It is a joy for us to share with you about the Amyloidosis Foundation’s accomplishments in 2020. We are proud that we continue to remain steadfast to our founding vision—supporting patients and families while promoting research, education and awareness. With your support, we expanded our reach in 2020 via virtual events and embarked on new social ventures 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
A Message From The President

What a year!! On March 16, 2020 the State of Michigan, for all intents and purposes, shut down due to Covid-19. At the foundation, we immediately started working remotely from the office. Fortunately, we already had systems in place to accomplish this, so the work of the foundation continued helping patients and caregivers understand amyloidosis, it’s diagnosis and treatment.

There were many challenges and surprises along the way, many that affected everyone; how to safely shop for groceries, how to get support from our physicians, how to safely see family members that don’t reside in our houses. We here at the foundation had to make many changes. All of the medical conferences that we normally attend to spread awareness of amyloidosis were either cancelled, or converted to virtual meetings. The support groups that we support had to be cancelled. We were unable to schedule any Grand Rounds, so educating physicians on amyloidosis was on hold. Many of these activities will continue to be on hold for the indefinite future.

Some positive things that have occurred in 2020;

◦ The generosity of our donors has continued throughout the pandemic
◦ We were able to support two research grants
◦ Zoom support group meetings started in December
◦ We continued to distribute informational pamphlets
◦ We had over 100 buildings around the world light up for ‘Light the Night for Amyloidosis’ in March, along with, and most exciting, we are able to support 2 Cardiac Amyloidosis Fellowships to educated young physicians

We can’t begin to thank you enough for your support and generosity. None of our accomplishments could be achieved without you, your support and generosity. As we continue to battle through the Covid-19 pandemic, please take care of yourself.

Be Safe,

Mary E O’Donnell
This is a pivotal time in the history of amyloidosis, with the approval of three drugs for ATTR in 2019 and a number of new therapies on the horizon. Increasing the level of support is essential for research in these underserved diseases. This creative and systematic work has been undertaken to increase the stock of knowledge that we currently have regarding amyloidosis. It involves the collection, organization, and analysis of information to increase understanding of amyloidosis.

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.

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 has decided to support two 1-year advanced Cardiac Amyloidosis Fellowship II in 2021.
My older sister, Barbara Kaplan, started having shortness of breath in October of 2019. She went to her internist in Miami, Florida, and a chest x-ray which showed fluid in her lungs. Her internist immediately referred her to a cardiologist who suspected amyloidosis. She was diagnosed a few days later and was started on Vyndamax shortly after. Her 3 siblings were advised to get tested for the gene. Our two brothers were quickly tested and both were deemed negative. Our mother was tested and is negative as well. Our dad is deceased.

My testing was a little more complicated due to the fact that I had a bone marrow transplant in 2010. After submitting a buccal swab that came back inconclusive, it was determined that they needed to do a skin biopsy to test for the gene. That was about the time the coronavirus ramped up and the test was postponed. Finally, I had the biopsy in May of 2020, and it came back positive for the gene. I started at Boston Medical Center and was diagnosed on June 22, 2020. We have the T60 (80) variant. I have since transferred to Cleveland Clinic/Dr. Hanna due to insurance. I have been on Vyndamax since Aug. 1.

My numbers indicate early onset of the disease with cardiac involvement, but no neuropathy. I did have carpal tunnel surgery in November of 2018. I had a procedure on my thumb in October 2020 and the doctor did a tissue biopsy to see if the problem is due to amyloid. I have no symptoms and continue to do life as normal except for being extra, extra cautious during this pandemic. I bike 30 minutes every morning and walk for 30 minutes every afternoon. I play golf at least once a week and continue to work full time.

Bio:
Jaime Kaplan was born and raised in Macon, Georgia. She started playing tennis at the age of nine and went on to hold junior rankings as high as first in the state, second in the south, and 18th in the United States. At Stratford Academy, she produced an undefeated record of 156-0 in singles and doubles along with 5 state titles. She also was an all-state basketball player, playing on 3 state championship basketball teams. After playing collegiate tennis at UGA then FSU, Jaime competed on the WTA Tour for six years, achieving world rankings as high as 91 in doubles and 252 in singles. She played in Wimbledon five times, the US Open four times, the French Open four times, and the Australian Open once.

Jaime has been inducted into the Stratford Academy Athletic Hall of Fame, the Macon Sports Hall of Fame, the Georgia Tennis Hall of Fame, the Georgia Sports Hall of Fame, and the Southern Tennis Hall of Fame. A knee injury at Wimbledon forced Jaime to retire in 1989 and she settled in back home in Macon where she has been very involved in the community, raising over $12,000,000 for various charities, mainly the Rescue Mission of Middle Georgia and United Way of Central Georgia, over the past 33 years. She serves or has served on over a dozen non-profit boards and in 2011 filled an unexpired term for six months on Macon’s City Council.

