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Board of Directors, June 30, 2017
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*Denotes diagnosed Alpha-1 Antitrypsin deficient
+Denotes diagnosed family member
Message from the Leadership

Founders’ legacy continues to drive research, patient care, education and advocacy

Our fiscal year 2017 — from July 1, 2016 through June 30, 2017 — was a year of achievements for the Alpha-1 community and the Alpha-1 Foundation. Among the highlights of the year, we can include:

- Research into both lung and liver diseases related to Alpha-1 made clear progress including breakthroughs that were considered impossible just a decade ago.
- The Foundation announced its 2017 research awards to 12 investigators who received a record $2.1 million for their projects. This was the third straight year that the Foundation has increased its funding of research grants.
- The John W. Walsh Translational Research Award in Alpha-1 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 Foundation teamed up with the COPD Foundation, the American Thoracic Society, and CRD & Associates — our Washington lobbying firm — to challenge Medicare’s competitive bidding program that endangers the health of Alphas in need of medical oxygen.
- Alpha-1 physicians from around the country gathered for the Foundation’s Clinical Resource Center (CRC) Forum in October 2016 to learn about updates on our research program and explore ways to improve their partnerships with the Alpha-1 community and support groups.
- The 26th Annual Alpha-1 National Conference in Chicago, on June 23-25, 2017, was the largest conference ever with more than 650 attendees. Nearly 33% were first-time attendees. Thirty-two speakers presented on 24 topics ranging from clinical trial design to what it means to be an Alpha-1 carrier.
- Alphas are living longer, healthier, more fulfilling lives by taking advantage of our disease management program, participating in research, and making their voices heard as they advocate for continued access to care and treatment. Many give-back by participating in our Building Friends for a Cure Program to raise money for research.

We have come a long way, as an organization and as a community. Today newly-diagnosed Alphas have a wealth of information to learn about Alpha-1, multiple options for treatment and a robust network of support groups nationwide.

John W. Walsh, Sandy Lindsey and Susan Stanley, the founders of the Foundation, had a mission to find a cure for Alpha-1 and improve the lives of Alphas, worldwide. We at the Foundation are proud to be a part of that mission.

Henry R. Moehring, MBA
President & CEO
Gordon E. Cadwgan, PhD
Board Chair
Alpha-1 Foundation continues

During FY 2017, the Alpha-1 Foundation (A1F) faced several challenges, which tested the strength and resilience of the Alpha-1 community and especially of the A1F.

Ab Rees, past Chair, had been serving as Acting President and CEO of the A1F since John Walsh — who co-founded the Foundation in 1995 and was President and CEO ever since — had an accident and went into an extended leave of absence from the A1F.

Rees presented then an executive transition plan to the Executive Committee of the Foundation Board that Walsh himself had brought in even before the accident, proposing himself as Founder and Chief Visionary Officer and naming Henry Moehring as new President and CEO. The plan was accepted unanimously.

Unfortunately, after just over a year of absence from the A1F, John Walsh passed away in early March 2017. For decades, Walsh had tirelessly forged a patient-centered movement that not only changed the Alpha-1 landscape, but also the way patients are seen and respected in the health sector.

Only four months after Walsh’s passing, in July 2017, longtime A1F Director of Communications and former AlphaNet coordinator, Bob Campbell, also passed away. The dozens of moving stories he wrote about Alphas, caregivers, physicians, researchers and staff are a testament to his dedication to the A1F and to the community it serves.

In the July issue of the COPD Foundation Journal the new “Clinical Practice Guidelines for the Diagnosis and Management of Alpha-1 Antitrypsin Deficiency in the Adult” was published, based on the latest evidence and six years of work, recommending the best practices for Alpha-1 testing, managing Alpha-1 lung and liver disease, and when augmentation therapy should be prescribed, among other recommendations. The guidelines were intended to update and simplify a 2003 document from the American Thoracic Society (ATS) and the European Respiratory Society on the diagnosis and management of Alpha-1.

