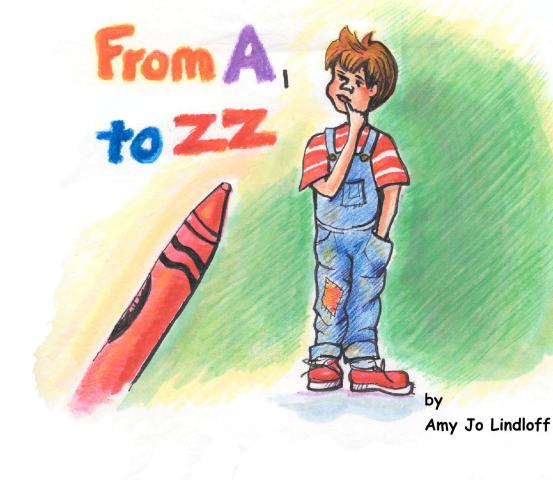
Alpha 1-Antitrypsin Deficiency Alphabet



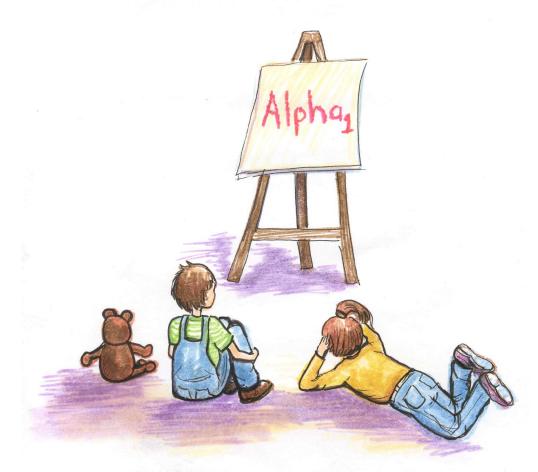
Alpha 1-Antitrypsin Deficiency Alphabet From A1 to ZZ

By Amy Jo Lindloff Illustrated by Christine Ohlsen One day, I started to wonder how I was going to tell my daughters, then ages 3 and 1, that they both had Alpha 1 Antitrypsin Deficiency. I wanted to be able to explain to them the risks of the disease, the precautions that they could take, and that it should in no way inhibit what they do in life. What follows is my gift to them.

To any family dealing with Alpha 1, my prayers are with you and I hope this book helps.

To Kaitlyn and Elizabeth, who have shown me that with hope, love and prayer, anything is possible.





That's hard to say. Can you say it? We can just call it Alpha 1.



Sometimes we find out that someone has Alpha 1 when they are a baby and get sick.





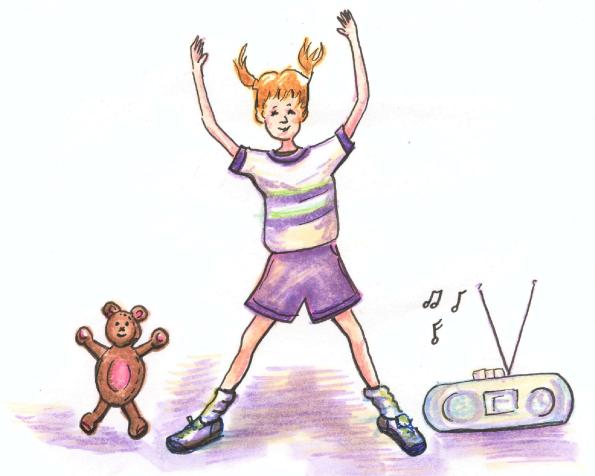


Other times, we don't know that children have Alpha 1 until they are older, and maybe even a grown up.



Alpha 1 is a disease. You didn't catch it like you catch a cold or the chicken pox and you can't give it to someone. There is absolutely nothing you did that caused this to happen.





It is important to exercise to keep your body strong and healthy.





There are a lot of fun things that kids with Alpha 1 can do, like football, finger painting and play with friends.



Now isn't that a funny word? Alpha 1 is a genetic disease, passed on by our parents. Genetics is what makes everything about you who you are, from the color of your hair and eyes, to the size of your feet.



H is for Hospital

When someone is sick, they may go to the hospital. In the hospital or at the doctor's office the lab technicians may take blood out of your arm with a needle. They will then test the blood to see if your liver is working right.











Jaundice means that a person's skin color is yellow. If you have Alpha 1 you may have had jaundice as a baby.



A kid with Alpha 1 can do anything!



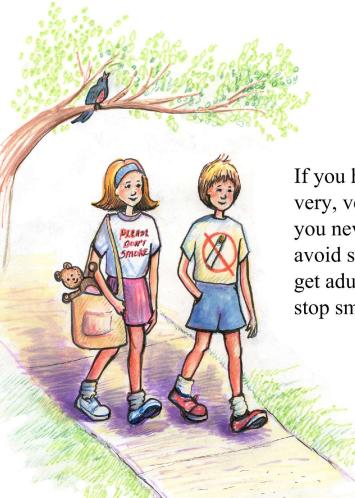
Alpha 1 may cause your liver or your lungs to get sick. In some people, the liver is sick because it can't get rid of the stuff inside of it. The liver is in the right side of your belly, just below your ribs. It helps to make the food you eat into useful fuel that your body needs for energy and to help ungs you grow. Waste, the Liver stuff your body doesn't need, is called bile. Bile is what makes poop brown.





