

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and improving the lives of people affected by Alpha-1 worldwide. The Alpha-1 Foundation has invested more than \$90 million to support Alpha-1 research and programs at more than 123 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. It is a resource for investigators seeking Alphas to participate in clinical trials, surveys, and other scientific and medical activities. For more information, email alpha1registry@alpha1.org or call toll-free 1-877-228-7321 ext. 252. <https://www.alpha1.org/alphas-friends-family/resources/participate-in-research/>

Alpha-1 Coded Testing provides free, confidential testing administered through a research study that evaluates perceived risks and benefits of genetic testing. For more information, email alpha1lab@alphaone.ufl.edu call toll free 1-855-476-1227 <https://www.alpha1.org/healthcare-providers/testing-and-treatment/alpha-1-coded-testing-study/>.

The Support Network is comprised of over 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 topics such as Alpha-1 Kids, Pre & Post Transplant issues, Caregivers and Timely Topics. To find a support group near you, visit a1f.org/support-groups.

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 1-855-476-1227, based at the University of Florida, is a free and confidential service that provides direct contact to a genetic counseling service 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 genetic illness. <https://www.alpha1.org/alphas-friends-family/support/genetic-counseling/>

The Peer Guide Program 1-877-346-3212 connects newly diagnosed Alphas with other Alphas who have 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. For more information contact jcollins@alpha1.org or call 1-877-228-7321 ext. 251. <https://www.alpha1.org/alphas-friends-family/resources/oxygen-resources/>

Patient Education Programs include an annual National Education Conference which brings together over 600 Alphas, caregivers, industry representatives, clinicians, allied health care workers and scientists to discuss a wide range of Alpha-1 related topics. For more information, visit a1f.org/alpha1conference. Additionally, a series of Alpha-1 Education Days are held each year in various cities throughout the U.S. to bring patient education to a regional audience. For more information, visit a1f.org/educationdays. Recordings of these events are available via E-Education at a1f.org/education-videos.

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. Visit a1f.org/building-friends contact amcbride@alpha1.org or call 1-877-228-7321 ext. 233 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, a virtual support group and a parent peer guide program. For more information, visit a1f.org/alpha1-kids or contact chenderson@alpha1.org.

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, a1f.org/a1-publications, or call 1-877-228-7321 ext. 251. 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. Join the mailing list here alpha1.org/alphas-friends-family/resources/join-mailing-list/ to receive the magazine. Presentations from previous Alpha-1 educational events are available via E-Education at a1f.org/education-videos.

The Foundation's Public Policy Program advocates for the Alpha-1 community by monitoring and influencing legislative and regulatory issues. Primary concerns 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. For more information, visit a1f.org/action-alert.

Grants and Awards: The Foundation'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 basic science and clinical research. For more information, contact David Fernandez at 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 other donors. The Bank is a resource for researchers investigating Alpha-1 and other conditions. Researchers should contact David Fernandez at dfernandez@alpha1.org or call 1-877-228-7321 ext. 242. 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. For further information, please call 1-877-228-7321 ext. 306.

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. To find an Alpha-1 specialist near you, visit a1f.org/alpha1doc. For more information, contact David Fernandez at dfernandez@alpha1.org or call 1-877-228-7321 ext. 242.

Scientific Meetings, Conferences, Workshops, Working Groups and 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. For more information, contact Adriana De Arce at adearce@alpha1.org or call 1-877-228-7321 ext. 269.

The Alpha-1 Global Initiative 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. For more information, visit alpha-1global.org, contact Randel Plant at rplant@alpha1.org or call 1-877-228- 7321 ext. 306.

Access and Reimbursement: The Alpha-1 Foundation is committed to providing the tools and resources necessary to assist Alphas in making informed decisions about their healthcare plan and assistance program selection. Patients with questions or issues concerning access or reimbursement should contact Cathey Henderson at 1-800-245-6809 or chenderson@alpha1.org. <https://www.alpha1.org/alphas-friends-family/resources/assistance-organizations/>

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. For more information, visit <https://www.alpha1.org/alphas-friends-family/resources/clinical-trials/> or contact Randel Plant at rplant@alpha1.org or call 1-877-228-7321 ext. 306.