It was a year of advocacy, growth and new

The Alpha-1 community’s meeting with the U.S. Food and Drug Administration (FDA) was among the most significant accomplishments for the Foundation and community in fiscal year 2016. Over 200 Alphas, their caregivers and supporters filled the room at the public meeting in September to discuss Patient-Focused Drug Development for Alpha-1 Antitrypsin Deficiency with the FDA. Another 600 participated online, and nearly 1,700 answered the Foundation’s online survey about the needs of the community.

Members of the Alpha-1 community told the FDA they were grateful to have augmentation therapy but pointed to the need for new therapies, especially therapies to treat Alpha-1 liver disease. Many Alphas said they were willing to participate in clinical studies — as long as they do not have to risk losing their augmentation therapy.

The FDA listened. Its Center for Drug Evaluation and Research (CDER) immediately granted a meeting for Alpha-1 patients, caregivers, leaders and investigators to discuss Alpha-1 liver disease and potential clinical trial design and therapeutic options.

The 2016 fiscal year (July 1, 2015 through June 30, 2016) brought both major Foundation achievements and challenges. In addition to the FDA meeting, the Foundation ushered in top leadership changes, announced new clinical practice guidelines, expanded its reach and influence into the global Alpha-1 community, and conducted a near record-setting National Education Conference that found fun ways to encourage community involvement in our programs.

In April, Henry Moehring became the Foundation’s president and CEO. John Walsh, who served as president and CEO from the Foundation’s beginning in 1995, had tapped Moehring as the new chief executive, and the two brought a transition plan to the executive committee of the Foundation Board at its October 2015 meeting.

At that meeting, Walsh proposed that Moehring — who had served as vice chair of the Foundation board since 2014 and chaired the Alpha-1 Association board before the merger — become the president and CEO, and that Walsh would step aside to the titles of founder and chief visionary officer. The board unanimously accepted the proposal. Walsh’s injury in a fall in January 2016 forced an acceleration of the plan.

Jean-Marc Quach was promoted in June to president and CEO of The Alpha-1 Project (TAP), the venture philanthropy arm of the Foundation. The mission of TAP is accelerating the discovery, development and commercialization of treatments and drug therapies for Alpha-1. Quach, who had been TAP’s executive director, “almost singlehandedly positioned the organization to achieve its goal,” according to members of the TAP board.

The organization of grassroots advocacy in the Alpha-1 community also saw a leadership change. Miriam O’Day, the Foundation’s former senior director of public policy, resigned after 15 years of service. O’Day had worked with members of the government relations firm CRD Associates for many years on public advocacy for people with rare diseases, and she endorsed the Foundation’s hiring of CRD. Since July 2015, the CRD team has been implementing the Foundation’s advocacy strategy, including the organization of the Alpha-1 community’s meeting with the FDA.
As the Foundation enhanced its grassroots advocacy in the U.S., it also extended its reach into other parts of the world. Alpha-1 Global, a program of the Foundation dedicated to building a collaborative network of organizations for patients and their families worldwide, held the first Latin American Alpha-1 Patient Congress in Buenos Aires, Argentina. The congress drew more than 50 people from nine Latin American countries including Panama, Costa Rica, Brazil, Chile, Ecuador, Argentina, Peru, Uruguay and Colombia.

The Foundation also sought to protect Alphas from Internet scams that claim to offer “stem cell therapies.” The Foundation’s Medical and Scientific Advisory Committee (MASAC) issued a letter warning that “patients should be skeptical about the usefulness of stem therapies.” The Winter 2015 issue of Alpha-1-To-One magazine also carried an article on the subject, “Don’t trust phony stem cell websites,” with links to trustworthy information.

Officials from the National Institutes of Health and the FDA were among the speakers at a Foundation-sponsored workshop in April on “Ethical Issues Related to Clinical Research and Rare Diseases.” Some key topics discussed were the continued need for institutional review boards (IRBs), proposals for patient involvement in IRBs, and how to streamline clinical research with flexible protocols for rare diseases while still protecting the rights of volunteer subjects.

The 2016 National Education Conference in June welcomed a near-record total of 610 attendees, 40 percent of whom took our quiz, “What is Your Alpha-1 Personality?” to encourage community involvement in our programs. The quiz fit right in with the conference theme, “Without YOU There Is No Solution.”

