

Alpha-1 Foundation



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Mission

The Alpha-1 Foundation was founded in 1995 by John Walsh, Susan Stanley, and Sandy Lindsey, all of whom were diagnosed with Alpha-1. The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency.

The Boards of the Alpha-1 Foundation and the Alpha-1 Association have recommended the merging of the organizations to improve the lives of Alphas everywhere. Recent years have led to increased collaboration and partnership between the organizations, and merging will strengthen advocacy efforts, educational opportunities, and fund critical research leading to a cure. **The goal of the Boards is to officially complete the merger in June at the 2014 Annual National Education Conference.**

More information on the merger can be found [here](#).

Strategy/Approach

The foundation seeks to achieve its mission by:

- **Developing the infrastructure and financial base** to promote research for the development of new therapies and, ultimately, a cure for Alpha-1.
- **Promoting a standard of care for a higher quality of life** for all Alphas by providing information on standards for diagnosis and treatment, resources, and information about Alpha-1 and testing.
- **Collaborating with investigators** throughout the United States and Europe, along with government agencies and pharmaceutical companies.

Research Portfolio

The foundation has invested nearly \$50 million to support Alpha-1 Antitrypsin (AAT) research and programs. The specific aim of the foundation's peer-reviewed grants program is to promote research that will eventually result in the improved health of individuals with Alpha-1, with a focus on the lung and liver disease of AAT deficiency. It funds basic, clinical, translational, and ethical issues research, and the promotion of education of members of the medical community regarding AAT. The foundation offers three funding mechanisms for extramural research:

- **Gordon L. Snider Scholar Award**—Provides additional career development support for young investigators who conduct research in Alpha-1 Antitrypsin Deficiency (AATD) related lung or liver disease.
 - *Up to \$225,000 (\$75,000 per year) over three years for one award*

- **In-cycle Investigator Initiated Grants** – Available in the following categories: Bridge, Ethical, Legal and Social Issues Relating to AAT Deficiency, Pilot and Feasibility, Postdoctoral Research Fellowship, Research, Scientific Meeting Sponsorship, and Travel Grants.
 - *Ranges from \$25,000 to \$100,000/year for one to two years, depending on the category*
- **Out-of-Cycle Grants** – Support large, typically clinical grants that do not fit into the in-cycle grant program.
 - *As approved*
- **Matching Grants** – Offered in collaboration with the American Association for the Study of Liver Diseases, the American Thoracic Society, and the CHEST Foundation.
 - *As approved*

Additional research programs and resources supported by the foundation include:

- The Alpha-1 Coded Testing Study at the Medical University of South Carolina
- The Alpha-1 Research Registry
- The Alpha-1 Antitrypsin Deficiency Detection Laboratory for the Alpha-1 Coded Testing Study at the University of Florida
- Alpha-1 Foundation Clinical Resource Centers – more than 70 nation-wide that specialize in patient care, education, and research
- Alpha-1 International Reference Database – providing genotyping, phenotyping, and serum levels for rare alleles
- Alpha-1 International Registry – to improve detection and treatment of the disease through multinational cooperation
- Alpha-1 Biomaterials Exchange—investigators willing to provide and interested in acquiring alpha-1 biomaterials including viruses, viral vectors, plasmids, mice, cell lines, patient samples (lung, liver), and data sets.

The **Alpha-1 DNA and Tissue Bank**, established in 2002, has completed enrollment of more than 2,300 members and is available for researchers to request medical information (the names of donors are not revealed) and samples for research projects.

Partnership Practices

The foundation has fostered collaborations with investigators throughout the United States and Europe, working closely with the National Institutes of Health, the Food and Drug

Administration, individuals affected with Alpha-1, and the pharmaceutical industry to expedite the development of improved therapies, including aerosol delivery for augmentation therapy.

The foundation participates in industry and government liaison groups and engages in strategic alliances with government, industry, and other national and international health and research organizations. **It partners with biotech and pharmaceutical companies.** Examples include Baxter Healthcare, Talecris Biotherapeutics, and CSL Behring, among others.

The Alpha-1 Project (TAP) is wholly owned, for profit subsidiary of the Alpha-1 Foundation dedicated to providing critical funding and advice to speed the commercialization of therapies for COPD and liver disease caused by Alpha-1. TAP partners with individual donors, patients, academia, pharmaceutical and biotechnology companies. By taking a venture capital-like approach to evaluating and making targeted investments, TAP aims to speed the development of new drug therapies for Alpha-1. TAP also provides matching funds to pharmaceutical and biotechnology companies with highly promising compounds and devices.

Financials

The foundation is a 501(c)(3) tax-exempt nonprofit organization. The most recent financial information available is from 2012.¹

Year ending 06/30/12:

- Revenue: \$7,985,052
- Assets: \$15,174,094
- Grants paid: \$2,154,029
- Gifts received: \$7,003,839
- Expenditures: \$4,662,714

Key Accomplishments

- Since its inception, the Alpha-1 Foundation has invested nearly \$50 million to support Alpha-1 research and research-related projects. Research projects have been conducted at 97 institutions in North America, Europe, the Middle East, and Australia.
- The Alpha-1 Foundation, partnering with the University Of Florida College Of Medicine and the Florida Department of Health and Human Services, sponsors an awareness, screening, and detection program for Alpha-1. Screening and testing are both confidential and free.
- CEO John Walsh co-founded AlphaNet, a nonprofit disease management services company that provides comprehensive healthcare exclusively for individuals with Alpha-1. AlphaNet provides healthcare services to more than 3,500 individuals with Alpha-1 in all 50 states, Puerto Rico, and the Virgin Islands. Revenues in excess of expenses generated by AlphaNet are

donated to the Alpha-1 Foundation. AlphaNet has so far contributed \$39 million to the Alpha-1 Foundation.

Leadership

The Alpha-1 Foundation is governed by a **Board of Directors** and relies on a **Medical and Scientific Advisory Committee** for counsel on related matters and policies.

- **President and CEO:** John W. Walsh, jwwalsh@alpha-1foundation.org
- **Chair of Board of Directors:** Gordon E. Cadwgon, PhD
- **Scientific Advisor:** William J. Martin II, MD
- **Director Emeritus:** Marilina V. Fernandez
- **Senior Public Policy Director:** Miriam O'Day

¹ Information obtained from Foundation Center Directory, <http://fconline.foundationcenter.org>, July 2013.