



Research for a Cure

The mission of the **Alpha-1 Foundation** is to provide the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency. The Foundation has invested \$39 million to support Alpha-1 Antitrypsin Deficiency research in nearly 70 institutions in North America, Europe and Australia. For more information, visit: www.alpha-1foundation.org.



Support, Education and Advocacy

The **Alpha-1 Association** is the leading national patient membership organization serving the Alpha-1 community since 1991. Its mission is to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education, advocacy and to encourage participation in research. Its programs include a national Support Network of 70 Support Groups, Patient Hotline, national and regional educational programs, Genetic Counseling Service, and grassroots advocacy program. For more information visit: www.alpha1.org.

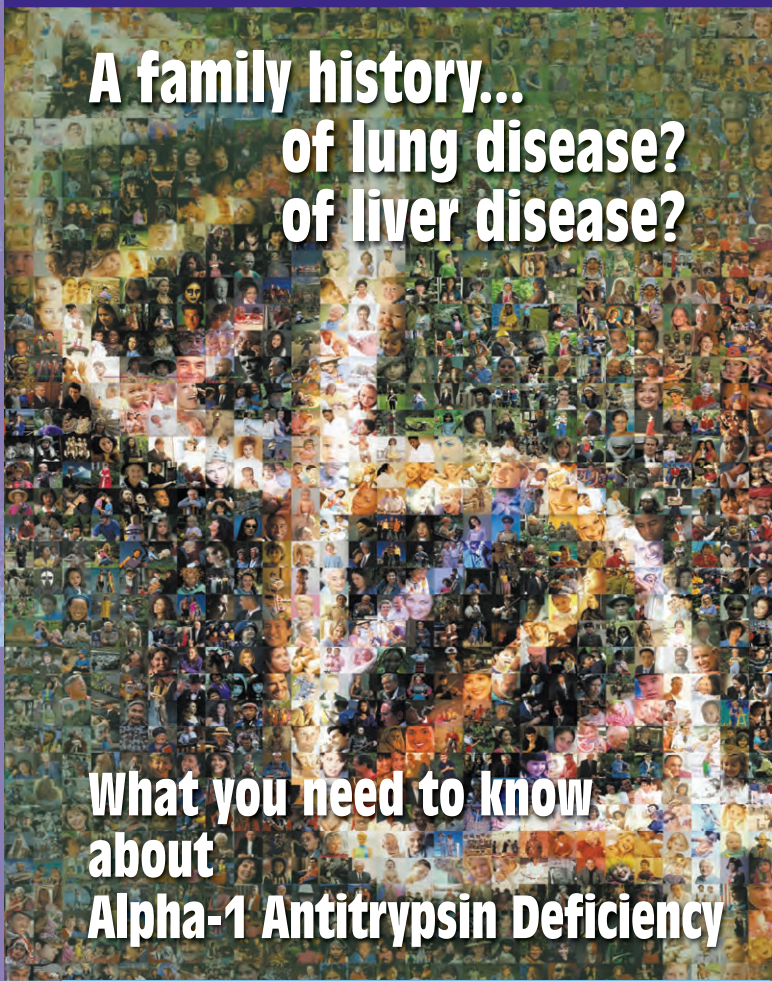
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Accredo Therapeutics
AlphaNet
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What is Alpha-1?



A family history...
of lung disease?
of liver disease?

What you need to know
about
Alpha-1 Antitrypsin Deficiency



Support, Education and Advocacy since 1991

What is Alpha-1?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a hereditary condition that is passed on from parents to their children through genes. This condition may result in serious lung disease in adults and/or liver disease in infants, children and adults.

Alpha-1 occurs when there is a severe lack of a protein in the blood called alpha-1 antitrypsin (AAT) that is mainly produced by the liver. The main function of AAT is to protect the lungs from inflammation caused by infection and inhaled irritants such as tobacco smoke. The low level of AAT in the blood occurs because the AAT is abnormal and cannot be released from the liver at the normal rate. This leads to a build up of abnormal AAT in the liver that can cause liver disease.



What are the most common symptoms of Alpha-1?

Symptoms related to the lungs:

- Shortness of breath
- Wheezing
- Chronic cough and sputum (phlegm) production
- Recurring chest colds

Symptoms related to the liver:

- Eyes and skin turning yellow (jaundice)
- Swelling of the abdomen (ascites)
- Vomiting blood or passing blood in the stool

Who should be tested for Alpha-1?