At the conference, Robert A. Sandhaus, MD, PhD, clinical director of the Foundation and medical director of AlphaNet, introduced new clinical guidelines for diagnosis and treatment of Alpha-1, weeks before their publication in the Journal of the COPD Foundation. The guidelines update and simplify the 2003 document from the American Thoracic Society and the European Respiratory Society.

ON OUR COVER:
Alphas and Alpha-1 caregivers packed the room in September 2015 at the meeting held by the U.S. Food and Drug Administration (FDA) to discuss Patient-Focused Drug Development for Alpha-1. Clockwise, from top left: John W. Walsh speaks on a panel, with Henry R. Moehring on his right; Marcie Heitzman talks about the heartbreak of losing her Alpha-1 child at six months old, after a liver transplant; Doreen Flook talks about life with Alpha-1 lung disease; Jesse Young tells his story of liver transplant; Marlene Buchanan, who for years was a support group leader and grassroots advocate, listens to the speakers. (Photos by Richard Lovrich)
In 2015, Christian Mueller, PhD, was looking at gaps in the research on Alpha-1 Antitrypsin Deficiency that his young Alpha-1 research team at the University of Massachusetts could fill. “The most obvious gap was the lack of an animal model for lung disease in Alpha-1,” he says.

A mouse has five genes for Alpha-1. In order to develop a mouse model for Alpha-1 lung disease, it is necessary to knock out all five genes for Alpha-1, and no one had been able to do it. After a number of failed attempts over decades to develop an Alpha-1 lung mouse, a medical journal published an article concluding that mice cannot survive even until birth without any alpha-1 genes, and this was often accepted as fact.

For that reason, Mueller applied for and received an Alpha-1 Foundation grant in 2015 to develop a ferret model of Alpha-1 lung disease. A ferret, like a person, has only one pair of alpha-1 genes, so it seemed a better bet. But Mueller never gave up on mice and in 2016 his lab succeeded in developing the long-sought mouse model of Alpha-1 lung disease. (They developed the ferret model, as well, but that took longer because ferrets take much longer to breed than mice.)

A year before these exciting successes, The Alpha-1 Project, the venture philanthropy arm of the Alpha-1 Foundation, awarded a commission to the UMass team to develop an antibody that detects the mutant ZZ gene in the body. Mueller says the The Alpha-1 Project commission was crucial to the growth and stability of his Alpha-1 research. “Thanks to that commission, I was able to retain lab personnel who were trained in Alpha-1.”

Adam Wanner, MD, Foundation scientific director, points out that the Foundation created The Alpha-1 Project to promote new therapeutic solutions — after Foundation grants laid the groundwork to make this possible. Two companies supported by The Alpha-1 Project have entered into early-phase clinical trials using novel gene-silencing approaches for treating Alpha-1 liver disease.

Adds Wanner: “The Alpha-1 Foundation is a small organization. Many larger research foundations have much larger budgets. Yet, the cumulative impact of Foundation grants seems much larger than their size, and the impact seems to be growing year after year.”

The UMass lab is now sharing both the mutant Z gene antibody and its new Alpha-1 lung mouse with other researchers.

Mueller reports to Terence Flotte, MD, a leader in Alpha-1 gene therapy for many years. In 1999, the year the Foundation began its research grants program, Sihong Song, PhD, then a postdoctoral fellow in Flotte’s lab at the University of Florida, received a Foundation grant to study Alpha-1 gene therapy using adeno-associated virus vectors injected into the long-sought mouse model of Alpha-1 lung disease. (They developed the ferret model, as well, but that took longer because ferrets take much longer to breed than mice.)
the muscles of animals — work that led to clinical trials that are still ongoing. Flotte serves as one of the Foundation’s Clinical Resource Centers and is editor-in-chief of the journal *Human Gene Therapy*.

A frequent collaborator with Mueller is the Alpha-1 Center (another Clinical Resource Center) at Boston University, where Andrew Wilson, MD, is director and Darrell Kotton, MD, is co-director.

Wilson, with Foundation funding, is developing an “open-source toolkit” designed to be shared with any investigator, that will allow researchers to correct the Alpha-1 Z mutation and make induced pluripotent stem cells from blood or skin cells donated by Alphas. Someday these cells may be used to repair damage to the Alpha’s own liver or lungs.

