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# ANNUAL REPORT

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2021



# About Us

## FUNDING IS A PART OF THE CURE

It is our pleasure for us to share with you about the Amyloidosis Foundation's accomplishments in 2021. Because of funding for amyloidosis research, there are treatment options available now that families didn't have just five years ago. Research is how we will find the most promising pathways to new amyloidosis treatments, and ultimately a cure. Throughout 2021, donors and volunteers at the Amyloidosis Foundation stood with us and helped ensure that the Foundation had a great year. In this Annual Report, we share how we are making an impact to make life better for people with amyloidosis now, and in the future. Our objective is clear — that all people affected by amyloidosis are engaged and empowered to live better lives.

We are proud that we continue to remain unwavering to our founding mission—supporting patients and families while promoting research, education and awareness. For almost 2 decades, The Amyloidosis Foundation has worked with partners around the world to come up with a strategy to beat amyloidosis. With your support, we expanded our reach in 2021, while meeting the needs of patients, caregivers and families.

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.



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](http://www.guidestar.org)

# A Message From The President

The COVID-19 pandemic has been a challenge to us here at the foundation. Fortunately, we were able to keep operations going, although some activities have been either cancelled or converted to virtual participation. For example, we had a virtual 5K fundraiser in 2021 which was one of our most successful fundraisers ever. We continue to be thankful for the generosity of our donors throughout these difficult times.



Even through these difficult times, we were able to continue with some of our more important activities:

- We awarded 3 Junior Investigator Research Grants
- For the 2nd year in a row, we awarded 2 Cardiac Fellowships to educate physicians
- We continue to provide support to patients and their caregivers

Again, we are truly appreciative of your continued support and will continue to invest in research and raising awareness of amyloidosis.

Be Safe,

A handwritten signature in cursive script that reads "Mary".

Mary E O'Donnell



# Research For Tomorrow

## Advancing TODAY.

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



We are proud of all of our accomplishments and are making a real difference in research, education and awareness. Increasing the level of support is essential for research in underserved diseases like amyloidosis. This work aims to bridge the gap and to increase the knowledge that we currently have regarding amyloidosis. We share the same sense of urgency and values about access to resources and research for amyloidosis patients and their families.

The Amyloidosis Foundation has a very successful Grand Rounds program, as part of our commitment to raise awareness of the amyloidosis diseases. We will sponsor an expert in amyloidosis to speak to doctors and medical staff regarding the diagnostic tools, clinical protocols and treatment therapies that are currently available.

Our speakers are among the most knowledgeable specialists in the U.S. and are involved in amyloidosis research and patient care. The Amyloidosis Foundation will arrange for the speaker and will cover all travel expenses and honoraria. The Amyloidosis Foundation was established in 2003 to support research for systemic amyloidosis by Junior Investigators. As the prognosis for late diagnosed amyloidosis patients is poor, the foundation supported two 1-year Cardiac Amyloidosis Fellowships in 2021.

# Coach Lew Hill



Lew Hill was a loving husband, amazing father, dependable son, marvelous big brother, outstanding grandfather, and a phenomenal college basketball coach.

Growing up in Mount Vernon, New York, Lew was intrigued by the game of basketball. He could be found playing at a park or the local Boys and Girls club with his friends. Lew always knew basketball would be his ticket for a better life. After graduating from Mount Vernon High, Lew received a basketball scholarship to San Jacinto Junior College, in Houston Texas. Lew helped lead San Jacinto College to a Basketball Championship receiving Juco All American. He went on to earn All-Missouri valley conference and an NCAA tournament appearance at Wichita State.

Lew Hill didn't stop there; he went on to play professional basketball overseas in Germany (German Euro League). After returning to the states, Lew began his coaching career at Wichita East High School. His career started to take off, landing several prominent coaching positions. He started his collegiate coaching career at South Alabama and transitioned to Southeast Missouri State, East Carolina, Texas A&M, UNLV, and The University of Oklahoma. 2016 was a phenomenal year for Coach Hill, as he helped take the Oklahoma "Boomer Sooners" to the Final Four.

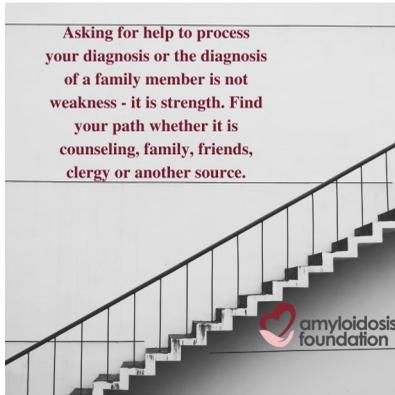
Shortly after his appearance in the big dance, Lew was offered the University of Texas Rio Grande Valley's head-coaching position. His dream of becoming a Division 1 Head Men's Basketball coach finally came true. Lew notably turned around the basketball program at UTRGV and helped lead the team to win eight of the final ten games, culminating in No. 2 seed at WAC Tournament.

