

## Alagille Syndrome

Alagille Syndrome (AGS/ALGS) is a rare genetic disorder that causes abnormal development of many organs in the body. It occurs in approximately one in every 30,000 live births and there is no known cure.

Individuals with ALGS may have some or all of the following symptoms:

- a scarcity of bile ducts inside the liver that causes little or no passage of bile to the small intestine and a build-up of substances in blood
- yellowing of the eyes and skin, itching, and fatty deposits in the skin (xanthomas)
- trouble gaining weight and growing because of mal-absorption of fat, fat-soluble vitamins (A, D, E, and K) and nutrients
- a heart murmur most commonly caused by a narrowing of the arteries in the lungs (pulmonary stenosis)
- Tetralogy of Fallot, which causes blood in the chambers of the heart to mix and the skin to be bluish because of limited oxygen in the blood
- pulmonary atresia in which the pulmonary artery does not form normally and may be closed or missing
- a specific facial appearance associated with ALGS
- unusually shaped spine bones (butterfly vertebrae)
- skeletal abnormalities
- kidney abnormalities
- blood vessel abnormalities
- an extra line in the eye (posterior embryotoxon)
- changes in the pancreas or thyroid



**Josi**

Most people with ALGS can lead long and productive lives. However, those with progressive liver disease or severe heart problems may have a shortened life span. In 20-30% of patients the liver disease is so severe that a liver transplant may be needed. Bleeding around the brain and strokes caused by abnormal blood vessels in the brain can sometimes be a serious complication. In every patient with ALGS, careful attention to taking medications and improving nutrition leads to substantially improved quality of life.



**Alaina**

## Alagille Syndrome Alliance

The Alagille Syndrome Alliance is an international support and advocacy network for people with Alagille Syndrome (AGS/ALGS) and their families. Founded in 1993, the Alliance now includes several hundred families located all over the world.



**Gabriel**

The Alliance works to provide a forum for families to meet on a regular basis for mutual support and sharing of information on ALGS. We strive to include as many families as possible in our programs and services so that all may benefit. We are dedicated to increasing public awareness of this rare condition. We recognize the wealth of knowledge that is gained through research and encourage families to participate in studies so that they may contribute to the growing data base about this disease. Our most recent initiatives include developing a registry for patients, and funding research grants.

We are here to answer questions, provide sound information, and lend a sympathetic ear as families enter the world of ALGS and the challenges it presents throughout one's life. We exist to celebrate the ALGS community and to help those challenged by this rare condition build a better life through education, collaboration and research.

## Donate Today!

The beauty of the Virtual Walk is that AGS families don't actually have to get out and do any walking, jogging, skipping or anything else, unless they want to. All they do is use the Virtual Walk as an excuse to raise money by talking to or emailing their friends, family, coworkers, church community, and everyone else they know and asking them to make a donation to the Alliance.

If families want to step outside the virtual world, however, they may show up anywhere and everywhere. The sky is the limit! That's the beauty of the ALGS Virtual Walk. A family might undertake a letter writing campaign to relatives and friends asking for their support. A "change for a cause" competition at work, with the winner getting a casual clothes day, is another possibility. They might decide to organize their own mini walk-a-thon around the local park, mall, or high school track. The adventure is limited only by the fundraiser's imagination!

Donations may be made in any of the following ways:

- Cash or check (payable to Alagille Syndrome Alliance) given directly to the fundraising individual or family
- Cash or check (payable to Alagille Syndrome Alliance) mailed to 10500 SW Starr Drive, Tualatin, OR 97062
- Online at [www.alagille.org](http://www.alagille.org) by clicking on the Donate button on the Virtual Walk page (<http://alagille.org/vw.html>)
- Online through our Cause page on Facebook (<http://www.causes.com/causes/328999?m=0d43bb06>)

Be sure to let us know the name of your Virtual Walk Team so we'll know who to credit for your donation.

Team Captain:

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Team Name:

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Contact Information:

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# AGS/ALGS VIRTUAL WALK FOR A BETTER LIFE

**AUGUST 15-OCTOBER 15, 2011**

The purpose of the Virtual Walk is to raise funds to support the programs and services of the Alagille Syndrome Alliance. It's also a great way to increase awareness of Alagille Syndrome (AGS/ALGS) in communities around the globe. Funds raised during the Virtual Walk will be used to publish our newsletter, maintain our website, fund educational programs like ALGS Family Days and our International Symposium, which is held every three years, and to help build our Julie Kelin Fund for ALGS Research and Education. Together we will build a better life for everyone with this rare condition.

