



Volunteer Leadership Opportunities

**Alpha-1 Foundation
3300 Ponce De Leon Blvd., Coral Gables FL 33134**

Revised 2.2026



Table of Contents

Introduction.....	4
Volunteer Service Opportunities.....	8
Alpha-1 Fast Facts	15
Summary of Programs	17



INTRODUCTION



**Volunteer Leaders Needed
For the
Alpha-1 Foundation**

Introduction

Volunteer Leadership Opportunities

Volunteer leaders are essential to the success of the Alpha-1 Foundation (A1F). A1F relies on the expertise of its volunteers to direct, build and provide oversight of its many programs through participation in Working Groups and Advisory Committees. For this reason, A1F actively seeks individuals who are willing to use their specific skills, knowledge, contacts and resources to benefit its programs and by extension, the Alpha-1 Community.

We at the Alpha-1 Foundation recognize the value of diverse viewpoints and experiences in the composition of our Working Groups and Advisory Committees and encourage those with a desire to serve to get involved. If you are interested in assisting A1F in the accomplishment of its mission, we invite you to read on and learn more about the opportunities to participate in this important work.

Alpha-1 Foundation

Alpha-1 Antitrypsin Deficiency, or Alpha-1 as it is commonly known, is a rare genetic condition that can cause severe liver disease in children and/or severe lung/ liver disease in adults. It is estimated that there are 100,000 people in the United States and a similar number in Europe who have the condition, yet less than ten percent have been accurately diagnosed (refer to the Alpha-1 Fast Facts). The Alpha-1 Foundation is a not-for-profit Florida corporation founded in 1995 by John Walsh, Sandy Lindsey and Susan Stanley, three people diagnosed with Alpha-1. A majority of the Board of Directors is either diagnosed with Alpha-1 or has a family member diagnosed with Alpha-1.

A1F has developed a solid infrastructure to promote research and the development of new therapies for improving the quality of life for those diagnosed with Alpha-1. It has fostered collaborations with investigators throughout the United States and Europe, working closely with the National Institutes of Health (NIH), the Food and Drug Administration (FDA), people affected by Alpha-1 and the pharmaceutical industry to expedite the development of improved therapies.



Mission Statement

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.

Foundation Programs

To fulfill that mission, A1F has built a strong infrastructure to facilitate research and detection and to support public policy issues that have a direct bearing on the health of Alphas. Patient support and education programs are central to the lives of Alphas and provide individuals with help in their daily lives.

At the core of A1F's scientific mission is a research program which provides grant funding to scientifically meritorious, peer-reviewed research projects which fall within the scope of the scientific agenda. Other research related programs which facilitate researchers' work include a DNA & Tissue Bank, Alpha-1 Research Registry, and Therapeutic Development Network (TDN). A1F also hosts and participates in Scientific Meetings and Conferences to promote scientific exchange on Alpha-1 and foster more research and collaboration.

Since Alpha-1 is often undiagnosed or misdiagnosed, A1F supports a number of efforts to bring greater awareness of the condition to the public as well as to allied healthcare professionals. It seeks to increase detection so that those with Alpha-1 can benefit from specialized care and treatment that can improve the quality of their lives. A nationwide network of over 100 Clinical Resource Centers (CRCs) provides specialized medical care for those with Alpha-1 lung and liver disease.

The Alpha-1 Foundation is an advocate on healthcare issues for those with Alpha-1 through its Public Policy Program. Issues include research, new therapeutics, detection, access to care, blood product safety, education, outreach and awareness.

A1F also develops educational materials for individuals with Alpha-1, carriers of the condition, and healthcare professionals and it offers the Alpha-1 community the opportunity to actively participate in funding a cure through its Building Friends for a Cure campaign, a volunteer fundraising program.

The patient information line offers the first helping hand to newly diagnosed Alphas by providing needed information and referrals to doctors with specific expertise in Alpha-1 and connections to support groups in their area. A support network of over 80 groups nationwide provides a forum (both in-person and virtual) for those with Alpha-1 and their caregivers to meet others coping with similar issues. Support group meetings provide an opportunity to learn valuable information from experts on topics such as access and reimbursement, nutrition, and health management. A series of six patient education days are conducted in various locales across the nation in addition to an annual A1F National Conference.



Rewards of Volunteer Leadership

The rewards of volunteer leadership are many. There is great satisfaction in knowing that you are performing a much-needed service to the Alpha-1 community and that you have played a significant role in the development of A1F's programs. It provides the opportunity to meet new people, develop new skills and network with colleagues. It is rewarding to be able to enhance critical business and leadership skills while working on behalf of others.

