

Could your **Asthma or COPD** be **Hereditary?**



A guide to Alpha-1 Antitrypsin Deficiency





Your Asthma or COPD could be a hereditary disease called **alpha-1 antitrypsin deficiency**

Alpha-1 antitrypsin deficiency, also called Alpha-1, A1AD or AATD is a common serious hereditary disorder and can result in

Common signs and symptoms of alpha-1 antitrypsin deficiency

Lung

- family history of lung disease
- rapid deterioration of lung function with or without a background of significant smoking or occupational exposure to lung irritants
- asthma that is not fully responsive to treatment
- shortness of breath or awareness of ones breathing
- decreased exercise tolerance
- recurring respiratory infections
- chronic cough and sputum (phlegm) production
- **Ask your doctor about being tested**

Liver

- family history of liver disease
- unexplained liver problems
- elevated liver enzymes
- **Ask your doctor about being tested**

life-threatening lung or liver disease. Knowing that you have Alpha-1 opens up many lifestyle and treatment decisions as well as the knowledge to avoid risk factors, all of which can improve your quality of life.

Everyone's liver produces alpha-1 antitrypsin (AAT). The job of AAT is to protect the body from inflammation, especially in the lungs. In people with Alpha-1 their AAT is malformed and can not be released by their liver. Most commonly this leads to lung disease but the build up of AAT in the liver can also lead to liver disease.

While it is important to know that not everyone who has Alpha-1 will develop symptoms, even people who are 'only carriers' can develop symptoms. We still don't know why this is so, but we do know that early detection, treatment and lifestyle changes can make a dramatic difference in the progress of the disease.

As a result, the sooner a diagnosis is made the more effective lifestyle and treatment options will be.

Who should be tested for alpha-1 antitrypsin deficiency?

- **The World Health Organization (WHO), the American Thoracic Society and Alpha-1 Canada recommend that everyone with COPD be tested for alpha-1 antitrypsin deficiency.**
- everyone with emphysema, chronic obstructive pulmonary disease (COPD), chronic bronchitis or asthma that is not fully responsive to treatment
- individuals with bronchiectasis
- newborns, children and adults with unexplained liver disease
- individuals with a family history of liver disease
- blood relatives of persons diagnosed with alpha1-antitrypsin deficiency
- anyone with panniculitis, a skin disease
- **Ask your doctor about being tested**

Testing for alpha-1 antitrypsin deficiency

Testing for alpha-1 antitrypsin deficiency is simple and quick. It is usually done through a blood test. People at risk for alpha-1 antitrypsin deficiency should be tested.



For more information about testing contact Alpha-1 Canada at 1-888-669-4583 or visit our web site at www.alpha1canada.ca. The Alpha-1 Canadian Registry provides information on research and testing, you can visit their website at www.alpha1canadianregistry.com or call 1-800-352-8186.

Your future with alpha-1 antitrypsin deficiency

A positive diagnosis of alpha-1 antitrypsin deficiency represents an opportunity to take concrete steps to avoid risk factors, limit symptoms, or slow the progression of symptoms you may already be experiencing. Proper care by you and your physician can have significant positive effects for the rest of your life.

Not everyone with A1AD develops symptoms and even if you have developed symptoms, proper treatment by your physician and lifestyle changes you can make will significantly increase the quality and quantity of your life. If you are symptom free, you have a good chance of remaining so by making small but important changes in the way you live. Similarly, even if you have developed symptoms, appropriate medication, treatments, exercise and lifestyle changes can go a long way toward ensuring you live a long and happy life.

A treatment called augmentation therapy is an option for many patients. Augmentation therapy increases the amount of alpha-1 antitrypsin in a patient's blood stream thereby providing protection for the lungs. Your physician is the best person to provide information about medications and treatment and to take care of you in medical terms, but there are important actions you can take to help take care of yourself.

Be involved in your healthcare

- The greatest risk factor for developing life-threatening symptoms is cigarette smoke. If you smoke, quit and avoid second hand smoke as well.
- Avoid other lung irritants, especially environmental pollutants used in agriculture, mineral dust, gas, and fumes.

- Regular exercise and good nutrition are beneficial in maintaining lung health, as are maintenance of fat-soluble vitamins (A, D, E and K). Eating a well balanced diet should provide good amounts of these fat-soluble vitamins, although extra supplements may be advised by your doctor. Remember, Alpha-1 is also a liver disease and fat-soluble vitamins are stored in the liver and fatty tissues. Mega doses of some vitamins can harm the liver.



- Even if your symptoms are limited to respiratory problems, you also need to take care of your liver in order to minimize the possibility of liver disease. Avoid things that may cause extra harm to the liver such as alcohol, street drugs, some over the counter drugs and certain prescribed medications.
- There is no specific treatment for Alpha-1 associated liver disease. Eating a well balanced, healthy diet that contains plenty of fruits and vegetables is essential to provide your liver with the antioxidants that it needs to protect against inflammation.
- Researchers around the world are studying Alpha-1 and learning more all the time. Visit the Alpha-1 Canada web site regularly for the latest news and advice on managing your Alpha-1. You can find us at www.alpha1canada.ca

Alpha-1 Canada, improving the lives of Alphas

The Canadian Alpha-1 Community faces many issues of concern that impact the quality of life for those affected today and for future generations. Alpha-1 Canada is committed to addressing these issues and to fostering a community that is well informed and responsive.

We are a registered not-for-profit charitable organization governed by a volunteer board of directors and assisted by a medical advisory board made up of Canada's top researchers and clinicians in the field of Alpha-1.

For more information about alpha-1 antitrypsin deficiency, Alpha-1 Canada, new programs and services for the Canadian Alpha-1 Community or to receive our newsletter and participate in information, education or support activities, visit our website at www.alpha1canada.ca or contact us at 1-888-669-4583.

**Join the Alpha-1 Canada
Community today at
www.alpha1canada.ca**



Get involved, stay informed

Join the Alpha-1 Canada Community

Joining the Alpha-1 Canada Community is easy. Just visit our web site at www.alpha1canada.ca and follow the menu link.

- Sign up and receive our regular e-newsletter, The Alpha-1 Canada Community News.
- Read the latest news and information about alpha-1 antitrypsin deficiency.
- Learn about new clinical trials.
- Login to access support discussion groups, information on educational events and notices of updates to the web site.

Don't have internet access? Contact us directly at 1-888-669-4583.

Donate

Whether it's \$5 or \$500, your donation will be put to good use providing information and support to the Alpha-1 Canada Community; informing the medical community about alpha-1 antitrypsin deficiency; generating broad awareness about this genetic liver, lung and skin disease, and helping us assist adults, children and their parents to cope with this disease.

If you would like to make a donation, please visit our web site to learn how. We are able to issue receipts for tax purposes.

Volunteer

Volunteers are the most important resource of Alpha-1 Canada. Volunteers are our board members, support group leaders, researchers and ambassadors.

Most importantly volunteers provide a valuable link to the medical community, the general public and others with alpha-1 antitrypsin deficiency.

Join the Alpha-1 Canada Community today at www.alpha1canada.ca

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