Also, the A1F teamed up with the COPD Foundation, the American Thoracic Society (ATS), and Cavarocchi, Ruscio, Dennis & Associates, our Washington lobbying firm, to challenge Medicare’s competitive bidding program that endangers the health of Alphas in need of medical oxygen. An oxygen working group wholly focused on ensuring appropriate patient-centered supplemental oxygen access resulted. A survey to evaluate Patient Perceptions of the Adequacy of Supplemental Oxygen Therapy was launched and results from 1,926 individuals were announced in March of 2017, indicated clear trends is issues related to supplemental oxygen access and services.

Alphas were encouraged to follow their representatives in Congress on social media, email them and attend events with them during district work periods, urging them to improve oxygen access and choice, making it clear to congress that obtaining appropriate supplemental oxygen is becoming increasingly difficult.

Research into both the lung and liver diseases related to Alpha-1 made clear progress, including breakthroughs that were considered impossible a decade ago. Two Alpha-1 research and clinical programs did some of the most advanced Alpha-1 research in the world, collaborating on their investigations, and getting involved with the Alpha-1 community as well. With help from The Alpha-1 Project (TAP) grants, investigators developed:

- an antibody to detect mutant alpha-1 proteins that was shared with researchers and industry working on therapies for Alpha-1 liver disease;
- the first mouse model of Alpha-1 lung disease, which is also being used to study new therapies (University of Massachusetts, the lab of Christian Mueller, PhD); and
- induced pluripotent stem cells (iPSCs) made from

John W. Walsh, co-founder of the Alpha-1 Foundation

Bob Campbell, A1F communications director 2007-2017
tissue donated by Alphas, to work on a cell-based treatment for Alpha-1 (Andrew Wilson, MD, at the Boston University School of Medicine and the Center for Regenerative Medicine, CReM).

In October 2016, in recognition of John W. Walsh’s many contributions, Mark Brantly, MD, announced a $225,000 gift from himself and his wife Judy Lew, MD, to the A1F, which was intended to establish the John W. Walsh Translational Research Award in Alpha-1. Bantly is a professor of medicine, chief of molecular genetics and microbiology and A1F research professor at the University of Florida.

The A1F announced its 2017 research awards to 12 investigators who received a record total of $2.1 million for their projects. This was the third straight year that A1F grants have broken the record for investment in new research grants. Annual in-cycle grants are a regular part of the overall research program. The Foundation has invested more than $71 million to support Alpha-1 research and programs at 112 institutions in North America, Europe, the Middle East and Australia.

The Foundation’s Donor Recognition Dinner, which takes place every two years to honor those whose generosity makes A1F’s research possible, was held in conjunction with A1F’s Investigators’ Meeting, which brought together the scientists who received research grants in 2014 and 2015.

Donors and researchers mingled and talked at dinner and the reception that preceded it, and donors got to hear firsthand about the research they helped to fund. During the Investigators’ Meeting, Karina Serban, MD, from National Jewish Health, gave a progress report on her research as the winner of the first Gordon L. Snider Scholar Award.

Serban studied the effect of the alpha-1 protein on inflammation in the lungs. Among her conclusions was the possibility that augmentation therapy may be indicated for all conditions that lead to “exuberant” lung inflammation. This award is named after Gordon L. Snider, MD, a longtime A1F board member who passed in 2013 at age 91. Snider, a pioneer in COPD and Alpha-1 research, emphasized the importance of encouraging young investigators to pursue a career in Alpha-1 research.

