Alpha-1 Foundation Board Members
July 1, 2017 - June 30, 2018

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Dell Witcher* ............................................................................................. AL

*Denotes diagnosed Alpha-1 Antitrypsin deficient
+Denotes diagnosed family member
The Alpha-1 Foundation has lived up to its reputation as the leading organization for Alpha-1 Antitrypsin Deficiency (Alpha-1) over the past year through innovation, new initiatives, and securing impact from medical research for the benefit of Alphas and the larger Alpha-1 community.

Through enriching existing programs and establishing new approaches and initiatives, the Foundation continued to aim high and achieve key accomplishments that meet — and exceed — the requirements and expectations of the community it serves.

The strength and support of our community, volunteers, researcher, clinicians, and corporate partners enables the Alpha-1 Foundation to continually push the boundaries of detection, research, advocacy, learning, and support to make a profound difference in the lives of Alphas, everywhere.

Finding a cure for Alpha-1 is the ultimate goal of the Foundation, and to this end, it has invested nearly $71 million to support Alpha-1 Antitrypsin Deficiency research and programs at 112 institutions in North America, Europe, the Middle East, and Australia. This year alone, over $2.1 million was awarded for new in-cycle grants to 112 investigators. Annual in-cycle grants are a regular part of the overall research program.

The Foundation was proud to announce and launch a new grant entitled, “The John W. Walsh Translational Research Award in Alpha-1 Antitrypsin Deficiency,” named after John W. Walsh, co-founder and past President & CEO of the Alpha-1 Foundation; a visionary leader who dedicated his life’s work to finding a cure for Alpha-1 Antitrypsin Deficiency and improve the lives of those affected by this genetic condition.

The award was established through a contribution from Mark Brantly, MD and his wife Judy Lew, MD. Additional contributions from AlphaNet and the Alpha-1 community have increased the Award to the point where annual grants can be given for a number of years. The inaugural award was given to Joseph Kaserman, MD, the inaugural John W. Walsh Translational Research Award grantee. Kaserman is an instructor of medicine at Boston University School of Medicine and a physician in Pulmonary, Allergy, Sleep and Critical Care Medicine at Boston Medical Center. His research study titled “Defining PiMZ AATD Liver Disease Susceptibility with CRISPR Targeted Syngeneic iPSCs” is specifically aimed at translating research findings into medical practice.
The Foundation participated as an exhibitor at the ATS 2019 International Conference to garner interest for its various research programs and to connect with pulmonologists, respiratory therapist, and physicians from around the world. During the annual American Thoracic Society (ATS) International Conference in San Diego, California, the Foundation hosted the highly anticipated Grant Awards Reception. Over 150 guests, including Alphas, physicians, researchers, and industry partners joined at The Prado, in Balboa Park, to recognize the newly awarded grantees.

The Building Friends for a Cure (BFC) program is a critical component of the Foundation’s goal of raising awareness of Alpha-1 while providing tools to the community to raise funds to support research and related programs. These events promote community interaction between Alphas, their friends and families, investigators, industry and medical professionals, including Clinical Resource Center physicians and staff. A record of 4,400 participants this fiscal year that participated in fundraising for the Foundation.

The Foundation launched a new online fundraising platform that helps encourage participants to raise more money, extend their reach and manage fundraisers. Our peer-to-peer and event fundraising software gives out BFC event participants the tools they need to be successful, social fundraisers.

The 2017 Escape to the Cape gave us the opportunity to honor the co-founder of the Alpha-1 Foundation, John W. Walsh. We had our largest bike trek ever with 175 riders and volunteers raise over $250,000.

The annual Celtic Connection held on March 3, 2018 hosted a gathering of 400 Alpha-1 friends and family for a St. Patrick’s Day gala in Boston, Massachusetts. The highlight of this event is the passing on of the famous “shillelagh award”, which is awarded to a prominent Alpha-1 researcher. The
The 2018 award was presented to Jeanine D’Armiento, MD, PhD, Professor in the Department of Medicine at Columbia University.

