From inception through Fiscal Year 2015 — ending June 30, 2015 — the Alpha-1 Foundation has invested nearly $60 million to support Alpha-1 Antitrypsin Deficiency research and programs at 103 institutions in North America, Europe, the Middle East and Australia.

Since 2015 was our 20th anniversary year, on pages 4-5 you’ll see some history about building the Foundation’s Alpha-1 research infrastructure and of our growing Alpha-1 research program over two decades.

We also highlight two key examples of efforts by the Foundation and The Alpha-1 Project during the year to encourage young scientists to begin careers in Alpha-1 research: The presentation of our first Gordon L. Snider Scholar Award, for investigators who continue to conduct research in Alpha-1 after completing their postdoctoral fellowship; and The Alpha-1 Project’s grant to support its first postdoctoral fellowship position at the National Institutes of Health’s (NIH) National Center for Advancing Translational Sciences (NCATS).

In what we believe is an indication of the quality of clinicians and researchers involved with Alpha-1, U.S. News & World Report released its list of the best hospitals for 2014, and the top three pulmonary hospitals were all Clinical Resource Centers of the Alpha-1 Foundation: the Mayo Clinic, Rochester, MN, whose Alpha-1 specialist is Michael Krowka, M.D.; National Jewish Health/University of Colorado Hospital, Denver, whose Alpha-1 specialist is Robert Sandhaus, M.D., the Foundation’s clinical director and medical director of AlphaNet; and Cleveland Clinic, Cleveland, whose Alpha-1 specialist is James Stoller, M.D., M.S. (Org. Dev.), a Foundation Board member.

Beginning the first day of the fiscal year, July 1, 2014, the Foundation expanded its services to include all programs of the former Alpha-1 Association, which merged into the Foundation on that day. Of course, we continue to support Education Days across the country as well as the National Education Conference.

Many activities involving all our programs are detailed on pages 8-9. Here are a few highlights:

- On Sept. 16 2014, after six months and 21 days on the Appalachian Trail beginning in Springer Mountain, Georgia, Jonathan Maidment reached trail’s end at the summit of Mount Katahdin, Maine, and raised more than $30,000 for Alpha-1 research programs.
- More than 100 walkers took part in the 8th annual George Washington Bridge Walk May 2, raising $25,000.
- Support group members helped to educate healthcare professionals about Alpha-1 at a series of National Association for Continuing Education events around the country.
- For the fifth 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, Guide Star and the Better Business Bureau’s Wise Giving Alliance.

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.
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 2015**

Our 2015 Peer Reviewed Principal Investigators are:

- **Tatsiana Beiko, M.D.**  
  - Proteomic signatures in individuals with severe deficiency of alpha-1 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

- **Edward David Chan, M.D.**  
  - What is the mechanism by which anomalous AAT predisposes to NTM lung disease?

- **Michael H. Cho, M.D., MPH**  
  - 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

- **Klavs Dolmer, Ph.D.**  
  - Propagation of the initial Z-α1PI dimer

- **N. Tony Eissa, M.D.**  
  - Factors affecting the translation of endogenous Alpha1 Antitrypsin

- **Terence R. Flotte, M.D.**  
  - 18th Annual Meeting of the American Society of Gene & Cell Therapy

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

- **Brian M. Gilfich, Ph.D., MDCM, FRCPC**  
  - Alpha1-Antitrypsin Genotyping by High-Resolution Melting

- **Monica Goldklang, M.D.**  
  - The Role of MMP-13 in COPD Exacerbations and Implications on Alpha-1 Antitrypsin Activity

- **Catherine Hawrylowicz, Ph.D.**  
  - Can vitamin D enhance α1-antitrypsin in airway disease?

