

PRE-TRANSPLANT

Listing for Transplant

Getting your child listed by the United Network for Organ Sharing (UNOS) on the national waiting list for a liver transplant requires several steps after your child has been evaluated by the Pediatric Liver Transplant Team.

Once the decision is made by the team that your child needs a liver transplant, the goal of the Pediatric Liver Transplant Team at the University of Michigan is to have your child listed as soon as possible. There are several steps that are required before a child can be listed by UNOS.

Steps for Listing Include the Following:

STEP 1: Approval by the University of Michigan Pediatric Liver Transplant Patient Evaluation Committee

A summary of your child's disease, including laboratory values, imaging reports, and nutritional/growth histories are presented to the entire committee. The team discusses your child's case and decides if a liver transplant is the best option for them.

If the team determines that a liver transplant is not the best option for your child, that your child is not a candidate for a liver transplant, or that your child does not need a transplant at this time, we will explain the reasons, and give you our recommendations for the best treatment plan for your child. If a liver transplant is recommended as the best option for your child, then with your approval, the process moves to step two.

STEP 2: Financial Approval for the Liver Transplant

Once the committee approves your child for a liver transplant, obtaining financial approval is the next step. Financial approval is required to notify the insurance company of a patient's plan to move forward with transplant. This helps to make sure there are no insurance issues when receiving the transplant. Many insurance companies cover liver transplant, but in some cases they require specific information from the Pediatric Liver Transplant Patient Evaluation Committee or others before granting financial approval. The transplant financial specialist at the University of Michigan Transplant Center works very closely with your insurance company to obtain financial approval as quickly as possible.

STEP 3: Listing with the United Network for Organ Sharing (UNOS)

After the first two steps are completed, the liver transplant nurse coordinator enters specific information into the listing databank. The coordinator enters your child's blood type, weight, and laboratory results that are required for listing with the United Network of Organ Sharing (UNOS) system.

Once this information is entered, your child is placed on the liver transplant UNOS waitlist; the transplant nurse coordinator will notify you when this is complete. In addition, both you and your referring doctor will receive written notification of listing.

The information entered will give a child a specific score (PELD/MELD). To prioritize liver transplant candidates, UNOS uses a scoring system call PELD/MELD (Model for End-stage Liver Disease). The PELD/MELD score indicates the level of priority or urgency with which a donor organ is needed, based on a list of medical indicators. The purpose of the score is to give the highest priority to those who need a liver soonest (sickest patients).

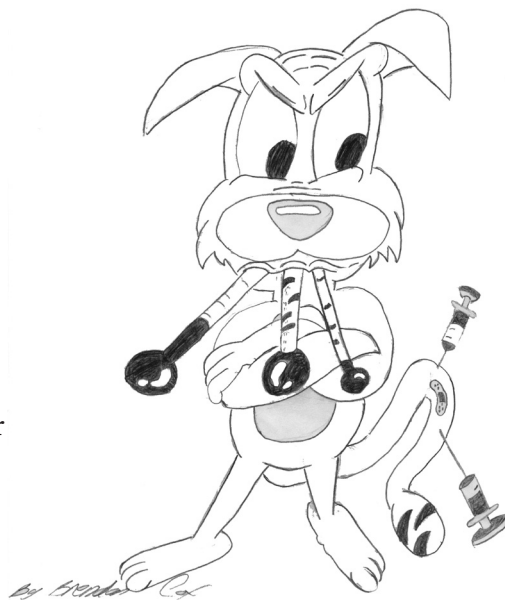
The PELD score is calculated for children less than 12 years of age. The score is based on the following:

- Albumin level
- Total Bilirubin level
- INR (clotting factor)
- Growth failure (based on gender, height and weight)
- Age at listing

The MELD score is used for children 12 years or older and adults. The score is based on the following:

- Total Bilirubin level
- INR (clotting factor)
- Serum Creatinine level (kidney function)
- Serum Sodium level

Every time your child has laboratory studies (locally or in clinic), the transplant office will calculate the PELD/MELD score. The higher the score, the higher a child will be on the list (priority for liver transplant is given to those with the highest scores). If your child is listed for a transplant, each time there is an increase in the score, the score will be updated in the UNOS database. How frequently the score must be updated, depends on the specific score



(higher scores must be updated more frequently), but UNOS requires that all PELD/MELD scores be updated on a regular basis. The transplant office will inform you when the routine lab studies will be needed.