A critical component of the Foundation is awareness and November is Alpha-1 Awareness Month. This year marked the 3rd annual “Alpha-1 Virtual Walk” promoting awareness of Alpha-1 throughout the month of November and raising over $110,000 for research and programs. Over 681 donors and participants rallied in their communities in all 50 states. Alphas from around the nation met with their congressional leadership in their home states and cities to obtain 30 state proclamations and 7 county, assembly and city proclamations/citations.

To increase awareness, the Foundation also participated in Rare Disease Day in conjunction with the National Organization for Rare Disorders (NORD), and on February 28th the entire rare disease community came together in solidarity.

The 2018 Celebration of Life Annual Golf Classic and Dinner Reception provided a wonderful opportunity to increase fundraising and encourage our loyal donors and volunteers to reach out to their contacts to continue to spread awareness while raising necessary dollars for the Foundation’s mission.

The “Havana Nights” themed dinner reception honored James Quill on his retirement after 10 years as general manager for AlphaNet and for his outstanding leadership and commitment to the mission of the Alpha-1 Foundation. The Foundation also honored Beth Labasky for 17 years of outstanding commitment and dedication to the State of Florida Alpha-1 Screening and Detection Program, through which over 25,000 Floridians have been tested for Alpha-1.

The city of San Francisco was the site of the 27th Annual Alpha-1 National Education Conference from June 28 through July 1. The event has 565 people in attendance, of which 30% were first-time attendees. The overwhelming response from attendees for attending the conference continues to be education, knowledge and learning.

The theme of the conference was “On Track for a Cure: Connecting the Community.” Alpha-1 Foundation Board members, over 65 Support Group Leaders, 55 AlphaNet Coordinators and Foundation staff took an active role at the conference and were a valuable resource to the attendees. Finding the cure is the Foundation’s number one goal and connecting the community is critical.

The Robert Seigman Memorial Scholarship provided 8 full scholarships for families to attend the National Education Conference and hosted 18 children in the Alpha-1 kids room. The Alpha-1 Kids program provides information to parents of Alpha-1 infants, children and teens about their child’s diagnosis and provides support, information and data about its impact.
“My biggest motivation has always been the Alpha-1 community”

— Jonathan Maidment
“Jonathan Maidment’s Hiking for a Cure”, attendance at the National Education Conference gave us the opportunity to highlight his successes, engage his family and bring the community together to help surpass his goal by raising over $80,000.

There were six Education Days during the FY 2018 in Tampa, Tulsa, Richmond, Omaha, Detroit, and Seattle, registering a total of 659 people. 45% of which were first-time attendees and 8% were respiratory therapists. Each Alpha-1 Education Day program agenda is developed by a committee with local Alphas, adapted to their specific requests. Building on past success, the BFC program held walks in conjunction with the Alpha-1 Education Days in Tampa, FL on February 24th and in Richmond, VA on April 28th.

The Foundation continues to foster relationships across the international patient, clinical and scientific communities through the Alpha-1 Global program. The program aims to strengthen awareness, earlier diagnosis, disease management, optimal access to care and streamlined communication.

The mission of finding a cure for Alpha-1 Antitrypsin Deficiency is the main force that keeps moving the Alpha-1 Foundation forward. At the same time, the Foundation continues to provide education to the Alpha-1 community and maintains a key focus on research initiatives that will lead us to achieve our main purpose.

Meanwhile, Alphas are living longer, healthier and more fulfilling lives than ever before by taking advantage of disease management programs, participating in research, and making sure their voices are heard as they advocate for continued access to care and treatment.
“I think it is very important for us, and also, our daughter, to be available for testing and research for the cure. We want to thank the Foundation for this opportunity to attend National Conference; we are so grateful for the fact that we are not alone in this journey.”