*All grants listed above were active between July 1, 2014 and June 30, 2015.*

**Program Grants Portfolio for 2015**

Our 2015 Program Grants Principal Investigators are:

- **Kristen Holm, Ph.D., MPH**  
  - Helping Alphas Succeed with Oxygen Therapy

- **Edward Ingenito, M.D., Ph.D.**  
  - Development of Stem Cell Scaffolds for Therapeutic Application in Emphysema

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

- **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

- **Emer Reeves, Ph.D.**  
  - Stopping the “nonsense” in Alpha-1

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

- **Anasuya Sarkar, Ph.D.**  
  - Emphysema and AAT; Injury from LL37 and Microvesicular Caspase-1

- **Lynn Schnapp, M.D.**  
  - Role of AAT deficiency in HIV-associated emphysema

- **Ronen Schuster, Ph.D.**  
  - Travel Grant to FIRN 2014 Conference to present the abstract entitled: “Mechanism of α1-antitrypsin mediated interleukin-1 receptor antagonist expression involves unique distribution of the NF-κB family member, p65”

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

- **Richard N. Sifers, Ph.D.**  
  - The modifying role of ER mannosidase I in ATZ liver disease

- **Rachel A. Smith, Ph.D.**  
  - Adult Alpha-1 Liver Clinical and Genetic Linkage Study

- **Alice Turner, Ph.D.**  
  - Function of genetic modifiers of AATD lung disease

- **Melissa A. Vance, Ph.D.**  
  - Development of shRNA/AATopt: a dual-function AAV vector

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

- **Chao Wang, Ph.D.**  
  - Managing Proteostasis to Correct A1AT Deficiency

- **Holger Willenbring, M.D., Ph.D.**  

- **Andrew A. Wilson, M.D.**  
  - A Next-Generation in vitro AATD Clinical Trial

- **Patrick L. Wintrode, Ph.D.**  
  - Modeling mistfolded Z α1-antitrypsin for in silico drug design

**ALPHA-1 FOUNDATION • 3**
Three people with Alpha-1, Sandy Lindsey, Susan Stanley and John Walsh, founded the Alpha-1 Foundation in 1995 to promote research and find a cure for Alpha-1 Antitrypsin Deficiency.

The first order of business was to build a research infrastructure and create an ongoing community of clinicians, researchers and people with Alpha-1 willing to take part in research.

The Foundation created its Clinical Resource Centers in 1996, based on the research centers involved across the country in the 1989-96 study of Alpha-1 at the National Heart, Lung, and Blood Institute (NHLBI), which was ending its Alpha-1 research at the conclusion of the study.

A year later, in 1997, the Alpha-1 Research Registry was opened at the University of Miami, later transferring to the Medical University of South Carolina, under the direction of Charlie Strange, M.D.. Enrollment has steadily grown and it is now by far the world’s largest Alpha-1 registry, including more than 5,200 Alphas and Alpha-1 carriers.

Also in 1997, the Foundation sponsored its first international scientific meeting to promote Alpha-1 research across disciplines. Such international meetings have become a regular event, with the Foundation now sponsoring a Biennial International Research Conference on Alpha-1 Antitrypsin Deficiency, held in conjunction with the Alpha-1 Global Patient Congress. The 5th Congress, in Barga, Italy in April 2015, drew 200 people from 26 countries.

In 1998, Mark Brantly, M.D., left the NHLBI to build the Alpha-1 research program at the University of Florida, including the Alpha-1 Detection Lab that also serves as an international reference lab for Alpha-1, the Alpha-1 DNA and Tissue Bank, and a busy clinical center specializing in Alpha-1 patients.

In 2000, Robert “Sandy” Sandhaus became clinical director of the Foundation and medical director of AlphaNet.

The Foundation began awarding the first grants in its research program in 1997.

Some other research achievements over the past two decades:

- The Fernandez Family Liver Initiative began in 2000 and over several years funded $5 million in research on Alpha-1 liver disease.
- The U.S. Food and Drug Administration in 2003 approved two additional Alpha-1 augmentation therapies, Aralast and Zemaira, and in 2010 the first liquid formula for augmentation, Glassia.
- The Alpha-1 Project (TAP) was launched in 2010 to accelerate therapeutic development for Alpha-1, the same year that the Cadwgan family made a $1 million donation to support the Foundation’s Alpha-1 research programs.
- Beginning in 2012, the Foundation began bringing researchers who received Foundation grants together every other year at investigators’
Building the infrastructure for two decades of Alpha-1 research

Continued

meetings in Miami to discuss their work and network with each other. The meetings are held in conjunction with the Donor Recognition Dinner held to honor those whose generosity makes the Foundation’s research possible.

In October 2014, 18 scientists from across the U.S., Ireland and the U.K. presented their work and later met with donors at the dinner. A highlight of the dinner was the presentation of the first Gordon L. Snider Scholar Award to Karina Serban, M.D., of Indiana University. The award is named for Gordon Snider, M.D., a pioneer in pulmonary and Alpha-1 research and longtime Foundation Board member who died in 2013.