At the prime of his career, Lew began facing unforeseen health issues. After a yearlong search for answers, he was diagnosed in January 2021 with a rare disease called Light Chain AL amyloidosis. Lew was experiencing significant pain off the court, but his love for basketball and his players kept him in the gym. Hill was ready to go to battle with the disease, but unfortunately, God had other plans. On February 7, 2021, Lew was called home. Thousands were saddened by the death of such a remarkable man.

Lew Hill leaves behind his wife Renee, children Sierra, Erica, Asya, Lewis Jr, and Elle. His grandchildren, Joshua, Shaniya, Johnathan, Ayden, Aria, Denim. Mother Annie, brother Emory, and a host of other loved ones.

The Hill family is devastated by Lew's sudden passing from AL amyloidosis. We hope to bring awareness around the disease, as well as encourage others to be tested.

# Instagram Inspiration



Thoughtful Tuesday

Every Journey is Different

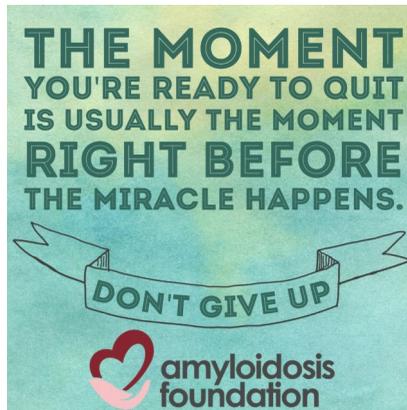
One thing at a time

Celebrate small wins

Honor your feelings

Make someone smile

*you are NOT  
alone AND this  
is NOT the  
END of your  
STORY*



**And sometimes  
against all odds  
against logic  
we still HOPE**

## TOGETHER WE CAN MAKE A DIFFERENCE

You are the reason we are able to provide vital support for people living with amyloidosis.

**GIVE ONLINE**

[www.amyloidosis.org](http://www.amyloidosis.org)

**GIVE BY PHONE**

248.922.9610

**GIVE BY MAIL**

Amyloidosis Foundation

7151 N. Main St., Suite 2

Clarkston, MI 48346

It is our mission to support patients and families while promoting research, education and awareness. Help us to do that.

**Donate today!**



Memorial/  
Honorarium



Estate/  
Property



Matching  
Employer Gifts



Facebook  
Birthday  
Donation



Host an  
event



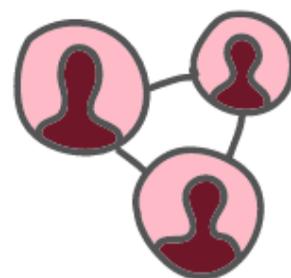
Planned  
Giving



Recurring  
gifts



Charitable Gift  
Annuities



Action Advocate

**“Giving is not just about making a donation.**

**It’s about making a difference”**

~Kathy Calvin

# The Numbers Speak For Themselves

**130,500**

New Users  
on our Website

**4,448**

Facebook Likes-  
Up 27%

**108**

Sites that lit for 'Light  
The Night for  
Amyloidosis'

**\$21K**

Raised on  
#GivingTuesday

**371**

Facebook  
Fundraisers

**80+**

Caregiver Binders Sent  
to Patients/Caregivers

**3**

Research Grant  
Awardees

**9,984**

Website Users-  
Up 9%

# Grant Recipients

*“What is research but a blind date with knowledge?”*

*~ Will Henry*

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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.

**Meet our grant awardees! We are proud to feature our grant recipients whose research targets the challenges in the field of amyloidosis.**