The world-class quality and the collaboration are both trademarks of many of today’s leading Alpha-1 programs funded by the Foundation and The Alpha-1 Project. The experience of these two Alpha-1 research labs, thriving with the help of Foundation grants, is one that has been repeated in many centers across the U.S. and the world.

Among the many widely-known Alpha-1 researchers whose work has been boosted by Foundation grants — all of whom have mentored others in the field — are Flotte, Richard Sifers, PhD, of Baylor University, David Lomas, MD, of University College London, and Noel G. McElvaney, MD, of the Royal College of Surgeons in Ireland.

Among researchers launching their careers with the help of our grants are Karina Serban, MD, of National Jewish Health, recipient of the first Gordon L. Snider Scholar Award, specifically intended for young researchers; Alice Turner, PhD, who credits a Foundation grant with helping her to win a permanent post at the University of Birmingham, UK; and Michael Iannotti, PhD, now working on a 3-year postdoctoral fellowship funded jointly by The Alpha-1 Project and the National Institutes of Health’s National Center for Advancing Translational Sciences.

The Foundation awarded a record total of $1.9 million to 14 grant recipients in fiscal year 2016, breaking the record of $1.8 million for in-cycle grants that was set just a year earlier. Among the projects awarded this year were a study of the way that drugs now in development can work to reverse liver disease in Alphas, and whether a new MRI technology can replace the CT scan as the most precise measure of COPD.

The Foundation also continues to fund the 5-year natural history study of Alpha-1 liver disease in adults at three centers across the U.S., headed by Jeffrey Teckman, MD, of St. Louis University.

One reason Alpha-1 research is thriving is the Alpha-1 Foundation Research Registry at the Medical University of South Carolina, which had a record 5,381 people enrolled by the end of fiscal year 2016. The Alpha-1 Coded Testing study, which offers free and confidential testing for people at risk of Alpha-1, tested 3,199 people over the year.
Committed to a cure and improving the lives of people affected by Alpha-1

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.

This is possible thanks to your support.

Activities and Events for Fiscal Year 2016 - July 1, 2015 - June 30, 2016.
Message from the Leadership

Our fiscal year 2016 — from July 1, 2015 through June 30, 2016 — was a year of both great challenge and great achievement for the Alpha-1 community and the Foundation.

When more than 200 Alphas and caregivers packed a public meeting held by the U.S. Food and Drug Administration in September 2015 to discuss Patient-Focused Drug Development, it was surely one of the year’s biggest triumphs for the Alpha-1 community. Some 600 more attended the meeting online and 1,700 people answered the Foundation’s online survey on the needs of the community, with the results reported at the meeting.

The Foundation faced one of the greatest challenges in its history when John W. Walsh, co-founder, president and CEO, was injured in a fall in January 2016. The Foundation responded quickly, naming Ab Rees, a Board member and immediate past chair, as acting CEO and president, then on April 29 appointing me, Henry R. Moehring, as president and CEO.

Many key achievements and transitions of the year are reported on pages 2-3 and the informative graphic on pages 6-7. Some of them:

- The 2016 National Education Conference in June was a great success, with a near-record total of 610 attendees, 40 percent of whom took our quiz, “What is Your Alpha-1 Personality?” to encourage community involvement in our programs. The quiz fit right in with the conference theme, “Without YOU There Is No Solution.”

- Through fiscal year 2016, the Alpha-1 Foundation has invested more than $65 million to support Alpha-1 Antitrypsin Deficiency research and programs at 106 institutions in North America, Europe, the Middle East and Australia.

- Research we’ve funded brought some landmark results over the year, not the least being the development of a mouse model for Alpha-1 lung disease after many attempts over two decades. We believe our research funding has led to remarkable results out of proportion to the small size of the diagnosed Alpha-1 community and the Foundation itself. (See The Impact, page 4.)

- Miriam O’Day resigned after many years as senior director, public policy and endorsed the hiring of the government relations firm CRD Associates to advise and implement the Foundation’s advocacy strategy.

- The Foundation’s Medical and Scientific Advisory Committee issued a letter warning Alphas against online claims of unproven “stem cell therapies,” with advice on where to find reliable information.

- For the 6th consecutive year, we received Charity Navigator’s highest rating. The Foundation also consistently receives the highest possible rating from three other key charity-rating services, the National Health Council, GuideStar and the Better Business Bureau Wise Giving Alliance.