Arrowhead Pharmaceuticals began a clinical trial in Australia in early 2015 of its RNA interference (RNAi) therapeutic designed to treat Alpha-1-related liver disease. The Alpha-1 Project is partially funding the drug development work under an agreement made the previous year.

In December, TAP awarded its first postdoctoral fellowship position at the National Institutes of Health’s (NIH) National Center for Advancing Translational Sciences (NCATS), to Michael Iannotti, Ph.D. During the 3-year fellowship, Iannotti is developing assays for potential therapies for Alpha-1.

In May, the Foundation awarded a record $1.8 million to 2015 research grant recipients at the American Thoracic Society’s annual conference. Also in May, the Alpha-1 Foundation hailed the publication of results of the RAPID trial in *The Lancet*, one of the world’s oldest and most prestigious medical journals. “We congratulate CSL on this landmark clinical trial, which provides the strongest evidence yet that augmentation therapy preserves the lung tissue of individuals with Alpha-1-related lung disease,” said John Walsh, Foundation president and CEO. “We hope these results will support Alpha-1 communities around the world in their efforts to win access to therapy.”

Researcher and robot — Michael Iannotti, Ph.D., stands in front of one of the robots used at NCATS for screening huge libraries of molecular compounds.

Karina Serban, M.D. accepts the Inaugural Gordon L. Snider Scholar Award.

ON THE COVER: Clockwise from top left: Jonathan Maidment raises an Alpha-1 banner and more than $30,000 in completing the 2,200 miles of the Appalachian trail; the founders of the Alpha-1 Foundation on the Spring 2015 cover of Alpha-1-To-One magazine; support group leaders from around the country pose at the 2015 national education conference in Garden Grove, CA; Sue Binnall and Alyce Yout at the annual Escape to the Cape bicycle trek; Charlie Strange, M.D., laughs as he answers a question during an Education Day; Alice Turner, PhD, of the University of Birmingham, UK, shares her work with 17 other recipients of Foundation research funding at our 2014 Investigators’ Meeting.
# Statement of Financial Position

**YEAR ENDED JUNE 30,** 2015 | 2014
---|---
## Assets

### Current Assets
- Cash and cash equivalents: $1,473,152 | $2,891,211
- Investment securities: $13,770,534 | $10,766,425
- Accounts receivable: $703,070 | $847,591
- Due from TAP: $5,431 | $4,056
- Other assets: $253,257 | $9,140
- **Total current assets:** $16,205,444 | $14,518,423

### Investment securities — non-current
- $3,994,136 | $3,414,687

### Investment in TAP
- $3,738,200 | $3,488,200

### Property and equipment, net
- $190,246 | $234,951

### Other assets
- $30,135 | $71,293

- **Total assets:** $24,158,161 | $21,727,554

## Liabilities and Net Assets

### Current Liabilities
- Accounts payable and accrued expenses: $1,294,236 | $900,811
- Due to TAP: $2,692 | $1,504
- Due to COPD Foundation: $4,418 | $2,737
- Deferred revenue: $83,500 | $152,000
- **Total current liabilities:** $1,384,846 | $1,057,052

### Net Assets
- **Unrestricted:** $19,418,825 | $17,784,150
- Temporary restricted: $3,354,490 | $2,886,352

- **Total net assets:** $22,773,315 | $20,670,502

### Total liabilities and net assets
- **Total:** $24,158,161 | $21,727,554

## Gross Revenues By Classification

**FOR THE FISCAL YEAR ENDED JUNE 30, 2015**

- AlphaNet: $3,525,000 (33%)
- Other Income: $1,042,764 (10%)
- Restricted Contributions: $3,488,155 (32%)
- Unrestricted Contributions: $2,717,926 (25%)
- **TOTAL:** $10,773,845

