

ALPHA-

1



University of Florida Alpha-1 Foundation DNA and Tissue Bank

What is the DNA and Tissue Bank?

- The University of Florida / Alpha-1 Foundation DNA and Tissue Bank is the central storage for DNA and tissue samples. The stored samples are not only from people who are lacking alpha-1 antitrypsin, they are also from people who do not have the deficiency but who wish to donate their DNA or tissue.
- The Bank is a resource for DNA and tissue samples that are studied by researchers investigating Alpha-1 Antitrypsin Deficiency and other diseases.

Why have a DNA Bank?

- At the present time, no researcher has access to enough Alpha-1 DNA to conduct studies that could lead to a cure or remedy.
- By having a large storage bank of DNA and tissue samples, questions important for the well-being of people with Alpha-1 (Alphas) can be answered.
- The Bank is part of a research study.
- It is run and "owned" by the Alpha-1 Foundation and overseen by the Tissue Bank Advisory Committee, a group composed of researchers and Alphas.



How can you be part of the DNA and Tissue Bank?

- Please call 1-866-284-2708 for more information. You will be told how you can become a part of the Bank and any questions that you may have will be answered.
- If you decide to be part of the Bank, you will receive an informed consent form that you will need to read and sign and complete a survey.
- Then, you may donate two tubes of blood that equal about 3 to 4 teaspoons of blood.
- You may also donate lung or liver tissue. For example, if you are going to have a lung or liver transplant, you may wish to donate your old/removed lung or liver tissue to the Bank, but you must call the Bank before your transplant at the number above to arrange to have the tissue collected.
- Again, you do NOT have to be an Alpha or a carrier to be part of the Bank. Any person can donate DNA or tissue to the Bank.

What about keeping my records private?

The DNA Bank has been designed to ensure that all samples and tissue remain anonymous and confidential.

- Your private data and records will be used only by DNA Bank staff to contact you if more samples are needed in the future. You can agree or not agree to have Bank staff contact you in the future. No private data or records such as name, address or social security number will be given to any researcher.
- Researchers whose projects have been approved by the Tissue Bank Advisory Committee may have access to samples and tissue, not to donors' names or other private health information.

What is the survey?

- The purpose of the survey is to gather background and health information about the person giving blood or tissue to the Bank.
- The background information includes age, sex, race, and other pertinent information.
- The health information includes smoking history and other health habits.
- The survey will take about 30 minutes to complete.

Why answer the survey?

- Your answers may be used to match your DNA or tissue sample to others who have backgrounds and health habits similar to yours. These people may or may not have the same disease as you. If they have Alpha-1 Antitrypsin Deficiency, they may have a different "version" of the disease, like lung versus liver disease or early onset of symptoms versus late or no onset of symptoms.
- By matching your samples against other samples, scientists will learn more about the disease that you have and how it varies from one person to another.



DNA AND TISSUE BANK

University of Florida Alpha-1 Foundation DNA and Tissue Bank

Be Part Of Finding A Cure.

