

Individual counseling

Individuals who are diagnosed with Alpha-1 need education and information, but they may also need support in dealing with their feelings or with the other social impacts of a genetic diagnosis. Your doctor and nurse can provide information about your medical condition, but the Counseling Program is there to help you understand the genetics and inheritance of Alpha-1, and cope with the social and family issues related to Alpha-1.

Before giving you advice, the genetic counselor may first ask you about your personal goals, what resources are available in your area, how many family members are involved, and what kind of economic impact Alpha-1 may have on your life. This way, the advice and information you are given fits your situation.

A particular focus on the family can assist affected individuals, parents and extended family members manage Alpha-1. All genetic counselors have special training and expertise.

For more information about the Alpha-1 Foundation, visit our website at www.alpha1.org or call 1-877-228-7321.

The Alpha-1 Foundation Genetic Counseling Program is located at



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 also offers a wide array of programs for people diagnosed with Alpha-1, their families, caregivers and healthcare providers.

www.alpha1.org
1 (877) 2 CURE A1 | 1 (877) 228-7321
3300 Ponce de Leon Blvd.
Coral Gables, FL 33134

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Alpha-1 Foundation Genetic Counseling Program

A Guide for Patients



**A free service for patients,
families, caregivers and
healthcare professionals.**



About the Alpha-1 Genetic Counseling Program

The Alpha-1 Genetic Counseling Program provides telephone-based free and confidential genetic counseling for individuals considering being tested for, or diagnosed with, Alpha-1 Antitrypsin Deficiency (Alpha-1).

The program also provides information and referrals to resources for parents, family members and medical professionals.



How Can I Contact the Genetic Counseling Program?

Call toll-free 1-877-228-7321 ext. 326.

What is Alpha-1 Antitrypsin Deficiency (Alpha-1)?

- Alpha-1 is a condition that is passed from parents to children through genes. Alpha-1 can cause serious lung disease in adults and liver disease in children or adults.
- There are at least 100,000 people with a severe form of Alpha-1 in the United States and many more with other abnormal Alpha-1 gene combinations that go from mild to moderate. Not everyone with Alpha-1 will develop symptoms, or the same symptoms. Exposure to cigarette smoke, dust or inhaled irritants can cause earlier or more severe lung disease.
- If you are diagnosed with Alpha-1, it means that one or both of your parents had some form of this genetic condition and passed it on to you. You in turn could pass it on to your children. Other family members, such as siblings or cousins, may also be at risk.

Questions we can help you answer:

Should I be tested? The genetic counselor will give you information that will help you decide whether or not to be tested for Alpha-1. The information is for you, not for your doctor, and will not include medical terms you do not understand.

What do I tell my family? The Counseling Program can help you communicate with family members about Alpha-1 and their own risks. The program can also help your family members understand who is affected and whether or not to be tested.

What do My Results Mean? The genetic counselor can explain your Alpha-1 results and answer questions about how Alpha-1 genes affect health risks and run in families.

What does a diagnosis of Alpha-1 mean?

If you or your child are diagnosed, the genetic counselor can help you understand the condition and the common symptoms. The genetic counselor can also help you cope with your feelings about having Alpha-1 and its effect on your life, work and family.

Where can I get treatment and support?

The Counseling Program can also provide information and referrals to doctors who are knowledgeable about Alpha-1 treatment in your area, other Alphas and Alpha-1 organizations who can support you and your family.

You can view other frequently asked questions at: a1f.org/genetic-counseling

Confidentiality

The Alpha-1 Foundation Genetic Counseling Program provides information about genetic testing for Alpha-1 Antitrypsin Deficiency, and how genetic testing may affect you and your family. The privacy of all callers is protected to the extent permitted by law. Information will not be shared with physicians or any other organizations unless authorized by the caller.

The Genetic Counseling Program is operated under the auspices of the Alpha-1 Foundation, and complies with HIPAA regulations to protect the privacy and confidentiality of callers.

How can our genetic counselor help?

Our Alpha-1 genetic counselor will provide support and guidance to help you understand the diagnosis of Alpha-1 and what it means to you and your family. The counselor is there to listen to your concerns, help you cope and gain control of your condition, and most importantly, give you and your family hope.