



2025 ANNUAL REPORT



July 1, 2024 - June 30, 2025

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A1F Mission



The Alpha-1 Foundation (A1F) is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and improving the lives of people affected by Alpha-1 worldwide. During FY2025, A1F advanced its mission through continued investment in research, expanded education and patient support, strengthened advocacy, and increased engagement across the Alpha-1 community. These efforts reflected A1F's commitment to transforming the patient journey and accelerating progress toward a cure.

A1F served as a leading global resource for education, advocacy, research, and support focused on Alpha-1. During FY2025, its programs expanded knowledge, improved detection, strengthened patient care, and supported the development of new therapies. Through collaboration with researchers, clinicians, industry partners, government agencies, patients, and families, A1F advanced innovative approaches to research and care.

The strength of this work came from the dedicated community of patients, volunteers, clinicians, researchers, partners, and donors who contributed their expertise, resources, and passion to the mission. Together, this community expanded knowledge, advanced therapies, and delivered meaningful impact.

As A1F marked its 30-year milestone, A1F looked ahead, guided by insight into patient needs, innovation across research and care, investment in groundbreaking science, and measurable impact for patients and families worldwide.

Alpha-1 Outreach & Education

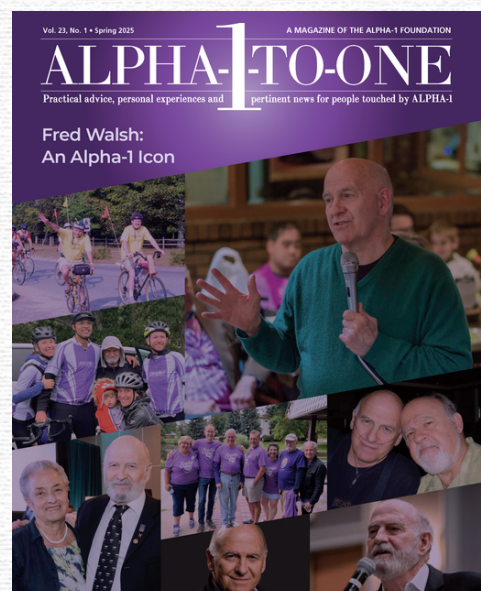


A1F's website, alpha1.org, served as a central hub for educational resources, community engagement, and information for patients, families, caregivers, healthcare providers, researchers, and partners around the world. In FY2025, the website received 499,000 total views, including more than 112,000 visits to the homepage and more than 12,000 visits related to liver disease. Frequently visited resources included information about Alpha-1, testing and diagnosis, and finding an Alpha-1 specialist.

A1F also expanded its digital outreach through targeted interest groups, Google Ad Grants, search engine optimization, and increased engagement on LinkedIn. These efforts helped connect individuals with information and resources relevant to their needs and strengthened A1F's reach across the Alpha-1 community.

The Alpha-1-To-One Magazine remained one of the community's most valued resources, providing research updates, patient stories, advocacy information, and practical resources. In FY2025, more than 32,500 printed copies were distributed per issue, with three issues published during the year. The publication also reached readers digitally through alpha1.org.

A1F also redesigned its educational brochures and refreshed Community Currents, its monthly e-newsletter. Community Currents added 11,599 new subscribers, a 36% increase from the beginning of FY2025, reaching 32,312 subscribers by June 30, 2025.



Alpha-1 Advocacy



A1F advocates served as a powerful voice for improving outcomes and advancing the priorities of people affected by Alpha-1. Through patient engagement, legislative advocacy, and collaboration with policymakers and federal agencies, A1F worked to address barriers to healthcare access, detection, treatment, and research.

In FY2025, A1F focused on improving access to care and essential therapies, including telehealth, home infusion, supplemental oxygen, and other services important to people living with Alpha-1. A1F supported the reintroduction of the John W. Walsh Alpha-1 Home Infusion Act (H.R. 2343), which would allow Medicare beneficiaries with Alpha-1 to receive essential augmentation infusions in their homes.

