



Volunteer Leadership Opportunities

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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. The Foundation 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, the Foundation 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 the Foundation 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 severe lung and 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 disorder, yet less than ten percent have been accurately diagnosed (refer to the Alpha-1 Fast Facts). There is no cure, an unacceptable fact for three individuals with Alpha-1 – John Walsh, Susan Stanley and Sandy Lindsay, who in 1995 established the Alpha-1 Foundation. Their goal in establishing this 501(c) 3 not-for-profit organization was to promote detection of the condition and to fund research which would result in new therapies for its management and, ultimately, a cure for this life-altering condition.

In July, 2014 the Alpha-1 Association, a patient support and education organization founded in 1991, merged with the Alpha-1 Foundation to create one organization dedicated to improving the lives of Alphas now, while supporting the scientific research that will lead to new therapies and a cure in the future.

Mission Statement

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.

Foundation Programs

In order to fulfill on that mission, the Foundation 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 the Foundation'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 Foundation's scientific agenda. Other research related programs which facilitate researchers' work include a DNA & Tissue Bank, Research Registry and International Reference Laboratory. The Foundation 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, the Foundation 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. Some of the programs in this area include the Alpha-1 Coded Testing (ACT) Study, a free and confidential testing program; the Targeted Detection Program which educates healthcare providers and individuals at risk for Alpha-1, such as those with Chronic Obstructive Pulmonary Disease (COPD), about the importance of testing for Alpha-1; a Family Testing Program which encourages testing of this genetic condition; and the Florida Detection Program funded by the Florida Department of Health which pilots education and testing activities within the state. Once diagnosed, a nationwide network of over 80 Clinical Resource Centers 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 access to care, reimbursement of treatment, and access to airline oxygen among others.

The Foundation 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.

A 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 National Education Conference and web-based education. A genetic counseling service, based at the Medical University of South Carolina, is offered free of charge to those seeking information on testing for this genetic condition.

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 the Foundation'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

The Foundation 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. The Foundation 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 via teleconference twice per year. Some committees such as the Development Committee and the Educational Materials Working Group 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 the Foundation per the Foundation's Non-Employee Travel Reimbursement Policy.

In the pages that follow, you will become acquainted with the work that each of the Foundation'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 the Foundation'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

Ethical Legal & Social Issues Working Group (ELSI):

ELSI is charged with identifying relevant issues and activities undertaken by the Foundation requiring bioethical or legal review and provides recommendations to the Medical and Scientific Advisory Committee. Specifically, ELSI is charged with providing bioethical and legal review on research study requests, clinical trial protocols, grant applications, informed consent, educational materials and conflict of interest issues on an ongoing basis.

Educational Materials Working Group (EMWG):

EMWG is charged with providing ongoing reviews and updates of the Foundation's educational resources in line with published data on Alpha-1 while revising review procedures and maintaining a schedule for the review of existing materials. EMWG works collaboratively with the Epidemiology and Detection Working Group and the Ethical Legal & Social Issues Working Group to ensure that the Foundation's educational materials include appropriate and accurate information.

Transplant Issues Working Group (TIWG):

TIWG is charged with providing the Foundation with information and recommendations regarding current and future issues related to organ transplantation, especially of the lung and liver, of individuals with Alpha-1. TIWG conducts an annual review of transplantation of Alphas, both lung (single and double) and liver, which includes current outcome summaries and data on waiting list numbers and duration.

Epidemiology and Detection Working Group (EDWG):

EDWG is charged with providing the Foundation with accurate epidemiologic data for use by the Foundation 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 the Foundation'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 of the Foundation, including the expansion of programs such as the Alpha-1 Research Registry, Tissue Bank or academic Alpha-1 programs. 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 the Foundation'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 the Foundation.

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.

DNA & Tissue Bank Advisory Committee (TBAC):

TBAC is charged with providing expert advice on the establishment of policies and standard operating procedures of the DNA & Tissue Bank and providing review and revision to existing policies on an annual basis. TBAC clarifies the long-term goals and anticipated outcomes by assisting with establishment of the clinical and research goals for tissue banking. TBAC assists with the establishment of criteria and a review mechanism to evaluate the merit of proposals from researchers to access tissue or DNA and the ethical considerations surrounding proposals for accessing tissue. Additionally, TBAC reviews and provides feedback on marketing plans, public information on the Tissue Bank and materials for the website and assists with the development of Frequently Asked Questions (FAQs) for the website on an annual basis.