Jaime was diagnosed with a rare form of acute myeloid leukemia on April 23, 2010. She underwent a bone marrow transplant on August 27 of 2010. On June 22, 2020, Jaime was diagnosed with hATTR Amyloidosis, a rare disease of which currently there is a treatment, but no cure. Jaime is the Director of Philanthropy at United Way of Central Georgia, Event Manager of the Five Star Kevin Brown Russell Henley Celebrity Classic and Head Coach of the Stratford boys and girls varsity tennis teams. Jaime’s individuals and teams have won 45 region titles and 16 state titles since she started coaching in 2005. If you ask Jaime her greatest accomplishment, she will tell you that it’s not being inducted into halls of fame. She will tell you that it’s the many lives she has touched through her charity work and her journey with cancer and amyloidosis.
Instagram Inspiration

If it doesn't nourish the soul, let it go

And if today, all you did was hold yourself together, I'm proud of you

Think BIG thoughts, but appreciate small successes.

I admire people who choose to shine even after all of the storms they've been through.

Amyloidosis may be RARE but HOPE should not be

BE STRONG when you are weak
BE BRAVE when you are scared
BE HUMBLE when you are victorious
BE A WARRIOR everyday
“Those who are happiest are those that do the most for others.”

~Booker T. Washington

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

**Revenue**
- Memorials: 34%
- Grants: 36%
- Events/Fundraising: 4%
- Mailings: 2%
- Other: 26%

**Expenses**
- Grants: 44%
- Salary: 29%
- Non-personnel: 19%
- Program Services: 8%
**Support & Revenue**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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<tr>
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<tr>
<td>Investment Income</td>
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<tr>
<td>Fundraising</td>
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<tr>
<td>Earned Revenues</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>697,112</strong></td>
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**Expenses**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grant Expenses</td>
<td>263,273</td>
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<tr>
<td>Personnel &amp; Related Expenses</td>
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<td>Other Personnel Expenses</td>
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<td>Program Services</td>
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<td>Occupancy Expenses</td>
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<td>Travel &amp; Meeting Expenses</td>
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<td>Non personnel Expenses</td>
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<tr>
<td>Miscellaneous Expenses</td>
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<td><strong>Total</strong></td>
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**Net Income/Liability**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td><strong>Net Income</strong></td>
<td><strong>99,798</strong></td>
</tr>
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</table>

**Gross Income**

**Four-Year Snapshot**

- 2017: $843,560
- 2018: $662,533
- 2019: $737,756
- 2020: $607,112
Awareness

The Amyloidosis Foundation had great participation in its inaugural ‘Light The Night For Amyloidosis’ campaign in 2020, with over 100 sites in 5 countries lighting for our cause. Some of those that lit up for amyloidosis were Niagara Falls, Aloha Tower, LAX Airport, Little Caesar’s Arena, JL Tower, Zakim Bridge, Wells Fargo’s Duke Energy Center, Detroit Ford Field, MLK Jr Memorial Bridge, Bank of America Plaza, The PA Capitol Building, Emirates Spinnaker Tower, Calgary Tower 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 a successful year of awareness!
Meet our grant awardees! We are proud to feature our grant recipients whose research targets the challenges in the field of amyloidosis.

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.

Timothy Poterucha, MD
Prospective Identification of Transthyretin Cardiac Amyloidosis Using Deep Learning
Amyloidosis Foundation David C. Seldin Memorial Junior Research Grant, 2021
Milstein Hospital, Columbia University, New York, NY

Maria Moscvin, MD
Targeting Free Light Chain Secretion as a Novel Therapeutic Strategy in AL Amyloidosis
Amyloidosis Foundation Donald C. Brockman Memorial Junior Research Grant, 2021
Brigham and Women's Hospital, Boston, MA

“Research is to see what everybody else has seen, and to think what nobody else has thought”

~Albert Szent-Györgyi
Generous Contributors

$4000-$9999

Barbara Carney
John Childs
Eli Dickinson
Veronica Gilles
Wiebren Jonkman
Shirley Grant-Brown
Bruce Carlson
Monica Cedarstrom
Charles Cornwell
Stephanie Daley
Mike Devenport
Robert Epstein
Patty Fowler
Larry Gauchman
Angela Gray
Alexandra Grulke
Camille Guth
Kieran Hanrahan
Linda Heald
Ruth Heyman
Pia Jala
Ruben Johnson
Blair Jones
Michael Van der Kieft
James Lee
Matthew Levenson
Carolyn Lloyd
Katherine Lund
Marion Margattis
Geoffrey McGrane
Michelle Medeiros
Robert Miller
John Moran
Amanda Myers
Jennifer Nakata
Andrea Nemit
Helen O'Donnell
Mary O'Donnell
Ronald Ostrowski
Podiatry Care Specialists
Howard Powell
Daniel Preast
Jordan Renner
The Rettie Family
Derek Riddle
Owen Saddler
Brian Schaezler
Mark Scher
Michael Sodaro
Mary Sundvold
Sandra Roberts-Taylor
Susan Toland
Celina Valenzuela
Nicolas Ziebarth