Everyone with emphysema, chronic obstructive pulmonary disease (COPD), chronic bronchitis or asthma that is incompletely reversible after aggressive treatment

- Individuals with bronchiectasis
- Newborns, children and adults with unexplained liver disease
- Individuals with a family history of liver disease
- Blood relatives of a person diagnosed with Alpha-1
- Anyone with panniculitis, a skin disease

Testing for Alpha-1

Testing for Alpha-1 is fairly simple, quick, and highly accurate. It is done through a blood test or a mouth swab test. People at risk for Alpha-1 should be tested because:

- There are treatments and preventive measures that may slow the progression of lung disease and help you take better control of your health.
- Since it is hereditary, Alpha-1 can be passed on to your children. It should be considered when making decisions about having children and should be discussed with your family members.

The test for Alpha-1 requires a physician's prescription and is usually covered by medical insurance. Confidential testing is available through the Alpha-1 Coded Testing (ACT) Study, through which anyone can have a free, confidential test and get their results. For more information on the ACT Study, call (877) 886-2383.

Informed Consent

Informed consent is the process through which a person receives appropriate information, understands that information and agrees to testing. It originates from the legal and ethical right the patient has to direct what happens to their body and from the ethical duty of the physician to involve the patient in their healthcare. You should discuss the decision to get tested for Alpha-1 with your doctor and make sure all of your questions are answered. (For more information on informed consent, please go www.alpha-1foundation.org.)

What should I Do With the results?

- Contact your physician or primary healthcare provider.
- Create an exercise program (under medical supervision).
- Create a nutrition program (under medical supervision).
- Think about your health behavior (smoking, alcohol use, and excess weight).
- Ask your healthcare provider for a copy of the brochure "**Guide to the Recently Diagnosed.**"
- Contact the resources listed in this brochure for more information.
- Avoid risk factors:
 - Stop smoking and avoid secondhand smoke as much as possible.
 - Avoid being around dust and fumes.
- Decide who to inform in your family, and urge anyone who might be affected to get tested also.

RESOURCES

Alpha-1 Association

Toll Free: (800) 521-3025

www.alpha1.org

The Association is a member-based not-for-profit organization helping to identify those affected by Alpha-1 Antitrypsin Deficiency, and dedicated to improving the quality of their lives through support, education and advocacy. The Association has a network of over 70 volunteer-led support groups throughout the United States.

Alpha-1 Foundation

Toll Free: (877) 228-7321

www.alpha-1foundation.org

The not-for-profit Foundation provides resources, educational brochures and information on testing and diagnosis for physicians and patients. It funds cutting-edge research to find treatments and a cure and supports worldwide detection of Alpha-1.

AlphaNet

Toll Free: (800) 577-2638

www.alphanet.org

AlphaNet assists patients and families with support, education and strategies to manage their health. It also sponsors clinical trials for Alpha-1 therapies and produces **The Big Fat Reference Guide to Alpha-1**, a complete guide to understanding, managing and living with Alpha-1, and includes key terms, testing, genetics, and treatment options. It is available through the website or number listed above.

The Alpha-1 Research Registry

Toll Free: (877) 886-2383

www.alphaoneregistry.org

The Research Registry is a confidential database of Alphas and carriers. The Registry gives patients the opportunity to provide information to help advance research on the disorder through questionnaires and clinical trials. It also provides access to experts on Alpha-1 care. Individuals enrolled in the Registry have the ongoing

opportunity to participate directly in clinical trials of new therapeutic approaches, in addition to other research opportunities.

Alpha-1 Kids

(877) 346-3212

www.alpha1kids.org

Alpha-1 Kids provides support and information for parents and children with Alpha-1.

American Association for the Study of Liver Diseases

(703) 299-9766

www.aasld.org

This is the leading organization of scientists and healthcare professionals committed to preventing and curing liver disease.

American Liver Foundation

Toll Free: (800) 465-4837

www.liverfoundation.org

The Foundation provides information on prevention, treatment and potential cures for liver diseases.

American Lung Association (ALA)

Toll Free: (800) 586-4872

www.lungusa.org

The ALA focuses on the prevention of lung disease through educational programs, research and advocacy.

Children's Liver Association for Support Services

Toll Free: (877) 679-8256

www.liverkids.org

This group serves the emotional, educational and financial needs of families and children with liver disease.

Cholestatic Liver Disease Consortium

(720) 777-2598

www.childrennetwork.org/families.html

The Consortium provides support and information for children and families with rare cholestatic liver diseases. For information on liver issues related to AAT, visit this website and click on the Alpha-1 link.

