ERN RARE-LIVER
European Reference Network on Hepatological Diseases

Autoimmune Hepatitis (AIH) for parents

Your child is diagnosed with Autoimmune Hepatitis (AIH)

It can come as a shock for you and your child to hear that your child is suffering from Autoimmune Hepatitis (AIH). The following text will explain what AIH is, the tests, diagnosis, treatment, vaccinations, and psycho-social issues you could face with your child.

Autoimmune hepatitis (AIH) can affect children of all ages and adults.
Here we describe AIH in children and young adults. This is different from AIH in adults.

What is Autoimmune Hepatitis

Autoimmune Hepatitis (AIH) is a less common cause of chronic hepatitis. Hepatitis means inflammation of the liver, and chronic means persistent or long-term. The inflammation is caused by the immune system. Chronic inflammation gradually damages the liver cells, which can result in problems.

You might have heard of hepatitis in the context of hepatitis A, B, C, D and E. These are completely different diseases caused by viruses and have nothing to do with the autoimmune hepatitis of your child. Hepatitis A, B, C, D, and E can be contagious, while AIH is not contagious.

AIH is an autoimmune disease

Autoimmune diseases are caused by the immune system's attack on the organ systems within the body. The immune system typically identifies and removes bacteria and viruses from the body. In autoimmune diseases, the immune system mistakenly identifies a part of the body as a foreign element and tries to damage it. This is caused by the production of autoantibodies in the immune system. It is unknown what causes the immune system to act this way.

The presentation of AIH

Your child might experience fatigue, itching, abdominal pain, and a general feeling of discomfort and may sometimes have a yellow tint to their eyes and skin. Even if AIH is present, the patient may not experience any symptoms for an extended period of time, and therefore it can be difficult to detect AIH in the first place. The symptoms are different from person to person, and every patient may need to explain their own experience of AIH to help the doctor monitor the disease.

Tests needed for diagnosis and follow-up

Several tests can be indicated to diagnose and monitor AIH in paediatrics and screen for simultaneous diseases of other organs: blood tests, urine analysis, stool test (faecal calprotectin), abdominal ultrasound, Fibroscan (specialised ultrasound), magnetic resonance imaging (MRI/MRCP) to investigate the bile ducts, liver biopsy, gastroduodenoscopy and/or colonoscopy.

Procedures can be challenging, especially for young children, so it is very important that both the caregivers and the child are well informed about what will happen.

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Here are some tips:

Before any procedure: Give correct information on what will happen during the procedure before it begins. This can help minimize discomfort and give the child the feeling that it can keep control of the situation.

During the procedure: Create a peaceful environment.

After the procedure: Congratulate the child and reinforce the positive things they did during the procedure. Decide and document a plan for next time, including what works and what should be done differently.

The diagnosis

The diagnosis will be based on results of the various tests. Sometimes the diagnosis of AIH is not the sole diagnosis. Your child may also have a diagnosis of IBD (Inflammatory Bowel Disease) and/or with primary sclerosing cholangitis (PSC). These diseases occasionally overlap in children with AIH, and are often discovered at the same time, using the same tests.

Your questions

The doctor will tell you about the expected prognosis and which medication is needed.

Some parents ask, 'Did I do anything wrong?', and the answer is: No it's now your fault. It can happen to anyone.

Others ask 'Is it hereditary?

Sometimes autoimmune diseases are more common in some families, but AIH as such is not hereditary.

Don't hold back any questions for your doctor. Unanswered questions may create unnecessary worry and can affect your wellbeing.

Treatment

Paediatric AIH most often responds well to immunosuppressive therapy reaching remission (no or minimal ongoing inflammation within the liver). If remission is reached and maintained the liver can recover and progress of the disease can be stopped. However, in most patients the treatment is necessary for lifelong to prevent inflammation.

The doctor will personalize the treatment because issues like growth and puberty must be considered in the treatment of children with AIH.

Relapse under treatment

During treatment, relapse of the disease can occur, particularly in adolescents. This can be due to lack of adherence in therapy or changes of hormone profiles, but it also happens without a certain cause.

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Adolescents and relapse under treatment

Adolescents relapsing under treatment is very common due to a lack of adherence to therapy. This occurs with many adolescents who have chronic diseases.

Education of the child and adolescent is part of the treatment. It is very important that the young person learns about the disease and understands the indication for the treatment, its side effects, and the potential detrimental consequences of non-adherence as early as possible. It is important not to wait until adolescence for them to understand that they have a chronic disease.

Side effects of treatment

Every medication may have side effects. The side effects of medications used to treat AIH may differ in children compared to adults. Talk to your child's paediatrician about the specific medications prescribed to your child.

Growing up

In general, children with AIH are not psychologically restricted in their growing up.

They will pass all the psychological stages as other children with good and bad times.

Enjoy the growing up stages! If you see that your child, or you as a parent, have difficulties, don't hesitate to discuss this with your child's paediatrician and ask for help if needed.

Transition

The time will come when your child will become a young adult and your child will transfer from paediatric to adult care. It's important that the paediatrician, you and your child prepare for this transfer slowly by supporting the transition process of your child.

Liver transplant in the future?

In case drug treatment do not work properly, there is a small risk that your child will need a liver transplant in the future. This is only if the liver has been damaged too much and is not functioning properly. The long-term risk factors for this are the amount of scar tissue seen in the biopsy/ies, the liver's ability to regenerate during treatment, and the overall response to treatment. Talk to your child's paediatrician about the risk for your child and how the status of the disease will be monitored.

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Vaccinations

In general, the recommendation is to vaccinate your child as described by the national vaccination program in your country.

If your child has been vaccinated, please pay attention to:

- Provide data on the previous vaccination schedule of the child to the treating physician and discuss all future vaccinations with the treating physician.
- The response to vaccinations can be suppressed under high doses of immunosuppression. Therefore, it is advisable not to give scheduled vaccinations in the initial phase of the treatment or in the immediate phase after a relapse. Ask your doctor about this.
- Because of the use of immunosuppressive drugs for some children, some vaccines can be contra-indicated. Discuss this with your child's paediatrician.
- Hepatitis A and B vaccination is recommended.
- Annual flu vaccination is recommended.

If a COVID-19 vaccination is available for children in your country, discus pros and cons with your child's paediatrician.

Sharing experiences

Check if a patient organization or a social-media group in your country has information on AIH. If not available, ask the doctor or nurse if any parents are willing to share their experiences with you.

More information are available on the ERN RARE LIVER Homepage: https://rare-liver.eu/

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