At the dinner, the Foundation expressed gratitude to its dedicated supporters. Donors of $5,000 and above were acknowledged for their generosity. The Foundation Circle, for donors of at least $25 million, recognized AlphaNet for a milestone $50 million in contributions. The Chairman’s Circle, for donors of at least $10 million, recognized Grifols. The Platinum Founder’s Circle, for donors of at least $5 million, recognized CSL Behring and the State of Florida. The Gold Founder’s Circle, for donors of at least $2.5 million, recognized Shire. Dohmen Life Science Services was recognized as a new member of the Founder’s Circle, for donors of at least $1 million. The Founder’s Circle included Ruth and Gordon Cadwgan, Marilina and Leopoldo Fernandez, and the Health Foundation of South Florida.

At the investigators meeting, Michael Iannotti, PhD, gave an update on his fellowship at the National Institutes of Health’s (NIH) National Center for Advancing Translational Sciences (NCATS). TAP
funded Iannotti’s research, which uses a powerful tool called high-throughput screening to test for molecules that could be developed into treatments for Alpha-1. Importantly, Iannotti utilized the stem cell lines created by Wilson to perform his assay development and drug screening.

Antonello Punturieri, MD, PhD, program director of the Division of Lung Diseases at the National Heart, Lung, and Blood Institute (NHLBI) at the NIH, said at the meeting that NIH funding for Alpha-1 research has been increasing in recent years. He cited an $11.5 million NHLBI grant earlier to Alpha-1 research at the University of Massachusetts.

Alpha-1 physicians from around the country gathered for the Alpha-1 Foundation’s Clinical Resource Center (CRC) Forum in October 2016 and heard presentations on issues including A1F research program and establishing partnerships with the Alpha-1 community and support groups. James Donohue, MD, of the University of North Carolina at Chapel Hill, who chairs the Clinical Resource Network Working Group, introduced the speakers.

Adam Wanner, MD, A1F’s Scientific director; Charlie Strange, MD, director of the A1F Research Registry; Robert Sandhaus, MD, PhD, Clinical Director of the A1F and Medical Director of AlphaNet; Jeanine D’Armiento, MD, PhD, of New York-Presbyterian Hospital/Columbia University Medical Center, and A1F Board member; Jeffrey Teckman, MD, of St. Louis University; Timothy Craig, DO, of Penn State University; and Karen Fraser, the A1F’s community and development relations coordinator, were present at the meeting. Alpha-1 support groups are also forming strong partnerships with Alpha-1 CRCs, which provide all the resources Alphas need to improve their quality of life.

A few months after having held a meeting on Patient-Focused Drug Development with over 200 Alphas present and more than 600 participating online, the U.S. Food and Drug Administration (FDA) showed it was indeed listening. The FDA Center for Drug Evaluation and Research (CDER) held a meeting for Alpha-1 patients, caregivers, leaders and investigators to discuss Alpha-1 liver disease and potential clinical trial design and therapeutic options. Then A1F leaders met with representatives from the FDA Center for Biologics Evaluation and Research (CBER), where CBER leaders agreed that the use of a placebo in Alpha-1 augmentation therapy trials would be “unethical.”

Traditionally, the FDA has spent much time before a new drug review in listening to doctors and scientists, and reviewing mountains of data. Under the Patient Focused Drug Development initiative, the FDA is also listening now to patients and their supporters to consider their needs and concerns before making decisions. The FDA posted a “Voice of the Patient” report on its website, summarizing the testimony the FDA received from the Alpha-1 community.

Alphas are living longer, healthier and more fulfilling lives by taking advantage of disease management programs, participating in research, and making their voices heard as they advocate for continued access to care and treatment, according to a study conducted by AlphaNet. Today’s Alphas who are members of AlphaNet are living far beyond the depressing estimate of a 54.5-year lifespan for Alphas as found in an often-quoted study from the 1990s.
The research conference, on April 5-6, was for invited researchers and speakers but it was open to anyone interested. The Global Patient Congress on April 7-8, included representatives from 36 countries and provided a platform for education, discussion and building a collaboration to increase awareness, detection, and access to care for Alphas worldwide. The conference culminated with a 2017-2019 action plan for the global Alpha-1 community.

