



2023 ANNUAL REPORT



July 1, 2022 - June 30, 2023

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Our Mission



The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by Alpha-1 worldwide. Our initiatives in four main areas- Research, Education/Outreach, Awareness/Fundraising, and Public Policy/Advocacy are paving the way for important discoveries, new therapies, and increased awareness and understanding of this rare genetic condition.

Our accomplishments and accreditations reflect our unparalleled commitment to medical research at its finest: we have invested over \$92 million to support Alpha-1 research and programs at 123 institutions in North America, Europe, South America, the Middle East, and Australia. These innovative, impactful projects have built a solid infrastructure for promoting ongoing research and the development of new therapies. We have also fostered collaborations with investigators throughout the United States and Europe, working closely with the pharmaceutical industry, the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), and Alpha-1 patients and families to push Alpha-1 research forward.

Our work would not be possible without our dynamic community of volunteers, researchers, clinicians, partners and donors - all of whom inspire and empower us every day in our mission to raise awareness and deliver results for those affected by Alpha-1. We are incredibly grateful to our global network of specialists, which spans multiple industries, areas of research, and academic expertise. It is thanks to these innovative and patient-centric groups that we are driving real, positive change.

Alpha-1 Outreach & Education



Our website, www.alpha1.org is a clearinghouse for information on Alpha-1 providing educational resources, highlighting news and upcoming events, and creating opportunities for virtual connection within the global Alpha-1 community.

The website received over 507,000 visits from over 238,131 unique visitors in FY 2023. The Alpha-1 Foundation's website is often the first contact that newly diagnosed Alphas and their family members have with the Foundation and, in many cases, their first source of information about Alpha-1 Antitrypsin Deficiency.

We connect with the Alpha-1 community across multiple social media platforms. In addition to promoting new Foundation initiatives, community education events, and fundraising campaigns, our presence on Facebook (20,409 followers, a 7.5% increase in FY23), Instagram (2,635 followers, a 5.6% increase in FY23), and Twitter has directly increased traffic to our website, where users can access the information they need.

The monthly Community Currents electronic newsletter keeps the Alpha-1 community and volunteer leadership updated on all Alpha-1-related news, upcoming events, research, programs, fundraising activities, and the Alpha-1 Research Registry.

The Alpha-1-to-One Magazine is a valued resource produced three times a year for the Alpha-1 community offering practical advice, personal experiences, and pertinent news for people touched by Alpha-1. In FY 2023, we distributed 32,000 printed copies of each issue, including bundles to Clinical Resource Centers (CRCs) and healthcare providers; each issue is also posted to a digital publishing platform on our website, where it is accessed by nearly 2,000 more visitors a year.



Alpha-1 Advocacy



Our advocates are a voice to improve outcomes for Alpha-1 patients. Together, we are fighting to improve the fact that Alpha-1 is under-recognized, under-diagnosed, and unknown to most people by ensuring our community's priorities are factored into public policy and legislation. Our advocacy program targets policymakers, regulatory agencies, the public, and the media with campaigns to promote research and raise awareness of the challenges faced by Alpha-1 patients and care providers. Our FY 2023 policy priorities included access to care, medical research, therapeutic development, screening and detection, federal and state funding, blood product safety, and education and awareness.

We are working with the 118th Congress to find a solution to the patient access problem facing Medicare beneficiaries who are not able to obtain a home infusion due to Medicare law. The John W. Walsh Alpha-1 Home Infusion Act (H.R. 4438) has been reintroduced by Representative Salazar.

We work strategically with federal agencies, memberships, and coalitions—focusing on the issues that matter most to Alphas—to inform legislators of the burdens of the patient community and to advance our public policy agenda for the benefit of the Alpha-1 community.

Additionally, working closely with the U.S. Food and Drug Administration (FDA), Critical Path Institute (C-Path), and National Institutes of Health (NIH) to determine how best to work collectively to ensure the Alpha-1 community has access to, and approval for, novel treatments and therapies.

Alpha-1 Education Days & Alpha-1 National Conference



The Alpha-1 National Education Series is comprised of regional Alpha-1 Education Days for Alphas, their families, and caregivers. These one-day educational programs provide access to current medical information, timely topics affecting Alphas, resources from leading Alpha-1 experts, and opportunities to connect with the Alpha-1 community.

