in my mouth every morning, and debilitating fatigue that even sixteen hours of sleep could not cure. By the time I realized I wasn't a hypochondriac but severely ill and actively dying, I had become a shell of my former self. Despite feeling discouraged, I decided to make another appointment with my primary physician, and my lab results came back showing abnormal renal function. Finally, a nugget of hope for a diagnosis and solution!

In a devastating turn of events, a renal biopsy confirmed this was bigger than just renal disease. I was urgently referred to the Cancer Institute of New Jersey. My symptoms continued to worsen, and by the time my bone marrow biopsy was scheduled, the local anesthetics used couldn't numb my pain. I had to endure several biopsies and surgeries without pain relief. In October 2019, just a month after the last biopsy, I was formally diagnosed with AL Amyloidosis. This disease was attacking my kidneys and would be fatal if I didn't take swift action. I had little to no time to process what was happening. I was young, in pain and despair, and declining rapidly. I was scheduled to be admitted into the hospital that November for a Stem Cell Transplant, but due to a dangerous increase in water weight and light chains, I was admitted in October due to the threat of multiple organ failure.

I received a high-dose infusion of Melphalan on November 6th, and by my 27th birthday on the 11th I had lost most of my hair, my skin became ashen, I had bloodshot eyes, and my kidneys failed. With the renal decline, the water weight increased by pounds each day, and my breathing began to decline. As my breathing declined, I began to lose consciousness, gradually waking up less and less. And... I eventually coded. I'll never forget that feeling of transitioning, it was an unexplainable peace, where everything seemed so simple; I remember telling my family not to grieve for me, that "God has been good to me, even in my suffering, I have been blessed."

(Continued on page 9)

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OVERFLOW OF GENEROSITY

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

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Benton Central High School

Oakdale High School Government

Penland Golf

Pin Boy’s at the Beach– Buddies Fun League

Seneca Valley High School Track Club

Trinity High School National Honor Society

(Continued on Page 10)

BY THE NUMBERS

270
Facebook Fundraisers

$21K
Raised on #GivingTuesday

2
Research Grant Awardees

13
Support Group Meetings

120
Sites lit for Amyloidosis Awareness

5.8K
Facebook Followers

2,113
Instagram Followers

256K
Website Page Views

84
Caregiver Binders Sent to Patients

(Continued from page 6)

It was my family and my oncologist Dr. Dennis Cooper who demanded the emergency dialysis and life support that saved my life. I returned home after Thanksgiving, with much to be thankful for; I was alive, and in remission.

I remained on dialysis until mid-2020 and continued taking chemotherapy & immunotherapy well into 2023. Even as I rang the victory bell for my final chemo treatment, many health professionals warned me that I wouldn't be able to walk long distances, that I would have limited energy, and that I would be limited in what I could do. Although my life is still much different than before, I have been blessed to recover and to continue to recover more than what was expected. I was able to complete maintenance immunotherapy and chemotherapy, months of dialysis, and recovered from almost dying; I can run long distances, and I'm able to excel at everything I continue to commit myself to. I have been renewed with a newfound joy for life and a completely new perspective. We are fragile creatures, indeed, but in that fragility lies our strength.

I have found strength in sharing my story to all who care to listen, in hopes of encouraging others to trust their intuition above all else; and to encourage survivors who are battling this difficult disease, to hold on to hope. To those who are suffering, remember that pain is a universal language, but so is hope. Let us speak hope to each other, for it is in our shared vulnerabilities that we find our most profound connections. God has been good to me, even in my suffering, and I share my story to affirm that joy, true joy, is possible for us all.

