



2024 ANNUAL REPORT



July 1, 2023 - June 30, 2024

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Our Mission



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. In FY2024, A1F experienced significant success and unprecedented engagement within the Alpha-1 community, from record-setting attendance at A1F Education Days and the A1F National Conference, to revitalizing its support group network, reaching \$100 million in Alpha-1 research funding, and advancing support for the John W. Walsh Home Infusion Act. All of these efforts strengthen the Alpha-1 patient journey and reinforce A1F's global leadership in education, advocacy, content, and support.

A1F is the leading source of information and resources focused on Alpha-1 and supports programs that expand the boundaries of existing data, detection, and patient services. These innovative and impactful initiatives have built a strong infrastructure for promoting ongoing research and the development of new therapies. A1F has 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 advance Alpha-1 research.

The dynamic and engaged community of volunteers, researchers, clinicians, partners, and donors makes A1F's work possible. Their dedication inspires and empowers A1F every day in its mission to raise awareness of Alpha-1 and deliver meaningful results for those affected by the condition. A1F is deeply grateful to its global network of specialists who provide Alpha-1 patient care — a network that spans multiple industries, research areas, and academic disciplines. Thanks to these innovative and patient-centered partners, A1F is driving real, positive change for the Alpha-1 community.

Alpha-1 Outreach & Education



A1F's website, alpha1.org, serves as a comprehensive hub for educational resources, community engagement, and up-to-date information for the diverse audiences connected to its mission.

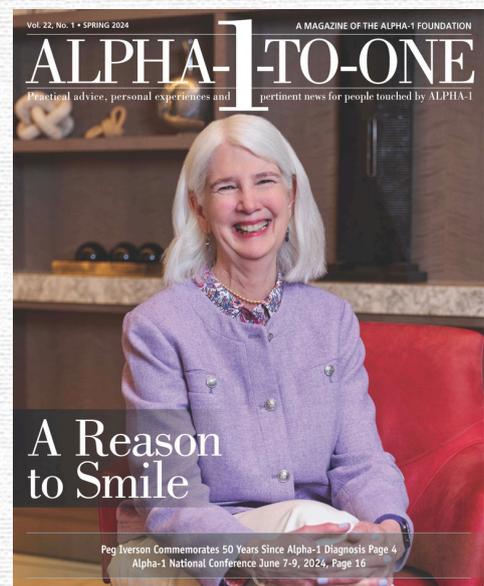
In FY2024, the website received more than 467,000 visits, including 70,594 visits to the homepage. For many newly diagnosed individuals with Alpha-1 and their family members, the A1F website is often their first point of contact and their initial source of information about Alpha-1 Antitrypsin Deficiency.

A1F connects with the Alpha-1 community across multiple social media platforms. In addition to promoting new initiatives, community education events, and fundraising campaigns, A1F's presence on Facebook, Instagram, X, and LinkedIn has directly increased traffic to the website, where users can access the information they need.

The A1F Community Currents monthly e-newsletter provides timely updates on upcoming programs and events, fundraising activities, and research initiatives, including 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 stories, and relevant news for individuals and families affected by Alpha-1.

In FY2024, A1F distributed 32,500 printed copies of each issue, including bundles sent to Clinical Resource Centers (CRCs) and healthcare providers. Each issue is also published digitally on the A1F website, where it is accessed by nearly 2,000 additional visitors annually.



Alpha-1 Advocacy



AIF advocates serve as a powerful voice for improving outcomes for Alpha-1 patients. Together, they work to address the fact that Alpha-1 remains under-recognized, under-diagnosed, and unfamiliar to much of the public by ensuring that the community's priorities are reflected in public policy and legislation. AIF's advocacy program engages policymakers, regulatory agencies, the public, and the media through campaigns that promote research and raise awareness of the challenges faced by Alpha-1 patients and care providers. FY2024 policy priorities included access to care, medical research, therapeutic development, screening and detection, federal and state funding, blood product safety, and education and awareness.

In FY2024, AIF continued its work with the 118th Congress to secure co-sponsors for the John W. Walsh Alpha-1 Home Infusion Act (H.R. 4438), which would allow Medicare beneficiaries living with Alpha-1 to receive essential augmentation infusions at home.

AIF also works strategically with federal agencies, membership organizations, and coalitions—focusing on the issues that matter most to the Alpha-1 community—to inform legislators about the burdens faced by patients and to advance public policy initiatives that benefit individuals affected by Alpha-1.

