WE ARE ON A MISSION

ANNUAL REPORT

MARCH 2017
On behalf of the foundation I would like to thank all of our generous donors and volunteers in supporting our mission. The importance of every donation is immeasurable.

Since 2002, we have been able to support the efforts of over 30 researchers, some seeking the cause of AL amyloidosis, some seeking the effects of investigational treatments on various types of amyloidosis and some just trying to determine the underlying mechanisms of the disease.

Although no miracle breakthroughs have been found, all of this research is important in the overall understanding of amyloidosis and future breakthroughs.

Your generosity also allows us to help patients and their families to better understand amyloidosis and raise awareness of this rare disease.

Again, your generosity is greatly appreciated.

Sincerely,

Mary E. O’Donnell
President
Amyloidosis Foundation

"Upon my diagnosis of AL amyloidosis in 2012, I was so pleased to find the Amyloidosis Foundation, an organization dedicated to discovering a cure through supporting research and increasing awareness in the medical and general populations.

The information and support they provide to patients and families impacted by this rare disease is comforting and powerful. All of these things together give us a fighting chance to survive.

I am extremely grateful for all of their accomplishments."

Darcy Tannehill, PhD
Our Focus

Supporting amyloidosis patients and families while promoting research, education and awareness.

Patient Support
Our services are available to people with amyloidosis, families, and caregivers.

- Toll Free Phone Line
- Webinars with Physicians
- Accurate Information & Publications
- Treatment Center Locations
- Clinical Trial Information

Research
The Amyloidosis Foundation has a grant program targeting young researchers and has awarded over $1.4 million since 2005.

The AF is also dedicated to encouraging scientists by providing travel grants. These grants enable participation in the bi-annual International Amyloidosis Symposium.

Medical Community
One of the foundations objectives is to increase awareness of the disease in the medical community. We accomplish this by:

- Providing Grand Rounds Speakers
- Exhibiting at Medical Conferences
- Publishing/Distributing Brochures
Making Progress

The Amyloidosis Foundation was founded by a patient, for all patients. We are determined to continue making a difference. With your help we can.

“The Amyloidosis Foundation has provided a haven for patients with support and information regarding new treatment options and updates on cutting edge research. This empowers patients following the diagnosis of amyloidosis. This function of the foundation is immeasurably important.

Their research grants support young investigators from around the world, striving for solutions to benefit patients.

Members of the AF are dedicated, driven and an inspiration to us all.”

Jonathan Wall, PhD
University of Tennessee, Graduate School of Medicine

Richard and Ruth Shapiro, longtime Amyloidosis Foundation volunteers, spreading awareness at our booth at the 58th American Society of Hematology (ASH) annual meeting in San Francisco in December 2016.
2016 Highlights

1,531
Grand Rounds Attendees - Doctors teaching doctors

2,050
2016 Total Number of Donors

62,487
Facebook Likes - Up 5.8%

48%
People using a mobile device to access our website

1,198
Twitter Followers - Up from 853 in 2015

283,085
Page Views on our Website
2017 Research Grant Recipients

We invest in outstanding scientific research and innovative research models to expedite promising therapies to patients. Through our research program we encourage, promote and invest in the medical study and exploration of the amyloidosis diseases.

Emily Martin - PhD

_A Method to Predict Amyloid Risk in Patients_

Amyloidosis Foundation Donald C. Brockman Memorial Research Grant

University of Tennessee Medical Center
Medicine Division: Amyloidosis

Lorena Saelices - PhD

_A Novel Strategy for the Treatment of ATTR_

Amyloidosis Foundation David Seldin, MD, PhD Memorial Research Grant

Regents of the University of California, Los Angeles

Petros Moustardas - PhD

_Novel Therapy for Renal Amyloidosis_

Amyloidosis Foundation Research Grant

Linkoping University, Sweden
Medicine Division: Microbiology & Molecular Medicine

Carolina Lemos - PhD

_New Biomarkers for FAP_

Amyloidosis Foundation Research Grant

University of Porto, Portugal
Medicine Division: Molecular Biology
Awareness in Action

#UNselfie
“A cure so my brother (in law) can see his kids grow old.”

Black Friday. Cyber Monday.
#GIVINGTUESDAY
November 29, 2016
Events Held Around the U.S.

Run #4Tres $10,700
Kelli Heald's birthday spin party $11,500

#GivingTuesday $4,600
Priebert Open $4,900
AF Golf Outing $7,300

Cincinnati Spin Fundraiser $760

Pittsburgh Benefit for Amyloidosis Research $34,600

Addison Lacy sold bracelets at school to benefit AF $410

Hills & Hollers Half Marathon/5K $3,000 to AF

Golf Tournament to benefit John Lindley and AF $500
Events Up Close

$34,600
The Amyloidosis Foundation hosted a benefit at the Montour Heights Country Club in Pittsburgh, PA on Friday, October 28, 2016 and what an amazing night it was! Over 120 people attended this event to raise funds for our AF Research Grant Program. Darcy Tannehill, Ed.D., and her daughter Courtney Sullivan were Chair and Co-Chairs.

