



Assessing the Unbearable Itch

A Guide for Caregivers and Patients With Alagille Syndrome (ALGS)

Intense itching—also known as cholestatic pruritus—can be one of the most unbearable symptoms of Alagille syndrome. As a person with Alagille syndrome or a caregiver of a child living with this disease, you've seen the impact that this itch can have.

You're not alone. While your doctor may not see just how intense the itch is, sharing symptoms in greater detail can help them better grasp how you or your child are feeling.

This guide will help you assess this frequent itching. Even more, this guide can help you decide what to share with your doctor and what to ask at your next appointment.

What Causes the Itch?

In Alagille syndrome, a buildup of bile acids in the liver and blood occurs because of a problem with the tubes—also called bile ducts—that normally allow bile acids to flow out of the liver. This buildup of bile acids in the liver and blood is often associated with an intense itch.

How the itch might impact your or your child's life

The scratching can greatly affect one's life and lead to:



Wounds and scars



Anxiety



Sleepless nights



Emotional grief



Exhaustion



Set Your Sights on Itch Relief

Your doctor may not be aware of how severe the itch is and how it is impacting you or your child. Detailing symptoms can help your doctor decide what steps to take next, such as more frequent check-ins or even a change to current treatment.



Describing the Itch

While it is important to discuss this unbearable itch with your doctor, we also know it can be hard to find the right words to describe it. To paint a more accurate picture, consider answering the following questions:

How often does itching result in skin damage (eg, red marks, scratches, and/or open wounds)?

- Every day
- Many times per week
- Once or twice per week
- Once or twice per month
- Never

How often does itching make it hard to fall asleep or stay asleep?

- Every day
- Many times per week
- Once or twice per week
- Once or twice per month
- Never

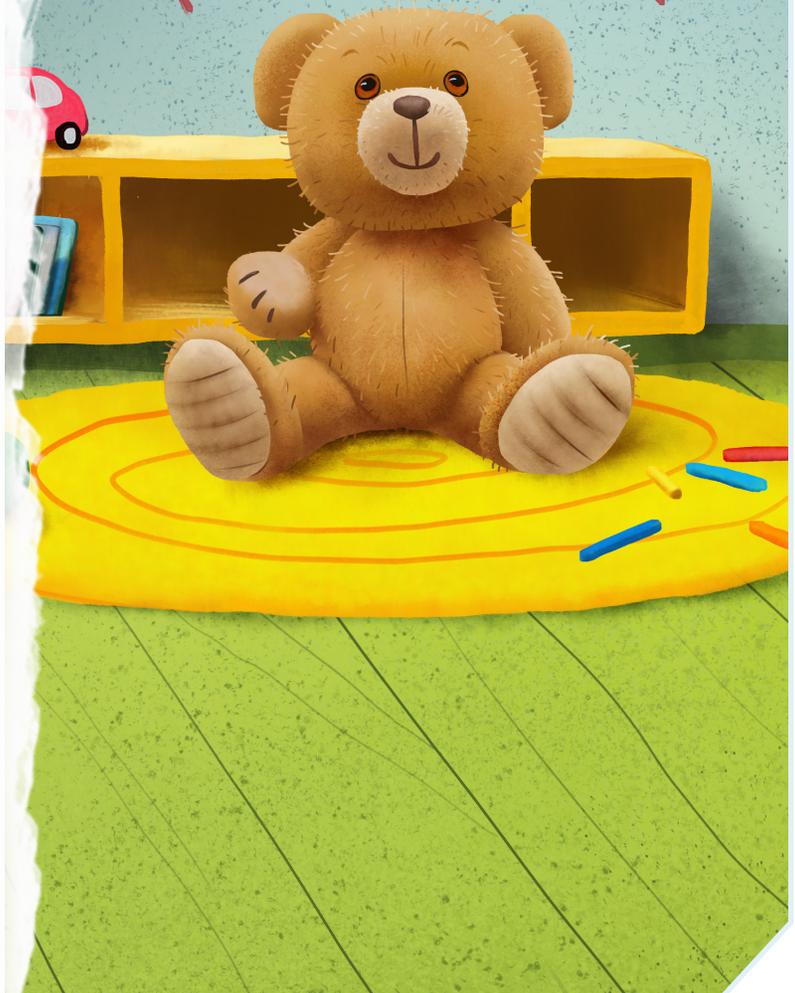
How often does feeling itchy impact daily life (eg, unable to focus in school, can't participate in activities, feeling left out with peers, etc)?

- Every day
- Many times per week
- Once or twice per week
- Once or twice per month
- Never

How much relief do you or your child get from the current itch treatment?

- A lot of relief
- Some relief
- No relief at all

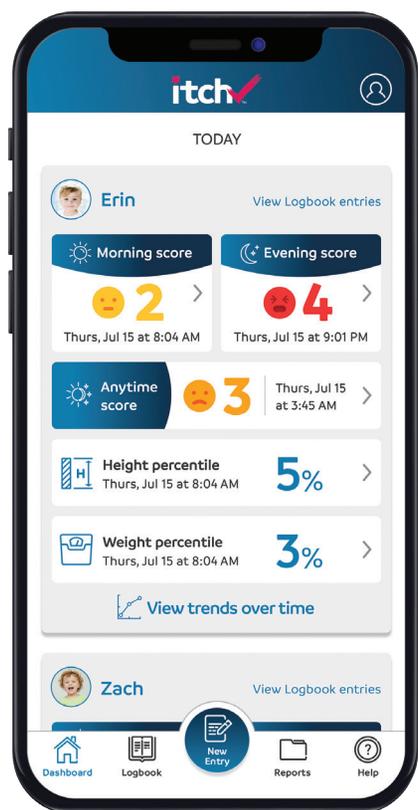
ALAGILLE SYNDROME



Tracking the Itch

Beyond describing the itch, it is also important to keep an ongoing record of your or your child's symptoms and observations. This daily log can feel overwhelming, though. To help make it easier, the **Itch✓ app** was created.

Available in the Apple® App Store®, Itch✓ measures itch severity based on a 5-point scale, from not itchy at all to extremely itchy. It is meant to be completed twice a day—once in the morning and once in the evening. Ultimately, this log will provide you with reliable, up-to-date records of your or your child's symptoms to share with your doctor.



When logging an entry, you can also add additional details to share with your doctor, including:

-  **Height**
-  **Weight**
-  **Photos**
-  **Notes**

More Itch✓ Features:

- **View graphs** to assess itch severity and growth over time
- **Create reports** to share with your doctor



Scan the code to download the app today.



Not using an Apple device? Visit [LifeWithALGS.com](https://www.lifewithalgs.com) to download and fill out a printable Itch✓ Journal.

When doctor visits are months apart, it can be difficult to recall symptom details, describe exactly how you or your child have been feeling, *and* pull up any pictures. That's why—using the data stored locally on your phone with Itch✓—you can more effectively discuss the itching and its impact with your doctor.*

*All personal data are stored locally on your device. Data are not available to developers.

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