About us

Alpha-1 Plus asbl
A non-profit organisation, by patients and for patients

Missions and goals

- Provide support and information to patients with Alpha-1 and their families

  Building a communication and support network
  Sharing resources and information available.

- Promote education and awareness of the disease

- Advocate for Alpha-1 patients and community

  On public policy issues, working with governments and relevant authorities, the pharmaceutical industry, Alpha-1 and rare disease organisations, medical and scientific research bodies, and any other relevant stakeholder, at national, European, and international levels.

  In order to ultimately improve the quality of life, ensure access to the best care, including early detection and optimal management of the disease (particularly for augmentation therapy), and foster research programmes and the development of novel therapeutic approaches.

Medical disclaimer

The content and information provided in this brochure are for general informational purposes only; they should not be considered medical advice or guidance, should not be used for self-diagnosis, and are not intended to represent a substitute for regular consultations with qualified healthcare professionals who are familiar with individual medical history and needs. The reader and user are strongly encouraged to always seek the advice of their physician for any matters and questions related to their personal health and medical condition.

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What is Alpha-1?

Definition

Alpha-1 antitrypsin deficiency (AATD) is a rare genetic disorder

Characterised by reduced blood level of AAT - a protein made by the liver that normally protects the lungs from injury and damage - and by an abnormal form of the protein itself

Can cause lung disease and inflammatory conditions in adults, and liver disease in both adults and children

Common genetic variants in Alpha-1 genes

- MM (Normal)
  - no altered/defective Alpha-1 genes - no disease
- MZ, MS, or other genetic type paired with one M gene
  - carries one defective gene (heterozygote)
  - mild AAT protein deficiency
  - rare development of Alpha-1-related disease
- SZ, or another combination of two different genes (compound heterozygote)
  - two different defective genes
  - moderate alpha-1 antitrypsin deficiency
  - possible development of Alpha-1-related disease
- ZZ, Null/Null, or other severe types (homozygote)
  - two identical defective genes
  - severe alpha-1 antitrypsin deficiency
  - possible development of Alpha-1-related disease

Clinical presentation of Alpha-1
Most common signs and symptoms

Lung disease

- Shortness of breath, wheezing, chronic cough
- Chronic bronchitis, recurrent pneumonia
- COPD, emphysema, bronchiectasis
- Asthma, sinus infections

Liver disease

- Jaundice (yellowing of the eyes and skin)
- Ascites (swelling of the abdomen)
- Fibrosis, cirrhosis, gastrointestinal bleeding, liver cancer

Skin disease

- Necrotizing panniculitis (red skin nodules and painful skin ulcers)

Testing for Alpha-1

Who should be tested?

Diagnostic testing to be considered in patients with:

Early-onset emphysema - onset at age 45 or younger
Emphysema in the absence of a recognised risk factor (smoking, occupational dust exposure)
Chronic obstructive pulmonary disease (COPD)
Bronchiectasis without evident aetiology
Asthma with incompletely reversible airflow obstruction after bronchodilator treatment
Unexplained liver disease, necrotizing panniculitis
Family history of Alpha-1 (first-degree relatives)

How and where to get tested?

Alpha-1 can be detected through the following blood tests:

Alphakit® QuickScreen (screening device)
Measurement of AAT protein level (blood sampling)
Additional specific genetic analysis tests (phenotyping and/or genotyping) can be performed by specialised laboratories

In practice

First contact your physician/general practitioner in order to evaluate if testing is appropriate for you
If indicated, your doctor can refer you to a pulmonologist for blood level and genetic tests



Management of Alpha-1

At present, there is no cure available for Alpha-1, but there are treatments and lifestyle options that can slow the progression of Alpha-1-associated illnesses:

General lifestyle and preventative measures

Do not smoke, or quit if you already do
Avoid outdoor and indoor pollution - such as ozone and dust - and other substances that can harm the lungs or liver, whether from the environment or the workplace.
Avoid alcohol consumption
Follow anti-inflammatory nutritional advice
Get vaccinated against influenza, pneumococcal infection, hepatitis A and B

Lung disease

- Optimal management of COPD and emphysema
  Treatment with bronchodilators
  Inhaled corticosteroid medications
  Pulmonary rehabilitation, oxygen therapy
  Lung-volume reduction, lung transplantation

- Aggressive and appropriate use of antibiotic treatment for respiratory infections

- Augmentation therapy
  Intravenous administration of normal Alpha-1 protein obtained from plasma blood donations
  Prescribed in accordance with medical guidelines

Liver disease

- Optimal treatment of liver failure
- Portal vein decompression
- Liver transplantation