Over 650 people from 46 states attended the 26th Annual Alpha-1 National Conference in Chicago, on June 23-25, 2017, making it the largest conference ever, with nearly 33% of first-time attendees. Every year, attendees are asked their primary reason for attending the conference. Their overwhelming response, as in years past was education. The 2017 conference accomplished that goal with 32 speakers presenting on 24 topics, ranging from clinical trial design to what it means to be an Alpha-1 carrier.

The conference culminated in a tribute dinner in honor of John W. Walsh. The program included videos presenting Walsh in “his own words” and the range of his influence, not only in the Alpha-1 and COPD communities, but also in the rare disease and lung disease patient communities. Speakers described the vast impact he made throughout his life and all he contributed to the Alpha-1 community and to the patient community at large.

There were six Education Days during FY 2017, in San Francisco, Austin, Atlanta, Denver, Pittsburgh, and Charleston, registering a total assistance of 745 people.

A critical component of the A1F’s strategic plan continued to raise awareness of Alpha-1 while providing tools to the community to raise funds to support research and related programs. Building Friends for a Cure (BFC) was designed to broaden the reach of the A1F and promote stronger links between the organization and the community.

BFC provides the platform in which members of the Alpha community can help A1F work towards the goal of finding a cure. These events promote community interaction between Alphas, their friends and family, investigators, industry and medical professionals, including Clinical Resource Center physicians and staff. These include events like Escape to the Cape, Celtic Connection and Virtual Walk, among others.
## Financial Statements

### Statement of Financial Position

<table>
<thead>
<tr>
<th>YEAR ENDED JUNE 30,</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash and cash equivalents</td>
<td>$ 732,804</td>
<td>$ 1,134,854</td>
</tr>
<tr>
<td>Investment securities</td>
<td>15,234,111</td>
<td>14,131,370</td>
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<tr>
<td>Accounts receivable</td>
<td>2,482,322</td>
<td>1,389,884</td>
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<tr>
<td>Due from TAP</td>
<td>2,523</td>
<td>7,010</td>
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<tr>
<td>Other current assets</td>
<td>19,687</td>
<td>34,637</td>
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<tr>
<td><strong>Total current assets</strong></td>
<td><strong>18,471,447</strong></td>
<td><strong>16,697,755</strong></td>
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<td>Investment securities — non-current</td>
<td>3,009,329</td>
<td>3,437,005</td>
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<tr>
<td>Investment in TAP</td>
<td>4,238,200</td>
<td>4,238,200</td>
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<tr>
<td>Property and equipment, net</td>
<td>121,771</td>
<td>157,118</td>
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<tr>
<td>Other assets</td>
<td>25,135</td>
<td>25,135</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$ 25,865,882</td>
<td>$ 24,555,213</td>
</tr>
<tr>
<td><strong>Liabilities and Net Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Current Liabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>$ 1,583,735</td>
<td>$ 1,489,525</td>
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<tr>
<td>Due to TAP</td>
<td>2,302</td>
<td>–</td>
</tr>
<tr>
<td>Due to COPD Foundation</td>
<td>–</td>
<td>2,579</td>
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<tr>
<td>Deferred revenue</td>
<td>158,000</td>
<td>159,500</td>
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<tr>
<td><strong>Total current liabilities</strong></td>
<td><strong>1,744,037</strong></td>
<td><strong>1,651,604</strong></td>
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<tr>
<td><strong>Net Assets</strong></td>
<td></td>
<td></td>
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<tr>
<td>Unrestricted</td>
<td>21,290,756</td>
<td>20,851,759</td>
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<tr>
<td>Temporarily restricted</td>
<td>2,831,089</td>
<td>2,051,850</td>
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<tr>
<td><strong>Total net assets</strong></td>
<td>$ 24,121,845</td>
<td>$ 22,903,609</td>
</tr>
<tr>
<td><strong>Total liabilities and net assets</strong></td>
<td>$ 25,865,882</td>
<td>$ 24,555,213</td>
</tr>
</tbody>
</table>