Sometimes you'll have to go to the doctor. The Medical Doctor will listen to your lungs with a stethoscope and push on your tummy to feel your liver.





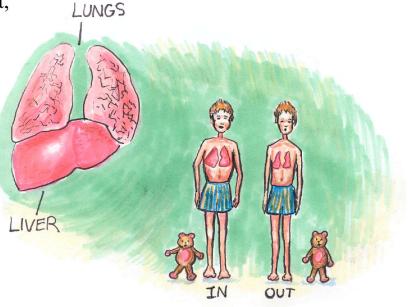
If you have Alpha 1 it is very, very important that you never smoke. Try to avoid smoky places and get adults you know to stop smoking too.

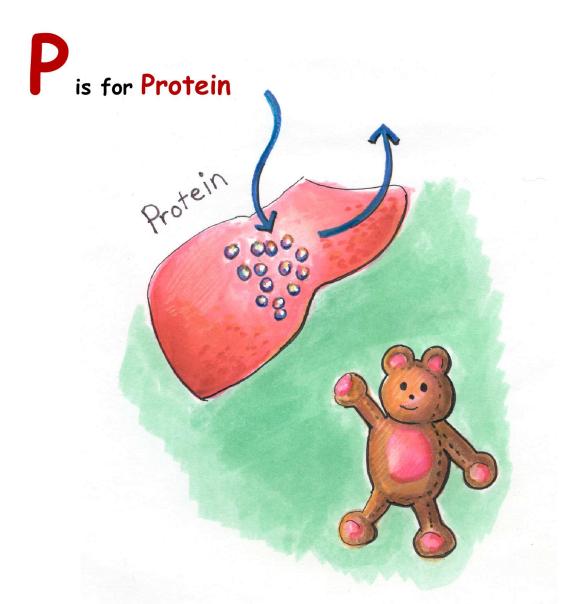


Organs are parts inside your body that help you to grow and do things, and to give you energy. The liver and lungs are organs in your body. The lungs may get sick when they are damaged from smoke and pollution. Alpha 1 may make it hard to protect the lungs from these things.

The lungs are located in your chest. When you breathe in, the oxygen in the air moves through your lungs into your blood.

When you breathe out, carbon dioxide (or "used" air) comes out of your lungs. All the cells in your body need oxygen to work. Now you try it. Take a deep breath in, feel your lungs fill up with air, now blow out. Good Job!!





Alpha 1 is a protein in your body that is made in the liver. It is sent out from the liver through your blood. It helps to protect your lungs. If you have Alpha 1 you don't have as much of this protein as people who don't have Alpha 1.



You can snuggle with a quilt when you don't feel good.

Q is for Questions. Never be afraid to ask your doctor questions.



Research means trying to find answers to what causes

diseases. There are people researching Alpha 1 to try to find ways to stop it from making people sick. There may even be ways that you can help in this research. Ask your doctor if you can help.





To protect your lungs and keep them healthy, it is very important to stay away from places with a lot of smoke or smog (pollution).



Sometimes a liver can become so sick that the doctors, called surgeons, have to do a transplant. They will take out the bad liver and put in a new healthy one.



An ultrasound is a test the doctors do to see what you look like inside. They squirt cold gel on your tummy to make the machine work, and you can watch on the monitor as the doctor looks at your liver, spleen, gallbladder and other organs.





Make sure you take your vitamins and eat all your vegetables. This will help your body to be strong and healthy It will also give you energy to play.



What are some of the things that you can do to help your body stay strong and healthy? Can you remember what we read?

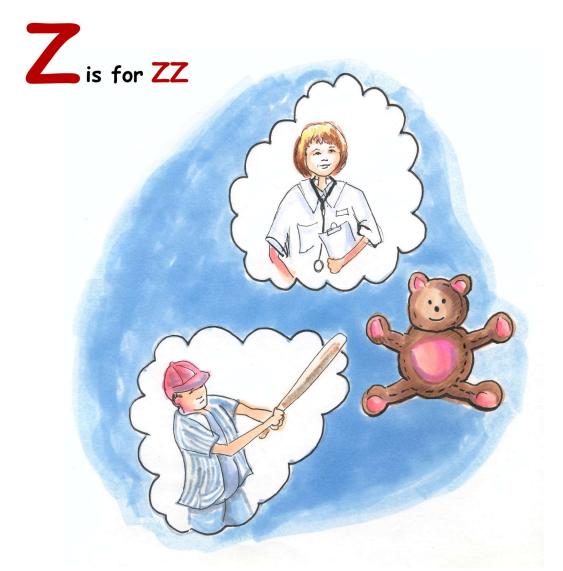


eXcellent answers to the question! You can exercise, play, eat your fruits and vegetables, take your vitamins, ask questions, never smoke and avoid smoky places. All of these things will help your body stay strong and healthy!





Sweet, wonderful, adorable YOU!



Remember the word genetics? If someone has the genetic code ZZ, then that person has Alpha 1. That very special person can do anything and be anything. What special things can you do? What do you want to be when you grow up?



The Alpha-1 Kids program is dedicated to providing support, education and information for parents and families of children affected by Alpha-1.

For more information about the Alpha-1 Kids program, please contact us at: Telephone: (877) 346-3212 • E-mail: <u>info@alpha1.org</u>

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