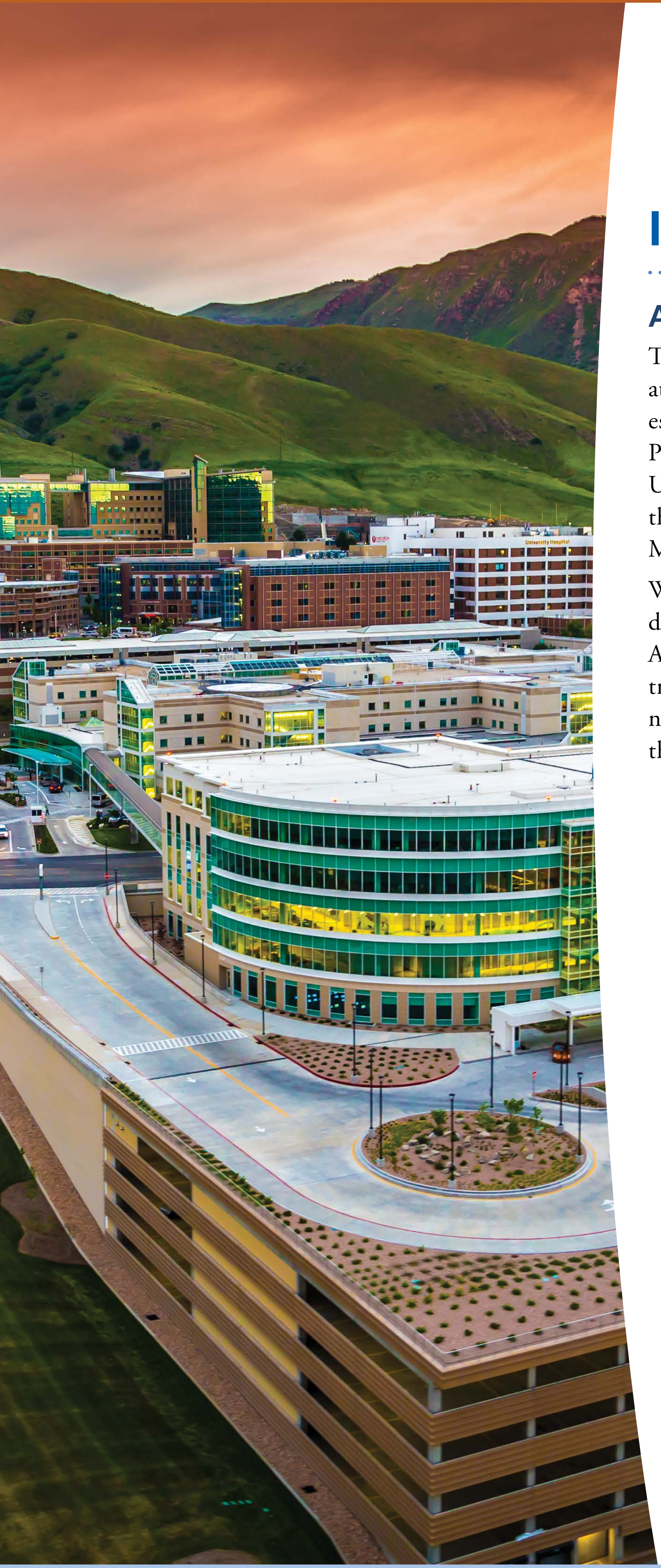
Liver Transplant
Information and Care

Intermountain
Primary Children's Hospital
The Child First and Always®

Liver Transplant

Information and Care

Contents



Introduction

About the Program

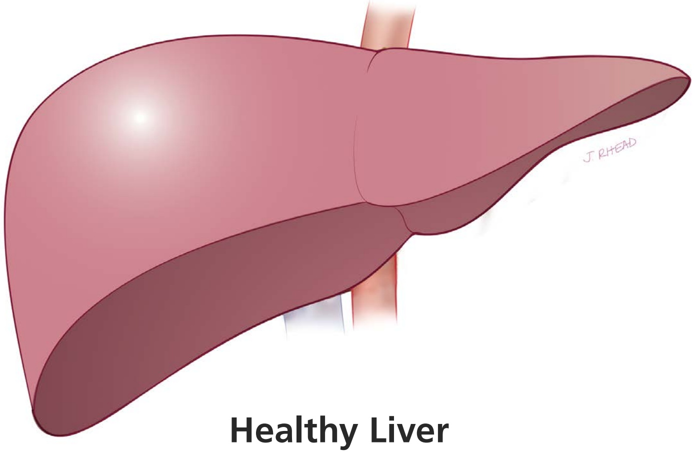
The liver disease and transplantation program at Primary Children's Hospital (PCH) was established in 1996 as a joint effort among PCH, Intermountain Healthcare, and the University of Utah. The liver program services the Intermountain West, including Utah, Idaho, Montana, Wyoming, and Nevada.

We provide complete care for children with liver disease from diagnosis through transplantation. And, we rank among the top 10 pediatric transplant programs in the United States for number of transplants performed. We are among the very best for transplant outcomes.