### Gross Revenues By Classification
FOR THE FISCAL YEAR ENDED JUNE 30, 2017

<table>
<thead>
<tr>
<th>Gross Revenues</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha-1 Research Network</td>
<td>$3,752,642</td>
<td>$3,419,899</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>$314,989</td>
<td>$236,126</td>
</tr>
<tr>
<td>Alpha-1 Global</td>
<td>$620,719</td>
<td>$535,413</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>353,413</td>
<td>353,413</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>$787,930</td>
<td>$787,930</td>
</tr>
<tr>
<td>Administration and general</td>
<td>$861,917</td>
<td>$861,917</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>$345,526</td>
<td>$336,121</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>$345,526</td>
<td>$336,121</td>
</tr>
<tr>
<td>Alpha-1 National Conference</td>
<td>$615,260</td>
<td>$615,260</td>
</tr>
<tr>
<td>Alpha-1 Patient Support</td>
<td>$336,121</td>
<td>$336,121</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td><strong>$9,601,950</strong></td>
<td><strong>$9,601,950</strong></td>
</tr>
</tbody>
</table>

### Functional Expenses
FOR THE FISCAL YEAR ENDED JUNE 30, 2017

Total Expenses: $9,601,950
## Financial Statements

### Statement of Activities and Changes in Net Assets

#### YEAR ENDED JUNE 30, 2017 2016

#### Changes in Unrestricted Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted Support and Revenue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>$6,473,006</td>
<td>$7,188,940</td>
</tr>
<tr>
<td>Donated shares</td>
<td>1,028</td>
<td>–</td>
</tr>
<tr>
<td>Fundraising revenues</td>
<td>328,420</td>
<td>298,921</td>
</tr>
<tr>
<td>Investment income</td>
<td>433,285</td>
<td>(157,055)</td>
</tr>
<tr>
<td>Other income</td>
<td>840,190</td>
<td>826,438</td>
</tr>
<tr>
<td>Net assets released from restriction —</td>
<td>2,217,177</td>
<td>2,877,640</td>
</tr>
<tr>
<td>satisfaction of program restrictions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total unrestricted support and revenue</td>
<td>10,293,106</td>
<td>11,034,884</td>
</tr>
</tbody>
</table>

#### Unrestricted Expenses

<table>
<thead>
<tr>
<th>Program services</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha-1 Research Network</td>
<td>3,752,642</td>
<td>3,858,825</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>353,413</td>
<td>340,313</td>
</tr>
<tr>
<td>Alpha-1 National Conference</td>
<td>615,260</td>
<td>835,104</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>787,930</td>
<td>752,062</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>341,989</td>
<td>673,174</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>345,526</td>
<td>259,208</td>
</tr>
<tr>
<td>Alpha-1 Patient Support Network</td>
<td>336,121</td>
<td>302,472</td>
</tr>
<tr>
<td>Alpha-1 Global</td>
<td>620,719</td>
<td>–</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>861,917</td>
<td>830,663</td>
</tr>
<tr>
<td>Total program services</td>
<td>8,015,517</td>
<td>7,879,802</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supporting services</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration and general</td>
<td>881,959</td>
<td>881,310</td>
</tr>
<tr>
<td>Fundraising</td>
<td>956,633</td>
<td>840,838</td>
</tr>
<tr>
<td>Total supporting services</td>
<td>1,838,592</td>
<td>1,722,148</td>
</tr>
</tbody>
</table>

| Total unrestricted expenses                      | 9,854,109    | 9,601,950    |

| Increase in unrestricted net assets              | 438,997      | 1,432,934    |

#### Changes in Temporarily Restricted Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2017</th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>2,996,416</td>
<td>1,575,000</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>(2,217,177)</td>
<td>(2,877,640)</td>
</tr>
<tr>
<td>(Decrease) increase in temporarily restricted net assets</td>
<td>779,239</td>
<td>(1,302,640)</td>
</tr>
</tbody>
</table>

| Increase in net assets                           | 1,218,236    | 130,294      |
| Net assets, beginning of year                    | 22,903,609   | 22,773,315   |

| Net assets, end of year                          | $24,121,845  | $22,903,609  |
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 $71 million to support Alpha-1 research and programs at 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, visit alphaoneregistry.org, email alphaone@musc.edu or call toll-free 1-877-886-2383.