A1F also advocated for the Supplemental Oxygen Access Reform (SOAR) Act of 2025 (H.R. 2902 and S. 1406), which seeks to improve access to supplemental oxygen, update payment policies, and protect beneficiary choice. These efforts reflected A1F's commitment to ensuring that patients had access to the care and therapies they needed.

A1F continued working with the U.S. Food and Drug Administration (FDA), National Institutes of Health (NIH), and Critical Path Institute (C-Path) to advance collaboration around clinical research, patient needs, and the development and approval of novel treatments and therapies.



A1F Education Days & A1F National Conference



The A1F National Education Series included regional A1F Education Days for Alphas, their families, and caregivers. In FY2025, A1F Education Days were held in Phoenix, Arizona; Omaha, Nebraska; Detroit, Michigan; St. Paul, Minnesota; and Charleston, South Carolina, in addition to a virtual Education Day. These programs provided access to current medical information, timely topics affecting the Alpha-1 community, resources from leading experts, and opportunities to connect with others who shared similar experiences. A total of 1,114 people attended A1F Education Days, with 74% patients and family members and 18% first-time attendees.

In FY2025, A1F continued offering virtual participation, expanding access for individuals unable to attend in person. The virtual platform also provided additional opportunities for engagement through social media, polls, surveys, and other tools that helped A1F better understand community needs.



The A1F National Conference remained the largest annual gathering of the Alpha-1 community, bringing together patients, families, caregivers, clinicians, researchers, and industry partners for education, networking, advocacy, and engagement. The conference provided access to scientific presentations, discussions with Alpha-1 experts, and opportunities to connect with the broader community and learn about advances in research and care.

The 2025 conference welcomed 834 attendees both in person in Miami, Florida and virtually. Eighty-four percent were patients and family members, while 33% were first-time attendees. In-person attendance increased by 9% compared with 2024, reflecting continued strong engagement across the Alpha-1 community.

Meetings and Conferences

Scientific meetings and conferences organized and supported by AIF generated awareness of Alpha-1, identified emerging areas of research, and strengthened collaboration across the rare disease community. These gatherings brought together academic researchers, physicians, industry representatives, government agencies, voluntary health organizations, and patients to share knowledge and advance the understanding and treatment of Alpha-1.

The 7th Global Research Conference, held April 4, 2025, in Lisbon, Portugal, brought together the worldwide Alpha-1 research community to strengthen partnerships and accelerate progress toward a cure. The conference featured expert-led sessions focused on both liver and lung disease, highlighting novel treatment paradigms and emerging approaches to Alpha-1 research.



PROFESSIONAL MEETINGS & CONFERENCES

AIF also participated in major professional meetings, including the American Thoracic Society (ATS) International Congress, European Respiratory Society (ERS) International Congress, American Association for Respiratory Care (AARC) Congress, American Association for the Study of Liver Diseases (AASLD) Annual Meeting, and NIH Rare Disease Day. Through these meetings, AIF shared research findings, emerging technologies, and priority areas with physicians, researchers, and industry partners.



Alpha-1 Awareness

Annual awareness campaigns and community fundraising activities helped strengthen the Alpha-1 community, increase understanding of Alpha-1, and generate support for research and programs. November was Alpha-1 Awareness Month, providing an opportunity for the community to share stories, educational resources, and information about Alpha-1 while encouraging participation in the search for a cure.

The Building Friends for a Cure (BFC) program continued to be an important source of community engagement and fundraising. During FY2025, Alphas, family members, friends, researchers, industry professionals, and healthcare providers participated in events and initiatives supporting A1F's mission.