Functions of the Liver

The liver is the largest organ in the body. It is located on the right upper side of the abdomen (belly) and to the right of the stomach. A healthy liver does a number of important jobs, including:

- Making proteins for growth, energy, and blood-clotting
- Storing fats, sugars, iron, and vitamins for later use
- Removing or chemically changing drugs, alcohol, and other harmful substances in the body
- Producing bile for digestion

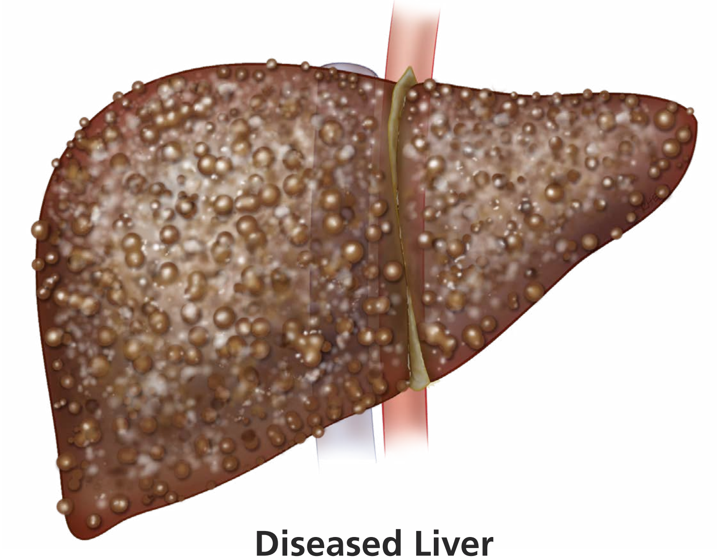


Healthy Liver

Causes of Liver Disease and Failure

A liver that isn't working right can cause many problems in the body. Some causes of liver disease or lover failure include:

- Hepatitis [hep-ah-TIE-tis] (a specific type of infection caused by a virus)
- Drug toxicity (too much of a drug in the body, causing harm or damage to the body)
- Acute liver failure
- Alagille [AL-uh-jill] syndrome
- Progessive familial intrahepatic cholestasis [koh-leh-STAY-sis] (PFIC)
- Autoimmune hepatitis
- Non-alcoholic fatty liver disease
- Alpha-1 antitrypsin [an-tee-TRIP-sin] deficiency
- Metabolic disorders
- Primary sclerosing [skleer-OH-sing] cholangitis [koh-lane-JIE-tis] (PSC)
- Biliary atresia (a disease of the bile ducts in the liver that starts in infancy)



Diseased Liver

Before Surgery

Pediatric Liver Transplant Evaluation

Children who are referred to the liver transplant team at Primary Children's Hospital will be scheduled for a visit in the liver clinic. During this visit, your child's liver condition will be assessed and discussed, and the transplant doctor will talk with you about treatment options.

A transplant evaluation will include consultations (visits) with a:

- Liver transplant doctor (hepatologist)
- Transplant surgeon
- Transplant coordinator
- Transplant social worker
- Transplant dietitian
- Transplant pharmacist
- Transplant financial coordinator
- Dentist (this may be with your family dentist)

In addition, your child will need:

- Lab work, including blood tests and urine tests
- Chest x-ray
- Ultrasound, CT scan, or MRI scan
- EKG or echocardiogram (echo)

Your child may also need:

- A liver biopsy
- Heart, kidney, or infectious disease consultations
- To return to the hospital several times to finish tests

Immunizations (shots or vaccinations)

Your child's immunizations should be up to date before their liver transplant. Take your child's immunization records to the transplant evaluation visit. The transplant coordinator and your child's doctor will tell you if any more immunizations are needed.

Required immunizations:

- Diphtheria, Pertussis, and Tetanus (DPT or Tdap)
- Polio
- Hepatitis A — if 2 years or older
- Hepatitis B series
- Haemophilus Influenzae type b (Hib)
- Pneumococcal
- Influenza (flu) every year — if 6 months or older
- MMR (measles, mumps, and rubella) — if 6 months or older
- Rotavirus, optional
- Varicella (chickenpox) — if 1 year or older

Your child can't receive certain immunizations after transplant, so they may need to receive them before transplant on a faster schedule. **Note:** Your child cannot receive a transplant for at least 4 weeks after receiving a live virus vaccine (such as MMR and Varicella). Talk about these immunizations with your transplant team before your child receives them.

Immunizations for household members

Household members (people living in the same home as your child) and anyone who will be providing care for your child should be up to date with their immunizations. The transplant coordinator and liver doctor will tell you which immunizations you and other household members need.

The immunizations may include:

- Flu vaccine every year (for everyone 6 months and older)
- MMR (for everyone 1 year and older)
- Varicella (chickenpox) vaccine (for everyone 1 year and older)
- Hepatitis B
- Hepatitis A

Waitlist

When the evaluation is finished, transplant team members will present your child's evaluation to the rest of the transplant team. This meeting occurs weekly. Together, the team will decide whether transplantation is the best option for your child. A member of the team will let you know the decision. If it's determined that transplant is not the best option at this time, you will be given information about the recommended treatment. If a transplant is recommended, the transplant assistant will request authorization from your insurance company. This can take up to 14 business days.

Once authorized by your insurance company, your child's name will be added to the national transplantation waitlist managed by the **United Network for Organ Sharing (UNOS)**.

UNOS Role

UNOS is a nonprofit charitable organization that helps people who need a transplant to receive one. When your child is added to the waitlist, the PCH team adds your child's medical information into the UNOS computer system. The system creates a ranked list of transplant candidates (matches) based on blood type, tissue type, medical need, waiting time, how sick the child is, and geography (where the donor and recipient are physically located when a donor liver becomes available). This list is used to decide who receives organs when they become available.

How they decide

UNOS has a point system to predict who needs a liver transplant most urgently so that it can prioritize candidates waiting for liver transplants. Points are given to each candidate based on:

- Blood type
- Height and weight of the recipient (person getting the liver)
- Age of the donor (person giving the liver)
- Recipient's medical urgency (1A/1B, MELD/PELD score)
- Distance from the donor hospital
- Blood test results: albumin, bilirubin, creatinine, and INR

PELD scores (ages 0 to 11 years)