Scientific Honors Advisory Committee (SHAC):

SHAC is charged with providing the Foundation with recommendations on the selection criteria for all Alpha-1 Foundation awards, including a recommendation of the recipient of the Sten Eriksson Distinguished Scientific Achievement Award to the Medical and Scientific Advisory Committee.

Alpha-1 International Registry (AIR)/Alpha-1 Foundation Liaison Group (AALG):

AALG is charged with promoting collaborative efforts between the Alpha-1 International Registry and the Alpha-1 Foundation, with a focus on harmonizing the Registries and planning joint scientific meetings. The Alpha-1 International Registry is a multinational research organization, representing a combined research effort of nearly 20 countries. Each member country has a National Registry of patients with Alpha-1 Antitrypsin Deficiency, and contributes detailed clinical information about individuals with Alpha-1 Antitrypsin Deficiency within the country to an international database in Sweden. This international cooperative effort can be expected to stimulate medical research through resources that are only available through multinational cooperation.

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 the Foundation 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 first hand. 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, 2nd Vice Chair, Secretary, Treasurer, Immediate Past Chair and Scientific Advisor. 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.

Budget, Program and Nominating Committee (BPNC) – Budget and Program open to non-Board members; Nominating closed to non-Board members

The Budget, Program and Nominating Committee is 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 and proposal of persons for election as Voting Directors, Directors Emeritus and Honorary Directors.

Audit, Finance, Personnel and Compensation Committee (AFPCC) – closed to non-Board members

The Audit, Finance, Personnel and Compensation 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; establishment of the organization’s Code of Ethical Conduct and Conflict of Interest policies and monitoring of compliance; review of salary guidelines and other benefits; review of personnel policies for compliance with governmental laws.

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.

John E. Kushner Advisory Council – closed to non-Board/Kushner Council members

The John E. Kushner Advisory Council makes recommendation to the Alpha-1 Foundation Board regarding use of the funds in the “Kushner Fund” established by the family of the late John E. Kushner to honor his memory.

Community Engagement Advisory Committee – open to non-Board members

The Community Engagement Advisory Committee serves as the steering committee for the Alpha-1 Foundation Support, Education and Alpha-1 Kids community programs with the goal of improving the lives of Alphas and their families. This committee has the responsibility to review and make recommendations regarding performance, program-related expenditures and guidelines for the operation of these programs. This committee identifies and assesses community program needs and makes recommendations to the Board of Directors regarding existing and/or new programs.

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 the Foundation 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**Corporate Advisory Committee – by invitation**

The Alpha-1 Foundation established and Industry Advisory Committee (IAC) to facilitate communication among companies delivering products and patient services to the Alpha - 1 Community. Through this forum the Foundation 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.

Public Policy Working Group (PPWG) – open to non-Board members

The Public Policy Working Group is charged with recommending regulatory and legislative priorities on an annual basis; developing a pool of candidates to serve on federal advisory committees; selecting individuals to serve as Community liaisons to strategic partners and organizations; helping to develop strategic responses to key issues relevant to Alphas; assisting in the development of the strategic plan for public policy. Objectives include advocating for: increased research spending, new therapeutics, targeted detection, access to care, increased Federal and State funding, education, outreach and awareness.

Support Advisory Committee – open to non-Board members

The Support Advisory Committee reviews the programs and services of the Support Network and makes recommendations to the Community Engagement Advisory Committee on matters such as operational guidelines, confidentiality, educational content of meetings and support services to ensure that the needs of Alphas are being met. This committee may conduct needs assessment surveys within the Alpha-1 community and make program recommendations based on survey results.

Patient Education Advisory Committee – open to non-Board members

The Patient Education Advisory Committee assesses the type, adequacy and accuracy of information that patients receive from Foundation sources. These sources include brochures, website, e-education videos, face-to-face and virtual support groups, education days and conferences, newsletters and social media. Its objective is to ensure that Alphas learn about various topics of importance and relevance to their disorder in an understandable way, compatible with different learning styles and abilities and gaps in knowledge are filled. This committee makes recommendations to the Community Engagement Advisory Committee.

Alpha-1 Kids Advisory Committee – open to non-Board members

The Alpha-1 Kids Advisory Committee works to assist parents of young Alphas by providing them with education, support and referral services related to this condition and the specific needs of children and young adults. This committee makes recommendations on education and programs to the Community Engagement Advisory Committee.

