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AMERICAN SOCIETY OF
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Getting A New Liver: Facts About Liver Transplants

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Children Receiving a New Liver

WHAT DOES THE LIVER DO?

The liver has many important roles that keep your child healthy. The liver controls the way the body uses food. It also collects harmful substances and converts them into harmless substances. Sometimes it also makes sure the harmful substances are released from the body.

The liver produces bile which helps the body digest and absorb nutrients. Nutrients come from food and are necessary to prevent disease, to help you grow and to stay in good health. Nutrients can be used by the body immediately or stored in the liver.

- The liver acts as a filter by cleaning or removing waste products made by the body or that we may eat. These may include things like alcohol, drugs and medicines.
- Proteins are made by the liver to promote growth and healing. For example, some of the proteins made can help the blood clot or help to grow muscle.
- A specific protein called albumin is made by the liver. This protein serves many purposes. It can help carry medicines or other products to different parts of our body. It can also help to prevent fluid from leaking out of blood stream and into the ankles, abdomen, and/or lungs.

WHAT CAUSES LIVER DISEASE IN CHILDREN?

The most common reason children have liver disease is due to a genetic problem that damages the liver.

Some of the common liver diseases that affect children include:

- **Biliary atresia**
In this condition, the large bile ducts outside the liver that carry bile from the liver to the intestine do not develop normally. The bile is unable to drain from the liver and builds up inside. This bile is toxic and can damage the liver, leading to scarring and may cause the liver not to work as it should.
- **Alpha-1 antitrypsin deficiency**
Alpha-1-antitrypsin deficiency is a genetic disease where your child has lower than normal amounts of this protein. This protein helps prevent breakdown of tissue in lungs.

- **Alagille syndrome**
In this genetic disease the smaller bile ducts inside the liver do not form as they should, and bile can build up and damage the liver.
- **Wilson disease**
In this genetic disease, too much copper is stored in the liver and other parts of the body, like the brain. This disease may cause liver damage and can even cause damage to the nervous system.
- **Cystic Fibrosis**
This disease causes the body to create thick, abnormal mucous which can clog the bile ducts and lead to inflammation. This inflammation can affect the liver and damage it.

WHAT HAPPENS WHEN THE LIVER BEGINS TO FAIL?

- Liver failure is most often diagnosed by noticing decreased production of proteins (including clotting proteins and albumin) and by the decreased removal of waste products like ammonia. Liver failure can be caused by
 - a severe infection
 - an overdose
 - a reaction to medicines, or
 - by certain chronic liver diseases.
- If the liver is not getting bile into the intestine the body cannot absorb vitamins and nutrients as it should. This can lead to poor growth, especially for children.
- Liver failure can prevent bile from leaving the liver. This may cause our skin and eyes to turn yellow (jaundice) and to feel itchy.
- In liver failure certain waste products, like ammonia, are removed from the body. This may cause children to be more tired than usual, become more fussy or irritable, or to act strangely (we call this encephalopathy).
- When the liver fails it cannot create certain proteins. These proteins are necessary and can lead to bad effects. These bad effects include,
 - Certain proteins help the blood to clot and not enough of them can cause children to bruise or bleed more easily than normal.

- Not enough albumin may cause fluid to leak out of our blood vessels leading to a large, fluid-filled stomach (we call this ascites).
- Decreased protein production may also lead to an increased risk of infection.
- Liver failure can result from long term damage and scarring in the liver. This may cause high pressure in the vessels flowing into the liver from other organs. This may cause the vessels to swell. If one of these swells too much, it can burst. The bleeding could be deadly.

WHO NEEDS A LIVER TRANSPLANT?

There are a number of reasons a child may develop liver disease. If your child has one of the conditions noted above, a transplant may be necessary, but not right away. However, as these diseases get worse, there may be signs that signal a transplant is necessary. The signs include:

- Difficulty making clotting proteins (coagulopathy)
- Distinct personality or nervous system changes (encephalopathy)
- Episodes of bleeding from swollen veins (vomiting blood, dark stools)
- An uncomfortable, fluid-filled abdomen (ascites) that does not improve with medicine
- Recurrent infections of the liver or ascites
- Poor growth in spite of proper nutrition
- Persistent and constant itching
- Cancer of the liver that cannot be fully removed

The liver care team may try medications, surgeries, or other therapies to improve how well your child's liver works. However, when there are no more medical or surgical options, your child may need to get a new liver. It is important to realize that a liver transplant may be offered not only to help your child live longer, but also to improve your child's quality of life.

WHO DECIDES IF TRANSPLANT IS AN OPTION?