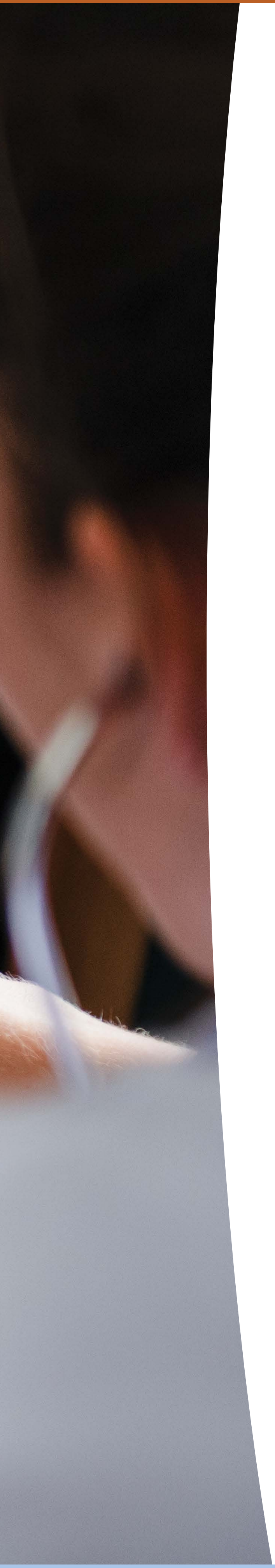
The pediatric end-stage liver disease (PELD) score is used for candidates 11 years old and younger. It is calculated from the bilirubin, albumin, INR (blood-clotting factors), height, and weight.

MELD scores (12 years and older)

The model for end-stage liver disease (MELD) score. is used for liver transplant candidates 12 years and older. It assigns a score based on how urgently the candidate needs a liver transplant — from 6 (less sick) to 40 (very sick). The score is calculated using 3 lab test results: bilirubin, INR (blood-clotting factors), and creatinine (kidney function).

The only priority exceptions to PELD and MELD scores are the status 1A and 1B categories. Status 1A patients have a sudden and severe onset of liver failure. Status 1B is reserved for very sick, chronically ill pediatric candidates (younger than 18 years old) and for certain conditions like liver tumors and metabolic diseases.

A patient's PELD or MELD score may go up or down depending on their liver disease. Most candidates will have their score updated many times while they are on the waiting list. This helps ensure donated livers go to patients who need it most at that time.



Waiting for a Liver Transplant

Listing

After your child completes the liver transplant evaluation and your insurance company has given approval for liver transplantation, we will put your child's name on the national transplantation waiting list. We will also include your child's height, weight, blood type, and other test results. At the same time, we will enter requirements for the donor, like size and blood type.

Depending on how long your child is on the waitlist, we may need to repeat labs in order to keep your child's profile up-to-date. Once your child is listed, our transplant center may receive a donated liver offer for your child's transplant at any time.

It is possible for your child to be listed at more than one transplant center at one time. If you need to move — and a different transplant center is closer than Primary Children's Hospital to your new home — all of the built-up waiting time can be transferred to the new center. Your child's coordinator and liver doctor can answer questions about this process.

Living donation

Living liver donation is a process by which a piece of liver is surgically taken from an adult to be transplanted into a child or another adult. This donated piece replaces the recipient's sick liver. The first living donation for liver transplant in the U.S. took place in November of 1989. Since that time, many centers have performed living liver donation for the benefit of children, and more recently, for adults with liver failure.

The transplant center at PCH has extensive experience performing living donation for children. Healthy parents, relatives, good friends, and even donors who do it "just because," can be considered living donors. If you or a loved one is interested in becoming a living donor, visit **intermountainhealthcare.org** and search “donor.” Click on “Become a Donor,” and then click on the blue button “Become a Living Donor.”

Some of the advantages associated with living donations are that the surgery can be planned for the best time for the child, and the liver does not have as much “downtime” between the donor and recipient. A disadvantage to living donor surgery is that a donor with no medical reason for surgery must have a major operation. If living donation is an option for your child, the liver doctor will talk with you and your child more about this process.

Important Information: When Your Child is on the UNOS Waitlist

Communication and staying available

Close communication is vital for a transplant to take place. **We need to be able to reach you about a donor offer at all times.** If any phone numbers, addresses, or family and neighbor contact information change, you must tell the transplant coordinators immediately. Coordinators are not automatically told if hospital registration information changes.

Travel

Be aware of the areas where your cell phone will work. **You must tell the transplant coordinator before traveling outside this area.** If you travel:

- You increase the risk that the transplant team won't be able to reach you if there is a donor organ offer.
- Your child may be considered inactive on the list until you return if you travel a significant distance from the transplant center.

The transplant team can help you decide whether or not to travel while your child is listed.

Waiting

The waiting time for a liver transplant is unpredictable and difficult. The offer could come very quickly, or it may not come for more than a year. To make this time easier:

- Know that it's normal to feel relieved and worried at the same time.
- Consider joining a transplant support group to talk with other parents and children with these experiences. The transplant social worker and your transplant coordinator can help connect you with other transplant families.
- Try to maintain as normal of a lifestyle as possible, and continue with your usual family routines.
- Remember to take time for yourself.
- Accept help from friends and family, and ask your transplant team for help.

Preparing

Be ready for the transplant call by thinking through what you'll need to do and bring with you when it's time to go to the transplant center. The following ideas may be helpful:

- Plan your transportation, including commercial or charter flights, if you live farther than a 6-hour car drive. If you need a flight, the social worker will help arrange it. You may need a charter flight if a commercial flight isn't available in the middle of the night.
- Be prepared financially. Many insurance companies will pay for flights, but you may have to pay with a credit card when you fly and be reimbursed by your insurance later.
- If you are from the Salt Lake metro area, know the fastest route to the hospital. Make sure you have a reliable car that has plenty of gas. If you'll be using a cab or ride-share service, be sure you have enough money to pay the fare.
- Pack a small bag for your child and any family members staying overnight. Confirm all visitor restrictions with the hospital before your arrival.
- Arrange in advance for someone to care for your children, pets, and home.
- Make a list of last-minute tasks you need to do, including items to add to bags and phone numbers you need.
- Remember phone chargers and special items to keep your child comfortable, such as a blanket or favorite stuffed animal.