**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



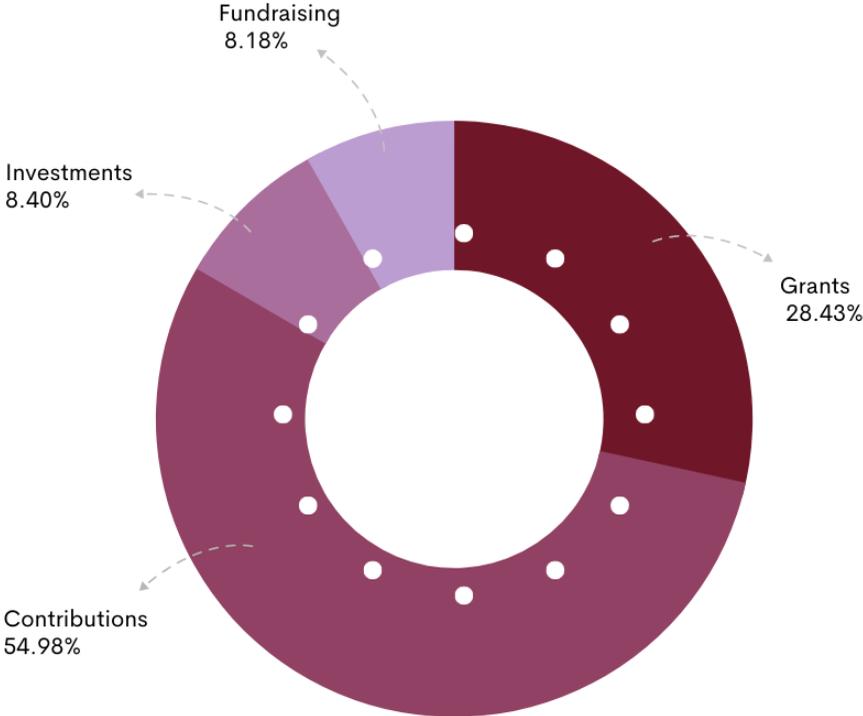
**Taxiarchis Kouelis, MD**

*Characterizing the Role of the Tissue Immunome in the Pathogenesis of Renal AL Amyloidosis*

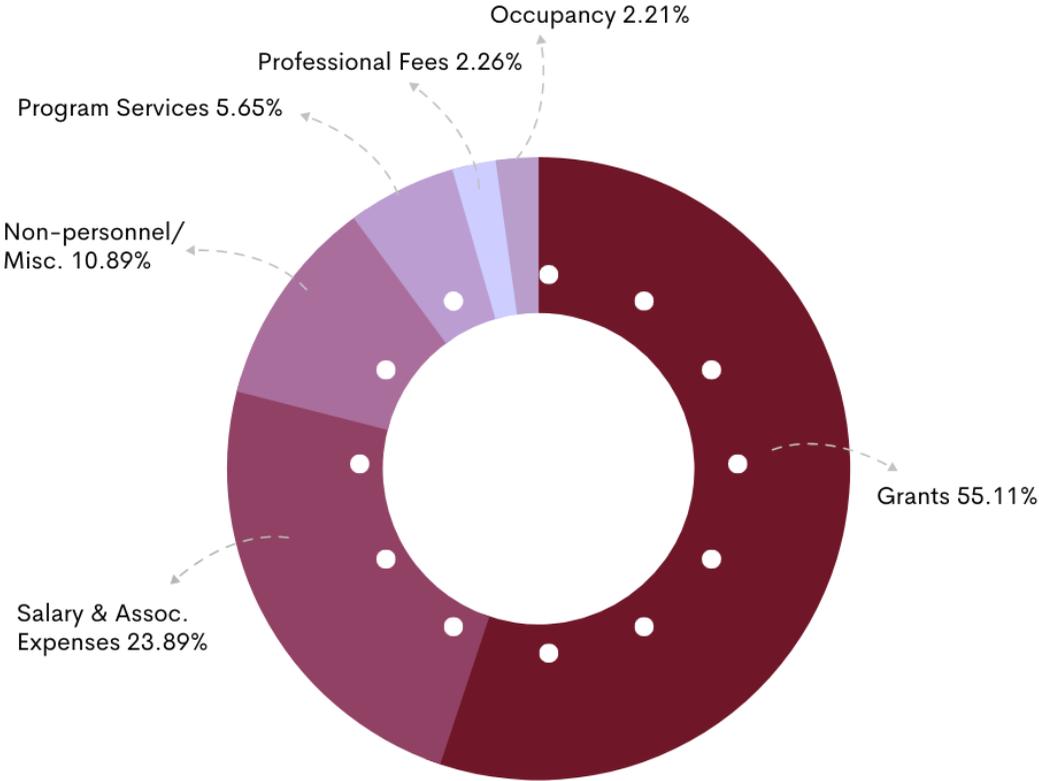
Amyloidosis Foundation Research Grant, 2022  
Mayo Clinic, Rochester, MN

# Financials

## REVENUE



## EXPENSES



**Support & Revenue**

Contributed Support	698,324
Investment Income	57,958
Fundraising	15,500
Earned Revenues	7,482