In 2023, we continued our use of a virtual event platform, enabling those who were unable to attend an Alpha-1 Education Day in person to participate and connect with the Alpha-1 community. Extending our education series into the virtual space has also created community-building and engagement opportunities through more direct access to social media, polls, and surveys.

More than 2,300 people registered for the FY 2023 Alpha-1 Education Days.



The Alpha-1 Foundation National Conference is the largest gathering of the Alpha-1 community, the National Conference provides important opportunities for networking, education, advocacy, and industry publicity. Held in Dallas, Texas, over the course of four days, attendees had access to scientific presentations, meet-and-greet and Q&A sessions with Alpha-1 experts, and other events hosted by sponsors.

The conference empowers the Alpha-1 Community with educational resources and direct support while making informed decisions about their care and take part in Alpha-1 research.

- 600+ Total National conference attendance participation
- 65% of attendees were patients/family members
- 36% first-time attendees to the Alpha-1 National Conference, an increase of 13% over last year

Meetings and Conferences

Scientific meetings and conferences organized by the Alpha-1 Foundation generate awareness of Alpha-1, identify new areas of research interest, and establish the Foundation's credibility within the rare disease community as a resource for serious research, education, and advocacy.

We reach thousands of physicians, academic researchers, and industry partners each year through our exhibitions at major national and international medical conferences, where we share insights into new technologies, research findings, and priority research areas.

The Foundation's scientific meetings and conferences focus on basic, translational, and clinical science of Alpha-1. Meeting and conference participants include academic scientists, physicians, industry, government agencies, other voluntary health organizations and patients.

GORDON L. SNIDER (GLS) CRITICAL ISSUES WORKSHOPS

These single-topic workshops facilitate exchange between experts to answer important questions or stimulate additional investigation and often result in collaborative, field advancing initiatives. The 24th Gordon L. Snider Critical Issues Workshop titled "The Alveolar Macrophage: Role in Lung Destruction and AATD" took place in November 2022 to discuss Alpha-1-related lung disease.

INVESTIGATORS MEETINGS

The Alpha-1 Foundation Investigators Meeting takes place every two years to encourage productive dialogues between the Alpha-1 Foundation research grant recipients and the broader scientific community. The event was held in October 2022 in Miami, FL and joined researchers from around the globe to present their recently funded research to the community.

INTERNATIONAL RESEARCH & PATIENT CONFERENCES

Research focused conferences hosted outside of the United States every two years, bringing together International Alpha-1 experts. Held in Dublin, Ireland in April 2023 the International Research and Patient Conferences joined together Alphas from around the world for a 2-day conference.

CLINICAL RESOURCE CENTER (CRC) FORUMS

Forums that bring together CRCs (Clinical Resource Center) from across the country to foster Alpha-1 awareness and engagement in patient outreach and support programs. Held in October 2022, over 60 physicians from across the nation came together to discuss opportunities to expand outreach and access to specialized care.

ALPHA-1 GRANT AWARDS RECEPTION

In addition to its participation in the exhibits at the American Thoracic Society International Conference, the Foundation hosts an annual Grant Awards Reception to highlight a new chapter for the Foundation's research program. This reception allows the Foundation to officially announce and acknowledge the newly awarded grantees. Held in Washington, D.C. in May 2023.

Alpha-1 Awareness

Annual campaigns help facilitate community support and improved approaches to care.

#Alpha1Awareness- November is Alpha-1 Awareness Month: 30 days of awareness-focused initiatives, through which the Alpha-1 community shares stories and resources while raising funds to support the search for a cure. A dedicated webpage, online training, digital resources, media outreach, community events, and a social media calendar are available throughout November specifically for awareness. The 2022 Alpha-1 Virtual Walks allowed anyone who wanted to make a difference in the Alpha-1 community to contribute in their own style, time, and pace. Over 700 participants tracked miles on STRAVA and raised over \$72,000 for Alpha-1 in just one month.



#RareDiseaseDay - During the month of February, we collaborated with the National Organization for Rare Disorders (NORD) to spread awareness of Alpha-1 on Rare Disease Day. The goal was to get patients interested and involved in rare disease research.

