



Patient Information Overview

What you should know about Alpha-1

WHAT IS ALPHA-1?

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic condition that affects your lungs and/or liver. It is a progressive condition, which means it may worsen over time. It can lead to serious lung and/or liver disease.

WHAT CAUSES ALPHA-1?

Alpha-1 is passed down from parents to children through genes. People with Alpha-1 have mutations in a gene called SERPINA1.

The SERPINA1 gene provides instructions for making a protein called alpha-1 antitrypsin (AAT), which protects the body from damage by its immune cells.

AAT is an anti-inflammatory protein, especially important for your body in regulating inflammation after bacterial and viral infections.

If you have Alpha-1, you inherited two copies of the abnormal SERPINA1 gene—one from each parent.

WHY SHOULD I GET TESTED NOW?

Alpha-1 is a progressive condition. Liver and lung disease can occur without you knowing, with symptoms developing only once significant and sometimes irreversible damage has happened. The only way to know if you have Alpha-1 is to get tested. This test is free and cannot be billed to you or your insurance company.

HOW WILL I KNOW IF I HAVE ALPHA-1?

Your confidential results will be sent to the healthcare provider who ordered your test. Only a healthcare provider can diagnose Alpha-1. If you have Alpha-1, support is available (see other side).

Patient Information Overview (Cont.)

WHO IS PROVIDING THE FREE TEST AND WHY?

AlphaDetect, a non-profit organization supported by the Alpha-1 Foundation, provides this free test. Their mission is to accelerate detection to uncover everyone genetically at risk for Alpha-1.

WHAT YOU'LL LEARN FROM GETTING TESTED

The test result will determine your risk for Alpha-1 based on the four most prevalent mutations, also known as deficient alleles. Testing may include gene sequencing of SERPINA1. Your healthcare provider will use the results to determine next steps.

LIMITATIONS

A normal test result does not mean you have no risk. It means you do not carry alleles with a known risk for Alpha-1.

PRIVACY

Test results are kept strictly confidential. Genetic results will only be shared with the healthcare provider who ordered the test.

SUPPORT

If your results show you are at risk for Alpha-1, the Alpha-1 Foundation (A1F) wants to support you and your needs. By providing your consent, A1F can send you important information and free resources. They would only know you are at risk and your name/email address. You can opt out at any time via email at A1F@alpha1.org

RESEARCH

As a non-profit, AlphaDetect wants to help researchers understand more about Alpha-1. De-identified* health history and genetic information can help healthcare providers and researchers understand how alpha-1 genes affect human health. While you will not receive any direct benefit or payment for sharing your data, agreeing will benefit the Alpha-1 community at large and may help provide better care for anyone at risk.

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The Alpha-1 Foundation is a non-profit organization committed to finding a cure for Alpha-1 and to improving the lives of people affected by Alpha-1 worldwide. Visit alpha1.org

*De-identified means that personal details are removed, such as your name, address, or date of birth, so no one can tell who the information belongs to.