— Nora and Mark Kemmerer
## Financial Statements

### Statement of Financial Position

**YEAR ENDED JUNE 30, 2018**

<table>
<thead>
<tr>
<th>Assets</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash and cash equivalents</td>
<td>$628,449</td>
<td>$732,804</td>
</tr>
<tr>
<td>Investment securities</td>
<td>15,992,512</td>
<td>15,234,111</td>
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<tr>
<td>Accounts receivable</td>
<td>2,127,798</td>
<td>2,482,322</td>
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<tr>
<td>Due from TAP</td>
<td>3,724</td>
<td>2,523</td>
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<tr>
<td>Other current assets</td>
<td>24,026</td>
<td>19,687</td>
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<tr>
<td><strong>Total current assets</strong></td>
<td>18,776,509</td>
<td>18,471,447</td>
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<tr>
<td><strong>Investment securities — non-current</strong></td>
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<td></td>
</tr>
<tr>
<td>Investment in TAP</td>
<td>4,469,734</td>
<td>3,009,329</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>69,378</td>
<td>121,771</td>
</tr>
<tr>
<td>Other assets</td>
<td>128,102</td>
<td>25,135</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$27,681,923</td>
<td>$25,865,882</td>
</tr>
</tbody>
</table>

### Liabilities and Net Assets

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$1,918,124</td>
<td>$1,583,735</td>
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<tr>
<td><strong>Total current liabilities</strong></td>
<td>2,078,124</td>
<td>1,744,037</td>
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<tr>
<td><strong>Net Assets</strong></td>
<td></td>
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</tr>
<tr>
<td>Without donor restrictions</td>
<td>22,835,856</td>
<td>21,290,756</td>
</tr>
<tr>
<td>With donor restrictions</td>
<td>2,767,943</td>
<td>2,831,089</td>
</tr>
<tr>
<td><strong>Total net assets</strong></td>
<td>25,603,799</td>
<td>24,121,845</td>
</tr>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td>$27,681,923</td>
<td>$25,865,882</td>
</tr>
</tbody>
</table>

### Gross Revenues By Classification

**For the Fiscal Year Ended June 30, 2018**

<table>
<thead>
<tr>
<th>Classification</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted Contributions</td>
<td>$3,269,553</td>
<td>30%</td>
</tr>
<tr>
<td>AlphaNet</td>
<td>$3,200,000</td>
<td>30%</td>
</tr>
<tr>
<td>Other Income</td>
<td>$2,607,075</td>
<td>24%</td>
</tr>
<tr>
<td>Restricted Contributions</td>
<td>$1,742,356</td>
<td>16%</td>
</tr>
<tr>
<td><strong>TOTAL: $10,818,984</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Functional Expenses

**For the Fiscal Year Ended June 30, 2018**

<table>
<thead>
<tr>
<th>Functional Expenses</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration and General</td>
<td>$861,696</td>
<td>10%</td>
</tr>
<tr>
<td>Fund raising</td>
<td>$1,001,550</td>
<td>11%</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>$806,878</td>
<td>9%</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>$300,059</td>
<td>3%</td>
</tr>
<tr>
<td>Alpha-1 Global</td>
<td>$396,605</td>
<td>4%</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>$373,281</td>
<td>4%</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>$25,346</td>
<td>0%</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>$334,536</td>
<td>4%</td>
</tr>
<tr>
<td>Alpha-1 Patient Support</td>
<td>$730,323</td>
<td>8%</td>
</tr>
<tr>
<td><strong>TOTAL: $9,337,030</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Statement of Activities and Changes in Net Assets