Join the DNA and Tissue Bank

**For more information about
participating, please contact:**



**University of Florida
Alpha-1 Foundation DNA and Tissue Bank**

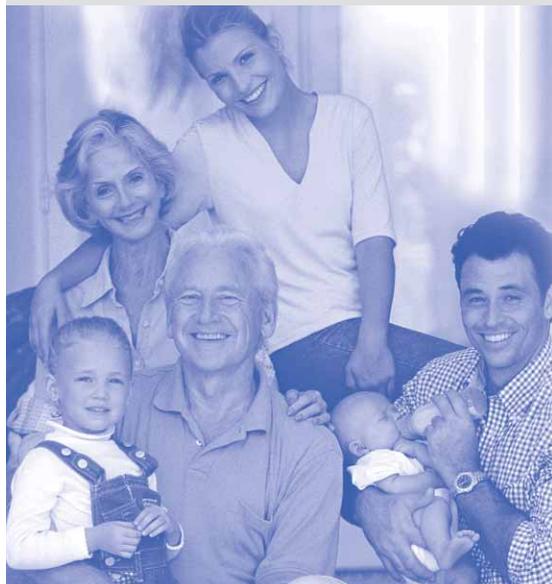
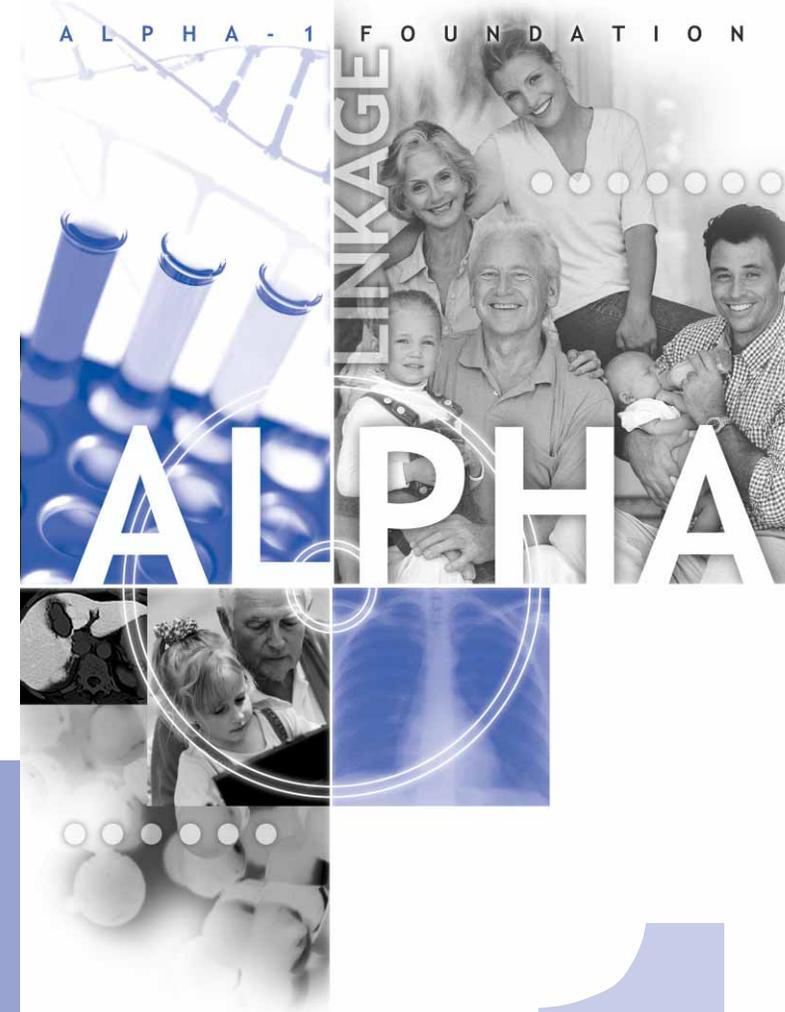
Alpha-1 Antitrypsin Genetics Research
PO Box 100225
1600 S.W. Archer Rd.
Gainesville, FL 32610
Toll Free Phone: 1-866-284-2708
Fax: (352) 846-3748
Email: alpha1lab@medicine.ufl.edu

About the Alpha-1 Foundation

The Alpha-1 Foundation is a not-for-profit organization 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 (Alpha-1). The leading experts in the field of Alpha-1 research are working with the Foundation through their participation on the Board of Directors, as members of the Medical And Scientific Advisory Committee (MASAC), directing Clinical Resource Centers, as members of Working Groups, or as participants at Foundation-sponsored scientific conferences and workshops. These experts, together with respected members of the Alpha-1 medical, professional, scientific, and patient communities are teaming up with the Alpha-1 Foundation to identify the most critical areas of research and support the development of new therapies. Importantly, the Alpha-1 Foundation has also formed collaborative relationships with government and industry to promote needed research and create awareness of this genetic disorder.

Additional information on the Foundation and its research programs is available at www.alphaone.org.

A L P H A - 1 F O U N D A T I O N



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

Toll free: (888) 825-7421

Fax: (305) 567-1317

www.alphaone.org

FORGING PARTNERSHIPS FOR A CURE