$2000-$3999

Portia Bamiduro
Bronwyn Davis
Cecil Loyd
Nikki Menard
Frances Mitchell
Sandra Pope

$1000-$1999

Mark Blackman
Henry Blaxter
Deb Boedicker
Zachary Christopherson
Dick Fowler
Sharron Gibson
Jay Godfrey
Thomas Green
Estate of Stuart Gruber
Sean Keller
David Lenz
Lois Lieberman
Paula Mitchell
Cecilia Polcyn
Myra Pomerantz
Stephanie Sherman
The John & Cindy Stemper Fund
Dorothy Watenmaker
Ted Wells
Lloyd Wenning
Lisa Werkstell

$500-$999

Dorothy Sintas-Abeyta
Betsy Barton
Jonathan Barton
Ralph Battat
Jillian Beverstock
Kevin & Bernadette Brockman
Walt & Nancy Brockman
John Arena
John Arlotta
Lee Ann Bachelder
Rachel Bain
Barbara Barry
Albert Benjamin
Kathleen Bilek
Douglas Brettler
Thomas Brockley
Richard Brooks
Barry Broussard
James Cannon
John Christman
Dorothy Chung
Richard Clark
Faith Colish
Kristine Cone
Katherine Cook
Joseph Crozier
Serac Dacosta
Sharon Davidson
Linda De Vries
Victor Demming
Ken DiBiasio
Alfred DiGiulio
Mary DiMartino
Jerome Doucette
Lynn Dowling
Charles Edmonson
Leslie Ellis
Ed Fitzmaurice
The Gallashaw Family
Samir Gandhi
Darrin Gonchar
Susan Grahamer
Philip Gundy
Jeffrey Haas
Judith Habel
Stanley Hanin
Terrance Hansen
David Helman
Jon Heyman
HJD (Dorothy Chung)
Susan Hutchins
Dorothy Ireland
Dozier Jones
Richard Jones
Nancy Jurcisek
Wendy Khabie  
Philip Kier  
KKC International Sullivan  
Robert Klemann  
David Levine  
Brian Lewis  
Joseph Lombardozzi  
Keith Lorensen  
Robert Lynch  
Thomas Maher  
Mam Orthopaedics, PA  
Jane Marks  
Lisa McCaig  
Heather McCollum  
Timothy McInerney  
Janiece McNichols  
William Mintzer  
Cassie Mishkin  
Randall Murray  
Lee Nackman  
Shalaun Newton  
William Pellegrini  
Amy Phillips  
Mauricio Plaza  
Kristen Raymond  
John Reser  
Robert Rolette  
Deborah Ross  
Jacob Rossmer  
Richard Rozman  
Terry Sage  
Lucille Sarkisian  
Sidley Austin LLP (Amy Phillips)  

Sid Smith  
Brian Spear  
Robert Stillman  
Sylvia Tilton  
Ryan Todtenbier  
Michael Trahan  
Robert Tunno  
Jodi Urquhart  
David Vesole  
Alison Waring  
Waypoint Wellness Center  
Dan Weinzheimer  
Marylou Weinzheimer  
Rachel Welch  
Joanne Wright

Fundraisers

The Zebra Dazzle— Zebras in Motion  
Cecilia Polcyn— Jewelry Fundraiser

Corporations and Foundations

Alnylam Pharmaceuticals  
Eidos Therapeutics  
Alexion Pharmaceuticals  
Pfizer Inc.  
Janssen: Pharmaceutical Companies of Johnson & Johnson  
Akcea Therapeutics  
Jane and Frances Stein Foundation

Special thanks to all of those that created Facebook Fundraisers. Your generosity is boundless!

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“Like” us on Facebook at facebook.com/amyloidosisfdn/  
Check out our website or make an online donation at www.amyloidosis.org

Follow us on Instagram at instagram.com/amyloidosisfoundation/  
Email us at info@amyloidosis.org
2020
By The Numbers

59.5%
of users access our website via mobile

2
Research Grant Awardees

297
Facebook Fundraisers

$17K
Raised on
#GivingTuesday

964
Instagram Followers

3,820
Facebook Likes

130,500
New Users on our Website

100+
Sites that lit for ‘Light The Night for Amyloidosis’
Scientific Advisors

Merrill Benson, MD
Indiana University Medical Center

Mathew Maurer, MD
Columbia University Medical Center, NY

Raymond Comenzo, MD
Tufts Medical Center – Boston

Giampaolo Merlini, MD
University of Pavia, Italy

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Morie Gertz, MD
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Jonathan Wall, PhD
University of Tennessee - Knoxville