Our Building Friends for a Cure (BFC) community fundraisers are designed to increase awareness and promote research. Support from the Alpha-1 community is a critical component of our goal to raise awareness of the disease and treatment options. Through the BFC program, we steward relationships with donors to boost awareness of Alpha-1 and get the community involved in working towards a cure.

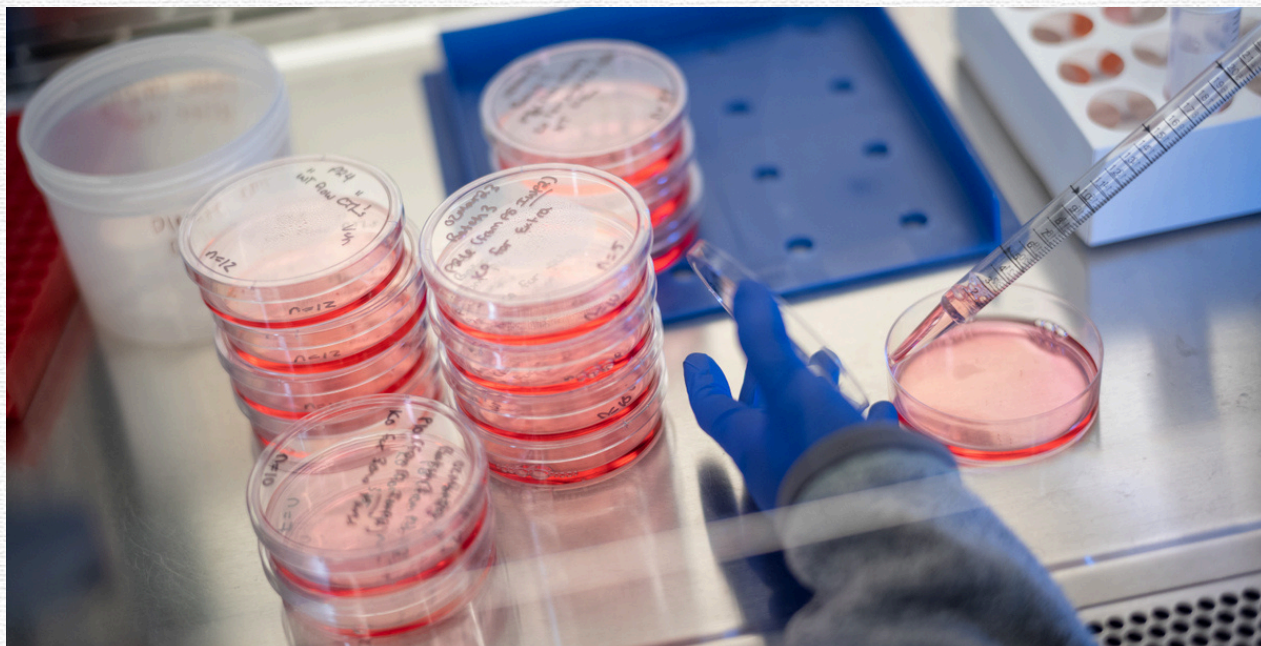


Building Friends for a Cure consisted of a series of community fundraising events this year in support of Alpha-1 research, including:

- Riding for a Reason
- Escape to the Cape
- Alpha-1 Virtual Walks
- Celtic Connection
- Walks, Run, and Marathons
- Alpha Hours
- Climbs and Hikes
- Video Game Streaming Marathons
- Golf Tournaments



Alpha-1 Funded Research



The Alpha-1 Foundation directed more than \$2 million in peer-reviewed research grants in FY 2023. These grants support innovative research spanning the spectrum of scientific discovery. The Foundation prides itself on being the #1 funders in Alpha-1 research having invested over \$90 million at 128 institutions in 14 countries worldwide. Research funded by the Alpha-1 Foundation has improved our understanding of the mechanisms underlying the clinical manifestations of Alpha-1 and identified novel drug targets likely to lead to new therapeutic solutions.

The Foundation is proud to announce its in-cycle grant awardees for 2023, with 10 grant recipients receiving over \$1.7 million for their projects. Of this year's grant recipients' fields of study, 40 % were lung focused, 40 % were liver-focused and 20 % were focused in both areas.