We continue to be focused on the Foundation’s mission and have a clear course going into 2017. While there are certainly going to be some changes in our healthcare system, we remain committed to the needs of the Alpha-1 community. As always, we thank you for your ongoing support and emphasize the importance of your continued commitment to help us reach our goal of a cure for Alpha-1.

Henry R. Moehring, MBA  
President & CEO

Gordon E. Cadwgan, PhD  
Board Chair
Alpha-1 Foundation Board of Directors

Executive Committee

Gordon E. Cadwgan, PhD*, Chair ................................... West Palm Beach, FL
Dell Witcher*, Secretary ..................................................... Vestavia Hills, AL
James Quill*, Treasurer .......................................................... Bluffton, SC
Ab Rees*, Immediate Past Chair ...................................... Kansas City, MO
Martin R. Zamora, MD, Scientific Advisor ............................... Aurora, CO

Board of Directors, June 30, 2016

Virginia Clark, MD ........................................................... Gainesville, FL
Thomas Corron* ............................................................... Fort Wayne, IN
Jeanine M. D’Armiento, MD, PhD ........................................ New York, NY
Sandra Ries Douglas + ............................................................... Pittsburgh, PA
Elizabeth Johnson* ................................................................. Winchester, MA
Jennifer Jopp* ................................................................. East Bethel, MN
Noel G. McElvaney, MD, BCh, BAO  ......................................... Dublin, Ireland
Judith Simon* ................................................................. Denver, CO
James K. Stoller, MD, MS (Org Dev)  ..................................... Cleveland, OH
Frank Willersinn, MD ............................................................. Bruxelles/Brussels, Belgium

Executive Staff

Henry R. Moehring, MBA* ................................... President and Chief Executive Officer
Marcia F. Ritchie .............................................................. Executive Vice President and Chief Operating Officer
Robert C. Barrett .............................................................. Executive Vice President and Chief Financial Officer
Adam Wanner, MD .............................................................. Scientific Director
Robert A. Sandhaus, MD, PhD ................................................... Clinical Director
John W. Walsh* .............................................................. Co-Founder and Chief Visionary Officer

*Denotes diagnosed Alpha-1 Antitrypsin deficient
+Denotes diagnosed family member
### Statement of Financial Position

**YEAR ENDED JUNE 30, 2016**

<table>
<thead>
<tr>
<th>Assets</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Assets</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cash and cash equivalents</td>
<td>$1,134,854</td>
<td>$1,473,152</td>
</tr>
<tr>
<td>Investment securities</td>
<td>14,131,370</td>
<td>13,770,534</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>1,389,884</td>
<td>703,070</td>
</tr>
<tr>
<td>Due from TAP</td>
<td>7,010</td>
<td>5,431</td>
</tr>
<tr>
<td>Other current assets</td>
<td>34,637</td>
<td>253,257</td>
</tr>
<tr>
<td><strong>Total current assets</strong></td>
<td>16,697,755</td>
<td>16,205,444</td>
</tr>
<tr>
<td><strong>Investment securities — non-current</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment in TAP</td>
<td>3,437,005</td>
<td>3,994,136</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>157,118</td>
<td>190,246</td>
</tr>
<tr>
<td>Other assets</td>
<td>25,135</td>
<td>30,135</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td>$24,555,213</td>
<td>$24,158,161</td>
</tr>
</tbody>
</table>

| Liabilities and Net Assets                  |           |           |
| Current Liabilities                         |           |           |
| Accounts payable and accrued expenses       | $1,489,525| $1,294,236|
| Due to TAP                                  | –         | 2,692     |
| Due to COPD Foundation                      | 2,579     | 4,418     |
| Deferred revenue                            | 159,500   | 83,500    |
| **Total current liabilities**               | 1,651,604 | 1,384,846|

| Net Assets                                  |           |           |
| Unrestricted                                | 20,851,759| 19,418,825|
| Temporarily restricted                      | 2,051,850 | 3,354,490 |
| **Total net assets**                        | 22,903,609| 22,773,315|