## Functional Expenses

**FOR THE FISCAL YEAR ENDED JUNE 30, 2015**

- Alpha-1 Research Network: $4,048,280 (47%)
- Alpha-1 Advocacy: $433,249 (5%)
- Florida Detection Program: $372,843 (4%)
- Administration and general: $754,453 (9%)
- Fund raising: $852,606 (10%)
- Other Alpha-1 Services: $999,013 (12%)
- Alpha-1 Patient Support: $302,472 (3%)
- Alpha-1 Education Days: $300,115 (3%)
- Alpha-1 Registry and ACT Trial: $608,001 (3%)
- **TOTAL:** $8,671,032
### Statement of Activities and Changes in Net Assets

**YEAR ENDED JUNE 30, 2015**

#### Changes in Unrestricted Net Assets

**Unrestricted Support and Revenue**

<table>
<thead>
<tr>
<th>Description</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>$5,631,266</td>
<td>$4,964,860</td>
</tr>
<tr>
<td>Donated shares</td>
<td>8,070</td>
<td>49,983</td>
</tr>
<tr>
<td>Fundraising revenues</td>
<td>603,590</td>
<td>402,706</td>
</tr>
<tr>
<td>Investment income</td>
<td>218,476</td>
<td>2,080,611</td>
</tr>
<tr>
<td>Other income</td>
<td>824,288</td>
<td>501,390</td>
</tr>
<tr>
<td>Net assets released from restriction —</td>
<td></td>
<td></td>
</tr>
<tr>
<td>satisfaction of program restrictions</td>
<td>3,020,017</td>
<td>1,441,512</td>
</tr>
<tr>
<td><strong>Total unrestricted support and revenue</strong></td>
<td>10,305,707</td>
<td>9,441,062</td>
</tr>
</tbody>
</table>

**Unrestricted Expenses**

Program services

<table>
<thead>
<tr>
<th>Description</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha-1 Research Network</td>
<td>4,048,280</td>
<td>2,889,915</td>
</tr>
<tr>
<td>Florida Detection Program</td>
<td>372,843</td>
<td>372,995</td>
</tr>
<tr>
<td>Alpha-1 Registry and ACT Trial</td>
<td>608,001</td>
<td>318,248</td>
</tr>
<tr>
<td>Alpha-1 Education Days</td>
<td>300,115</td>
<td>—</td>
</tr>
<tr>
<td>Alpha-1 Patient Support Network</td>
<td>302,472</td>
<td>—</td>
</tr>
<tr>
<td>Alpha-1 Advocacy</td>
<td>433,249</td>
<td>317,522</td>
</tr>
<tr>
<td>Other Alpha-1 Services</td>
<td>999,013</td>
<td>835,290</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td>7,063,973</td>
<td>4,733,970</td>
</tr>
</tbody>
</table>

Supporting services

<table>
<thead>
<tr>
<th>Description</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>852,606</td>
<td>694,754</td>
</tr>
<tr>
<td>Administration and general</td>
<td>754,453</td>
<td>573,163</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td>1,607,059</td>
<td>1,267,917</td>
</tr>
</tbody>
</table>

**Total unrestricted expenses**                             | 8,671,032 | 6,001,887 |

**Increase in unrestricted net assets**                     | 1,634,675 | 3,439,175 |

#### Changes in Temporarily Restricted Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2015</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>3,488,155</td>
<td>1,540,399</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>(3,020,017)</td>
<td>(1,441,512)</td>
</tr>
<tr>
<td><strong>Increase in temporarily restricted net assets</strong></td>
<td>468,138</td>
<td>98,887</td>
</tr>
</tbody>
</table>

**Increase in net assets**                                   | 2,102,813 | 3,538,062 |

**Net assets, beginning of year**                            | 20,670,502| 17,132,440|

**Net assets, end of year**                                   | $22,773,315| $20,670,502|
A year of growth, expanded services and progress for the Foundation

Fiscal Year 2015, which ran from July 1, 2014 through June 30, 2015, marked a period of growth and accomplishments for the Alpha-1 Foundation. We celebrated our 20th anniversary, merged with the Alpha-1 Association, and launched a new website, among numerous other achievements.

Following the merger, the Foundation expanded its services to include all the programs that were formerly under the umbrella of the Association. Among them are the Alpha-1 Support Groups, whose members provided the critical support for each other that is so important to anyone living with a chronic health condition, and in addition held fundraisers for Alpha-1 research, spoke to nursing students at universities, joined pulmonary health seminars, and shared the rule-it-out message at COPD conferences, among many other activities.