If the transplant team believes that, due to your child's disease, he/she needs a transplant more than the PELD/MELD score indicates, we apply for what is called an exception. This means we request a certain number of extra points, and a regional review board of physicians from different transplant centers votes on whether to approve the exception request.

Some Children Cannot be Listed for a Liver Transplant:

When a child has one of the following conditions, they will not be able to be listed at the University of Michigan because a transplant for these conditions is considered not to be in the best interest of the child.

- AIDS
- Untreated cancer occurring outside the liver – except for benign tumors and minor skin cancers
- Irreversible brain injury
- Uncontrollable infection of the blood, originating outside of the liver
- Severe impairment of vital organ systems function such as heart, lung or kidney that would limit anticipated survival
- Presence of another disease for which anticipated survival is poor
- Strong history of parent or child not listening to medical recommendations without a plan to address

The following conditions require careful review and may prevent transplant at the University of Michigan:

- Active alcohol or substance abuse
- HIV positive
- Under 3.5 kilograms (~8 pounds)
- Malignant tumor within the liver involving the bile ducts, cholangiocarcinoma
- Extensive previous abdominal surgery (depending on the type of surgery)
- Rapidly growing late-stage primary liver cancer
- Clots within major blood vessels into and out of the liver
- Problematic, poorly controlled psychiatric disease that interferes with ability to engage in medical care
- Limited and/or poor social support systems that interferes with ability to engage in medical care

Patients with insufficient insurance coverage or financial resources to cover the transplant, follow-up care, and medications will not be approved as candidates for transplant. It would be dangerous for your child to undergo a transplant without being able to get the care and medications necessary to recover and stay healthy afterward.

Step 4: Patient and Family Education Class

The Liver Transplant Patient Education class is designed to provide your child and you (caregivers) an explanation of the entire liver transplant experience. It is a requirement for listing at the University of Michigan that you and your child attend one of the education classes. There may be occasions when because of the rapid onset or severity of your child's disease that this may not be required. The transplant nurse coordinator and social worker will discuss the transplant team, the process leading up to the surgical procedure, the surgical procedure, the in-patient hospital stay, and long-term follow-up care.

You Should Know

It is a requirement for listing at the University of Michigan that you and your child attend one of the scheduled education classes.

The three-hour class is taught via Zoom. Patient, family, and caregiver interaction is encouraged.

STEP 5: Immunizations

Depending on the age of your child, your child may or may not be up-to-date with his/her immunizations. It is very important that before your child's transplant, his/her immunization list is reviewed and recommended immunizations be obtained before his/her transplant, if possible. We may recommend against live viral vaccines before transplant if the transplant is going to happen quickly. If live virus vaccines are given before transplant, we will likely hold off on transplant for four weeks. Your local physician will be given guidelines for administering the required immunizations at an accelerated schedule if necessary. For example, if your child has not had an MMR or a Varicella immunization, the transplant team would like your child to get those two before transplant. Those two immunizations are considered **LIVE** virus vaccinations. Once your child has the transplant, they will not be able to have any live virus immunization for at least several years after transplant, and potentially not at all. The reason for this is when your child is on high doses of anti-rejection medication, receiving a live virus vaccine could potentially cause a very serious viral infection. However, the risk of community-acquired natural varicella is also high, so immunity before transplant is important.

Accelerated Immunization Schedule

Vaccine	Comment
DTaP	Minimum age to begin series is six weeks; doses two and three can be administered four weeks following the preceding doses; doses four and five may be administered six months after the preceding doses
Hepatitis A	Minimum age to begin series is six months; dose two can be administered four weeks after the first dose
Hepatitis B	Minimum age to begin series is birth; dose two can be administered four weeks following the first dose; dose three can be administered eight weeks after the second dose
HIB	Minimum age to begin series is six weeks; dose two and three can be administered four weeks following the previous dose; dose four can be administered eight weeks after the third dose
Influenza	Minimum age to begin series is six months; patients requiring a second dose should receive it four weeks following the first
IPV	Minimum age to begin series is six weeks; doses two, three and four can be administered four weeks following the previous dose
MPV	Minimum age to vaccinate is 18 months
MMR	Minimum age to begin series is nine months; dose two can be administered four weeks after the first; do not administer if patient is likely to receive transplant within four weeks of vaccination
PCV	Minimum age to begin series is six weeks; doses two and three may be administered four weeks after the previous dose; dose four may be administered eight weeks after the third dose
PPV	A single dose of vaccine should be administered eight weeks after completion of the PCV series
Varicella	Minimum age to administer vaccine is nine months; do not administer if patient is likely to receive transplant within four weeks of vaccination

After Being Listed

Once your child has completed all of the listing requirements including any testing needed before listing, and has been approved for listing by the Pediatric Liver Transplant Patient Evaluation Committee, the transplant coordinator will place your child on the liver transplant waiting list. You will be notified of your child's listing status in two ways. First, the transplant coordinator will telephone you and tell you about your child's listing for the transplant. In addition, the transplant coordinator will mail a letter explaining your child's listing status to both you and your child's referring physician.