Read more patient stories at: https://amyloidosis.org/category/stories

GRANT AWARDEES

Shilpa Vijayakumar, MD

Molecular Imaging of Myocardial Fibrosis in Transthyretin Cardiac Amyloidosis

The Charlotte L. Haffner Memorial Research Grant, 2023

Brigham and Women’s Hospital, Boston, MA

Oshrat Rokah, MD

Drug Repurposing for AL Amyloidosis: Exploring New Mechanisms

Amyloidosis Foundation Research Grant, 2023

Assuta Medical Center Hospital, Tel Aviv, Israel

GENEROUS DONORS

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

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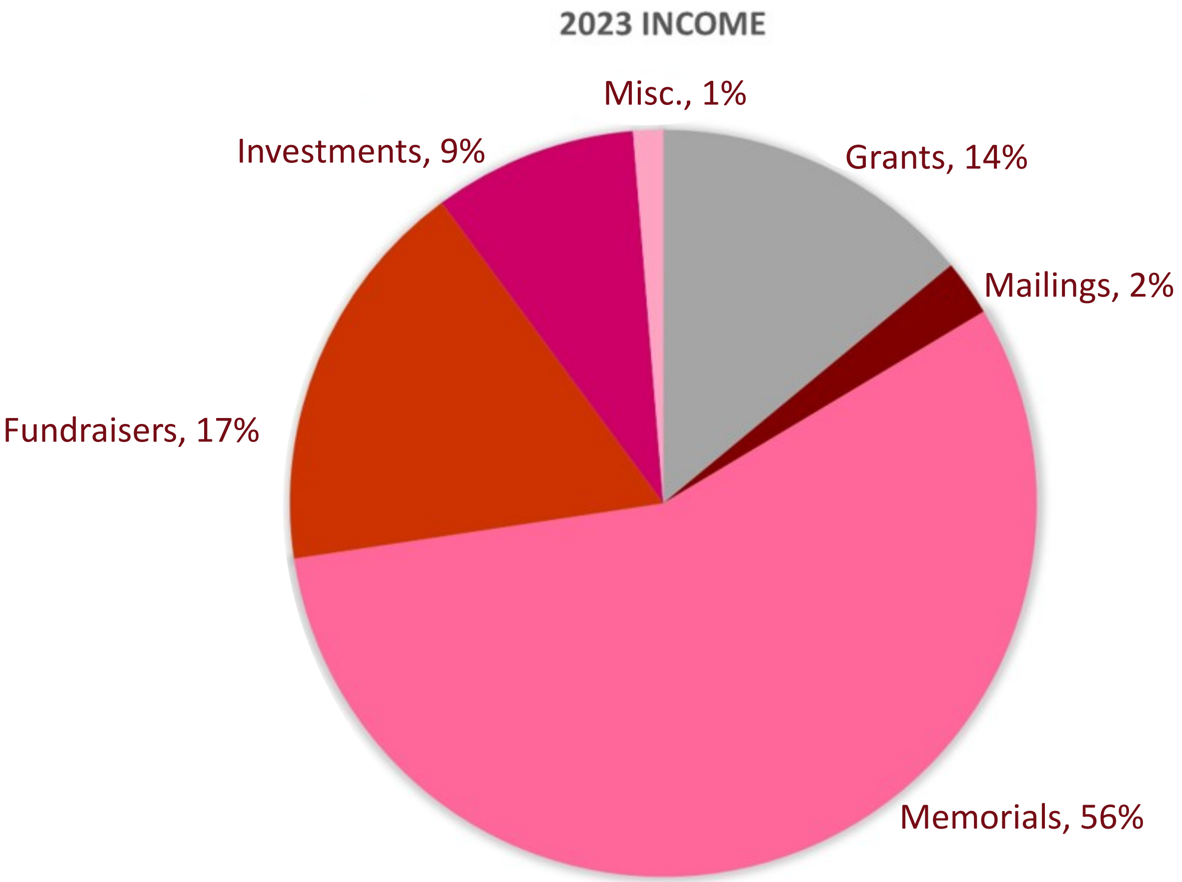
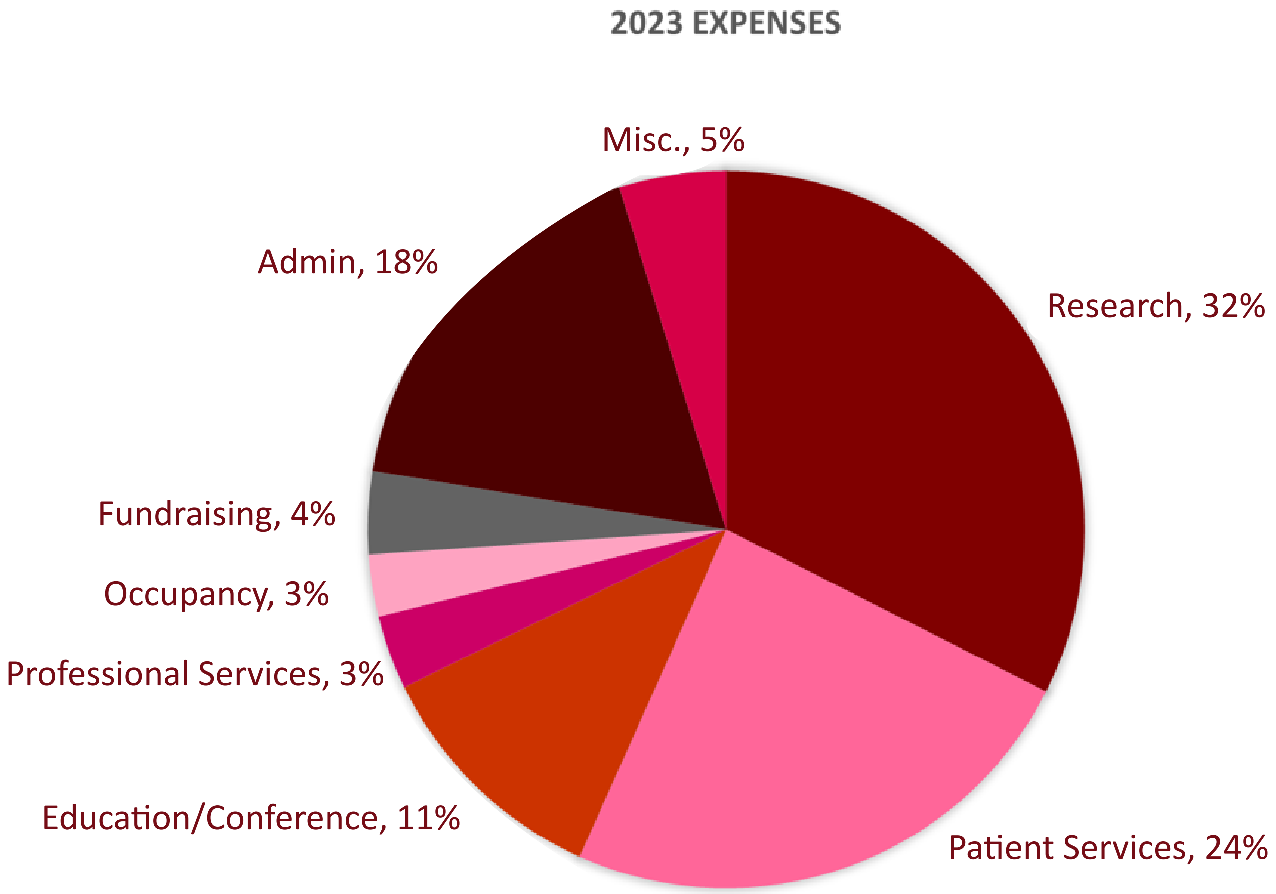
FINANCIALS