Likewise, Alpha-1 Kids, another former Association organization that is now part of the Foundation, sent parents of Alpha children to sit on several committees — including a key hearing before the U.S. Food and Drug Administration — hosted virtual support group meetings for parents of Alpha kids, and provided a kids room with adult supervision at the July 2015 National Education Conference — a service the group provides year after year — so that parents who attended could get the most out of the event.

Other programs that have become part of the Foundation’s expanded services include Genetic Counseling, Family Awareness, Peer Guide, the Patient Information Line and Access to Care and Reimbursement services.

Educating the Healthcare Professionals — Foundation Support Group and Program Coordinator Barbee Bennington, left, and Support Group Leader Cindy Parsons helped to educate healthcare professionals about Alpha-1 at a National Association for Continuing Education event in Sacramento, CA.

At 2015 Global Patient Congress — the Alpha-1 Global Steering Committee, from left: Karen North, Shane Fitch, Global Director Gonny Gutierrez, Chairman Frank Willersinn, M.D., Gunhil Nørhave, Mimi McPhedran, Catarina Pyrrait and John Walsh. Bianca Coimbra and Steve Knowles are not pictured.
Among the high notes for the Foundation in 2014, Team Alpha-1 brought home five medals from Transplant Games of America, including two gold medals, one silver and two bronze.

In September, a Communications team joined Team Alpha-1 at the Escape to the Cape bike trek, participating in the ride, writing about the event’s history, and capturing it in video and photos.

As it always does, Team Alpha-1’s presence loomed large over the event: Its 63 riders included people with oxygen tanks strapped to their bikes, pedaling uphill again and again with dogged determination, and motivating others to keep riding, too. The team was made up of Alphas, friends and family, researchers, doctors and industry partners from Baxter, CSL Behring, Dohmen Life Science Services and Grifols. For the first time, five Boston University doctors, led by Alpha-1 Clinical Resource Center co-director Andrew Wilson, joined the ride.

As it has every year, Team Alpha-1 won the Silver Spoke award for having the largest number of riders at the event.

In November, we created and regularly updated an Alpha-1 Awareness Month website page with events, awareness suggestions and state proclamations, using social media to encourage awareness activities. We collaborated with the COPD Foundation on content for awareness toolkits.

As part of the Awareness Month activities, John Walsh joined National Heart, Lung, and Blood Institute’s former director James Kiley, M.D., in a World COPD Day radio interview. World COPD Month was also marked in November. The discussion between Walsh and Kiley about COPD was heard on more than 20 U.S. stations. Walsh was also interviewed in the European Lung Foundation’s November newsletter.

In January 2015, we created a month-by-month plan for social media, the website and events to mark the Foundation’s 20th anniversary since its inception as a tiny, three-person and all-volunteer organization opening in donated office space in 1995.

In February, we wished ourselves a Happy Birthday with the first of our monthly stories celebrating the 20th anniversary of the Foundation’s founding on Feb. 3, 1995.

March saw John and Fred Walsh honored with the shillelagh award at the Celtic Connection. The twins, the first non-researchers to receive the shillelagh, joined Bart Celli, M.D. in being honored with the shillelagh, the emblematic cudgel of Ireland.

The University of Miami placed a 7-foot statue of the late UM baseball coach Ron Fraser at Mark Light Field, “the house that Ron built,” in April 2014. Fraser became a legend — both for his many winning teams and his showmanship — while he built the UM Hurricanes into a powerhouse in college baseball during a 30-year career at the school. Fraser and his wife Karen helped to put the Alpha-1 Foundation on the map with its first major fundraisers, featuring stars of the New York Yankees and Miami Marlins, in the late 1990s.

Also in April, we launched our new website, transitioning from the WordPress platform to DNN. We collaborated with Alpha-1 Global on web and social media coverage of the Global Patient Congress and Scientific Conference in Barga, Italy.

The website continued to grow at an impressive rate, overcoming a temporary decline resulting from the changeover to the new site. The site had 28,441 recorded visits in June 2015, a 13% increase over the previous year.

A year of growth, expanded services and progress for the Foundation

Continued
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, 2014 and June 30, 2015.

$2.5 Million or More
AlphaNet, Inc.