Receiving the call

When the transplant coordinator calls to tell you about a possible organ donation, they will ask if your child:

- Has any symptoms of illness (including cold symptoms)
- Has recently been exposed to communicable diseases like chickenpox
- Has had any recent immunizations

It is important for us to know if they have any signs of an infection before transplant begins. If your child has an infection when they have a transplant, it could become serious after your child starts immunosuppressive [im-myoo-no-suh-PRESS-iv] medicines (medicines to prevent organ rejection).

If your child is healthy, the transplant coordinator will tell you when your child should stop eating and drinking to prepare for surgery. The coordinator will tell you when to arrive at PCH and where to check in.

Note: Sometimes the transplant surgery will need to be canceled, and your child will be discharged, or sent home before admission. There are many reasons why a transplant may not work out, such as the donor liver is the wrong size, has functional or anatomical problems, or is not healthy enough when it is evaluated in person.

Arriving at the hospital

When you arrive at PCH, the healthcare team will prepare your child for surgery. This includes:

- Talking with the admitting doctor
- Drawing blood samples
- Taking chest x-rays
- Collecting a urine sample
- Swabbing the nose and throat for viral tests
- Starting an IV

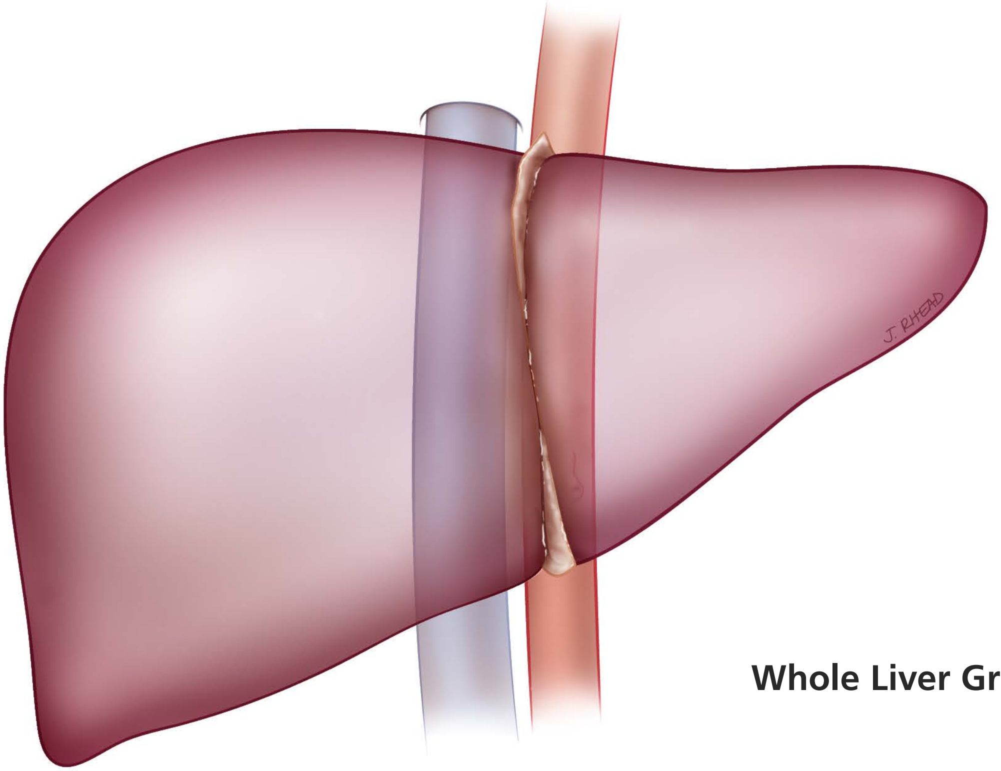
This can be a stressful time for your child. The nurses and other caregivers will minimize the stress of these procedures, and you can be present to comfort your child. Child Life specialists can also be called to help make things easier for your child.

When it's time for your child's surgery, you'll go together to the operating room door. Your child will continue on to surgery, while family members wait in the waiting room. The operating room nurses will update you on the surgery progress. It typically lasts anywhere from 4 to 8 hours.

