ALAGILLE SYNDROME (ALGS)

A rare disease that can affect multiple organ systems in the body, including the liver, heart, skeleton, eyes, and kidneys.

1 in 30,000 to 50,000 people are diagnosed each year.[1,2]

COMMON SIGNS

ALGS doesn't affect everyone the same, but common symptoms include[3,4]:

Itching (pruritus)

Yellowing of skin (jaundice)

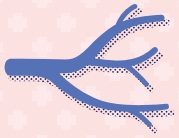
Failure to thrive

Enlarged spleen

Spinal growth changes

Eye abnormalities

Swishing heartbeats (heart murmurs)



Change in size or shape of blood vessels

Decreased or imparied kidney function

WHAT HAPPENS IN THE LIVER

A healthy liver produces bile, a liquid that helps with digesting fats and absorbing vitamins. Bile is transported through bile ducts.

90% **of people with ALGS have fewer bile ducts which can lead to an increase in bile acids in the liver (cholestasis).** This prevents the liver from draining the bile properly, leading to liver damage.

This **can also lead to a backup of bile in the liver and bloodstream, and may lead to itching**[5] which can be so bothersome that patients may scratch through their skin.

DIAGNOSES & TREATMENT

It is important to diagnose ALGS early to begin a treatment plan. A pediatrician or general practitioner may recommend a care team of specialists, including hepatologists (liver specialists), cardiologists (heart specialists), nephrologists (kidney specialists), and/or ophthalmologists (eye specialists).

A doctor can help determine the best treatment approach for you or your child.

References: 1. National Organization for Rare Disorders. Rare Disease Database: Alagille Syndrome. https://rarediseases.org/rarediseases/alagille-syndrome. Accessed August 23, 2022. **2.** Leonard L. et al. *European Journal of Human Genetics*. 2014;22(3). **3.** Kamath BM. et al. *J Pediatr Gastroenterol Nutr*. 2018;67(2):148-156. **4.** Kamath BM, et al. *Hepatol Commun*. 2020;4(3):387-398. **5.** Ben Ameur S. et al. *Archives de Pédiatrie*. 2016;23(12). 1247-1250.

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