| Total liabilities and net assets            | $24,555,213| $24,158,161|

### Gross Revenues By Classification

**FOR THE FISCAL YEAR ENDED JUNE 30, 2016**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted Contributions</td>
<td>$3,822,861</td>
<td>39%</td>
</tr>
<tr>
<td>AlphaNet</td>
<td>$3,665,000</td>
<td>38%</td>
</tr>
<tr>
<td>Other Income</td>
<td>$699,383</td>
<td>7%</td>
</tr>
<tr>
<td><strong>TOTAL: $9,732,244</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha-1 Research Network</td>
<td>$3,858,825</td>
<td>40%</td>
</tr>
<tr>
<td>Alpha-1 Patient Support</td>
<td>$330,453</td>
<td>3%</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>$259,208</td>
<td>3%</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>$673,174</td>
<td>7%</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>$340,313</td>
<td>3%</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>$830,663</td>
<td>9%</td>
</tr>
<tr>
<td>Alpha-1 National Conference</td>
<td>$835,104</td>
<td>9%</td>
</tr>
<tr>
<td><strong>TOTAL: $9,601,9,50</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Functional Expenses

**FOR THE FISCAL YEAR ENDED JUNE 30, 2016**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fund raising</td>
<td>$811,310</td>
<td>9%</td>
</tr>
<tr>
<td>Administration and general</td>
<td>$840,838</td>
<td>9%</td>
</tr>
<tr>
<td><strong>TOTAL: $9,601,9,50</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Statement of Activities and Changes in Net Assets

**YEAR ENDED JUNE 30, 2016**

### Changes in Unrestricted Net Assets

**Unrestricted Support and Revenue**

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>$ 7,188,940</td>
<td>$ 5,631,266</td>
</tr>
<tr>
<td>Donated shares</td>
<td>–</td>
<td>8,070</td>
</tr>
<tr>
<td>Fundraising revenues</td>
<td>298,921</td>
<td>603,590</td>
</tr>
<tr>
<td>Investment income</td>
<td>(157,055)</td>
<td>218,476</td>
</tr>
<tr>
<td>Other income</td>
<td>826,438</td>
<td>824,288</td>
</tr>
<tr>
<td>Net assets released from restriction — satisfaction of program restrictions</td>
<td>2,877,640</td>
<td>3,020,017</td>
</tr>
</tbody>
</table>

**Total unrestricted support and revenue** | **11,034,884** | **10,305,707**

**Unrestricted Expenses**

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alpha-1 Research Network</td>
<td>3,858,825</td>
<td>4,048,280</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>340,313</td>
<td>372,843</td>
</tr>
<tr>
<td>Alpha-1 National Conference</td>
<td>835,104</td>
<td>182,774</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>752,062</td>
<td>608,001</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>673,174</td>
<td>433,249</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>259,208</td>
<td>300,115</td>
</tr>
<tr>
<td>Alpha-1 Patient Support Network</td>
<td>330,453</td>
<td>302,472</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>830,663</td>
<td>816,239</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td><strong>7,879,802</strong></td>
<td><strong>7,063,973</strong></td>
</tr>
<tr>
<td><strong>Supporting services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>881,310</td>
<td>852,606</td>
</tr>
<tr>
<td>Administration and general</td>
<td>840,838</td>
<td>754,453</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td><strong>1,722,148</strong></td>
<td><strong>1,607,059</strong></td>
</tr>
</tbody>
</table>

**Total unrestricted expenses** | **9,601,950** | **8,671,032**

**Increase in unrestricted net assets** | **1,432,934** | **1,634,675**

### Changes in Temporarily Restricted Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2016</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>1,575,000</td>
<td>3,488,155</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>(2,877,640)</td>
<td>(3,020,017)</td>
</tr>
</tbody>
</table>

**(Decrease) increase in temporarily restricted net assets** | **(1,302,640)** | **468,138**

**Increase in net assets** | **130,294** | **2,102,813**

**Net assets, beginning of year** | **22,773,315** | **20,670,502**

**Net assets, end of year** | **$22,903,609** | **$22,773,315**
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. The Alpha-1 Foundation has invested more than $65 million to support Alpha-1 Antitrypsin Deficiency research and programs at 106 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 information, visit www.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 www.alphaoneregistry.org, email alphaone@musc.edu or call toll free 1-877-886-2383.

The Support Network is comprised of about 80 support groups nationwide that provide support 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 www.alpha1.org or email bbennington@alpha1.org.