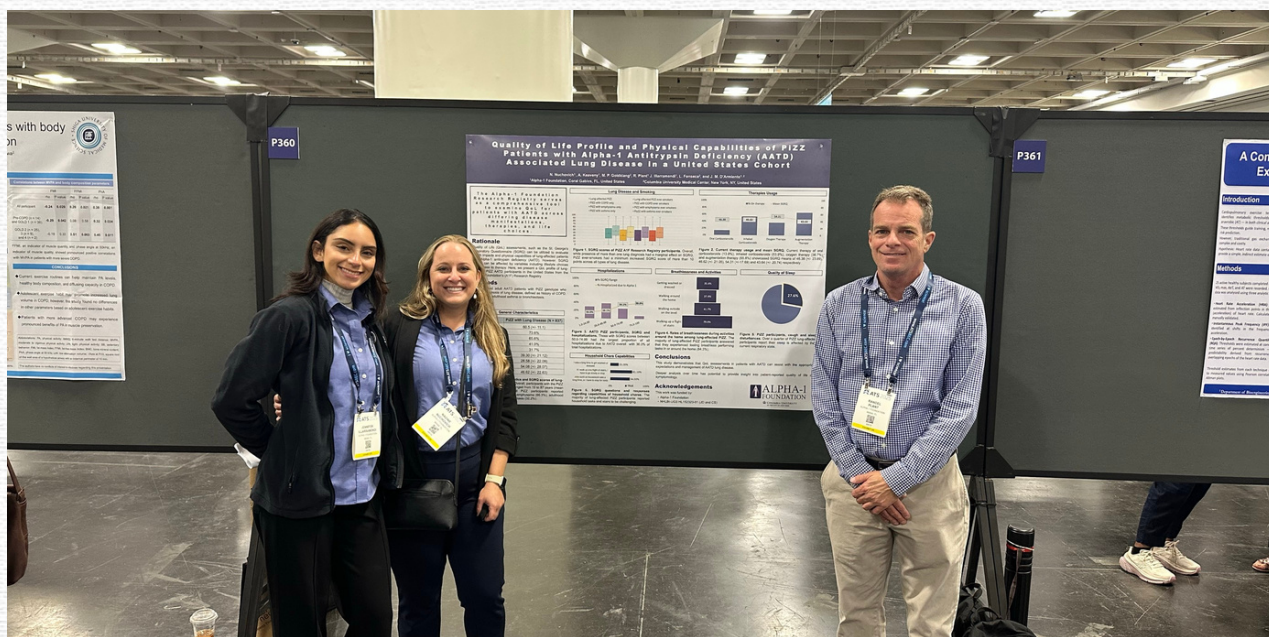


Community fundraising activities included A1F Riding for a Reason, Escape to the Cape, A1F Virtual Walks, Celtic Connection, Extreme Sports, local events, and youth activities. These events gave individuals and families opportunities to support Alpha-1 research while building connections within the community.

FY2025 also brought new opportunities to engage supporters. The launch of Ice Cream for Alpha-1 provided families and friends with a fun and accessible way to raise awareness and funds, while Cruising for a Cure on Lake Norman demonstrated the impact of community-led fundraising. Together, these initiatives strengthened relationships with donors and volunteers while helping advance A1F's mission to increase awareness, support research, and find a cure.



Alpha-1 Funded Research



A1F continued to make significant investments in research aimed at understanding Alpha-1, identifying new therapeutic targets, and advancing potential treatments. In FY2025, A1F directed more than \$3.8 million in peer-reviewed research grants, supporting innovative projects across 130 institutions in 14 countries. By the end of FY2025, A1F had invested more than \$100 million in Alpha-1 research, making it the world's leading funder dedicated to Alpha-1 research.

A1F-funded research spanned the full spectrum of scientific discovery, from basic research into disease mechanisms to translational studies focused on developing new approaches to treatment. These investments helped advance understanding of Alpha-1 and identified potential therapeutic strategies that could improve outcomes for patients.

During FY2025, A1F supported 19 in-cycle grant recipients, including 11 research grants, four Pilot and Feasibility grants, and four postdoctoral research fellowship grants. The projects addressed a wide range of questions related to Alpha-1 biology, disease progression, biomarkers, treatment approaches, and patient outcomes.

Research supported by A1F continued to build the scientific foundation needed to move promising discoveries toward clinical application. By investing in researchers and emerging ideas, A1F strengthened the Alpha-1 research pipeline and helped accelerate progress toward better treatments and, ultimately, a cure.