$4900
On August 13, 2016, over 300 golfers took to the links in The Prieber Open, to honor the memory of Christopher Priebe and raise awareness. He was diagnosed in October 2015 and passed in February 2016. His wife Johna wanted to share his spirit for life and raise funds for others struggling with this rare disease.

$7300
The annual AF golf outing was held at The Fountains in Clarkston, MI on Friday, September 30, 2016. A great day was had by all – our raffle had over 40 baskets and gift certificates for our participants, including many families affected by amyloidosis. Special thanks to Prothena for being a sponsor as well.
Support & Revenue

- Fundraising: 17%
- Q-give: 20%
- Memorial: 23%
- Other: 7%
- Grants: 33%

Expenses

- Salaries: 22%
- Non-Personnel: 24%
- Other: 8%
- Travel: 6%
- Grant Awards: 40%
Financials

Statements of Activities (Non-audited) - Year End December 31, 2016

Support & Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Contributed Support</td>
<td>576,381.69</td>
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<tr>
<td>Investment Income</td>
<td>2,995.37</td>
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<tr>
<td>Fundraising</td>
<td>132,494.22</td>
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<tr>
<td>Earned Revenues</td>
<td>2,621.50</td>
</tr>
<tr>
<td>Realized Gain/Loss</td>
<td>-2,729.49</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>711,763.29</strong></td>
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Expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grant Expense</td>
<td>255,486.08</td>
</tr>
<tr>
<td>Salaries &amp; Related Expenses</td>
<td>140,426.77</td>
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<tr>
<td>Other Personnel Expenses</td>
<td>14,825.00</td>
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<tr>
<td>Non-personnel Expenses</td>
<td>154,262.42</td>
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<tr>
<td>Occupancy</td>
<td>13,260.04</td>
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<tr>
<td>Travel &amp; Meeting</td>
<td>39,267.98</td>
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<tr>
<td>Miscellaneous Expenses</td>
<td>17,950.43</td>
</tr>
<tr>
<td>Business Expenses</td>
<td>3,885.00</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>-639,363.72</strong></td>
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</table>

Net Income/Liability

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Net Income</strong></td>
<td><strong>72,399.57</strong></td>
</tr>
</tbody>
</table>

Gross Income

Five-Year Snapshot

- 2012: 195,000
- 2014: 390,000
- 2016: 585,000
- 2016: 780,000

36% increase since 2012

GuideStar Platinum
We thank the following individuals and families who have donated to the Amyloidosis Foundation. Our work is made possible by your generosity. It is through these donations that we are able to continue to support research.

$4000-$9999
Barbara Carney
Gail Craddock
Roland Gilles
Eleanor Laughlin
Sandy Pope

$2000-$3999
Doreen Finnerty
Sharon Gibson
Joseph Hardy
Eric Heald
Otis Heald
Present Troubles Racing
Quattro
Southern Historical Showcase
Lisa Werkstell

$1000-$1999
Alnylam US, Inc.
Baird Foundation, Inc.
Janet Baldwin
Mark Blackman
Henry Blaxter
City National Bank
Wilkie Colyer
Dennis Cregar
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Joseph Debeliso
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George & Murph’s LLC
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Waterway AG, Inc.
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Vinni Gonella
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Greg Kloiber
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Robert Moseley
Eric Mueller
Kristine Nakutis
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O & W, Inc.
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Overbrook High School Class of 1986
Panera Bread Company
Per Peterson
Lou Pirronello
PNC Financial Services Group
Steven Porter
POS of Michigan
Lois Priebes
Rich Priebes
Ronald Priebes
Amy Rappaport
Renovations Roofing & Remodeling, Inc.
Lisa Ricks
Robert Morris University
Kyle Roberts
Jeanne Rosenthal
Paul Ryan
Owen Saddler
The Salem Country Club, Inc.
The Amyloidosis Foundation would like to acknowledge the following for their generous gifts:

- Chip Miller Charitable Foundation
- Henry J. Kaiser Family Foundation
- IGD Solutions Corp.
- IONIS Pharmaceutical
- Prothena Biosciences
- The Rueter Foundation
- Jane and Frances Stein Foundation
- Phyllis & Perry Schwartz Foundation
- Takeda Oncology
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Donations

Our vision is to help amyloidosis patients and families who need us and fund research for a cure.

Help make this happen by donating today:

www.amyloidosis.org

Visit our website for upcoming 2017 events.