$1 Million-$2,499,999
CSSL Behring, L.L.C.
Grifols

$500,000-$999,999
Baxalta

$250,000-$499,999
Dohmen Life Science Services
State of Florida

$100,000-$249,999
The Harry A. Sisson Charitable Trust

$25,000-$99,999
Accredo Health/Express Scripts
BioRx
Michael R. Bloomberg
Ruth and Gordon E. Cadwgan, Jr., Ph.D.
Caram, Inc.
Ruderman Family Charitable Foundation
Diane L. and John W. Walsh, Co-Founder
Toni and Greg White

$10,000-$24,999
Altus One Fund, Inc. – Catherine and Randall J. Weissénburger
Anonymous Donor
Arrowhead Research Corporation
Midge and Greg Bertles
Medical Research Charities
Theresa Mersky
Jean-Marc Quach
Scotiabank
Judith and Kenneth Simon
The William L. Richter Family Foundation

$5,000-$9,999
Barbara and Anthony G. Andrikopoulos
Anonymous Donor
ASD Healthcare
Atlantic Associates, Inc.
Stacy and John Castillo
Community Healthcare Services, Inc.
Joan and Albert “Curts” Cooke
Kathleen and Albert C. Cooke, III
Cynthia M. and Hugh D. Cooley
Karen L. and Ron Fraser
Kim Girards
Cheryl L. and Lawrence P. Glascott, III
Kenneth A. Irvine
Kedron
Preferred Income Partners
Lyle D. Schutte
Anna P. and Laurence B. Simon
Elisabeth and Alan P. Sklar
Marion and Andrew Steele
Steward Health Care System, LLC
Christine Wierland and Robert “Bob” Webster
Dell Witcher and Brunson White

$1,000-$4,999
Arcadia Healthcare Solutions
AT&T United Way Employee Giving Campaign
Charlotte S. Ayers
Paul F. Balser
Bank of America Charitable Foundation
Charlotte S. and Robert C. Barrett
Baxter International Foundation
Kenneth E. Benson
Kathleen Benau
Alan S. Bernstein
Judy Xiao and Kenneth Bonnet, Ph.D.
Brandle, Inc.
Judy Lew, M.D. and Mark L. Brantly, M.D.
Breathless Wines
Bristol-Myers Squibb Company
Richard P. Brooks

B.T. Rocca, Jr. Foundation
Alexander Clarke
Jessica and David Colarusso
Jane-Ellen and Joseph Collins, III
Continental Broadband, LLC/Expedient Datapoint
Allison and Thomas Corron
GSL Behring – Kankakee employees
Cullari Carrico, LLC – Dennis Bartlett
Dearborn Rotary Foundation
Carol and Frank Deford
Lois Desimone
Robin Diamant
James F. Donohue, M.D.
Dorothy and Herbert Dorf
Charles Donway
Jennifer Dunton
Sarah E. “Sally” Everett, Esq.
Mohammad S. Fahim
Nona S. Feltnor
Susan and Donald C. Ferro
Judy and Don W. Flischauer
Joan and Oliver Garry
Kenneth A. Geary, Jr.
Geneia Clinical Care Solutions, LLC
Brandon Godby
Goldman, Sachs & Co.
Matching Gift Program
Igor Gonda, Ph.D.
Grace Jones Richardson Trust – Catharine and Charles MacDonald
Pat F. and Charles B. Griffis
Hillegonda “Gonny” Gutierrez
Danny Harris
Michelle Heffey
William V. Hickey, Jr.
Terri L. and Steven G. Himes
Lauren Doner and Brent Hirt
Marion T. and Larry L. Hoffman
Bridgette Holbrook
Susan and Peter A. Hut
Peg and Peter Iverson
J.S. Sherman & Associates, Inc.
Claudia and Steven H. Jackson
Leslie D. Johnson
Holly and Bruce Johnstone
Deborah H. and Richard C. Keiser
KLS Diversified Asset Management, LP
Miekeleen Koerth
Camille N. and Darrell N. Kotton, M.D.
Christine and Michael J. Krowka, M.D.
Jeffrey C. Kruzel
Christine Lathrop
Kevin Lello
Levin, Bartlett, Swantic & Co.
Austin Locke
Robert Lojewski
Karen and David Maidment
Sandra and R. Paul Maidment
Karlynyne M. Martin
Patricia A. and Joseph E. Masterson
Elizabeth M. McKenna
Kenneth A. McNish
Mary Louise and Henry Moehring
Laine M. Moody
Morgan Stanley c/o Cybergrants, Inc.
Neighbor To Nation
Steve Nelson
Joanne and Terry R. Nickerson
National Organization for Rare Disorders
Michael O’Mara
Pacific Gas & Electric Company
Par 4 Technology Group, LLC
Patient Services, Inc.
Lorena and Larry E. Payne
Peak 10, Inc.
Paul R. Perreault
Sharon Phillips
Plasma Protein Therapeutics Association
Shelley J. Pollock
Barbara Poresky
Barbara J. and David Pusey
Margaret L. and James A. Quill
John R. Raben, Jr.
Vicki and Sidney Rader
Raising Hope for Others
Tui and Joseph M. “Joe” Reidy
Stephen I. Rennard, M.D.
Rolling Prairie Lions Club
Rotary Club of Middletown
Rick Roth
Susan G. Ryan
SA Boney & Associates Company
Dorothea and Robert A. Sandhaus, M.D., Ph.D.
Christopher Sault
Timothy Schieffelin
John Schoolfield
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Audrey M. and L.G. Shorika
Radin and William Spier
William Stark
Stephen McOnahey Family Foundation
Terry and James K. Stoller, M.D., M.S.(Org. Dev.)
Charlie Mathews and Gus Straub
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Patricia and William Tew
The Barrett Group
The Cobb Family Foundation, Inc.
The Harry E. & Bobby H. Ingram Family Foundation
Patricia and Kenneth Thime
The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2014 and June 30, 2015.