A1F GRANT AWARDS RECEPTIONS

A1F also hosted Grant Awards Receptions to recognize researchers receiving new Alpha-1 research funding. These gatherings brought together Alphas, physicians, researchers, and industry partners and celebrated the scientists whose work was helping move the field closer to a cure. In FY2025, A1F hosted a Grant Awards Reception in San Francisco, California, on May 19, 2025, during the American Thoracic Society (ATS) International Conference.

Statement of Financial Position

Current Assets	2025	2024
Cash and cash equivalents	\$2,994,966	\$2,312,462
Investment securities	\$34,857,461	\$29,723,852
Accounts receivable	\$498,946	\$921,723
Other current assets	\$171,451	\$195,920
Total Current Assets	\$38,522,914	\$33,153,957
Investment securities- non-current	\$8,760,437	\$11,275,694
Property and equipment, net	\$147,738	\$10,705
Other assets	\$25,000	\$25,000
Total assets	\$47,456,089	\$44,465,356
Current Liabilities	2025	2024
Accounts payable and accrued expenses	\$1,419,516	\$1,001,601
Refundable advances	\$202,500	\$412,500
Deferred revenue	\$613,333	\$227,333
Grants Payable	\$1,193,830	\$941,034
Total current liabilities	\$2,582,468	\$2,582,468
Net Assets	2025	2024
Without donor restrictions	\$41,418,273	\$39,896,406
With donor restrictions	\$2,608,637	\$1,986,482
Total net assets	\$44,026,910	\$41,882,888
Total liabilities and net assets	\$47,456,089	\$44,465,356

Statement of Activities & Changes in Net Assets

Changes in Unrestricted Net Assets Unrestricted Support and Revenue	2025	2024
Contributions, bequests and grant revenues	\$6,868,381	\$7,000,563
Donated securities	–	\$354,410
Fundraising revenues	\$287,375	\$334,116
Net realized and unrealized investment (losses)/gains	\$4,431,090	\$5,783,087
Interest and dividends	\$974,402	\$939,909
In-kind rental income	\$230,000	\$222,500
Milestone payments under collaborative agreements	-	–
Net assets released from restriction- satisfaction of program restrictions	\$2,379,380	\$2,073,110
Other Income	\$468,844	\$380,247
Total support/revenue without donor restrictions	\$15,639,472	\$17,087,942
Unrestricted Expenses	2025	2024
Research and Clinical Studies	\$7,509,268	\$5,589,726
Patient Education	\$3,768,790	\$2,615,585
Patient Advocacy	\$693,362	\$442,874
The Alpha-1 Project	\$13,189	\$14,753
Total program services	\$11,984,609	\$8,662,938
Administrative and general	\$883,044	\$632,669
Fund raising	\$1,249,952	\$991,401
Total supporting services	\$2,132,996	\$1,624,070
Total unrestricted expenses	\$14,117,605	\$10,287,008
Increase in unrestricted net assets	\$1,521,867	\$6,800,934
Changes in Temporary Restricted Net Assets	2025	2024
Contributions, bequests and grant revenues	\$3,001,535	\$1,649,598
Net assets released from restriction	(\$2,379,380)	(\$2,073,110)
Change in Net Assets with Donor Restrictions	622,155	(\$423,512)
Increase in net assets	\$2,144,022	\$6,377,422
Net assets, beginning of year	\$41,882,888	\$35,505,466
Net assets, end of year	\$44,026,910	\$41,882,888

Honor Gallery

AIF's Honor Gallery salutes the individuals, corporations, and foundations that share AIF's commitment to finding a cure for Alpha-1 and to improving the lives of people affected by Alpha-1 worldwide. AIF gratefully welcomes several new members who have supported our mission for the first time through their generous contributions.

AIF also 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, 2024, and June 30, 2025.

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The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2024 and June 30, 2025.

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The Alpha-1 Foundation (A1F) 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.

A1F has invested over \$100 million to support Alpha-1 research and programs at 130 institutions in North America, Europe, the Middle East, and Australia.

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