**YEAR ENDED JUNE 30, 2018**

<table>
<thead>
<tr>
<th>Description</th>
<th>2018</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Changes in Unrestricted Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Unrestricted Support and Revenue</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>$6,130,590</td>
<td>$6,473,006</td>
</tr>
<tr>
<td>Donated shares</td>
<td>2,238</td>
<td>1,028</td>
</tr>
<tr>
<td>Fundraising revenues</td>
<td>336,725</td>
<td>328,420</td>
</tr>
<tr>
<td>Investment gains/(losses)</td>
<td>1,786,207</td>
<td>433,285</td>
</tr>
<tr>
<td>Other income</td>
<td>820,868</td>
<td>840,190</td>
</tr>
<tr>
<td>Net assets released from restriction — satisfaction of program restrictions</td>
<td>1,805,502</td>
<td>2,217,177</td>
</tr>
<tr>
<td><strong>Total unrestricted support and revenue</strong></td>
<td>$10,882,130</td>
<td>$10,293,106</td>
</tr>
<tr>
<td><strong>Unrestricted Expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alpha-1 Research Network</td>
<td>3,792,907</td>
<td>3,752,642</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>25,346</td>
<td>353,413</td>
</tr>
<tr>
<td>Alpha-1 National Conference</td>
<td>584,949</td>
<td>615,260</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>730,323</td>
<td>787,930</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>334,536</td>
<td>341,989</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>308,959</td>
<td>345,526</td>
</tr>
<tr>
<td>Alpha-1 Patient Support Network</td>
<td>372,321</td>
<td>336,121</td>
</tr>
<tr>
<td>Alpha-1 Global</td>
<td>396,605</td>
<td>620,719</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>806,878</td>
<td>861,917</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td>7,353,784</td>
<td>8,015,517</td>
</tr>
<tr>
<td>Supporting services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration and general</td>
<td>981,696</td>
<td>881,959</td>
</tr>
<tr>
<td>Fundraising</td>
<td>1,001,550</td>
<td>956,633</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td>1,983,246</td>
<td>1,838,592</td>
</tr>
<tr>
<td><strong>Total unrestricted expenses</strong></td>
<td>9,337,030</td>
<td>9,854,109</td>
</tr>
<tr>
<td><strong>Increase in unrestricted net assets</strong></td>
<td>1,545,100</td>
<td>438,997</td>
</tr>
<tr>
<td><strong>Changes in Temporarily Restricted Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>1,742,356</td>
<td>2,996,416</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>(1,805,502)</td>
<td>(2,217,177)</td>
</tr>
<tr>
<td><strong>(Decrease) increase in temporarily restricted net assets</strong></td>
<td>(63,146)</td>
<td>779,239</td>
</tr>
<tr>
<td><strong>Increase in net assets</strong></td>
<td>1,481,954</td>
<td>1,218,236</td>
</tr>
<tr>
<td><strong>Net assets, beginning of year</strong></td>
<td>24,121,845</td>
<td>22,903,609</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td>$25,603,799</td>
<td>$24,121,845</td>
</tr>
</tbody>
</table>
The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and improving the lives of people affected by Alpha-1 worldwide. The Alpha-1 Foundation has invested more than $76 million to support Alpha-1 research and programs at more than 112 institutions in North America, Europe, the Middle East and Australia.

The Alpha-1 Research Registry is a confidential database of people with Alpha-1 (Alphas) and Alpha-1 carriers. It is a resource for investigators seeking Alphas to participate in clinical trials, surveys, and other scientific and medical activities. For more information, email Randel Plant alpha1registry@alpha1.org or call toll-free 1-877-228-7321.

Alpha-1 Coded Testing provides free, confidential testing administered through a research study that evaluates perceived risks and benefits of genetic testing. Email alphaone@musc.edu or call toll free 1-877-886-2383.

The Support Network is comprised of over 80 support groups nationwide that provide guidance and education to Alphas and family members, create awareness in local communities, and advocate for national and state issues that affect Alphas. Four Virtual Support Groups provide a forum for topics such as Alpha-1 Kids, Pre & Post Transplant issues, Caregivers and Timely Topics. To find a support group near you, visit a1f.org/support-groups.

The Patient Information Line — 1-800-245-6809 is available free of charge to anyone affected by Alpha-1 and provides support and answers to topics such as Alpha-1 testing, emotional impact, and physician and support group referrals.

The Genetic Counseling Program — 1-877-228-7321 ext. 326, based at the Alpha-1 Foundation, is a free and confidential service that provides direct contact to a certified genetic counselor to provide information on the risks and benefits of testing for Alpha-1, interpreting test results, understanding the genetics of Alpha-1, and other issues associated with having a genetic illness.

The Peer Guide Program — 1-877-346-3212 connects newly diagnosed Alphas with other Alphas who have a similar set of circumstances to provide emotional support, discuss resources available and assist in making choices about health.