Commitment

A1F needs individuals who are willing and able to share their talents. The many Working Groups and Advisory Committees demand a cross-section of skills, experience, and viewpoints so that matters under consideration are fully vetted. A1F fosters an environment which allows for open discussion with respect for the opinions of all.

The time commitment required is dependent upon which Working Group or Advisory Committee you belong to and the work before it at the time. Generally, committees meet face-to-face once per year and meet virtually twice per year. Some committees such as the Development Committee, may meet more frequently. In order to be respectful of our volunteers' time, all meetings follow a strict agenda and timeline developed by the staff liaison in conjunction with the Working Group or Advisory Committee chair.

Volunteers do not receive remuneration for their time but may be reimbursed for travel expenses related to their work for A1F per the Non-Employee Travel Reimbursement Policy.

In the pages that follow, you will become acquainted with the work that each of A1F's Working Groups, Advisory Committees and Board of Directors' Committees perform in service to the Alpha-1 Foundation and the Alpha-1 community. We invite you to explore these opportunities for service and encourage you to use your talents as a volunteer of the Alpha-1 Foundation.



VOLUNTEER SERVICE OPPORTUNITIES



Volunteer Service Opportunities

The Alpha-1 Foundation has many opportunities available for volunteers to utilize their skills. There are Working Groups, Advisory Committees and Board Committees. Each serves a unique and essential function which contributes to the goals of the organization. Please refer to A1F's Standing Committees Organizational Chart.

Non-Board Working Groups and Advisory Committees

Membership to these groups and committees is by appointment. Terms of appointment are three or five years with a staggered rotation in order to ensure infusion of new ideas while maintaining continuity of program goals. Each Working Group and Advisory Committee operates under a structure and is charged with specific responsibilities. The chair of each scientific/medical Non-Board Working Group or Advisory Committee, in addition to other representatives, sits on the Foundation's Medical and Scientific Advisory Committee (MASAC) which informs and advises the Board of Directors on medical and scientific matters. A list of these Working Groups and Advisory Committees and their charges follows.

Working Groups

Epidemiology and Detection Working Group (EDWG):

EDWG is charged with providing A1F with accurate epidemiologic data for use by A1F in its publications, marketing materials, development projects and on its website. EDWG conducts a bi-annual review to ensure that the numbers provided on diagnosed Alphas, carriers, phenotypic distribution and risks are accurate and scientifically validated. EDWG identifies relevant issues and activities undertaken by the Foundation relating to testing and detection of Alpha-1 and summarizes these activities and provides recommendations to the Medical and Scientific Advisory Committee. EDWG coordinates with the Ethical Legal & Social Issues Working Group to identify and address issues relating to diagnosis of Alpha-1 Antitrypsin Deficiency that may impact a patient's family relations, insurance, employment, or quality life.

Clinical Resource Network Working Group (CRNWG):

CRNWG is charged with identifying issues and activities undertaken by the Research Registry requiring input and advisement by the working group. This can include advice on procedures to ensure confidentiality, recommendations for utilizing existing data, methodologies for analyzing data or increasing the type or quality of data. The CRNWG summarize these activities and provide recommendations to the Medical and Scientific Advisory Committee. CRNWG assists in the development of marketing tools for increasing utilization of Registry data and for utilizing the enrolled patient cohort in research studies and clinical trials. In addition, CRNWG assists in the development of informational pieces for distribution among physicians treating Alpha-1 patients and researchers working in the field of Alpha-1 about the Registry and provides advice on increasing



awareness of both Alpha-1 and the Research Registry in the physician and patient communities.

Also, the CRNWG is charged with identifying issues and activities undertaken by the Alpha-1 network of Clinical Resource Centers (CRCs) and providing recommendations to the Medical and Scientific Advisory Committee. This can include advice on ways to increase the involvement of the existing CRCs and/or ways to attract new centers to the Alpha-1 CRC Network. CRNWG conducts a bi-annual review of the CRCs and revisions to Center applications and provides recommendations for the designation of any specific CRC in response to applications for this status. The working group assists in the organization of CRC Forums and brings to the attention of MASAC emerging issues regarding the Registry and/or CRCs, including multicenter trials and research studies.

