

Understanding the basics of **Alagille syndrome** and a treatment for it

This guide can help you discuss Alagille (pronounced *a-luh-jeel*) syndrome, also known as ALGS, and a treatment for itch with your doctor, with tips for those conversations if you're not sure what to ask.

Alagille syndrome is a rare genetic disease that causes damage to the liver, and can affect the heart, eyes, skeleton, kidneys, face, and nervous system.

Asking your doctor about Alagille syndrome

How is Alagille syndrome affecting my or my child's liver and other parts of the body?

Are any tests needed to get a fuller picture of the impact of Alagille syndrome?

Do I need to visit other doctors who specialize in parts of the body affected by Alagille syndrome?



What is Bylvay® (odevixibat)?

Bylvay is a medicine to treat cholestatic pruritus in patients 12 months of age and older with Alagille syndrome.

IMPORTANT SAFETY INFORMATION

- Speak with your healthcare provider if you experience abdominal pain, vomiting, diarrhea, hematoma, decreased weight, or dehydration as these have been reported with the use of Bylvay. Patients should contact their healthcare provider if they experience new onset or worsening of diarrhea

Please see additional [Important Safety Information](#) throughout, and the full [Prescribing Information](#).



Talking to your doctor about **treatment** for itch from Alagille syndrome

Ask your doctor

There are different ways of managing Alagille syndrome. Ask your doctor to explain



**Nutritional
supplements**



**Medications
to treat itch**



**Surgery,
liver transplant**

**Bylvay is an FDA-approved medicine to treat cholestatic pruritus (itch)
in patients with Alagille syndrome as young as 12 months of age**

**Use the questions below as a starting point for talking to your
doctor about whether Bylvay is right for you.**

Could Bylvay help me or my child with itch from Alagille syndrome?

How is Bylvay taken?

How does Bylvay work?

Can Bylvay help with any level of itch?

How soon can results be seen when starting Bylvay?

What side effects can occur when taking Bylvay?

What support is available for people starting Bylvay?

IMPORTANT SAFETY INFORMATION (CONT'D)

- Elevations in liver tests (for example, AST, ALT, TB) have been observed with use of Bylvay. The patient's healthcare provider will obtain liver tests before starting Bylvay and periodically during treatment with Bylvay. Patients should report to their healthcare provider any symptoms of liver problems (for example, nausea, vomiting, skin or the whites of eyes turn yellow, dark or brown urine, pain on the right side of the abdomen, loss of appetite)





All images are actor portrayals.

**Bring this discussion guide
to your next appointment to
help you have a full conversation
with your doctor about itch
from Alagille syndrome**

Notes: _____



Talk to your doctor about how itch from Alagille syndrome impacts you or your child

IMPORTANT SAFETY INFORMATION (CONT'D)

- Bylvay may impair absorption of fat-soluble vitamins (FSV), which include vitamins A, D, E and K (vitamin K is assessed by measuring INR). The patient's healthcare provider will obtain serum levels of vitamins A, D, E, and INR (for vitamin K) at baseline and periodically during treatment to assess for worsening of FSV deficiency
- Do not swallow the 200 mcg or 600 mcg capsule(s) containing Oral Pellets whole. These are intended to be opened and the contents mixed into soft food. Take Bylvay in the morning with a meal
- For patients taking bile acid binding resins, take Bylvay at least 4 hours before or 4 hours after taking a bile acid binding resin

You are encouraged to report side effects to FDA at 1-800-FDA-1088 or at www.fda.gov/medwatch. You may also report side effects to Ipsen Biopharmaceuticals, Inc. at 1-855-463-5127.

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