

What is the Alpha-1 Research Registry?

The Alpha-1 Research Registry is a confidential database of people with Alpha-1 Antitrypsin Deficiency (Alpha-1) and Alpha-1 carriers.

The Alpha-1 Foundation created the Alpha-1 Research Registry to advance Alpha-1 research, including research into new treatments and, ultimately, a cure for the condition. Located at the Alpha-1 Foundation (A1F) in Miami, FL, the Alpha-1 Research Registry employs procedures that ensure the most stringent confidentiality for participants.

The Alpha-1 Research Registry operates under the direction of the A1F Board of Directors and is guided by an Advisory Committee composed of medical and scientific experts and patients. Participants have the opportunity to be connected directly to clinical trials of new therapeutic approaches in addition to other research studies.

Scan the QR code to learn more.



The Alpha-1 Foundation (A1F) is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by Alpha-1 worldwide.

ALPHA1.ORG

1 (877) 2 CURE A1 | 1 (877) 228-7321

Unrestricted educational grants provided by:

AlphaNet
CSL Behring
Grifols
Takeda



ALPHA-1 RESEARCH REGISTRY

Be Part of Finding a Cure





How do I enroll?

Anyone interested in joining the Alpha-1 Research Registry can enroll through the Registry Portal in a few easy steps:


- ▶ Complete a registration form
- ▶ Read and sign the informed consent
- ▶ Complete a questionnaire
- ▶ Provide medical records (optional)

Alpha-1 Research Registry participants are asked to provide their most recent medical records, if possible. You are not required to provide medical records to join.

Visit alpha1.org/join-the-alpha-1-research-registry/ and click “Enroll” to join today!

For more information, contact the Alpha-1 Research Registry:

 alpha1registry@alpha1.org

 (877) 228-7321 ext 252

Who is eligible to enroll?

Anyone diagnosed with Alpha-1, including carriers and regardless of age, can enroll; children diagnosed with Alpha-1 can enroll with parent or guardian consent. Currently, the Alpha-1 Research Registry is only open to residents of the United States.

What are the benefits of joining?

- Amplify your voice as an Alpha-1 patient
- Help improve patient care and get connected to potential new treatments
- Be part of studies to advance Alpha-1 scientific and medical knowledge
- Gain access to Alpha-1 experts
- Receive the newsletter with information on the latest research activities

Who will have access to my name & how is my privacy protected?

The Alpha-1 Research Registry is required to conceal participants' identities and personal information from researchers and organizations unless consent is granted. It uses established confidentiality procedures to protect participants' identities. Data is housed in a secure database managed by A1F. The database is hosted by a HIPAA-compliant party, a secure environment for data systems and servers.

How does my participation help promote Alpha-1 research?

By providing your information, you are supporting the development of an Alpha-1 natural history database that helps researchers learn more about Alphas. In addition, 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, the Alpha-1 Research Registry is supporting new therapies and important research studies that get the Alpha-1 community closer to a cure. Participation in research is voluntary and you are always given the option to accept or decline research invitations.

Not sure if you are in the Alpha-1 Research Registry? Use the lookup tool to confirm.