The Oxygen Fund provides oxygen equipment for Alphas in financial need to travel to physicians, hospitals, Alpha-1 educational events and other activities. For more information contact jcollins@alpha1.org or call 1-877-228-7321 ext. 251.

Patient Education Programs include an annual National Education Conference which brings together over 600 Alphas, caregivers, industry representatives, clinicians, allied health care workers and scientists to discuss a wide range of Alpha-1 related topics. For more information, visit a1f.org/alpha1conference. Additionally, a series of Alpha-1 Education Days are held each year in various cities throughout the U.S. to bring patient education to a regional audience. For more information, visit a1f.org/educationdays. Recordings of these events are available via E-Education at a1f.org/education-videos.

Building Friends for a Cure is a program designed to nurture ongoing friendships in the Alpha-1 community. The goal is to increase awareness and promote research which will ultimately lead to a cure for Alpha-1, by becoming involved in fundraising efforts, such as special events, letter writing campaigns, potential donor introductions, and assisting in local, national and international social and sporting events. Visit a1f.org/building-friends, contact amcbride@alpha1.org or call 1-877-228-7321 ext. 233 for more information.

The Alpha-1 Kids Program is geared to the special needs and concerns of parents of children with Alpha-1. A committee of volunteer parents helps direct the program, which consists of a hotline, age appropriate informational books, a virtual support group and a parent peer guide program. For more information, visit a1f.org/alpha1-kids or contact chorsak@alpha1.org.
Educational materials include Alpha-1-To-One Magazine, the Research Registry Update newsletter, an Alpha-1 Family Awareness Video Series and other educational materials for Alphas, their families and healthcare providers. These materials are available at our website, a1f.org/a1-publications, or call toll-free 1-877-228-7321 ext. 251.

The Foundation’s Public Policy Program advocates for the Alpha-1 community by monitoring and influencing legislative and regulatory issues. Primary concerns include stimulating medical research, blood product safety, developing new therapies, screening and detection, access to care and reimbursement, federal and state funding, education, awareness and the recognition of the special needs of people with Alpha-1. For more information, visit a1f.org/action-alert.

Grants and Awards: The Foundation’s peer-reviewed grants program is intended to promote research that will lead to improved health for Alphas and ultimately, find a cure. We offer grants for both basic science and clinical research. For more information, contact David Fernandez at dfernandez@alpha1.org or call 1-877-228-7321 ext. 242.

The Alpha-1 Foundation DNA & Tissue Bank at the University of Florida is the central storage site for DNA and tissue samples from Alphas and other donors. The Bank is a resource for researchers investigating Alpha-1 and other conditions. Researchers should contact David Fernandez at dfernandez@alpha1.org or call 1-877-228-7321 ext. 242. For other information, call toll-free 1-866-284-2708.

The Targeted Detection Program promotes worldwide awareness among medical professionals, the media and public and the identification of Alphas in population groups at risk. For further information, please call 1-877-228-7321 ext. 306.

The Alpha-1 Clinical Resource Center Network is a steadily growing group of centers throughout North America that specialize in patient care and education for those with Alpha-1. Centers also offer other resources for Alphas such as support groups, transplant centers and pulmonary rehabilitation. Alphas and their physicians are encouraged to contact their regional Clinical Resource Center for information and guidance. To find an Alpha-1 specialist near you, visit a1f.org/alpha1doc. For more information, contact David Fernandez at dfernandez@alpha1.org or call 1-877-228-7321 ext. 242.

Scientific Meetings, Conferences, Workshops, Working Groups and Symposia bring scientists together to focus on special topics related to Alpha-1, to advance knowledge of the genetic condition and to work toward new therapies and a cure. For more information, contact Adriana De Arce at adearce@alpha1.org or call 1-877-228-7321 ext. 269.

The Alpha-1 Global Initiative works on a global, national and local level to enhance care and support for all those affected by Alpha-1. The Foundation is committed to providing reliable resources and information worldwide. As part of the Global Alpha-1 Initiative, the Foundation is creating new tools focusing on connecting Alphas all over the world with resources — and with each other. For more information, visit alpha-1global.org, contact Randel Plant at rplant@alpha1.org or call 1-877-228-7321 ext. 306.