Advisory Committees

Medical and Scientific Advisory Committee (MASAC):

MASAC is charged with providing scientific advice, guidance and support to the Alpha-1 Foundation's Board of Directors and appointed Working Groups and Advisory Committees. MASAC oversees many of A1F's Working Groups and Advisory Committees and provides input and guidance for the development of targeted detection programs, educational materials, website development and other outreach activities. MASAC assists in the development and revisions to the Foundation's Research Agenda, which prioritizes research initiatives and establishes both long and short-term objectives for A1F's research portfolio. MASAC provides input during the planning phase by identifying relevant themes related to Alpha-1 Antitrypsin Deficiency research for meetings and participates in international scientific conferences and critical issues workshops that are organized by A1F.

Grants Advisory Committee (GAC):

GAC is charged with providing scientific review for all research, travel and meeting grant proposals submitted to the Foundation. GAC identifies relevant issues relating to grant receipt, review or administration that require formalized policies and identifies areas not covered by current policies or that address specific issues that arise during the grant review process. GAC assists in the review of existing policies and updates and revises them as necessary, which may include recommendations of additional grant mechanisms, changes to the grant cycle schedule, policies on IRB fees, overhead and indirect costs, and/or changes to the format and schedule for review of grants.

Board of Directors Committees and Working Groups

There are Board Committees and Working Groups which allow for both Board and non-Board member participation. The Board committees that are closed to non-Board members are the Executive Committee, Nominating Committee and the Audit, Finance, Personnel and Compensation Committee.

Candidates to the Board of Directors are elected by the full Board to serve after having their name



placed in nomination by the Nominating Committee. There is a one-year prior service eligibility requirement on a Working Group, Advisory Committee or Board Committee as a non-Board member before one can be nominated to the Board of Directors. That requirement is in place for two reasons – 1) for the Board candidate to understand the workings of A1F and be willing to commit to playing an integral part in its leadership and 2) for the Board of Directors to evaluate the skills, experience, and commitment that the candidate brings to the Board. After the one-year service requirement has been satisfied, if a volunteer would like to be considered for Board candidacy, he or she will be invited to attend a Board of Directors meeting as a guest to meet with Board members and to witness a Board meeting firsthand. If there is mutual interest and an open Board seat, the Nominating Committee will place the candidate’s name in nomination to be voted on by the full Board.

Board members serve three-year terms with a term limit of three consecutive terms. There are three face-to-face meetings per year. Each Board member serves on a Board Committee commensurate with their skills and interests. A listing of these committees and their oversight role follows:

Board of Directors Standing Committees

Executive Committee (ExCom) – open to Officers of the Corporation

The Executive Committee consists of the Offices of Chair, Vice Chair, Secretary, Treasurer, Immediate Past Chair and Physician Director. The Executive Committee acts on behalf of the Corporation in any matter when the board is not in session within the limits established by the Bylaws.

Governance Committee – closed to non-Board members

The Governance Committee shall consist of no less than three Voting Directors and shall propose persons as voting Directors, establish the Code of Ethical Conduct and Conflict of Interest policies and monitor compliance, review personnel policies of the organization.

Finance Committee – closed to non-Board members

The Finance Committee is responsible for recommending to the Board the firm to be employed as the organization’s independent auditor, including compensation and term of engagement; review, in consultation with the independent auditor, the result of each independent audit of the organization and other related duties; responsible for review and recommendation of the annual operating budget to the Board; review of programs including cost projections and goals, assurance of the financial health of the organization.

Medical and Scientific Advisory Committee (MASAC) – open to non-Board members. See description under Advisory Committees.

Development Committee (DC) – open to non-Board members

The Development Committee is responsible for providing guidance, oversight, planning and support for all fundraising efforts. Members of the committee are charged with identifying and cultivating



relationships with individuals, corporations and grant making organizations for the purpose of securing financial gifts to help fund Foundation programs.

Patient Advisory Council - open to non-Board members

The Patient Advisory Council consists of representation of all Alphas, personas, liver and lung effected patients, rare alleles representation, transplant recipient, caregiver, parent of child alphas, a representative group of patient/family community, etc.

The council's experience and insight will be utilized as a sounding board on issues, challenges, specific needs that arise impacting the community and/or A1F. The council will function as needed and utilize their knowledge as a focus group for certain projects and initiatives, their function would be as an Ad Hoc group. The establishment of this structure will benefit A1F and the community in an exciting way and allow for a broader representation of all constituents.

Investment Committee – open to non-Board members as non-voting members

The Investment Committee evaluates and recommends to the Board of Directors the firm to be employed as Investment Advisor. It reviews the Investment Policy for A1F, and if necessary, recommends revisions to the Board, with the objective of allocating, monitoring, evaluating, and preserving the Foundation's investments. The Investment Committee is authorized to execute securities transactions and to transfer funds between Alpha-1 Foundation accounts.