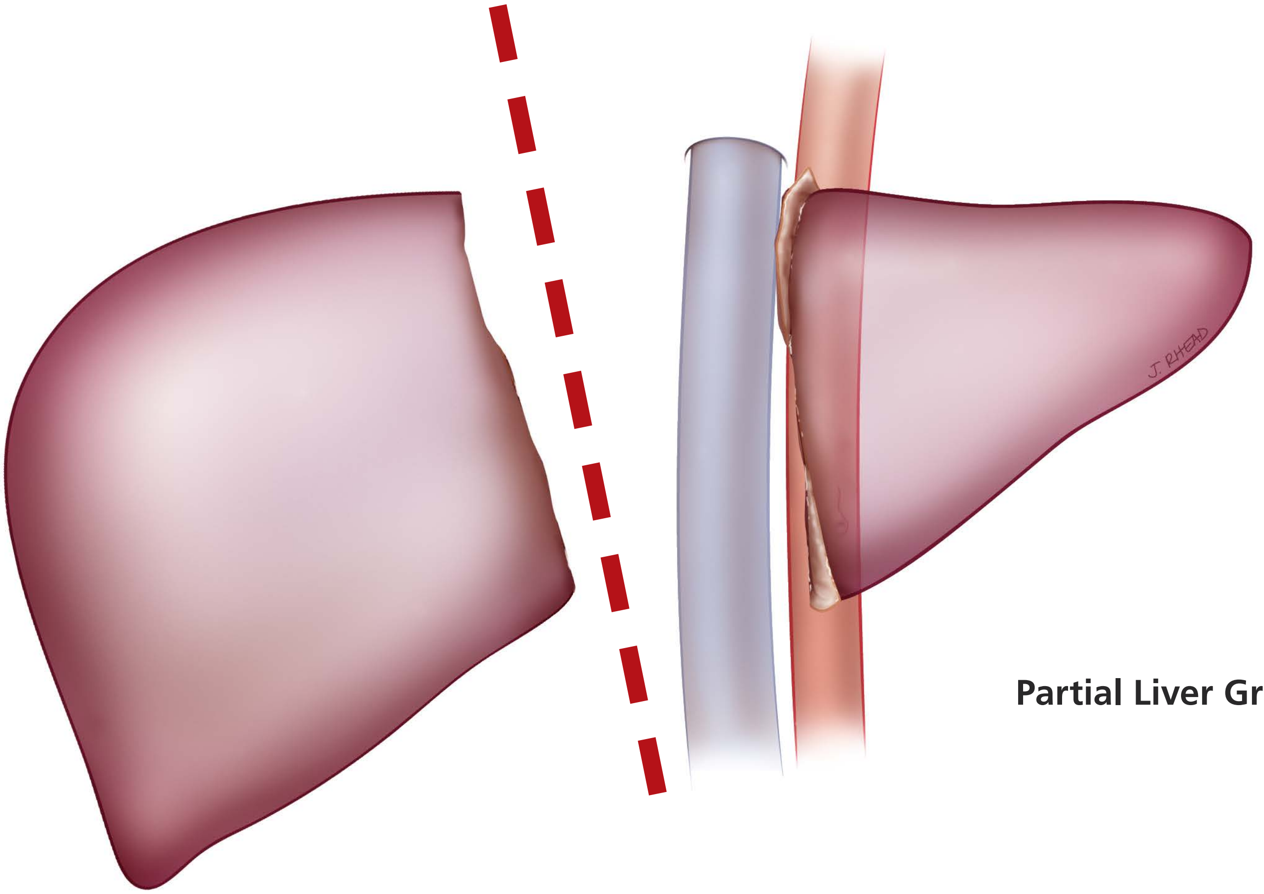
After the transplant surgery, your child will go to the **pediatric intensive care unit (PICU)** for close monitoring during the next few days. When your child's condition is stable, they will be transferred to the **immunocompromised unit (ICS)**. While your child is recovering, caregivers will teach you how to care for your child so you'll be prepared when you are sent home.

Ask the liver transplant team for any help you need, including:

- Booking a stay at the Ronald McDonald House or local hotels
- Finding meals for you and other family members
- Insurance and discharge questions



Whole Liver Graft



Partial Liver Graft

Liver Transplantation Surgery

The first phase of liver transplant surgery begins with anesthesia (medication to put your child to sleep during surgery so they don't feel anything. Once your child is asleep, IVs are placed for monitoring and for giving fluids and transfusions during surgery.

Next, the transplant surgeon removes your child's "old" liver, separating it from all of the connections in the abdomen. The surgeon then "puts in" the "new" liver, connecting all of the blood vessels and the bile duct.

Surgical drains will be placed through the skin, close to your child's surgical opening, to drain fluid. These drains are removed when the drainage decreases or stops. This typically takes 3 to 5 days, but some children will go home with a drain in place if they have a lot of drainage.

Liver transplant surgery typically lasts 4 to 8 hours. However, your child's surgery could be longer. A longer surgery doesn't necessarily mean there are problems. Each transplant surgery is different, and the time it takes is different with every child.

Whole, partial, and living donation

There are three types of liver transplants: whole graft, partial graft (including split-liver and reduced-size grafts), and living liver donation.

- **Whole liver graft:** Donor liver is transplanted as a whole organ.
- **Split-liver graft:** Donor liver may be split into two parts and transplanted into two different people.
- **Reduced-size liver graft:** Donor liver is reduced in size so it is the right size for the recipient.
- **Living liver donation:** Part of the liver is removed from a living donor and transplanted into another person.

Your child's liver doctor and surgeon will determine which type of liver transplant is the best option for your child.

Immediately After Transplant Surgery

When the surgeon finishes the transplant surgery, the healthcare team will take your child to the PICU (Pediatric Intensive Care Unit).

The surgical team will tell the PICU team about the surgery, and the PICU team will set up all the equipment and medication they need to care for your child.

The PICU team will check your child's vital signs and see how they are doing. This usually takes 30 to 45 minutes. You will be able to see your child once they are settled in at the PICU. (See the next section, starting on page 19, for what to expect when you see your child for the first time following surgery.)

Risks of Transplant Surgery

Most liver transplant surgery problems will get better with minor interventions. Some complications are serious and may require another surgery or medical procedure. The liver team will watch closely for complications, which may include:

- A blood clot in the artery or vein for the liver (your doctor may call this "thrombosis")
- Bleeding during or after surgery (may require blood transfusions or blood products)
- Infection (can be more serious after transplant because your child's immune system will be suppressed so it is less likely to reject the new liver)
- Bile duct problems
- Poor function of the transplanted liver
- Rejection
- Sadness, depression, or anxiety

After Liver Transplant Surgery: In the Hospital

Pediatric Intensive Care Unit (PICU)

Seeing your child for the first time after liver transplant surgery may be overwhelming. Your child's face and hands may look swollen. This is because they received a lot of fluids during the surgery. The swelling may increase over the next few days, and then will begin to decrease over time. Your child may also have:

- A breathing tube in their mouth that is attached to a ventilator (breathing machine)
- A tube in their nose to remove stomach fluids until the intestines and stomach wake up from the anesthesia
- Wires attached by stickers to their chest to monitor their heart rhythm
- A large bandage on their abdomen covering the surgical site
- Surgical drains around the surgical site
- A urinary catheter (small tube) draining urine from your child's bladder
- A wire with a light probe taped to a finger or toe to monitor oxygen in the blood
- IVs to monitor blood pressure and fluids and to give your child fluids and medicine
- Pumps and machines around the bed to help the team care for your child

These tubes and monitors will be removed by your child's care team as they heal from transplant. At least one PICU nurse will care for your child and will watch them carefully. The PICU team will test your child's blood, give medication and blood products, and perform ultrasounds and chest x-rays.