Additionally, AIF works closely with the U.S. Food and Drug Administration (FDA), the Critical Path Institute (C-Path), and the National Institutes of Health (NIH) to determine how best to collaborate in ensuring that the Alpha-1 community has access to, and approval for, novel treatments and therapies.



AIF Education Days & AIF National Conference



The AIF National Education Series is comprised of regional AIF 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 2024, AIF continued its use of a virtual event platform, enabling individuals who were unable to attend an AIF Education Day in person to participate and engage with the Alpha-1 community. Expanding the education series into the virtual space has also created new opportunities for community-building and engagement through enhanced access to social media, polls, and surveys.

More than 1,040 people registered for the FY2024 AIF Education Days; 71% were patients and family members, and 31% were first-time attendees.



The AIF National Conference is the largest annual gathering of the Alpha-1 community and provides important opportunities for networking, education, advocacy, and industry engagement. Held in Miami, Florida over the course of four days, the conference offered attendees access to scientific presentations, meet-and-greet and Q&A sessions with Alpha-1 experts, and a variety of sponsor-hosted events.

The conference empowers the Alpha-1 community by providing educational resources and direct support, helping attendees make informed decisions about their care and participate in Alpha-1 research.

- 811 Total National conference attendance participation in-person & virtually
- 75% of attendees were patients & family members, a 10% increase over 2023
- 37% first-time attendees to the AIF National Conference, an increase of 30% over last year

Meetings and Conferences

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

AIF reaches thousands of physicians, academic researchers, and industry partners each year through its exhibitions at major national and international medical conferences, where the organization shares insights into new technologies, research findings, and priority research areas.

AIF's scientific meetings and conferences focus on the basic, translational, and clinical science of Alpha-1. Participants include academic scientists, physicians, industry representatives, government agencies, voluntary health organizations, and patients.



GORDON L. SNIDER (GLS) CRITICAL ISSUES WORKSHOPS

These single-topic workshops facilitate expert exchange to address important scientific questions, stimulate further investigation, and often lead to collaborative, field-advancing initiatives. The 25th Gordon L. Snider Critical Issues Workshop, titled “Z Variant Heterozygosity: Disease Risk and Treatment Implications,” took place in October 2023 in Bethesda, Maryland. The 26th Gordon L. Snider Critical Issues Workshop, titled “Pragmatic Solutions to Clinical Trial Endpoints for Lung Diseases in AATD, and AAT Variant Nomenclature,” was held in March 2024 in Coral Gables, Florida.



AIF GRANT AWARDS RECEPTION

In addition to participating in the exhibits at the American Thoracic Society International Conference, AIF hosts an annual Grant Awards Reception to highlight a new chapter in its research program. This event provides an opportunity to officially announce and recognize newly awarded grantees. The 2024 reception was held in San Diego, California in May.

Alpha-1 Awareness

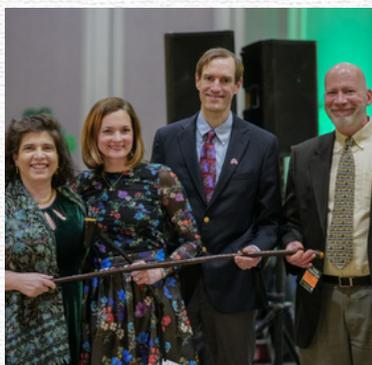
Annual campaigns help facilitate community support and improved approaches to care.

#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 2023 A1F Virtual Walks, themed “Make Your Move for Alpha-1,” allowed anyone who wanted to make a difference in the Alpha-1 community to contribute in their own style, time, and pace. Over 885 participants on 75 teams from around the country raised more than \$78,000 for Alpha-1 in just one month.



#RareDiseaseDay - During the month of February, A1F collaborated with the National Organization for Rare Disorders (NORD) to spread awareness of Alpha-1 on Rare Disease Day. The goal was to encourage patients to become 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 efforts to raise awareness of the disease and available treatment options.

Through the BFC program, A1F stewards relationships with donors to boost awareness of Alpha-1 and encourage community involvement in working toward 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
- A1F Virtual Walks
- Celtic Connection
- Extreme Sports (hiking, mountain climbing)
- Local Fun Events
- Youth Events (Baseball Tournaments)

Alpha-1 Funded Research



The Alpha-1 Foundation directed more than \$3.5 million in peer-reviewed research grants in FY2024. These grants support innovative research spanning the full spectrum of scientific discovery. The Foundation prides itself on being the leading funder of Alpha-1 research, having invested more than \$100 million at 130 institutions worldwide. Research funded by the Alpha-1 Foundation has improved understanding of the mechanisms underlying the clinical manifestations of Alpha-1 and has identified novel drug targets that are likely to lead to new therapeutic solutions.