This year for the first time the Ab Rees Fast Track Grants were awarded to four awardees to fund the preliminary work needed to apply for ancillary funds from the NOH or the Alpha-1 Foundation for the A1BC Study. The Alpha-1 Biomarkers Consortium study, funded by the NOH, was created to identify and characterize biomarkers in Alpha-1 that are needed to advance a cure for this disease.

Statement of Financial Position

Current Assets	2023	2022
Cash and cash equivalents	\$1,936,698	\$12,721,008
Investment securities	\$25,766,066	\$16,856,371
Accounts receivable	\$949,746	\$675,117
Other current assets	\$86,986	\$167,500
Total Current Assets	\$28,739,496	\$30,419,996
Investment securities- non-current	\$8,899,050	\$5,039,394
Property and equipment, net	\$9,752	\$12,983
Other assets	\$25,000	\$25,000
Total assets	\$37,663,298	\$35,497,373
Current Liabilities	2023	2022
Accounts payable and accrued expenses	\$877,846	\$1,021,750
Refundable advances	\$397,500	\$505,000
Deferred revenue	\$164,000	\$210,000
Total current liabilities	\$2,157,832	\$2,624,477
Net Assets	2023	2022
Without donor restrictions	\$33,095,472	\$29,569,884
With donor restrictions	\$2,409,994	\$3,303,012
Total net assets	\$35,505,466	\$32,872,896
Total liabilities and net assets	\$37,663,298	\$35,497,373

Statement of Activities & Changes in Net Assets

Changes in Unrestricted Net Assets Unrestricted Support and Revenue	2023	2022
Contributions, bequests and grant revenues	\$6,312,869	\$6,211,034
Donated securities	\$36,252	-
Fundraising revenues	\$155,204	\$49,150
Net realized and unrealized investment (losses)/gains	\$1,630,763	(\$3,296,404)
Interest and dividends	\$690,915	\$465,634
In-kind rental income	\$215,000	\$210,000
Milestone payments under collaborative agreements	-	\$475,000
Net assets released from restriction- satisfaction of program restrictions	\$2,749,089	\$2,447,606
Other Income	\$377,140	\$374,788
Total support/revenue without donor restrictions	\$12,167,232	\$6,936,808
Unrestricted Expenses	2023	2022
Research and Clinical Studies	\$4,109,175	\$3,450,654
Patient Education	\$2,226,810	\$1,197,628
Patient Advocacy	\$747,329	\$429,678
Total program services	\$7,198,364	\$5,297,145
Administrative and general	\$620,463	\$555,657
Fund raising	\$822,817	\$628,414
Total supporting services	\$1,443,280	\$1,184,071
Total unrestricted expenses	\$8,641,644	\$6,481,216
Increase in unrestricted net assets	\$3,525,588	\$455,592
Changes in Temporary Restricted Net Assets	2023	2022
Contributions, bequests and grant revenues	\$1,856,071	\$2,629,096
Net assets released from restriction	(\$2,749,089)	(\$2,447,606)
(Decrease) Increase in temporarily restricted net assets	(893,018)	\$181,490
Increase in net assets	\$2,632,570	\$637,082
Net assets, beginning of year	\$32,872,896	\$32,235,814
Net assets, end of year	\$35,505,466	\$32,872,896

Programs and Services

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 \$91 million to support Alpha-1 research and programs at more than 123 institutions in North America, Europe, the Middle East, and Australia.

The Alpha-1 Research Registry is a confidential database of people with Alpha-1 (Alphas) and Alpha-1 carriers. It is a resource for investigators seeking Alphas to participate in clinical trials, surveys, and other scientific and medical activities. For more information, email alpha1registry@alpha1.org or call toll-free 1-877-228-7321 ext. 252. <https://www.alpha1.org/alphas-friends-family/resources/participate-in-research/>.

Alpha-1 Coded Testing provides free, confidential testing administered through a research study that evaluates the perceived risks and benefits of genetic testing. For more information, email alphalab@alphaone.ufl.edu or call toll-free 1-855-476-1227 <https://www.alpha1.org/healthcare-providers/testing-and-treatment/alpha-1-coded-testing-study/>.

