Have you been diagnosed with alpha-1 antitrypsin deficiency?

Ask your doctor to enroll you in

EARCO: the international collaboration network for research on alpha-1 antitrypsin deficiency

Alpha-1 antitrypsin deficiency is a rare genetic disease primarily affecting the lungs and liver. Understanding the natural history of alpha-1 lung disease can be achieved via a European wide registry of diagnosed patients.

Join the initiative

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What is EARCO?

The European Alpha-1 Research Collaboration (EARCO) is an organisation endorsed by the European Respiratory Society whose main objective is the promotion of clinical research and education in alpha-1 antitrypsin deficiency (AATD), as well as early diagnosis, and access to health care.

Its central project is the international registry of people with AATD, which facilitates the investigation and a better knowledge of the deficiency. The registry is open to collaboration with all international clinicians and researchers to gather standardised data on patients with AATD, necessary to better understand the natural history of this genetic condition, the influence of risk factors and other possible genetic outcomes, and the role of treatment to increase the prognosis of lung disease, among other issues.

The Steering Committee comprises 11 clinicians from European countries as well as patients from two European patient associations. There are currently 49 centers from 18 countries who participate in the EARCO registry. The European Lung Foundation is also a supporter of EARCO.

Why should you be included?

EARCO has already promoted several investigations, such as the development of a quality program for the laboratory diagnosis of this genetic condition; the recruitment of young researchers; and a greater understanding of alpha-1 augmentation therapy in countries where treatment is available.

Through the EARCO patient registry, we want to answer questions such as the identification of genetic or environmental factors that may be influencing the development of lung and liver diseases in patients with AATD; the knowledge of the impact of the treatment to improve the quality of life; expanding knowledge relating to the impact of the less studied variants.

Finding an answer to these questions requires data on a large number of patients, not accessible from the countries individually.

How do I register?

EARCO targets adult patients with AATD with two mutated alleles, regardless of whether or not they have developed associated disease.

Patients cannot register themselves directly. The registration of patients must be carried out by doctors, so you should ask your pulmonologist or hepatologist if they are collaborating with EARCO and, if they are not, encourage them to do so.

The union of knowledge will help advance the knowledge of AATD and the search for a cure.

You can find all the information you need on the website:

www.earco.org

Join the initiative

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