The Foundation is proud to announce its in-cycle grant awardees for 2024, with 19 recipients receiving more than \$3.5 million for their projects. This represents a doubling of the number of grant recipients compared to FY23. This year's awards consisted of eleven research grants, four pilot and feasibility grants, and four postdoctoral research fellowship grants.

Statement of Financial Position

Current Assets	2024	2023
Cash and cash equivalents	\$2,312,462	\$1,936,698
Investment securities	\$29,723,852	\$25,766,066
Accounts receivable	\$921,723	\$949,746
Other current assets	\$195,920	\$86,986
Total Current Assets	\$33,153,957	\$28,739,496
Investment securities- non-current	\$11,275,694	\$8,899,050
Property and equipment, net	\$10,705	\$9,752
Other assets	\$25,000	\$25,000
Total assets	\$44,465,356	\$37,663,298
Current Liabilities	2024	2023
Accounts payable and accrued expenses	\$1,001,601	\$877,846
Refundable advances	\$412,500	\$397,500
Deferred revenue	\$227,333	\$164,000
Grants Payable	\$941,034	\$718,486
Total current liabilities	\$2,582,468	\$2,157,832
Net Assets	2024	2023
Without donor restrictions	\$39,896,406	\$33,095,472
With donor restrictions	\$1,986,482	\$2,409,994
Total net assets	\$41,882,888	\$35,505,466
Total liabilities and net assets	\$44,465,356	\$37,663,298

Statement of Activities & Changes in Net Assets

Changes in Unrestricted Net Assets Unrestricted Support and Revenue	2024	2023
Contributions, bequests and grant revenues	\$7,000,563	\$6,312,869
Donated securities	\$354,410	\$36,252
Fundraising revenues	\$334,116	\$155,204
Net realized and unrealized investment (losses)/gains	\$5,783,087	\$1,630,763
Interest and dividends	\$939,909	\$690,915
In-kind rental income	\$222,500	\$215,000
Milestone payments under collaborative agreements	-	-
Net assets released from restriction- satisfaction of program restrictions	\$2,073,110	\$2,749,089
Other Income	\$380,247	\$377,140
Total support/revenue without donor restrictions	\$17,087,942	\$12,167,232
Unrestricted Expenses	2024	2023
Research and Clinical Studies	\$5,589,726	\$4,109,175
Patient Education	\$2,615,585	\$2,226,810
Patient Advocacy	\$442,874	\$747,329
The Alpha-1 Project	\$14,753	\$115,050
Total program services	\$8,662,938	\$7,198,364
Administrative and general	\$632,669	\$620,463
Fund raising	\$991,401	\$822,817
Total supporting services	\$1,624,070	\$1,443,280
Total unrestricted expenses	\$10,287,008	\$8,641,644
Increase in unrestricted net assets	\$6,800,934	\$3,525,588
Changes in Temporary Restricted Net Assets	2024	2023
Contributions, bequests and grant revenues	\$1,649,598	\$1,856,071
Net assets released from restriction	(\$2,073,110)	(\$2,749,089)
(Decrease) Increase in temporarily restricted net assets	(\$423,512)	(893,018)
Increase in net assets	\$6,377,422	\$2,632,570
Net assets, beginning of year	\$35,505,466	\$32,872,896
Net assets, end of year	\$41,882,888	\$35,505,466

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 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, 2023, and June 30, 2024.

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

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

\$500,000 - \$999,999

Inhibrx, Inc.
Vertex Pharmaceuticals, Inc.

\$250,000 - \$499,999

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\$100,000 - \$249,999

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Praxis Communications, L.L.C.
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\$25,000 - \$99,999

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Honor Gallery

\$1,000 - \$4,999

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Julie W. Wright
Daniel Yates
Christine and Doug Young

Denotes Deceased

In Memory Of

The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2023 and June 30, 2024.

Kevin J. Ahearn
Ann M. Alciatore
Laura Aldermann
Alpha Angels
Chris H. Amason
Judith L. Anderson
Gilbert Arias
Teresa A. Arominski
Fred Ashmore
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Arlynn Baber
Kenneth A. "Kenny" Bakaitis
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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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