For your child to remain active on the transplant waiting list, they must continue to do the following:

- Have routine evaluation during clinic visits at the transplant center.
- Have routine general pediatric care with his/her primary doctor (usually a pediatrician).
- Obtain laboratory testing as requested by the transplant center, which can be at the time of the transplant clinic visits, or locally when a clinic visit is not required.
- Yearly dental examination if your child is greater than three years of age.
- Obtain other testing or evaluations as indicated by his/her medical condition, such as cardiology evaluation.

Pre-Transplant Planning

For many patients and families, it is helpful to plan ahead by developing a specific plan for what will make a transplant go more smoothly. We have listed questions that have helped other families plan for the transplant. We suggest that you make a list of your answers and write down phone numbers and other contact information in several places.

Preparation Questions:

- Who will be the primary care person for your child (the new transplant recipient) after his/her transplant?
- Who will be a 'back up' care person?
- Who will drive your child to the hospital for the transplant?
- Who will pick up and/or take care of your other children or vulnerable people at home?
- Who will take care of any pets?
- Who will look after your home (water plants, pick up mail, pay rent/bills) while you are away?
- Who will notify school administrators, employers, etc. about what is happening while you are at the hospital?

*What to Pack – For the Kids**

The call about a possible transplant could come when you least expect it. It could come in the middle of the night or when you are sitting down to dinner. When the call comes to ask you to come to the hospital for the transplant, you may only have an hour to get ready to leave for the hospital. Some kids and families tell us that it was helpful to keep a bag packed and ready to go or to keep a list of things to pack handy.

You Should Know

Please mark all of your child's items with his or her name.

How about packing a bag now? How about making a list of what you and your child must have when you go to the hospital? Other children who have had liver transplants have suggested a list of items that they felt were needed. Here's their list to help get you started.

- Pajamas
- Books or games
- Robe
- Comfortable clothes to wear home
- Slippers
- Favorite toys, stuffed animals, or blankets
- Sweatpants with a stretchy waist
- Photos of family, friends, and pets
- Toothbrush and paste
- Autograph books/journal
- Camera for taking photos after transplant
- Radios with headphones
- Addresses of friends and family
- Hand-held electronic games
- Current list of medications

What to Pack – For the Parents, Guardians, and Family

You, like other parents, guardians, and family members, may choose to stay at the hospital when your child is recovering from transplant surgery. We recommend this for all parents. Below is a list of items that other families have suggested that adults bring with them. Remember that your child (new transplant recipient) will likely be in the hospital at least one to two weeks (on average).

- Three or four changes of comfortable clothes
- Under clothes and socks
- Slippers and shoes
- Toiletry items
- Contacts/eyeglasses
- Your medicines
- Wallet/money/credit cards
- Phone card/cell phone/pager/charger
- Insurance cards
- Stationery/stamps
- Books/crosswords/diversions
- Camera
- Umbrella
- Laptop computer

Special Considerations:

- You will have access to a clothes washer and dryer on the inpatient unit where the child will stay.
- Smoking is prohibited in and around the hospital. There are some designated areas away from the hospital entrances that allow smoking. Please follow the signs directing you to those areas.
- Because of potential latex allergies, latex balloons are not allowed in any patient rooms. Silver Mylar balloons are permitted and can be purchased in both of the hospital gift shops.
- Because of potential problems with infections, floral arrangements are not allowed in patient rooms while in the intensive care unit or moderate unit.

Maintaining Health While Your Child is Waiting for a Liver Transplant

Maintain a Healthy Lifestyle

Promoting your child's physical and mental health is essential to a good long-term outcome. We recommend that you learn about your child's liver disease, testing, medications, and the transplant process before transplant when possible.

Promoting Physical Health Includes the Following:

Stay as active as possible. Your child should remain as active as possible. Unless there is a specific restriction such as no gym or no contact sports, there are usually no restrictions on a child's activity. The effects of a diseased liver such as tiredness, feeling sick, poor appetite, and depression can take a toll on your child's ability to perform routine daily activities, but regular exercise appears (even in these circumstances) to promote a better quality of life. Keeping your child active with play and exercise is important. We will let you know if there are specific restrictions that we recommend.