Alpha-1 Coded Testing provides free, confidential testing administered through a research study that evaluates perceived risks and benefits of genetic testing. Visit alphaoneregistry.org, 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 (1-800-785-3177), based at the Medical University of South Carolina, 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 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](http://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](http://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 [dfernandez@alpha1.org](mailto: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 [dfernandez@alpha1.org](mailto:dfernandez@alpha1.org) or 1-877-228-7321 ext. 242. For further 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. 275.

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. Contact information is available at [a1f.org/alpha1doc](http://a1f.org/alpha1doc).

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 [adearce@alpha1.org](mailto: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](http://alpha-1global.org), contact [ggutierrez@alpha-1global.org](mailto:ggutierrez@alpha-1global.org) or call 1-877-228-7321 ext. 212.

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 Barbee Bennington at 1-855-351-6610 or [bbennington@alpha1.org](mailto:bbennington@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 2017 | Our 2017 Peer Reviewed Principal Investigators are:

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

Ashley Buckle, Ph.D.
- Monash University, Australia
  Engineering a-1 antitrypsin for augmentation therapy

Lisa Cabrita, Ph.D.
- University College London, United Kingdom
  Co-translational folding and misfolding studies of alpha-1-antitrypsin

N. Tony Eissa, M.D.
- Baylor College of Medicine
  Lysosomal Origin for Emphysema

Patrick Geraghty, Ph.D.
- The Research Foundation of SUNY
  Alpha-1 antitrypsin regulates S100A9-mediated inflammation

Monica Goldklang, M.D.
- Columbia University Medical Center
  In vivo imaging of lung apoptosis in alpha-1 antitrypsin deficiency

Maurizio Molinari, Ph.D.
- Fondazione per l’Istituto di Ricerca in Biomedicina Bellinzona, Italy
  The role of novel ER-resident autophagy receptors in clearance of polymeric ATZ

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

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

Brian Varisco, M.D.
- Cincinnati Children’s Hospital Medical Center
  Cela1 is Required for Bullous Progression in AAT-Related Lung Disease

Alpha-1 Foundation Postdoctoral Research Fellowship Grant 2018
Killian Hurley, M.D., Ph.D.
- Royal College of Surgeons in Ireland, Ireland
  Modelling AATD Lung Disease Using Alveolar Epithelial Cells Derived from Gene-Edited iPSC

Alpha-1 Foundation Pilot & Feasibility Grant 2018
Maria Elena Miranda Banos, Ph.D.
- Sapienza University of Rome, Italy
  Dissecting immunomodulatory mechanisms of A1AT with function-neutralising monoclonal Ab

Alpha-1 Foundation Gordon L. Snider Scholar Awards 2018
Monica Goldklang, M.D.
- Columbia University Medical Center
  A Role for MMP-13 in COPD Exacerbations in the Alpha-1 Community

Pasquale Piccolo, Ph.D.
- Telethon Institute of Genetics and Medicine, Italy
  Regulation of autophagy in liver disease due to Z a1-antitrypsin

Alpha-1 Foundation/ATS Research Grant 2018
Alice Turner, Ph.D.
- University of Birmingham, United Kingdom
  Improving access to augmentation therapy in AATD: the effect of augmentation on quality of life

