

The benefits of joining the registry

- Opportunity to participate in clinical trials for new treatments.
- Opportunity to participate in survey studies to determine health care costs, environmental risks, and assist in collection of other specific data to advance scientific and medical knowledge about Alpha-1.
- Access to experts in Alpha-1 clinical care through participation in clinical trials.
- Update Newsletter with information on latest research activities.

If you have questions

Please contact the Alpha-1 Research Registry for more information.

Toll free: 1-877-886-2383

Email: alphaone@musc.edu

Web site: www.alphaoneregistry.org

The Alpha-1 Foundation Research Registry 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 has invested more than \$54 million to support Alpha-1 Antitrypsin Deficiency research at 100 institutions in North America, Europe, the Middle East and Australia.

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

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Coral Gables, FL 33134

The Alpha-1 Research Registry Be Part of Finding a Cure



Allowing new therapies
and important research
studies to be evaluated



What is the 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 in 1997 by the Alpha-1 Foundation to facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1. Located at the Medical University of South Carolina (MUSC) in Charleston, the registry employs procedures that ensure the most stringent confidentiality of participants. The Registry operates under the direction of the Alpha-1 Foundation Board of Directors and is guided by an Advisory Committee comprised of leaders in the medical, ethical, scientific and Alpha communities. 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.



Who is eligible to enroll in the Registry?

Individuals of all ages who are diagnosed with Alpha-1 Antitrypsin Deficiency and individuals identified as carriers of Alpha-1 Antitrypsin Deficiency are encouraged to enroll in the Research Registry.

How do I enroll in the Registry?

Simply fill out the 4-page Questionnaire! This can be done by mail or over the Internet, at www.alphaonregistry.org. Please mail all applications to the address on the front of the Questionnaire. If you receive more than one copy of the enrollment Questionnaire, do not complete additional copies, but pass on extras to other Alphas, Alpha-1 Carriers or your physician. If you know of others interested in enrolling in the Registry but do not have additional copies, please refer them to the Alpha-1 Registry web site or have them call the Registry Coordinating Center toll free in Charleston at 1-877-886-2383 for information.

Who will have access to my name? How confidential is this database?

Your Questionnaire will go directly to the Registry Coordinating Center at the Medical University of South Carolina, which is under the academic supervision of the University system. This supervision includes strict adherence to established confidentiality procedures that are intended to protect the identity of those who participate. The Registry is required to conceal a member's identity and personal information from researchers and organizations unless consent is granted by the Registry member. The database is

kept under tight security at all times. This means that it is password protected and inaccessible from the Internet. Also, all hard copies of personal information are kept under lock and key. Only the Registry Director and Coordinators have access to a member's personal information.

How can my participation help promote research?

One of the largest obstacles in Alpha-1 research is finding a sufficient number of volunteers to participate in studies. By establishing a database of thousands of people with Alpha-1 and promoting its use to the Alpha-1 research community, the Registry will allow new therapies and important research studies to be evaluated. Through the voluntary participation of Registry members, basic scientific questions about Alpha-1 can be answered, enabling the disorder and its impact on Alphas to be more thoroughly understood. Participation in research is voluntary and Registry members are always given the option to accept or decline research invitations. The Registry accepts different levels of commitment to research from its members. Simply filling out the enrollment Questionnaire provides the Registry with valuable research material on the numbers of patients diagnosed with Alpha-1 and their clinical symptoms of disease. Your enrollment helps because the ability to contact a large number of Alphas motivates medical and scientific investigators to conduct important research in Alpha-1 otherwise thought impossible due to an insufficient number of available participants.