Your child's stay in the PICU will vary from a few days to a week. Parents can stay with their child at all times. Other visitors will be asked to leave the bedside when there are shift changes to allow the new providers to receive patient reports. This takes place between the hours of 6:30 and 8:00 each morning and evening. One parents can spend the night at the hospital, sleeping at the bedside or in a PICU sleep room if available. You can also stay in the Ronald McDonald Family Room at the hospital, at the Ronald McDonald House, or at a nearby hotel. Ask your social worker for help booking your stay or arranging a sleep room in the PICU.

After PICU: Immunocompromised Unit (ICS)

When your child no longer needs to be in the PICU, they will be transferred to the hospital's immunocompromised unit (ICS). Your child will stay in the ICS until they are ready to go home.

Here, you can stay in your child's room day and night. The hospital staff will include you in the care they are providing so you will be prepared to care for your child at home.

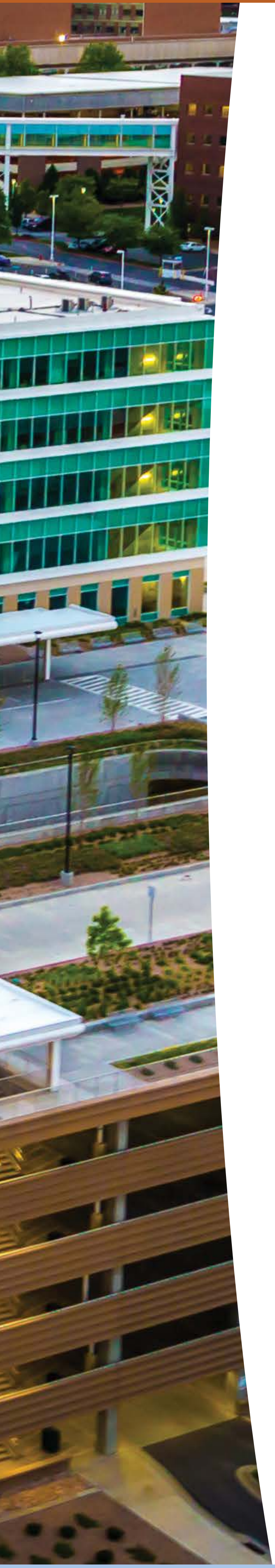
Most hospital stays last 10 days or less, but this can be longer if your child has any problems (complications) after transplant.

Your child's stay in the ICS: A time to learn to care for your child at home

During your child's stay in the ICS unit, the liver transplant coordinator will prepare you — and others who will help with your child's recovery — to care for your child by teaching you specific skills and information.

This will prepare you for when it is time to go home. **Make sure all adults who will be caring for your child attend this teaching to learn from the coordinator.**


Eccles Primary Children's Outpatient Services



After the Liver Transplant

Hospital Discharge and Follow-up

The first few weeks after a transplant is a critical time for your child. Once your child is discharged, **you must stay within an hour of Primary Children's Hospital for 2 to 3 months.** Your child will have blood drawn often during those 2 to 3 months and will be seen in the Transplant Clinic 1 to 2 times per week. The number of blood tests and clinic visits will decrease as your child's condition becomes stable.

Even years after transplant, your child will have lab tests at least once every 3 months. They will need to visit the transplant clinic every 6 to 12 months. Transplant problems become less likely as time passes, but they are possible for the rest of your child's life. Regular follow-up lab work and clinic visits are the best way to catch problems in their early stages.

Liver transplantation gives children a second chance at life. The care they need after their transplant will seem overwhelming at first, but families soon figure out a good routine. Your liver doctor will tell you when it is safe for your child to return to school (usually within 6 to 8 weeks of discharge). Learning about transplantation will be an ongoing process throughout your child's life. Joining support groups and talking with your social worker can help you and your family through this difficult but rewarding process.

Guidelines for follow-up care

A typical follow-up care schedule will include blood tests and clinic visits, but vary depending on your child's condition. Below is the typical clinic schedule:

Clinic visits and lab tests:	Time since transplant:
1 to 2 times a week	0 to 1 month
Weekly	1 to 3 months
Every 2 weeks	3 to 6 months
Every month	6 to 12 months
Every 3 months	Greater than 12 months
Every 3 months	More than 12 months

Rejection

After the transplant, your child's body may see the new liver as foreign and may respond by trying to attack it. This is called **rejection**, which can be treated but should be prevented.

To keep the body from attacking or fighting the new liver, your child must take medication. **Your most important responsibility after transplant is making sure your child takes their medication as directed.** Do not stop giving your child medication or reduce their dose unless the liver doctor tells you to. If your child stops taking medication without asking the doctor, their body can reject the liver or have other serious problems. Your child's liver doctor will decrease the medications slowly over the first few months to a year. However, it's likely that your child will have to take some medication for the rest of their life.

Failing to take medication is one of the leading causes of transplant graft failure in pediatric and adolescent patients. Teach your child to prepare the daily doses and how to call the pharmacy for refills once your child is mature and old enough to understand.

Common medications

Medications and doses differ for each patient and depend on weight, height, and drug absorption. Support your child by:

- Telling the transplant team about all the medications your child takes, including over-the-counter and herbal remedies, inhalers, patches, injections and vitmin supplements. Some medications do not mix well with others.
- Always having at least a week's supply of medication so your child doesn't run out.
- Calling the transplant coordinator as soon as you're running low to refill the prescription.
- Talking to the transplant team if you can't afford the medication or if your child is having side effects. The social worker can help find ways to pay for the medication, and the doctor can change the dose or prescribe a new medication if needed.
- Never allowing your child to stop taking the medication unless a doctor tells them to.