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 (1-800-786-3177), 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 a newly diagnosed Alpha with another Alpha who has a similar set of circumstances to provide emotional support, discuss resources available and assist in enabling peers to make 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 through a travel fund program and a portable oxygen concentrator (POC) loaner program. 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 500 Alphas, caregivers, industry representatives, clinicians, allied health care workers and scientists to discuss a wide range of Alpha-1 related topics. Additionally, a series of 6 education days are held in various cities to bring patient education to a regional audience. Recordings of these past events are available via E-Education at www.alpha1.org. To learn more about these programs, visit www.alpha1.org or contact aartiles@alpha1.org or call 1-877-228-7321 ext. 331.

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 raise funds for research, ultimately leading to a cure for Alpha-1. Anyone can take action and raise money by becoming involved in fundraising efforts, which include special event planning, letter writing campaigns, potential donor introductions, and assisting in local, national and international social and sporting events. Contact amcbride@alpha1.org or call 1-877-228-7321 ext. 233.
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 www.alpha1.org 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 on our website, www.alpha1.org, 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, developing new therapies, screening and detection, access to care and reimbursement, federal and state funding, blood product safety, education, awareness and the recognition of the special needs of people with Alpha-1. For more information, email kerickson@alpha1.org.

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 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 or 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. An important component of the Targeted Detection Program is the State of Florida Detection Program. This program is a collaboration between the State of Florida Department of Health and Human Services, the Alpha-1 Foundation and the University of Florida College of Medicine. Testing through the Florida Detection Program is free to Florida residents and is administered through physicians’ offices. Contact rbalderas@alpha1.org or rsobkowiak@alpha1.org, or call 1-877-228-7321, ext. 205 or 203.

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. For more information, contact kwelch@alpha1.org or 1-877-228-7321 ext. 275.

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 disorder and to work toward new therapies and a cure. For more information, contact adearce@alpha1.org or call 1-877-228-7321 ext. 269.

Alpha-1 Global Initiative: The Alpha-1 Foundation 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, contact ggotierrez@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 bbennington@alpha1.org or 1-855-351-6610.
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 2016**

Our 2016 Peer Reviewed Principal Investigators are:

- **Carrie P. Aaron, M.D.**
  - Targeting Pulmonary Perfusion in α1-Antitrypsin Deficiency
- **Tatsiana Beiko, M.D.**
  - Proteomic signatures in individuals with severe deficiency of α1-antitrypsin
- **Phillip Bird, Ph.D.**
  - A zebrafish model of antitrypsin-induced liver disease
- **Florie Borel, Ph.D.**
  - Improvement of the AAV1-CB-AAT gene therapy vector
- **Lisa Cabrita, Ph.D.**
  - α1-Antitrypsin folding during synthesis on the ribosome
- **Michael Campos, M.D.**
  - The Airway Microbiome in Subjects with Alpha-1 Antitrypsin Deficiency on Augmentation Therapy
- **Jeanine D’Armito, M.D., Ph.D.**
  - Implications of MMP-13 Mediated Cleavage of Alpha-1 Antitrypsin
  - Investigating Effect of Smoke Exposure in Alpha-1 Antitrypsin
- **Edward David Chan, M.D.**
  - What is the mechanism by which anomalous AAT predisposes to NTM lung disease?
- **Michael H. Cho, M.D., M.P.H.**
  - Exome Determinants of Lung Function in Alpha-1
- **Andrew Chu, M.D.**
  - Mechanisms of action for autophagy enhancer drugs on alpha-1-antitrypsin deficiency-associated liver disease
- **Francisco Dasi, Ph.D.**
  - 1st International Meeting on Rare Respiratory Diseases
- **Klaus Dolmer, Ph.D.**
  - Propagation of the initial Zα1PI dimer
- **Terence R. Flotte, M.D.**
  - 19th Annual Meeting of the American Society of Gene & Cell Therapy
- **Robert Forony, 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
- **Monica Goldklang, M.D.**
  - The Role of MMP-13 in COPD: Exacerbations and Implications on Alpha-1 Antitrypsin Activity
- **Catherine M. Greene, Ph.D.**
  - miRNA-mediated effects of AAT Augmentation Therapy
- **Kristen Holm, Ph.D., M.P.H.**
  - Helping Alphas Succeed with Oxygen Therapy
- **Edward Ingenito, M.D., Ph.D.**
  - Development of Stem Cell Scaffolds for Therapeutic Application in Emphysema
- **James A. Irving, Ph.D.**
  - Tools to study polymerization intermediates
- **Ziv Kaner, Ph.D.**
  - Travel Grant to 12th World congress on inflammation in Boston, Massachusetts to present the abstract entitled: “Dual functionality of alpha1-antitrypsin: an inflammatory S-nitrosylated form stimulates macrophages during bacterial infections”
- **Zahida Khan, M.D., Ph.D.**
  - Hepatocyte repopulation by liver progenitor cells in A1AT Deficiency
- **Dara E. Leto, Ph.D.**
  - Systematic genetic interaction map of mammalian ERAD
- **Ravi Mahadeva, M.D.**
  - The effect of Z antitrypsin on oxidative and nitrosative stress
- **Ani Manichaikul, Ph.D.**
  - Alpha-1 antitrypsin in African Americans and Hispanics
- **Beatriz Martinez-Delgado, Ph.D.**
  - Travel Grant to 2016 ATS Meeting in San Francisco, California to present the abstract entitled: “Molecular Characterization of Novel Rare Variants of SERPINA1 Gene In Alpha-1 Antitrypsin Deficiency Patients from Spain”
- **Karen A. McDonald, Ph.D.**
  - In-Vitro Evaluation of a Plant-Made Alpha-1-Antitrypsin
- **Noel G. McElvaney, MB, BCh, BAO**
  - Alpha-1 antitrypsin deficiency: Which is important phenotype, level, activity or all three?
- **Ray Moseley, Ph.D.**
  - An Interactive Tool Addressing & Communicating Alphas EOL issues
- **Christian Mueller, Ph.D.**
  - Ferret Knockout Model for Alpha-1 Antitrypsin Deficiency
- **Tamir Rashid, Ph.D.**
  - Advanced hiPSC models for α-1 Antitrypsin Deficiency research
- **Chiara Rigobello, Ph.D.**
  - Investigation of susceptibility factors in alpha-1 antitrypsin deficiency: a whole exome approach
- **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.**
  - AAT-Z as the Client of a Novel Post-ER Proteostasis Intersection
  - The modifying role of ER mannosidase I in ATZ liver disease
  - Establishing the contribution of microRNAs as a disease modifier
- **Dorota Skowrya, Ph.D.**
  - The Proteasome Load Tolerance in Alpha 1 Deficiency
- **Chris Sullivan, Ph.D.**
  - The role of microRNAs in Alpha-1 Antitrypsin deficiency-associated disease
- **Jeffrey Teckman, M.D.**
  - Adult Alpha-1 Liver Clinical and Genetic Linkage Study
- **Alice Turner, Ph.D.**
  - Function of genetic modifiers of AATD lung disease
- **Dragos Mihai Vasilescu, Ph.D.**
  - Molecular determinants of small airway disease in AATD
- **Emily S. Wan, M.D.**
  - Metabolomic Profiling in Alpha-1 Antitrypsin Deficiency
- **Chao Wang, Ph.D.**
  - Managing Proteostasis to Correct A1AT Deficiency
- **Yan Wang, Ph.D.**
  - A new drug for antitrypsin deficiency from computational pharmacological screening
- **Daniel J. Weiss, M.D., Ph.D.**
  - 2015 Stem Cells and Cellular Therapies in Lung Biology and Lung Diseases Workshop
- **Holger Willenbring, M.D., Ph.D.**
- **Andrew A. Wilson, M.D.**
  - Open Source CRISPR Gene Correction of PIZZ iPSCs
- **Patrick L. Wintrode, Ph.D.**
  - Modeling misfolded Z α1-antitrypsin for in silico drug design

**Program Grants Portfolio for 2016**

Our 2016 Program Grants Principal Investigators are:

- **Mark L. Brantly, M.D.**
  - Alpha-1 Coded Testing Study
  - Alpha-1 DNA and Tissue Bank
  - Alpha-1 State of Florida Detection Program
- **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
  - Alpha-1 Genetic Counseling Center
- **Adam Wanner, M.D.**
  - Scientific Director, Alpha-1 Foundation

All grants listed above were active between July 1, 2015 and June 30, 2016.
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, 2015 and June 30, 2016.

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The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2015 and June 30, 2016.

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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.