

Autoimmune Hepatitis

Caring for your child or teen with autoimmune hepatitis

What is autoimmune hepatitis?

Autoimmune hepatitis, or AIH, is a disease in which the body's immune system attacks the liver and causes inflammation. Normally, the body's immune system only attacks substances that are seen as foreign invaders, such as viruses and bacteria. In AIH, the immune system malfunctions and attacks the liver.

What causes it?

The exact cause of AIH is unknown. We do know that certain factors can increase the likelihood of getting AIH. These include:

- Other diseases of the immune system
- Past infections
- Certain medicines
- Family history of autoimmune disease.

What are the symptoms?

AIH can range from a 'silent disease,' meaning there is active disease without showing many signs or symptoms, to acute liver failure, where a child has many signs and symptoms.

Symptoms that often appear first include:

- Tiredness and generally feeling unwell
- Loss of appetite

Other symptoms:

- Jaundice (yellow coloring of the skin or eyes)
- Pale (white or grey) colored stool
- Very dark yellow urine
- Unintentional weight loss
- Prolonged nose bleeds, bleeding gums and bruising easily
- Blood in the stool
- In adolescent girls, periods may cease or become irregular

How is autoimmune hepatitis diagnosed?

Your hepatology team will do several tests to rule out other liver or gastrointestinal diseases, while also testing for AIH. These tests can include:

- Lab tests (blood draws)
- Ultrasound scan
- Liver biopsy
- MRI-MRCP scan (special scan to look at the liver and pancreas)
- Upper and lower gastrointestinal endoscopy if there are intestine-related symptoms

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To Learn More

- Gastroenterology/Hepatology
206-987-2521
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

How is it treated?

AIH is a chronic illness, meaning the disease may require life-long treatment. This disease can have flares, where the disease is very active, as well as remissions where it gets better for a long period of time. We treat AIH with medicines, regular blood testing, imaging (looking at pictures of the inside of the abdomen), and close monitoring.

Medicines

Corticosteroids (also known as steroids)

Your child may be started on a steroid (prednisone) when they are diagnosed with AIH. Steroids help reduce the inflammation in the body very quickly. This helps get the liver healthy again. Often we start this medicine at a higher dose and then start decreasing the dose as the liver labs return to normal. This helps lessen side effects. Some children might be able to be weaned off prednisone, but most stay on a low-dose for a long time. Side effects of steroids can include:

- Increased appetite and weight gain
- Behavioral changes
- Acne
- Increased risk of infection

Immune modulating medicines

AIH is also treated with medicine that suppresses the immune system. These immune modulating medicines aren't used to treat flare ups, but are helpful once inflammation is already under control with corticosteroids. By modifying the immune system, they can help prevent AIH from flaring up again. These medicines include:

- Azathioprine
- Mycophenolate Mofetil (MMF)

The medicine used to treat your child's AIH will depend on their body's response to treatment, side effects, and how much they can tolerate.

What happens if autoimmune hepatitis gets worse?

Children with AIH usually do well on regular consistent treatment. If AIH is left untreated or progresses, some symptoms may include:

- Weight loss/poor weight gain
- Fluid in the stomach area
- Spleen enlargement
- Jaundice
- Gastrointestinal bleeding
- Liver failure requiring a liver transplant

Regular visits with your healthcare team, taking medicine regularly, and doing required testing will help prevent disease progression.

How should I care for my child with autoimmune hepatitis?

Activity and eating:

- Have your child eat a balanced diet of proteins, fats and carbs from a variety of foods
- Encourage regular exercise
- Please talk to your doctor if your child plays contact sports. Ask about which sports are included.

General tips:

- Let us know if you start a new prescribed medicine like antibiotics or medicine for acne.
- It is especially important for your child to avoid illegal drugs or alcohol. These substances are processed by the liver and can cause more liver damage.
- Have your child wash hands often and maintain good health hygiene
- Get all recommended vaccinations, including a yearly flu shot

When should I call my healthcare team?

Call your GI provider if your child has any of the following:

- Yellowing of the skin or eyes
- Pale (white or grey) colored stools
- More bruising than usual
- Bleeding from the gums or nosebleed that is hard to stop
- Severe stomach pain
- Vomiting blood or bile (green)
- Blood in the stool, or stool that is black in color

To call your provider on weekdays between 8 a.m. and 4:30 p.m., call the GI clinic to talk with a nurse 206-987-2521 option 4. Ask for the hepatology nurse or liver team.

For weekends, holidays, or after hour needs, call the hospital operator and ask for the GI/Hepatology doctor on call 206-987-2000

Resources

- Seattle Children's Family Resource Center
- Children's Liver Disease Foundation childliverdisease.org
- American Liver Foundation