In Honor Of

The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2014 and June 30, 2015.

**Honor Gallery**

- The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2014 and June 30, 2015.
- Kenneth E. Benson
- Carole L. Benson
- Grace Bauernfiend
- AlphaNet Coordinators
- Alpha-1 Support Group
- Alpha-1 Foundation Staff
- Clint D. Allison
- Kelly and Kyle Aaronson
- American Express Company and Foundation Matching Gifts Program
- John J. Austin
- Bank of America United Way Campaign
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- Bill & Melinda Gates Foundation Matching Gifts Program
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- Booth Construction, LLC
- Linda and Robert P. Brigance
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- Lisa and Robert C. Gibson
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- Lance R. Helsel
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- Carol M. Hutchinson
- Patricia L. and William A. Jackson
- Michael W. Jedlicka
- Susan G. Johffrin
- Norman K. Johnson
- Jennifer M. and Randy P. Jopp
- Jack Kanfer
- Craig L. Kephart
- Paul C. Kimball
- Sarah A. Emerson and Edward N. Krapelis
- Barbara Kushner
- Jeanne and Brian Kushner
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- Betty J. and Alan E. Liberty
- Steven E. Lindahl
- Karen and Gene L. Lombardo
- Lore Kann Foundation
- Mary C. and James W. Lyle
- Megan L. Lyle
- Adam Marr
- Patsy and Larry Marti
- Angela T. McBride
- Paige McLaren
- Patricia and Robert Meurer
- Kimberly S. Mill
- Richard K. Mill
- Thomas L. Moran
- Joellyn and Darrell J. Nall
- Barbara Nickerson
- Kathy E. and Bruce T. Ogg
- Anuj Patel
- Diana J. and James J. Patterson
- Wendy Becker Payton
- Mary K. and Todd M. Pierce
- Judith A. Piscione and David Palmer
- Linda Parker
- Karen M. Payne
- Janet L. and Harry Pottinger
- Veronika Pozmentier
- Holly and Donovan Quill
- Diana and Franck Rahaghi, M.D.
- Lynne and Gregory J. Raymond
- Lynne E. and Albert W. “Ab” Rees
- Deirdre A. and John L. Richardson
- Virgie Rees Riedl
- Marcia F. Ritchie
- Ruben Roy
- Sheri-Ann Sendzisich and Bruce J. Rubin
- Sherry R. and Mitchell Ruttner
- Leon G. Satkowski
- Shane Smith
- Judy and Gary Sobocinski
- Adam Sonnhalter
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- Pamela and Charlie Strange, M.D.
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- Janice Weppler
- Ann E. Weronke
- Alethe I. Wilkins
- Marlene and Thomas B. Witt
- Judith A. and James E. Workman
- Claudia and D.C. Young
- John C. Young
- Scott Young
- Bradley T. Youngblood
- Theresa J. and Otis H. Youngblood