A multidisciplinary team of doctors, nurses, and coordinators will evaluate your child and decide if a transplant is possible. The team will also evaluate how your child will benefit from the transplant and if transplantation is the best treatment at this time.

WHAT IS THE EVALUATION PROCESS?

- During the evaluation the team will review your child's medical history, surgical history, and perform a physical exam.
- The team will also obtain a variety of lab tests.
- Some of these tests check for viruses in the blood. These tests will help match your child with an appropriate donor.
- There will also be tests to get a better look at your child's body. These tests include X-rays and other types of pictures.
- The evaluation team may also perform other procedures. These can include taking a small sample of your child's liver or putting a camera that looks down the throat and into the stomach while your child is asleep.

WHAT HAPPENS AFTER THE EVALUATION?

There are three possible results from the evaluation.

A. Accepted

This means your child has been accepted to receive a new liver. Your child's name is then placed on a list to receive a transplant operation.

B. Deferred

This means that more information and testing is required or that your child is not sick enough to be accepted to receive a new liver.

C. Not accepted

This means that your child does not meet the requirements to receive a new liver (see the potential reasons below).

What types of things may prevent a child from being a liver transplant candidate?

- An infection outside of the liver
- A malignancy (cancer) outside of the liver
- Current substance abuse (drugs or alcohol)
- Other organ failure besides the liver (heart failure, for example)
- Technical impossibility (determined by a transplant surgeon)
- Non-adherence to medication or medical care

WHAT ARE DONOR ORGAN OPTIONS FOR CHILDREN?

There are three different possibilities for getting a new liver for your child.

- **Reduced size liver graft**

The liver your child will receive is custom-made to fit your child's size by using several sections or parts of the new liver

- **Split liver Transplant**

The whole liver of a donor is used for two children

- **Living donor transplant**

A part of the liver from a living person is transplanted into your child

WHAT CAN I DO TO PREPARE MY FAMILY AND CHILD FOR LIVER TRANSPLANT?

There is no way to know how long your child will need to wait for a new liver. The wait could be a few days or many months or even years. Waiting for a transplant can be emotional. There are several things you can do to prepare while you wait.

- **Stay in touch**

Make sure all of your contact information is up to date. Sometimes providing several phone numbers (work, home, cell phone) can help us to reach you.

- **Plan ahead**

Make sure you have transportation to get to the hospital the day of the transplant. If your vehicle is not reliable, ask a friend, relative or social worker for help to get to the hospital. Pack a bag for the hospital stay ahead of time and leave it in your vehicle.

- **General health care**

Notify the transplant team of any changes in your child's health as this may affect the treatment plan. Check with the transplant office before your child receives any vaccinations. While we encourage vaccinations, your child should not have a transplant operation within one month of receiving certain vaccines, if possible.

WHAT HAPPENS AFTER THE TRANSPLANT OPERATION?

- After the operation to receive a new liver your child will be taken to the Pediatric Intensive Care Unit (PICU). This is where the medical team will start monitoring and evaluation your child's condition after the operation. Depending on your child's

condition, your child can stay in the PICU for a few days to a few weeks before moving to the regular part of the hospital to continue healing before going home.

- During your child's stay in the hospital, the transplant team will teach you about medicines your child will need to take. You will also be given special instructions that need to be followed before your child can leave the hospital.
- After leaving the hospital your child will need frequent visits to the transplant clinic. Depending on how well your child is doing after the first few months, the number of visits to the clinic will decrease. For several months after surgery your child will need to be tested frequently. These tests check how your child's liver transplant is working, the amount of medicine in your child's body to prevent rejection, signs of possible rejection, and signs of infection or other problems.
- To prevent rejection from occurring, your child will need to take several medicines after surgery. Each of these medicines has a specific purpose. Although the transplant team may decide to decrease or stop some medicines, your child will need to take some medicines to prevent rejection for the rest of his or her life.

WHAT MAKES A TRANSPLANT SUCCESSFUL?

- **Commitment**

A successful transplant requires continuing commitment from everyone involved. This includes your child, the entire family, nurses, doctors, and coordinators.

- **Following your doctor's instructions**

The key to preventing rejection is making sure the right amount of medicine is in the bloodstream. Since some of these medicines last a short time, they may need to be given several times a day. This is why it is important that your child takes each medicine at the time your doctor recommends.

- **Asking questions**

It is important to try and learn as much as you can about your child's treatment schedule.

You are the person who must speak out, and fight for your child.

Your transplant team is available to answer any questions you may have. The team knows that this is a lot of information to absorb. If you do not understand something, ask questions until you feel that you understand.