Access and Reimbursement: The Alpha-1 Foundation is committed to providing the tools and resources necessary to assist Alphas in making informed decisions about their healthcare plan and assistance program selection. Patients with questions or issues concerning access or reimbursement should contact Cathey Horsak at 1-800-245-6809 or chorsak@alpha1.org.
The Alpha-1 Foundation’s Grants and Awards Program continues to expand the scope, number and types of grants awarded to qualified researchers.

**Peer Reviewed Research Portfolio for 2018**

Our 2018 Peer Reviewed Principal Investigators are:

- **Carrie P. Aaron, M.D.**  
  - Targeting Pulmonary Perfusion in α1-Antitrypsin Deficiency

- **Maria Elena Miranda Banos, Ph.D.**  
  - Dissecting immunomodulatory mechanisms of A1AT with function-neutralising monoclonal Ab

- **Boris Baranovski, Ph.D.**  
  - Travel Grant to 2017 Joint Congress of the IPITA-IXA-CTS in Baltimore, Maryland to present the abstract entitled: “Human alpha-1-antitrypsin therapy synergizes with temporary T cell depletion: modified repopulating T cell profile in concordant and discordant xenoinnate models”

- **Phillip Bird, Ph.D.**  
  - Mapping pathways of human Z-antitrypsin turnover in transgenic zebrafish

- **Marion Boucheareilh, Ph.D.**  
  - Travel Grant to 16th Gordon L. Snider Critical Issues Workshop: MZ Carrier State in Alpha-1 Antitrypsin Deficiency

- **Russell Bowler, M.D., Ph.D.**  
  - Proteomic signatures of COPD severity and progression in alpha-1 antitrypsin deficient patients

- **Russell Braeuer, Ph.D.**  
  - John W. Walsh Memorial Travel Scholarship Award to 2017 Stem Cells and Cellular Therapies in Lung Biology and Lung Diseases Workshop to present abstract entitled: “Identification of Distinct Resident Mesenchymal Cell Populations in Adult Lungs”

- **Ashley Buckle, Ph.D.**  
  - Engineering a-1 antitrypsin for augmentation therapy

- **Lisa Cabrita, Ph.D.**  
  - Co-translational folding and misfolding studies of alpha-1-antitrypsin

- **Diana Crossley, MBChB**  
  - Functional Magnetic Resonance Lung Imaging using Inhaled Hyperpolarised 129Xenon: A pilot study of the clinical utility in Alpha One Anti-Trypsin Deficiency (AATD)

- **Danielle Detlich, M.D.**  
  - Alpha-1 Antitrypsin for Prevention of Hepatic Ischemia-Reperfusion Injury During Normothermic Machine Perfusion

- **N. Tony Eissa, M.D.**  
  - Lysosomal Origin for Emphysema

- **Robert Foronjy, M.D.**  
  - Effect of Alpha-One Antitrypsin on PP2A Activity and Lung Inflammatory Responses

- **Patrick Geraghty, Ph.D.**  
  - PLTP resolves inflammation in Alpha-1 deficiency  
  - Alpha-1 antitrypsin regulates S100A9-mediated inflammation

- **Mordechay Gerlic, Ph.D.**  
  - The role of Necroptosis and IL-33 in lung pathology of A1AT deficiency

- **Monica Goldklang, M.D.**  
  - In vivo imaging of lung apoptosis in alpha-1 antitrypsin deficiency
  - A Role for MMP-13 in COPD Exacerbations in the Alpha-1 Community

- **Daniel Hebert, Ph.D.**  
  - Optimizing alpha-1-antitrypsin folding for gene therapy

- **Killian Hurley, M.D., Ph.D.**  
  - Modelling AATD Lung Disease Using Alveolar Epithelial Cells Derived from Gene-Edited iPSC

- **Dara E. Leto, Ph.D.**  
  - Systematic genetic interaction map of mammalian ERAD

- **Ali Manichaikul, Ph.D.**  
  - Alpha-1 antitrypsin in African Americans and Hispanics

