

ALPHA-1

The Alpha-1 Coded Testing (ACT) Study



Why "ACT" Now?

Many people at risk for Alpha-1 Antitrypsin Deficiency delay being tested for this genetic condition due to concerns about the privacy of test results. Finding out the test results early may affect the onset and progression of the disease. As a result, the Alpha-1 Foundation supports testing for people at risk. The Medical University of South Carolina (MUSC) sponsors a free and confidential test. This test is available through a research study, the Alpha-1 Coded Testing (ACT) Study. The Study investigates people's thoughts and feelings about the risks and benefits associated with learning genetic information.

How can a family member or I be tested?

This Study provides a way for family members of Alphas and others at risk to learn their Alpha-1 genotype.

The study is run through the Alpha-1 Research Registry site in Charleston, SC under the direction of Dr. Charlie Strange. For questions or to request a free test kit, please call the ACT Study Coordinator toll free at 1-877-886-2383 or email at alphaone@musc.edu. A finger-stick blood test can be self-administered. The test kit will be shipped to anyone who requests one. The mailing will include:

- A blood test kit with directions
- A consent form that explains the research test
- A research questionnaire

When the paperwork and blood test are complete and returned to the Medical University of South Carolina, the blood test will be coded with a unique research number. It will then be mailed to the University of Florida Alpha-1 Antitrypsin Genetics Research Laboratory for testing. Results will be faxed back to Charleston, linked with the participant and mailed to the participant's home.

Confidentiality

This program is being offered as a research Study to gain knowledge about issues surrounding genetic testing. The privacy of people who take part in the Study will be protected to the extent permitted by law. Dr. Strange and two staff members are the only people who will have access to your test results. All records will be kept under lock and key and/or in a secure database. Finally, after receipt of results, a participant's name and other identifying information (such as an address) can be deleted from ACT Study records by request.

What is the Alpha-1 Research Registry?

The Alpha-1 Research Registry is a confidential database made up of individuals diagnosed with Alpha-1 Antitrypsin Deficiency (Alpha-1) and individuals identified as Alpha-1 Carriers. The Registry was established by the Alpha-1 Foundation to facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1.

The Registry is located at the Medical University of South Carolina (MUSC) in Charleston, SC. Individuals enrolled in the Registry have the ongoing opportunity to participate directly in clinical trials of new therapeutic approaches in addition to other research studies.

For more information about the Registry, please contact the ACT Study Coordinator. Please note, individuals who choose to participate in the ACT Study are not required to participate in the Alpha-1 Research Registry, but will be invited to participate when diagnosed with Alpha-1 or as an Alpha-1 Carrier through the ACT Study.





RESEARCH REGISTRY

For more information:

For more information on the Alpha-1 Research Registry, please contact the Research Registry Coordinator toll free at 1-877-886-2383 or email at alphaone@musc.edu

MUSC
MEDICAL UNIVERSITY
OF SOUTH CAROLINA

Alpha-1 Research Registry

c/o Medical University of South Carolina
Division of Pulmonary and Critical Care Medicine
96 Jonathan Lucas St., Suite 812-CSB
PO Box 250623
Charleston, SC 29425
Toll Free Phone: 1-877-886-2383
Regular Phone: (843) 792-0260
Fax: (843) 792-0297
Email: alphaone@musc.edu

About the Alpha-1 Foundation

The Alpha-1 Foundation is a not-for-profit organization founded in 1995 by Alphas. Its mission is to provide the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1. Most members of the Board of Directors either have Alpha-1 or have a family member with Alpha-1. The Foundation has had continuous growth since its inception. It has also developed a solid infrastructure to promote research and the development of new therapies for improving the quality of life for those with Alpha-1. Due to the confidential nature of the Alpha-1 Coded Testing Study, you should call the ACT Study Toll Free number at 1-877-886-2383 for more information.



2937 S.W. 27th Avenue
Suite 302
Miami, FL 33133

Phone: 1-877-2-CURE-A1
(877-228-7321)

Fax: (305) 567-1317

www.alphaone.org

The Alpha-1 Coded Testing (ACT) Study

*A Confidential Opportunity to Be Tested for Alpha-1
Antitrypsin Deficiency*

We Encourage You to "ACT" Now!

ALPHA-1 FOUNDATION



FORGING PARTNERSHIPS FOR A CURE

RESEARCH REGISTRY

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