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 alf.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 1-855-476-1227, based at the University of Florida, is a free and confidential service that provides direct contact with a genetic counseling service 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. <https://www.alpha1.org/alphas-friends-family/support/genetic-counseling/>

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 Joy Collins at jcollins@alpha1.org or call 1-877-228-7321 ext. 251. <https://www.alpha1.org/alphas-friends-family/resources/oxygen-resources/>

Patient Education Programs include an annual National Education Conference which brings together over 600 Alphas, caregivers, industry representatives, clinicians, allied healthcare workers, and scientists to discuss a wide range of Alpha-1-related topics. For more information, visit alf.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 alf.org/educationdays. Recordings of these events are available via E-Education at alf.org/education-videos.

Programs and Services

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 and related programs which will ultimately lead to a cure for Alpha-1. By becoming involved in fundraising efforts, such as virtual events, letter-writing campaigns, and other social and sporting events, you are making a difference. 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 Cathey Henderson at chenderson@alpha1.org.

Educational resources about Alpha-1 and related topics are available for Alphas, their families, caregivers, and healthcare providers. Informational brochures such as 'What is Alpha-1?', 'Am I an Alpha Carrier?', 'The Liver and Alpha-1', and 'It's All In The Family: Family Testing' are available to download and order through our website, a1f.org/a1-publications, or by calling toll-free 1-877-228-7321 ext. 251. The Alpha-1 to One Magazine is published three times a year and includes timely articles about Alpha-1 research and Alpha life, as well as answers from Alpha-1 experts to questions from the Alpha-1 Community. Join the mailing list here at alpha1.org/alphas-friends-family/resources/join-mailing-list/ to receive the magazine. Presentations from previous Alpha-1 educational events are available via E-Education at a1f.org/education-videos.

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, contact Jeanne Kushner at jkushner@alpha1.org or call 1-877-228-7321 ext. 204 or visit a1f.org/action-alert.

Grants and Awards: The Foundation's peer-reviewed grants program is intended to promote research that will lead to improved health for Alphas and ultimately, find a cure. We offer grants for both basic science and clinical research. For more information, contact Vanessa Valencia at vvalencia@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 Vanessa Valencia at vvalencia@alpha1.org or call 1-877-228-7321 ext. 242. For other information, call toll-free 1-866-284-2708.

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

Programs and Services

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

Scientific Meetings, Conferences, Workshops, Working Groups, and Symposia

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

The Alpha-1 Global Initiative works on a global, national, and local level to enhance care and support for all those affected by Alpha-1. The Foundation is committed to providing reliable resources and information worldwide. As part of the Global Alpha-1 Initiative, the Foundation is creating new tools focusing on connecting Alphas all over the world with resources – and with each other. For more information, visit alpha1global.org, contact Randel Plant at rplant@alpha1.org, or call 1-877-228-7321 ext. 306.

Access and Reimbursement: The Alpha-1 Foundation is committed to providing the tools and resources necessary to assist Alphas in making informed decisions about their healthcare plan and assistance program selection. Patients with questions or issues concerning access or reimbursement should contact Cathey Henderson at 1-800-245-6809 or chenderson@alpha1.org. <https://www.alpha1.org/alphas-friends-family/resources/assistance-organizations/>

The Clinical Trial Outreach and Education Program is an online tool used to educate Alphas about clinical trials with curated educational materials for Alpha-1. For more information, visit <https://www.alpha1.org/alphas-friends-family/resources/clinical-trials/> or contact Alison Keaveny at akeaveny@alpha1.org or call 1-877-228-7321 ext. 206.

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 several 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, 2022 and June 30, 2023.

\$1 Million - \$2,499,999

AlphaNet, Inc.
CSL Behring, L.L.C.
Grifols
Takeda Pharmaceutical Company

\$250,000 - \$499,999

Inhibrx, Inc.

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Janie Trimble
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Wave Life Sciences

\$10,000 - \$24,999

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Lyle D. Schutte
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Honor Gallery

\$1,000 - \$4,999

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Anonymous Donors
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Honor Gallery

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The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2022 and June 30, 2023.

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The Alpha-1 Foundation has invested over \$91 million to support Alpha-1 research and programs at 123 institutions in North America, Europe, the Middle East, and Australia.

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