After liver transplantation, these are some of the medications your child may have prescribed (next page):

Medication	Purpose	Major Side Effects
Tacrolimus (Prograf)	Prevents liver rejection	• Increased risk of infection • Headaches • Tremors and seizures • High blood pressure • Diarrhea • Nausea • High blood sugar • High potassium • Low magnesium • Abnormal kidney function • Numbness and tingling in hands and feet • Trouble sleeping • Thinning hair • Increased risk for some types of cancer
Prednisone	Prevents liver rejection	• Increased risk of infection • Fluid retention • High blood sugar • High blood pressure • Bone thinning/fractures • Stomach ulcers • Muscle weakness • Acne • Mood swings • Slowed healing • Slowed growth • Trouble sleeping • Excess hair growth • Vision problems • Weight gain • Puffy cheeks and round face • High cholesterol
Mycophenolic acid (CellCept) Mycophenolate (Mofetil)	Prevents liver rejection	• Increased risk of infection • Stomach ulcers • Heartburn • Nausea • Diarrhea • Vomiting • Low white blood cell count • Increased risk for some types of cancer

Medicine	Purpose	Major Side Effects
Cyclosporine (Neoral or Sandimmune)	Prevents liver rejection	• Increase risk of rejection • Headache • Tremors • Abnormal kidney function • High blood pressure • High potassium levels • Gum overgrowth • Excess hair growth • Trouble seeing • Increased risk for some types of cancer
Septra (Bactrim)	Antibiotic (prevents a certain type of pneumonia)	• Nausea and vomiting • Diarrhea • Rash • Itching • Decreased appetite • Decreased white blood cell count
Acyclovir, Ganciclovir, or Valganciclovir (Zovirax, Cytovene, or Valcyte)	Antiviral (prevents or treats viral infection)	• Nausea and vomiting • Rash • Diarrhea • Headache • Abnormal kidney function • Decreased white blood cell and platelet counts
Nystatin or Clotrimazole (Nyamyc or Mycelex) Fluconazole (Diflucan)	Antifungal (prevents thrush)	• Diarrhea • Nausea and vomiting • Stomach pain • Itching • Abnormal liver function tests
Ranitidine or Omeprazole (Zantac or Prilosec) Famotidine (Pepcid)	Prevents stomach ulcers	• Headaches • Nausea and vomiting • Diarrhea • Constipation • Gas

Medicine	**Purpose**	**Major Side Effects**
Magnesium	Replaces magnesium	• Decreased blood pressure • Diarrhea • Abdominal cramps • Gas • Muscle weakness
Calcium	Replaces calcium	• Kidney stones • Fatigue • Headache • Decreased appetite
Aspirin	Prevents blood clots	• Bleeding • Rash • Stomach ulcers • Reye's syndrome
Magnesium supplements	Replaces magnesium	• Decreased blood pressure • Diarrhea • Abdominal cramps • Gas • Muscle weakness
Multivitamin	Enhances nutrition	• Nausea and vomiting
Antihypertensive (for example: Amlodipine, Nifedipine, or Losartan)	Decreases blood pressure	• Lower or faster heart rate • Dizziness • Swelling • Fatigue • Bleeding • Bruising
Enoxaparin (Lovenox)	Prevents blood clots	• Bleeding • Bruising • Nausea • Diarrhea and vomiting • Fever • Redness at injection site

Common Medications (continued)

When to Call the Transplant Team

Call the transplant team if:

- Your child can't take their medication because they are feeling sick, nauseated, or are vomiting
- Your child has diarrhea and may not be absorbing the medications
- You forgot to give your child the medication or missed a dose
- The directions on the pharmacy bottle are different from what you've been told
- Your child is having unusual reactions or side effects from the medication
- You want to give your child an over-the-counter medication you haven't asked their doctor about

Medications NOT Prescribed by the Liver Transplant Team

Certain medications can also make tacrolimus (medication to prevent liver rejection) levels high or low. If another doctor prescribes a new medication for your child, call the transplant team before starting the new medication. The team can see if it affects your child's tacrolimus levels. If your child needs new medication, the tea
need to monitor medication levels more c
adjust the dose as needed.

You can give your child 10 mg/kg acetaminophen (Tylenol) every 6 hours for mild pain or fevers. The maximum dose is 500 mg, or one tablet. Do not give your child acetaminophen (Tylenol) for more than 2 days in a row.

It is best if you call the transplant team with any question or concern about giving Tylenol or any other medication.

Over-the-Counter Medications

Don't give your child over-the-counter medication, including:

- **Cold medication.** Specifically, do not give anything with a decongestant in it. Please be sure to call our office before giving anything for colds). These can cause high blood pressure and other serious side effects because of how they interact with other transplant medications. They usually do not treat cold symptoms well and have potential side effects.
- **Ibuprofen.** When taken with tacrolimus, it can cause kidney damage and clotting problems.

Missed or Incorrect Medication Doses

Your child must take all of their medications at the same times each day. If your child misses a dose, takes too much, or vomits their medication, follow the guidelines below or call the transplant team.

Tacrolimus or Cyclosporine

- **Missed dose:**
  - If your child misses a dose and you remember within 6 hours of the time it should have been given, give the full dose. Give the next dose when it is scheduled.
  - If you missed a dose, and it has been 6 or more hours since it was due, please call our office. We will instruct you on what to do.
  - If your child misses a dose within 2 days of a lab draw, please tell the transplant team. This may affect the medication level that shows up in lab results, and it is important for the team to know so they can determine the best plan for your child.
- **Extra dose:** If your child accidentally gets more than double their dose, call the liver transplant office or on-call GI physician for help.
- **Vomiting Doses**
  - If your child throws up 30 minutes after taking medication, do NOT repeat the dose.
  - If your child throws up less than 30 minutes after taking the medication, repeat the dose.
  - If your child throws up the second dose or you are having problems with giving any medications, call the transplant office or GI physician on call.

Labs (Blood Tests)

Your child will have labs drawn regularly to monitor their health and liver function. The labs results may be the first sign of rejection or other liver problems so it is very important for your child to have labs drawn according to the liver team's recommendations.