*Italics denote deceased*
### In Honor Of

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<th>Name</th>
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<td>Barbara Michaelson</td>
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**Italics denote deceased**
Roxanna Nowak
Carole O’Mara
Oliver Family
Sally Parks
Julianna Patterson
Richard Alan Pine
James David Pitts
David M. Pogue, M.D.
Dennis W. Pollock
Charles Poore
Sandy Peggy Porter
Russell G. Post
The Quill Family
Michael Ratner
George William Reamer
Marie Reaume
Neta Dial Recht
Gerardine, Kate, Janice and Stella Reddy
Cecil Ray Redmill
Peggy J. Reese
William F. Reese
Carolyn Richardson
Marilyn “Lyn” Roberts
John Robinson
Terry Robinson
Debbie Bruhn Rogers
Frances Jones Roloff
Mary Beth Roof
Judy K. Rose
Mike Rosella
Edward Roxberry
Edith Jane Rubin
Morton E. Ruderman
Michael J. Rudner
Robert C. Ryan
Christopher Sardzinski
Robert Joseph Savard
Lawrence Schmidt
Allen Schwarz
Jim Schwarz
Gerald “Jerry” Seifert
Joel Shumaker
L. Charles “Chuck” Sidener
Mike Skivington
Lorna Smith
Richard S. Smith
Ronald “Ron” L. Smith
Vicky Smith
Gordon L. Snider, M.D.
James E. Snowden
Davis Snyder
Ann J. Soderstrom
Donna Sommatino
Jerry Spencer, Jr.
Richard Gordon Stanley
Susan Gerrard Stanley, Co-Founder
Mary Ann Stanton
Doris M. Stanton
Charles Steckler
Mary Steckler
Michelle Steckler
Sue Steinmetz
LaVonne “Scottie” Stewart
Marta C. Strock
Randall “Randy” Strock
Norma Suarez
Pat Swanson McQuarrie
Sherry Swanson McMillen
Wini Swanson
Jennifer Tamburro
Joel J. Tartell
Patrick Allen Tenant
Richard L. Teunissen
James W. Thayer, III
Thaker Family
James “Jimmy” Thomas
Kevin M. Treu
Steven Trost
Jill JoAnne Tschirhart
Roslyn Upoff
Cathy Urish
Ken Vickers
Barbara Visser
Ed Von Kattengell
Helen Chase and Jack “Coach” Walsh
Stanley L. Wepking
Howard Werdehoff
Nancy D. Wheeler
Mary Anne White
Michael Wierenga
Doug Willes
Dan Carl Wilkins
Michael Paul Williams, Sr.
Patricia G. Williams
Jim Wiscombe
Lyle Wiscombe
Sam Wiscombe
Brady L. Woessner
Joan Marlowe Wood
Mary Ann Workman
Ronald J. Worshwick
Terry L. Young
William “Bill” E. Young
Anne Zahler
Anne B. Zimmerman
Christopher Zinni
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 Foundation has invested nearly $60 million to support Alpha-1 research and programs at 103 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](http://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](http://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](http://www.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** (1-800-785-3177), 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 chronic 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.

**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 six 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](http://www.alpha1.org). To learn more about these programs, visit [www.alpha1.org](http://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 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 an information line, 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 at 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 as implementation of the Affordable Care Act moves forward.

**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. The bank is not currently accepting new tissue samples. 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 lpearson@alpha1.org or call toll-free 1-877-228-7321 ext. 250.

The **Alpha-1 Clinical Resource Center Network** is a steadily growing group of centers throughout North America that specializes 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 on the Foundation website, www.alpha1.org.

**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.

**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 information on any program, visit www.alpha1.org or call the Foundation toll-free at 877-228-7321.

Alpha-1 Foundation Board Member and researcher Prof. Gerry McElvaney, left, and Adam Wanner, M.D., Foundation Scientific Director, at the 2014 Investigators’ Meeting for winners of Foundation research grants.
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.

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Adam Wanner, M.D. ....................................................... Scientific Director
Robert A. Sandhaus, M.D., Ph.D. ................................. Clinical Director

*Denotes diagnosed Alpha-1 Antitrypsin deficient
+Denotes diagnosed family member