2023 INCOME
Misc., 1%
Investments, 9%
Grants, 14%
Mailings, 2%
Fundraisers, 17%
Memorials, 56%


2023 EXPENSES
Misc., 5%
Admin, 18%
Research, 32%
Fundraising, 4%
Occupancy, 3%
Professional Services, 3%
Education/Conference, 11%
Patient Services, 24%

Statements of Activities (Non-audited) - Year end December 31, 2023

Income

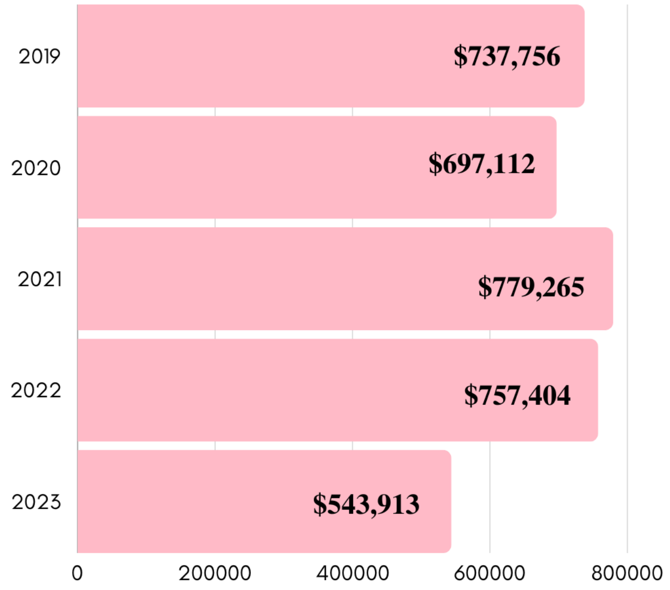
Grants	14%	$76,150	
Mailings	2%	$13,180	
Memorials	56%	$305,728	
Fundraisers	17%	$93,839	
Investments	9%	$47,960	
Miscellaneous	1%	$7,056	
		$543,913	**$543,913**

Expense

Research	32%	$196,694	
Patient Services	24%	$146,871	
Education/Conference	11%	$66,887	
Professional Services	3%	$20,230	
Occupancy	3%	$16,891	
Fundraising	4%	$22,625	
Administration	18%	$106,387	
Miscellaneous	5%	$29,230	
		$605,815	**$605,816**

Gross Income

5-year Snapshot



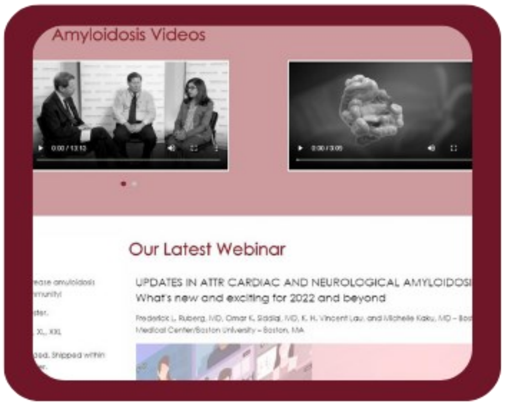
A YEAR OF IMPACT

Join Us for a Webinar

Beyond Standard of Care Treatment for Light Chain (AL) Amyloidosis: The Promise of Tomorrow

Dr. Landau has dedicated her career to improving the outcomes of patients with plasma cell disorders including multiple myeloma (MM) and light chain (AL) amyloidosis.

Tuesday, September 26, 2023
3:00 PM EDT



Amyloidosis Videos

Our Latest Webinar

UPDATES IN ATTR CARDIAC AND NEUROLOGICAL AMYLOIDOSI
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 – Bos
Medical Center/Boston University – Boston, MA

"A life is not important except in the impact it has on other lives."

— *Jackie Robinson*

20-YEAR HIGHLIGHTS

2003
Amyloidosis Research Foundation founded

2007
Merger results in Amyloidosis Foundation

2014
AF surpassed $1 Million in Research Grants

2015
The AF adds 2 more Research Grants

2018
The AF 15-year Anniversary!

2019
Creation of Patient/ Caregiver Binder

2021
AF awards 3 Research Grants and 2 Cardiac Fellowships

2023
AF celebrates 20 years!

www.amyloidosis.org

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