- **Stefan Marciniak, M.D., Ph.D.**  
  - Endoplasmic reticulum heterogeneity in a1-antitrypsin deficiency

- **Noel G. McElvaney, MB, BCh, BAO**  
  - Alpha-1 antitrypsin deficiency: Which is important phenotype, level, activity or all three?  
  - Clarifying the Risk of Lung Disease in SZ AATD

- **Maurizio Molinari, Ph.D.**  
  - The role of novel ER-resident autophagy receptors in clearance of polymeric ATZ

- **Christian Mueller, Ph.D.**  
  - Phenotyping a Novel SerpinA1 Mouse Knockout

- **C. Daniel Mullins, Ph.D.**  
  - Medical Costs of Alpha-1 Antitrypsin Deficiency-Associated COPD in the U.S.

- **Alexei Ouriadov, Ph.D.**  
  - MRI Morphomics of Emphysema in Alpha1 Antitrypsin Deficiency

- **Irina Petrache, M.D.**  
  - Aspen Lung Conference’s 61st Annual Meeting entitled, “Translating Resilience and Pathogenesis to Personalized Therapy for COPD”

- **Pasquale Piccolo, Ph.D.**  
  - Regulation of autophagy in liver disease due to Z α1-antitrypsin

- **Emer Reeves, Ph.D.**  
  - Platelet-neutrophil interactions in alpha-1 antitrypsin deficiency

- **Keith Robertson, Ph.D.**  
  - The Epigenome as a Modulator of Alpha1 Antitrypsin Deficiency Liver Disease

- **Elizabeth Sapey, Ph.D.**  
  - Improving detection of early lung disease and decline in AATD

- **Karina Serban, M.D.**  
  - Endothelial-monocyte interactions modulated by A1AT

- **Richard N. Sifers, Ph.D.**  
  - Early onset end-stage liver disease parameters and model generation

- **Dorota Skowrya, Ph.D.**  
  - The Proteasome Load Tolerance in Alpha 1 Deficiency

- **Jeffrey Teckman, M.D.**  
  - Adult Alpha-1 Liver Clinical and Genetic Linkage Study

- **Alice Turner, Ph.D.**  
  - Elastin degradation in exacerbations of AATD lung disease  
  - Improving access to augmentation therapy in AATD: the effect of augmentation on quality of life

- **Brian Varisco, M.D.**  
  - Cela1 is Required for Bullous Progression in AAT-Related Lung Disease

- **Emily S. Wan, M.D.**  
  - Metabolomic Profiling in Alpha-1 Antitrypsin Deficiency

- **Yan Wang, Ph.D.**  
  - A new drug for antitrypsin deficiency from computational pharmacological screening

- **Daniel J. Weiss, M.D., Ph.D.**  
  - 2017 Stem Cells and Cellular Therapies in Lung Biology and Lung Diseases Workshop

- **Andrew A. Wilson, M.D.**  
  - Open Source CRISPR Gene Correction of PIZZ iPSCs

**Program Grants Portfolio for 2018**

Our 2018 Peer Reviewed Principal Investigators are:

- **Mark L. Brantly, M.D.**  
  - Alpha-1 Coded Testing Study
  - Alpha-1 DNA and Tissue Bank

- **Robert Sandhaus, M.D., Ph.D.**  
  - Director, Alpha-1 Program, National Jewish Health

- **Ronald Sokol, M.D.**  
  - Childhood Liver Disease Research Network (ChiLDReN)

- **Charlie Strange, M.D.**  
  - Alpha-1 Coded Testing Study
  - Alpha-1 Clinical Resource Center Registry

- **Adam Wanner, M.D.**  
  - Scientific Director, Alpha-1 Foundation

*All grants listed above were active between July 1, 2017 and June 30, 2018.*
The Alpha-1 Foundation’s Honor Gallery salutes the individuals, corporations and foundations that share our commitment to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide. The Foundation gratefully welcomes a number of new members who have supported our mission for the first time through their generous contributions.

