

Some important words to know about Alpha-1 – what they mean and how to pronounce them:

Alpha-1 Antitrypsin Deficiency (ALF-a-ONE-anty-TRIP-sin Da-FISH-in-see) – A hereditary condition which may result in serious lung disease in adults and/or liver disease at any age. Called just Alpha-1 for short. People with Alpha-1 are usually called simply Alphas.

Alpha-1 antitrypsin (ALF-a-ONE-anty-TRIP-sin) – A protein in the blood that protects the lungs from inflammation caused by infection or inhaled irritants. Alpha-1 protein (often called AAT) is mainly produced by the liver.

Ascites (a-SITE-ease) – Fluid buildup in the belly, often caused by liver disease.

Augmentation (AUG-min-TAY-shun) **therapy** – Giving purified alpha-1 antitrypsin protein through the veins to increase the amount of protein in the blood and lungs of an Alpha. Also called “replacement therapy.”

Bronchiectasis (BRONK-ee-ECK-ta-sis) – Permanent enlargement of the bronchial tubes. People with bronchiectasis often cough up phlegm every day.

Chronic bronchitis – (KRON-ic bron-KITE-is) Chronic inflammation of the bronchial tubes. (Chronic means lasting a long time.)

Bronchodilator (BRONK-o-DIE-later) – Medicine that opens the airways.

Carrier — An Alpha-1 carrier has one normal alpha-1 gene (M) and one abnormal alpha-1 gene (usually Z or S). Carriers may have lower blood levels of alpha-1 protein and can pass on the alpha-1 gene to their children. There are an estimated 19 million carriers in the United States.

Cirrhosis (sir-ROCE-is) –Severe scarring and hardening of the liver.

COPD – (the initials for Chronic Obstructive Pulmonary Disease) – Lung diseases, including emphysema, chronic bronchitis and bronchiectasis, that cause shortness of breath. An Alpha with breathing problems is often first diagnosed with asthma or COPD.

Deficiency (Da-FISH-in-see) – A lack or low level of alpha-1 antitrypsin protein in the blood and lungs.

Exacerbation (ex-ASS-er-BAY-shun) –Flare-up or episode when a health condition gets worse. Pneumonia is an example of a severe exacerbation of Alpha-1 lung disease.

Genes (jeans) –Genes are DNA sections that cause human characteristics, like your eye color or whether your hair is straight or curly. You generally get one gene from each parent. Genes also hold the instructions for making proteins.

Genotype (JEAN-o-type) — When referring to Alpha-1, the type of gene in your Alpha-1 DNA. While this is different from phenotype (see below), both are usually expressed with the same letters, for example, ZZ or MZ.

Genetic or Hereditary (ja-NET-ick or ha-RED-a-TARRY) — Passed on from parents to their children through genes. Alpha-1 is a genetic condition.

Panniculitis (pa-NICK-you-LITE-is) — Inflammation in fat beneath the skin which causes the skin to harden and form painful red lumps and patches. It is a rare condition associated with Alpha-1.

Phenotype (FEE-no-TYPE) — The type of alpha-1 protein circulating in your blood. Also called Pi-type. “Pi-ZZ” and “Pi-SZ” mean the same thing as just “ZZ” or “SZ”.

Pulmonologist (PULL-ma-NOLL-a-gist) –A doctor who specializes in lung health. In Canada and the United Kingdom, usually called a respirologist.

Pulse oximeter (ox-IM-mitter) – A device that measures the oxygen levels in your blood and how fast your heart is beating.

Spirometry (spy-ROM-it-tree) –A simple test that gives a basic measure of how well your lungs are working.