Staying Emotionally Healthy Includes the Following:

Monitor your child for signs of emotional stress. Feelings such as guilt, anger, frustration, and irritability are common in children with chronic liver disease and who are awaiting a transplant. Symptoms of depression and anxiety are not uncommon in the pediatric liver transplant population. If you see any emotional or personality changes in your child, it is very important to let the transplant team know. The transplant social worker and psychologist are trained to assist patients and their families in coping with the challenges of chronic illness and its treatment. Many times the use of support groups, counseling and medications may be helpful.

Encourage your child to stay involved with his/her friends and other social activities. We recommend that your child remain in school and participate in the daily school routine. Some children may be limited to only a half day by their liver disease. However, encouraging your child to remain active and maintain his/her friendships is extremely important. If there is a need for home bound teaching, it is still important to have his/her teacher and friends involved while he/she is at home. Children that are isolated from their friends are more likely to have changes in their behavior, changes in mood, and depression.

Family Members and Friends

Support from both friends and family is very important for your child. They can provide emotional support and are needed for providing assistance to your family and child during this difficult time. All chronic illnesses are stressful and disruptive for the entire family. When a family member becomes ill, it often requires changes in roles and responsibilities for all family members. There may be changes in the daily routines, in plans for the future (e.g., vacation travel), and relationships among family members and with friends. Many family members can have difficulty dealing with their fears about a child's illness and possible death and the changes in their lives. They may adopt coping strategies to protect themselves that can interfere with or disrupt family communication. Parents are encouraged to be honest with themselves and other family members about their feelings about all these issues including your child's illness.

Complications Which May Occur While Waiting for a Liver Transplant

Many of the signs or symptoms shown below may indicate a **life-threatening complication** requiring **immediate medical care**. If your child experiences any of these signs and/or symptoms, you should contact the transplant team or your primary physician's office immediately.

- Increased fluid in the abdominal cavity (ascites)
- Swelling of legs and/or feet from retained fluid (edema)
- Sleeping more than usual and/or difficult to wake up (arouse)
- Fever of 101°F or greater
- Black, tarry stools or blood in stool
- Vomiting blood
- Nose bleeding that won't stop after several minutes
- Increased yellowing of eyes or skin or dark colored urine (especially if these are new)
- Shortness of breath or difficulty breathing
- New onset of severe stomach (abdominal) pain
- Persistent nausea, vomiting, and diarrhea

Symptoms that require a call the next day (but not generally an emergency):

- Severe itching (pruritis)
- Newly noted trouble with concentration, forgetfulness, changes in personality, or confusion
- Weight loss
- Decreased appetite
- Weakness

The following additional information is provided to assist caregivers in recognizing, understanding, and managing the symptoms their child may experience before transplantation.

Recognizing Ascites

Ascites is an accumulation of fluid in the abdominal cavity. When this occurs, the following steps are recommended:

- Discuss with the dietitian if there is a need for sodium restriction in your child's diet. If so, the dietitian will instruct how to reduce sodium without compromising growth based on your child's age and weight.
- Your child may require medicines, called diuretics (water pills), to help remove some of the retained fluid. We use these medicines to promote loss of sodium in the urine. The most commonly used water pills are Lasix (furosemide) and Aldactone (spironolactone). If your child is started on either of these medicines, close monitoring of the electrolytes (salts in your blood) and kidney function will be necessary.
- If the diuretics do not improve the retention of the fluid, it may be necessary to have your child go to the hospital to have the fluid drained through a procedure called a paracentesis (abdominal tap).
- With ascites, there is always a potential problem of an infection developing in the fluid. If this should occur, your child will need to be treated with IV antibiotics, IV albumin, and be maintained on long-term oral antibiotics to help prevent a recurrence of an infection.
- You should call the Transplant Office if your child develops ascites, has a marked increase in abdominal girth, seems to have difficulty breathing because of the large abdomen, develops severe abdominal pain, fever greater than 101°F, and/or notable decreased urine output.

Hepatic Encephalopathy

Encephalopathy is a condition of the brain and central nervous system caused by toxins not filtered out of the blood by the liver. It is characterized by personality changes, irritability, increased sleepiness, and when severe, depressed levels of consciousness. Patients with mild and moderate encephalopathy may have decreased short-term memory, increased sleepiness, decreased concentration, and irritability. If the encephalopathy is severe, patients may be difficult to arouse. High ammonia levels are often associated with this problem. At its most severe level, patients can lapse into a coma.