The Foundation acknowledges the continued support of the many long-time donors who have invested in our mission through contributions, events and workplace giving. It is with sincere gratitude and appreciation that we recognize our Honor Gallery. The following is a list of donors who contributed $500 or more between July 1, 2017 and June 30, 2018.

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**$5,000-$9,999**
- American Association for Respiratory Care
- Grifols

**$1 Million - $2,499,999**
- CSL Behring, L.L.C.
- Shire

**$1 Million - $2,499,999**
- CSL Behring, L.L.C.
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**$500,000 - $999,999**
- Alnylam Pharmaceuticals
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- Robert B. Webster

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- Viasys Healthcare
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- John E. Haffty
- Miekkeleen D. Hart
- HBO Box Office, Inc.
- Kenneth A. Irvine
- Peg and Peter Iversen
- Judy F. Lew, M.D. and Mark L. Brantly, M.D.
- Medical Research Charities
- Barbara E. and David M. Perreault
- Philips Respironics
- Proteostasis Therapeutics
- Holly and Donovan Quill
- William Richter
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- The Benefitery Community Impact Fund
- The Ergonomic Group
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**Honor Gallery**

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- Marcia Ruderman

**$250,000 - $499,999**
- State of Florida

**$100,000 - $249,999**
- Dohmen Lifescience Solutions, Inc.
- Marcia Ruderman

**$25,000 - $99,999**
- Accredo Health
- Anonymous Donor
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- Coram, Inc.
- Diplomat Specialty Infusion Group
- Facebook Payments, Inc.
- Presidio Networked Solutions, L.L.C.
- Jean-Marc Quach
- Sime Realty Corporation
- Steele Hotels

**$10,000-$24,999**
- Shire
- Accredo Health
- Anonymous Donor
- Ruth and Gordon E. Cadwgan, Jr., Ph.D.
- Coram, Inc.
- Diplomat Specialty Infusion Group
- Facebook Payments, Inc.
- Presidio Networked Solutions, L.L.C.
- Jean-Marc Quach
- Sime Realty Corporation
- Steele Hotels

**$5,000-$9,999**
- American Association for Respiratory Care
- American Respiratory Care Foundation
- Arrowhead Pharmaceuticals
- Robert C. Bueker
- Dicerna Pharmaceuticals
- Cheryl and Lawrence P. Glasscott
- John E. Haffty
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**$1,000-$4,999**
- Viasys Healthcare
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- American Respiratory Care Foundation
- Arrowhead Pharmaceuticals
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Renie M. Shoberg
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Anna and Laurence B.

Denotes Deceased
In Honor Of

The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2017 and June 30, 2018.

Blake Aaronson
George Adamietz
Alpha-1 Foundation Staff
Alpha-1 Support Group
Leaders
AlphaNet Coordinators
Alphas for Building
Friends for a Cure
Jesus Alvarez
Karen Anderson
Eric L. Augustyniak
Elizabeth Bailey
Robert W. Bailey
Kim Bair
Roxanne Balderas
Robert C. Barrett
Roxanne Balderas
Kim Bair
Robert W. Bailey
Elizabeth Bailey

Denotes Deceased
The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2017 and June 30, 2018.
In Memory Of continued

Don McAmis
Alyce Mae (Carlson) McArdle
Philip McBride
Maureen Hickey McCaffrey
Brooke McCarter, Jr.
Dorothy and Charles McCarthy
William “Billy” McClellan
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Jennifer Meredith
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Kenneth Minnigerode
Michele D. Mitchell
Thomas L. Mitchell
Dolline Mixter
R. Bruce Moody, M.D.
Francis N. Meister
Nancy Merchant
Jennifer Meredith
Tim Miller
Kenneth Minnigerode
Michele D. Mitchell
Thomas L. Mitchell
Dolline Mixter
R. Bruce Moody, M.D.
Francis N. Meister
Nancy Merchant
Jennifer Meredith
Tim Miller

Our Mission

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide.

By 30th of June 2017, the Alpha-1 Foundation had invested $71 million in research and related programs at 112 institutions in North America, Europe, the Middle East and Australia.