

Talking to your doctor about **itch** (cholestatic pruritus) from Alagille syndrome

Itch from Alagille syndrome is more than normal itching and may be frequent, deep, and frustrating

If you or your child experience any of these, talk to your doctor about the impacts of itch

- | | |
|---|--|
| <input type="checkbox"/> Bleeding or scarring from scratching | <input type="checkbox"/> Changes to nightly routine |
| <input type="checkbox"/> Difficulty falling or staying asleep | <input type="checkbox"/> Needing to sleep with a caregiver |
| <input type="checkbox"/> Blood on bedsheets from scratching | <input type="checkbox"/> Needing medications to sleep |

What other ways does itch from Alagille syndrome impact daily life for you or your child? Write them down here and share with your doctor.



Signs of itch aren't always obvious

Babies and young kids may

Rub themselves or rub against objects

Kick their legs and be restless

Cry, be irritable and fussy

Struggle to fall and stay asleep



Older kids and adults may

Feel embarrassed or be impacted socially

Feel effects on mood

Struggle to concentrate

Struggle to fall and stay asleep

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
- 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)

Your Alagille syndrome **itch tracker**

Itch is a common symptom of Alagille syndrome, and tracking it over time can help you give doctors a full picture of how things are going

At the end of each day, use the table below to track itch and share the results with your doctor

No scratching



0

A little scratching



1

Medium scratching



2

A lot of scratching



3

Worst possible scratching



4

___/___ - ___/___
MM DD MM DD

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Use this space to write down any specific notes (for example, was itch worse at night or during the day?).

Share this with your doctor to keep them informed about how itch is affecting 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



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