

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



Allowing new therapies  
and important research  
studies to be evaluated



**ALPHA-1**  
FOUNDATION

## 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 to facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1. Located at the Alpha-1 Foundation, Miami, FL, 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 Alpha-1 Research Registry?**

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

## **How do I enroll in the Alpha-1 Research Registry?**

Individuals interested in joining the Alpha-1 Research Registry will need to complete a registration form, sign an informed consent, complete a questionnaire and provide medical tests and labs.

You can enroll in the Research Registry in one of the following ways:

- Visit the Alpha-1 Research Registry home page and click on the Research Registry Portal link to enroll online  
*[www.a1f.org/alpha1registry](http://www.a1f.org/alpha1registry)*.
- Request hard copies of the registration page, informed consent, and questionnaire be mailed to you by calling 1-877-228-7321 ext. 252 or email *[alpha1registry@alpha1.org](mailto:alpha1registry@alpha1.org)*.

After you have completed registration, signed the informed consent and completed the questionnaire, you will be asked to provide up to 5 of the following most recent medical tests and labs:

- Pulmonary Function Testing Results
- Lung and Liver Radiology Imaging CD and Reports
- Liver Biopsy Reports
- Fibroscan Results
- Exercise Test/6-Minute Walk Test Results
- Lab reports that include INR, GGT, total cholesterol, triglycerides, HDL and LDL

Medical test and labs can be provided by email, mail, or uploaded directly to the Alpha-1 Research Registry portal. You may also be contacted every 1-2 years after the baseline visit to determine if you have any updated medical information. During these follow up communications, you may be informed of future research studies for which you may qualify for.

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

Your questionnaire will go directly to the Registry Coordinating Center at the Alpha-1 Foundation. There is 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 staff at the Alpha-1 Foundation 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. Participation in research is voluntary and Registry members are always given the option to accept or decline research invitations.

## **The benefits of joining the Alpha-1 Research Registry:**

- Participate in clinical trials for new treatments.
- Be part of 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.
- Update Newsletter with information on latest research activities.

## **Alpha-1 Antitrypsin Disease Cohort: Longitudinal Biomarker Study of Disease Grant**

An investment in 2020 by the National Institutes of Health provided resources to enhance the Alpha-1 Research Registry under the direction of Principal Investigator Jeanine D'Armiento, MD at Columbia University in New York City, NY. The grant will support and significantly strengthen the Alpha-1 Research Registry to help investigate unanswered research questions and provide evidenced based data for future clinical trials.

### **For more information**

Please contact the Alpha-1 Research Registry at 1-877-228-7321 ext 252 or [alpha1registry@alpha1.org](mailto:alpha1registry@alpha1.org).





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