Alpha-1 Foundation/CHES Foundation Research Award in Alpha-1 Antitrypsin Deficiency 2018
Diana Crossley, MBChB
- Queen Elizabeth Hospital Birmingham, United Kingdom
  Functional Magnetic Resonance Lung Imaging using Inhaled Hyperpolarised 129Xenon: A pilot study of the clinical utility in Alpha One Anti-Trypsin Deficiency (AATD)

Alpha-1 Foundation/AASLD Foundation Clinical and Translational Research Fellowship Award 2018
Danielle Detelich, M.D.
- Massachusetts General Hospital, Division of Transplantation
  Alpha-1 Antitrypsin for Prevention of Hepatic Ischemia-Reperfusion Injury During Normothermic Machine Perfusion

Alpha-1 Foundation Travel Grants 2018
Russell Braeuer, Ph.D.
- University of Michigan
  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”

Boris Baranovski, Ph.D.
- Ben-Gurion University of the Negev, Israel
  Travel Grant to 16th Gordon L. Snider Critical Issues Workshop: MZ Carrier State in Alpha-1 Antitrypsin Deficiency
### Honor Gallery

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, 2016 and June 30, 2017.

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- Grifols Shire
- State of Florida

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- Neighbor To Nation

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- Anemaps
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- Syrian

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- American Respiratory Care
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- American Lung Association
- American Thoracic Society
- American Thoracic Society

#### $1,000-$4,999
- Anemaps
- Anemaps
- Anemaps
- Anemaps

#### $5,000-$9,999
- AlphaNet, Inc.
- Accredo Health/Express Scripts
- Anonymous Donor
- Kamada, Ltd.

#### $1 Million - $2,499,999
- CSL Behring, L.L.C.
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Bradley T. Youngblood
Theresa J. and Otis H. Youngblood
Wendy M. and William C. Zabel
Vincent “Todd” Zinni

Denotes Deceased
The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2016 and June 30, 2017.

Blake Aaronson  
Alpha-1 Foundation Staff  
Alpha-1 Support Group  
Leaders  
AlphaNet Coordinators  
Alphas for Building  
Friends for a Cure  
Karen Anderson  
Julianna Aquino  
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Kim and Kerri Cannata  
Llette R. and Joseph A.  
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Caregivers of Alpha  
Patients  
Andrea and Mark  
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Christine M. Brininstool  
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Kendall and J. Capron  
Lorraine F. and Joseph A.  
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Dell Witcher  
Casey Wolff  
The Wolff Family  
Claudia and DC Young  
Tom Young  
Bradley T. Youngblood  
Alyce M. Yout  
Denotes Deceased
In Memory Of

The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2016 and June 30, 2017.

Kathleen “Kate” (O’Connell) Adams
Marian Aguilar
Patricia A. Alexander
Larry G. Allen
Patrick J. Anderson
Susan (Insell) Andrews
Regina L. Angeli
Alpha Angels
Elizabeth “Betty” (Small) Ascani
Fred Ashmore
Arlynn Baber
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Roberta Bailey-Wambold
Kenneth A. “Kenny” Bakaitis
Judith “Julie” Crowell Bakula
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Minnie Goodlett
Annie Goodwin
Ettiene Goyeneche
Sharon Graber
Frank Granfors
Larry R. Gray
Sherry C. Gray
Marjorie A. and Paul Green
Ted J. Green
Roger S. Greene, Sr.
Edwin Griffin
Cynthia E. Grzegorowicz
Charles B. “Charlie” Gudaitis
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Andrea “Andi” Henry
Pamela Herman
Julia Hernandez
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Robert H. Hessler
Rebecca Hicks
Terrance “Terry” Highland
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James “Jim” Hixon
Ruth A. Hogan
Timothy “Tim” Harry Holdeman
Rebecca “Becky” Holland
Dianna B. Holt
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Robert D. McAuliffe
Brooke McCarter
William “Billy” McClellan
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.

We thank you for your ongoing support!
We couldn’t fulfill our mission without you.