Other Board Committees

Industry Advisory Committee – by invitation

The Alpha-1 Foundation established an Industry Advisory Committee (IAC) to facilitate communication among companies delivering products and patient services to the Alpha - 1 community. Through this forum A1F provides information on programs and services delivered to the Alpha-1 community, shares clinical advances in Alpha-1, presents awareness and detection efforts and discuss public policy issues relevant to individuals with Alpha-1.

How to Become Involved

If you or someone you know is ready to begin a fulfilling leadership role with the Alpha-1 Foundation or would like more information on any of the opportunities discussed above, please contact amcbride@alpha1.org.

You will be contacted by the Chair or staff liaison of the Working Group or Advisory Committee that meets your interests to discuss how you can become involved and answer any questions you may have. Then, your name will be placed in consideration for the next round of appointments.



The Alpha-1 Foundation needs your talent. You will find working for the betterment of the Alpha-1 community a very fulfilling role. Please join the hundreds of volunteers who have, through their leadership, made a significant difference in the course of Alpha-1 research, detection, education, support, advocacy and fundraising. We appreciate your consideration and look forward to speaking with you soon.



ALPHA-1 FAST FACTS



Alpha-1 Fast Facts

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic condition – passed on from parents to their children through genes. Alpha-1 may result in serious lung disease in adults and/or liver disease at any age. In the United States there are at least 100,000 people with Alpha-1 (ZZ).

The most common signs and symptoms of Alpha-1 are:

- Shortness of breath
- Wheezing
- Chronic cough and sputum (phlegm) production (chronic bronchitis)
- Recurring chest colds
- Decreased exercise tolerance
- Non-responsive asthma or year-round allergies
- Bronchiectasis
- Unexplained liver disease or elevated liver enzymes
- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites)

Alpha-1 has been identified in virtually all populations. About **1 in every 2,500** Americans has Alpha-1.

An estimated 19 million people in the U.S. have one normal and one defective alpha-1 gene. People with one normal gene and one defective gene (for example MZ) are called “carriers”. Carriers may pass the defective gene on to their children.

Alpha-1 **can lead to lung destruction** and is often misdiagnosed as asthma or smoking-related **Chronic Obstructive Pulmonary Disease (COPD)**.

Alpha-1 is the **most common known genetic risk factor for emphysema**.

The **American Thoracic Society (ATS)** and the **European Respiratory Society (ERS)** recommend that everyone diagnosed with **COPD**, emphysema, or asthma that is not completely reversible with aggressive treatment, be tested for Alpha-1.

Alpha-1 **can lead to liver disease**. The most serious liver diseases are cirrhosis and liver cancer.

Alpha-1 cannot be diagnosed by symptoms or by a medical examination alone; you need to get a simple blood test to know for sure.

For more information, call the Alpha-1 Foundation toll-free: 1-877-228-7321 or visit www.alpha1.org.



SUMMARY OF PROGRAMS



Alpha-1 Foundation Programs

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 \$100 million to support Alpha-1 research and programs at 120 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. The Registry was established to facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1.

The Support Network is comprised of 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 important topics such as Alpha-1 Kids, Pre & Post Transplant issues, Caregivers and Timely Topics.

The Patient Information Line 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 Peer Guide Program connects newly diagnosed Alphas with another Alpha who has 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.

Patient Education Programs include an annual A1F National Conference which brings together over 1,000 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 A1F Education Days are held each year in various cities throughout the United States to bring patient education to a regional audience.

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.

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', 'It's All in The Family: Family Testing' are available to download and order through our website. 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.



The Foundation's Public Policy Program advocates for the Alpha-1 community by monitoring and influencing legislative and regulatory issues. Primary concern 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.

Grants and Awards: A1F'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 science and clinical research.

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 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.

Scientific Meetings, Conferences, Workshops, Working Groups & Symposia bring scientists together to focus on special topics related to Alpha-1, to advance knowledge of the genetic condition and to work toward new therapies and a cure.

Alpha-1 Global: works on a global, national and local level to enhance care and support for all those affected by Alpha-1. A1F is committed to providing reliable resources and information worldwide. As part of the Global Alpha-1 Initiative, A1F is creating new tools focusing on connecting Alphas all over the world with resources – and with each other.

Access and Reimbursement: The Alpha is committed to providing the tools and resources necessary to assist Alphas in making informed decisions about their healthcare plan and assistance program selection.

The Clinical Trial Outreach and Education Program is an online tool used to educate Alphas about clinical trials with curated educational materials towards Alpha-1.