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 Adriana de Arce, Manager of Scientific Events at 877-228-7321, ext. 269 or Karen Erickson, Associate Executive Director of Community Engagement at 877-228-7321 ext. 214.

You will be contacted by the Chair or staff liaison to 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 \$54 million to support Alpha-1 research and programs at 100 institutions in North America, Europe, the Middle East and Australia.

The Alpha-1 Research Registry is a confidential database of Alphas and Alpha-1 carriers. It is a resource for investigators seeking individuals with Alpha-1 to participate in clinical trials, surveys, and other scientific and medical activities. For information, visit 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, which evaluates perceived risks and benefits of genetic testing. Please visit www.alphaoneregistry.org, email alphaone@musc.edu or call toll free 1-877-886-2383.

The Support Network is comprised of 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 important 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.

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 newly diagnosed Alphas 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 chorsak@alpha1.org or 1-877-346-3212.

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 6 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. To learn more about these programs,

visit 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 a hotline, age appropriate informational books, newsletters, 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 on behalf of the Alpha-1 community by monitoring and influencing legislative and regulatory issues. Of primary concern is the stimulation of medical research, the development of 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 individuals 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 result in improved health for those with Alpha-1 (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 others who do not have the deficiency, but simply wished to donate their DNA or tissue. The Bank is a resource for researchers investigating Alpha-1 and other conditions. Researchers please contact dfernandez@alpha1.org or 1-877-228-7321 ext. 242. The bank is not currently accepting new tissue samples. 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 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 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. Contact information is on the Foundation website, www.alpha1.org.

Scientific Meetings, Conferences, Workshops, Working Groups & 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.

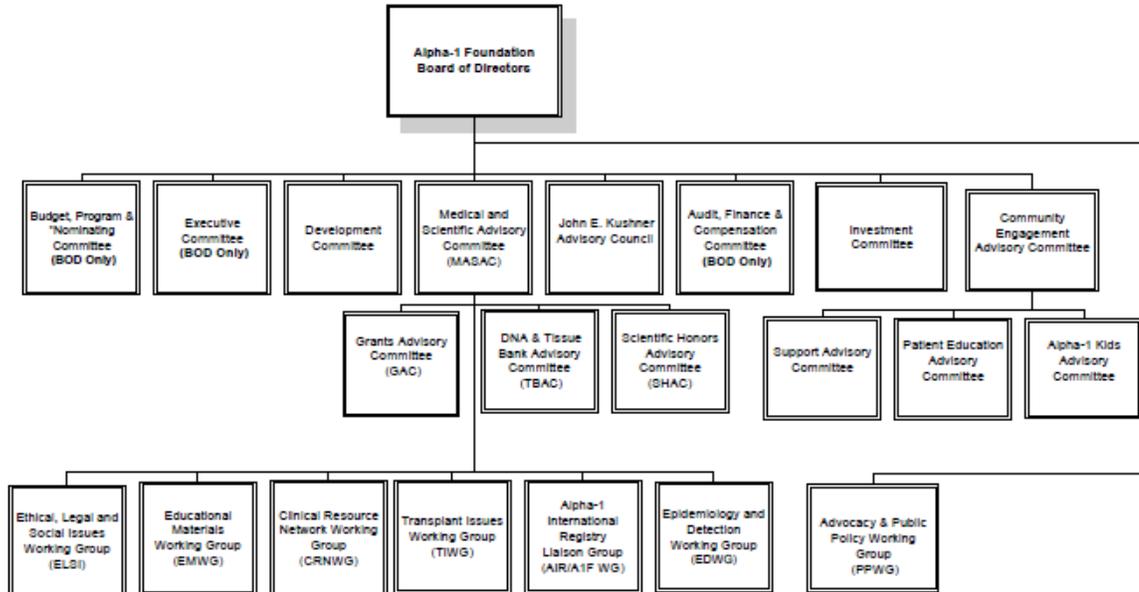
Alpha-1 Global Initiative: The Alpha-1 Foundation works on a global, national and local level to enhance care and support for all those affected by Alpha-1. The Foundation is committed to providing reliable resources and information worldwide. As part of the Global Alpha-1 Initiative, the Foundation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



STANDING COMMITTEES

ORGANIZATIONAL CHART

Alpha-1 Foundation Standing Committees Organizational Chart



A1F Committees Org Chart-January 2015.vsd*Nominating Committee Closed to Non-Board Members