You should call the Transplant Team if the following should occur:

- If you notice changes in mental status, personality changes, extreme irritability without a clear cause, or a big change in sleeping pattern in your child. Acute changes may require admission to the hospital for observation and treatment.
- If encephalopathy is noticed, your child may be started on treatment with a medication called Lactulose or possibly an antibiotic. This medication changes the acidity of stool and the ability to absorb ammonia from the intestine and increases the number of bowel movements. The dosage of the medication will be adjusted to achieve no more than four bowel movements per day.

Esophageal and Gastric (Stomach) Varices

Esophageal varices are dilated veins in the walls of the esophagus; gastric varices are dilated veins in the wall of the stomach. These are collaterals (new pathways of blood vessels) that develop to try and decrease the pressure in the portal vein (the largest vein to your liver). The increased pressure in the portal vein results from increased resistance to blood flow through the liver. These distended veins may rupture (break) from the high pressure of blood within them, which can result in vomiting blood, bloody stools, or black tarry stools.

What to do if Blood is Noted:

- If your child vomits blood, has bloody stools, has black tarry stools, develops dizziness, or light-headedness, you should consider all of these a medical emergency. Your child needs to be evaluated and treated in the emergency room immediately. **If there is active bleeding, treatment to stop it must be started as soon as possible to prevent shock and death.**
- Once your child is in the emergency room, either you or the ER staff should contact the Transplant Office or on-call Pediatric GI Physician to inform the team of these problems. It may be necessary to transfer your child from the local emergency room or hospital to C.S. Mott Children's Hospital for further evaluation and treatment.
- Patients with a history of esophageal variceal bleeding will require medical and/or surgical monitoring and treatment to reduce the risk of esophageal bleeding in the future.

The interventions may include one or both of the following:

- Endoscopic therapy (most common) involves using a device with a light, called an endoscope that allows the physician to look into the esophagus, stomach, and beginning of the small intestine (duodenum). If there is active bleeding, evidence of recent bleeding, or varices that appear at high risk for bleeding, the physician may directly inject the varices with a sclerosant (clotting medicine) or place a rubber band around the varices (banding of the varices).
- In cases where the variceal bleeding cannot be controlled by endoscopy and IV medications, it may be necessary to have a shunt placed to decrease the portal vein pressures. Transjugular Intrahepatic Portosystemic Shunt (TIPS) is a medical procedure (done by interventional radiologists) that shunts blood from the portal vein system to the hepatic vein system to decrease the portal pressure. The interventional radiologist will make a small tunnel through the liver with a needle connecting the portal vein to one of the hepatic veins through which blood can flow out of the liver. After the tunnel is made, the radiologist will insert a small metal tube (called a shunt or stent) into the tunnel to make sure the tunnel stays open. Patients can develop encephalopathy, or pre-existing encephalopathy can worsen after TIPS, or cause other problems. Therefore, TIPS is primarily used only when other procedures have failed to stop the bleeding.

Being Placed on HOLD (Temporary Inactive Status)

Your child may be placed on HOLD for medical concerns that could cause your child to die if he/she underwent a transplant; an example, of such a medical issue is an active infection. Even having a mild infection such as an ear infection or strep throat can be harmful to your child if not treated before undergoing a transplant, and thus, he/she would be placed on HOLD until the infection is treated. It is very important that your child be seen by his/her local physician and evaluated and any appropriate treatment be started as soon as possible. Once the infection has cleared, and your child is no longer having any signs of the infection (such as fever), he/she can be re-activated on the transplant list. The transplant nurse coordinator will ask you to take your child to the local laboratory for lab tests that will be needed to update his/her status in the UNOS database for reactivation.

You Should Know

Being on hold does not mean you are off the list. It just places you on non-active status.

Other reasons for putting your child on HOLD include:

- Not attending the required clinic visits and obtaining routine lab studies (non-adherence)
- Not responding within an appropriate time to calls from the transplant office
- Not responding to a call from the transplant coordinator to come in for a transplant
- Active substance abuse (drug or alcohol)
- Concerns about your child's social support system (particular concern is related to ability to deliver appropriate care after a transplant)
- Changes in your child's insurance, such as a lapse in their primary plan (BCBS or Medicaid for example), may require being placed on hold until insurance re-approval can be obtained.
- Leaving town (usually means out of state) for an extended period of time