**Total 779,264**

**Expenses**

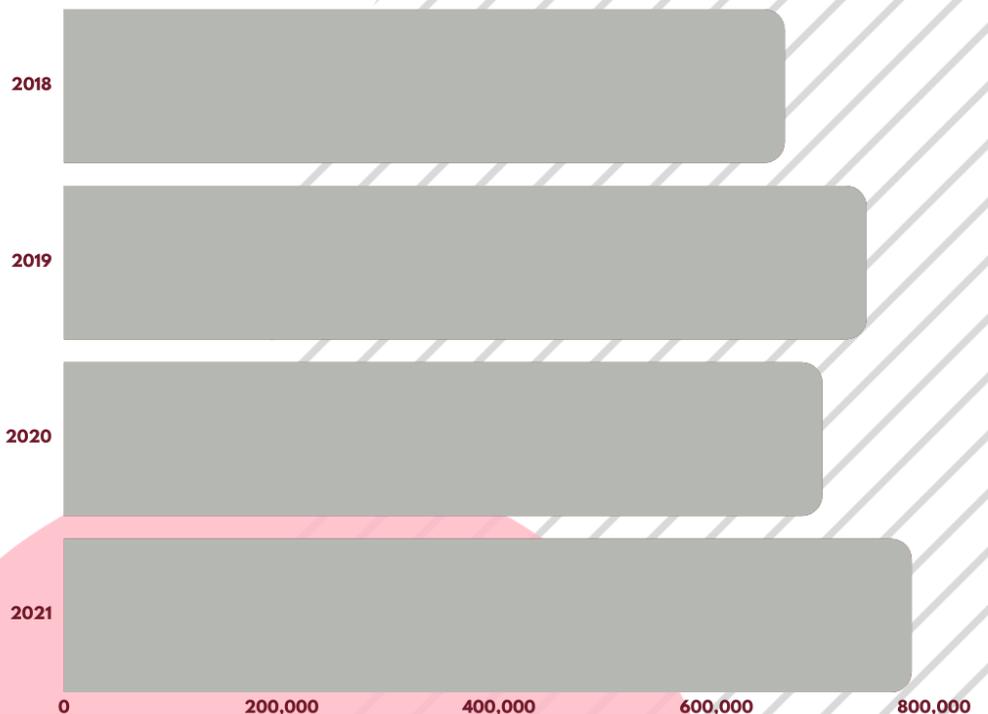
Grant Expenses	395,000
Personnel & Related Expenses	171,203
Professional Fees	16,210
Program Services	40,492
Occupancy Expenses	15,807
Travel & Meeting Expenses	0
Non personnel Expenses	44,752
Miscellaneous Expenses	33,382

**Total 716,846**

**Net Income/Liability 62,418**

**Gross Income**

**Four-Year Snapshot**



# Events

## Light The Night For Amyloidosis

The Amyloidosis Foundation had great participation in our 'Light The Night For Amyloidosis' campaign in 2021, with over 100 sites in 5 countries lighting for our cause. Some of those that lit up for amyloidosis were the entire Chicago City Skyline, Niagara Falls, Aloha Tower, Calgary Tower, Zakim Bridge, Wells Fargo's Duke Energy Center, Detroit Ford Field, Bank of America Plaza, The PA Capitol Building, and many other notable locations across the globe. Supporters of the foundation also bought red lights to light up their front porches and homes. Thank you to all for another successful year of awareness!



## Run For Your Life

Thank you to the 350+ runners, walkers and rollers we had for this event! The participants could walk, run or bike at their leisure to help raise awareness of amyloidosis, in their local community. This event raised over \$15,000 for research, education and awareness. We truly appreciate the wonderful support we have received.



# Board of Directors



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# Generous Contributors

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

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Chip Miller Charitable Foundation  
Linda Dupree

## \$4000-\$9999

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The ERS Fund

## \$2000-\$3999

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### **Fundraisers**

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Cocktails For A Cause– Conway Family  
Jeff Brenna Golf Outing  
John Marnell Foundation  
Kilter Miles For Meaning  
NY Run– Lori Harrington  
Pinboy's At The Beach  
Pampered Chef  
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Senneta Gower  
Scoops For Fun

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Omaha Community Foundation  
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Tudor Foundation



**Special thanks to all of those that created  
Facebook Fundraisers. You raised over \$132,000!  
Your generosity is boundless!**

**And thank you to the over 1200 other donors that  
mean so much to us. We can't support our mission  
without all of your help!**



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