The timing of labs is very important. Your liver doctor will want to check your child's tacrolimus level 12 hours after the last dose was given and right before the next dose is due (this is called the trough level).

Your child's labs can be drawn before the morning or evening dose. To make sure you're as close to the right time as possible, arrive at the lab 30 minutes before your child's tacrolimus dose would be due.

Do NOT give your child their tacrolimus dose until after the labs are drawn, even if the lab is running a little bit late.

Other labs we will be checking include:

- Liver function tests
- Mineral tests, especially for magnesium levels
- Kidney function tests
- Coagulation studies to monitor blood clotting
- Complete blood count, which monitors white and red blood cells and platelets
- Cytomegalovirus (CMV) and Epstein-Barr virus (EBV) tests
- Cystatin C (once a year) to monitor kidney function
- Lipid panel (once a year) to monitor fat and cholesterol levels in patients 5 years and older

Bring the tacrolimus with you to the lab and give it to your child immediately after labs are drawn. Your child can take all other medications at their normal, scheduled time. The transplant team will watch for the results or contact the lab if they don't get them.

If your child has labs drawn at a non-Intermountain Healthcare facility, the results will not appear in our computer system. Please call the transplant center with the location and date of the blood tests. The transplant coordinator will call with the results within 24 to 48 hours or less, depending on the urgency of the results.

Your child will need labs drawn up to 3 times per week during the immediate post-transplant period after they first leave the hospital. When tacrolimus levels are stable and need fewer changes, your child won't need labs drawn as often.

Clinic visits

Clinic visits will include a physical exam; a discussion of how you and your child are doing; medication changes (if needed); social work follow-up; diet help (if needed); and continuing education. These visits will be in the outpatient liver clinic.

Your child's labs may be drawn the morning of the clinic visit. Bring your child's medication bottles to each clinic visit. Your doctor may also ask for you to bring a record of blood pressure measurements or blood glucose.

More Testing

After transplant, your child may need other tests to monitor their new liver. These tests may include:

- **Ultrasound:** Gel is put on your child's abdomen, and a transducer (wand-like tool) will be moved over their abdomen to look at their liver. Your child will have an ultrasound on day 1 and day 2 after the transplant to see if the main blood vessels of the liver are flowing normally. The ultrasound also shows if fluid, such as blood or bile, is collecting in the abdomen.
- **CT scan:** Your child drinks a liquid and has dye injected through an IV so a technician can take x-rays of their liver and blood vessels. Your child may need sedation to relax during this test if they are unable to hold still.
- **Liver biopsy:** A physician inserts a small needle 1 to 2 inches into the liver to test a piece of liver tissue for rejection and other problems. Your child will be sedated during this procedure.
- **ERCP:** A physician performs an endoscopic retrograde cholangiogram, or ERCP, to study the liver's bile ducts. A long, lighted tube is guided down your child's throat to look at the organs and inject dye so the organs appear on an x-ray.
- **PTC:** During a percutaneous transhepatic cholangiogram, or PTC, a radiologist inserts a needle into the liver through the abdomen and puts a catheter in the bile ducts. This catheter can be connected to special bags and allow the bile from the liver to drain.

Calling the Transplant Team

Call the liver transplant office if your child has:

- A fever higher than 101°F (38.3° C) or has a fever of 100.4°F (38° C) that lasts for more than 2 days.
- Signs of jaundice (yellowing of the skin and whites of the eyes), itching, or liver pain (pain in the right upper quadrant of your child's abdomen)
- Sudden fatigue, weakness, light headedness, irritability, or unusual sleepiness
- Signs of dehydration (see **page 39**)
- Been vomiting for more than 6 to 8 hours or is vomiting bile
- Blood in stool, urine, or vomit (look for a bright red color or a dark brown color like coffee grounds)
- Cool, clammy, and pale skin
- Severe diarrhea (not able to eat or drink without having diarrhea)
- Distended or bloated abdomen
- Flu-like symptoms Blood pressure higher or lower than discharge guidelines
- Reactions to medication such as nausea, vomiting, diarrhea, rash, or hives
- Persistent diarrhea (more than 4 watery stools in a day)

Weekdays during business hours, call the transplant office at **(801) 213-3599**.

Afterhours and during weekends, call the hospital operator at **(801) 662-1000** and ask them to page the on-call GI physician.

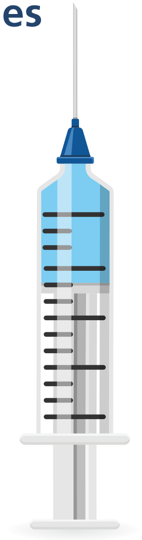
- Has blood pressure higher or lower than discharge guidelines
- Been exposed to contagious diseases like chickenpox, shingles, measles, mumps, or hepatitis. (It's important to let us know right away because your child must be treated within 96 hours of exposure.)
- Has signs and symptoms of infection, including:
  - Fever, redness, warmth, pus, or drainage around the incision site, or
  - Cough, rash, painful urination, sore throat, or ear pain
- Any other concerning findings, or you are having worries about your child for a reason not listed here

Please call if you have any concerns about your child's health. Remember, no question is a dumb question. We'd much rather you ask than miss something that could lead to harm or complications for your child.

Immunization Guidelines

NO LIVE Vaccines

- ~~Chickenpox~~
- ~~Measles~~
- ~~Mumps~~
- ~~Rubella~~
- ~~FluMist~~



Transplant recipients

Children who have had a liver transplant should:

- Wait until the transplant team says it's OK to resume the regular vaccine schedule (usually 6 to 12 months after the transplant).
- Get the transplant team's approval before receiving ANY live-virus vaccines. This includes varicella (chickenpox); measles, mumps, and rubella (MMR); rotovirus; and FluMist.
- Get a yearly flu shot if they are at least 6 months old. **This should only be given as a shot in the muscle, not as FluMist (which is a live virus).** The transplant team will let you know how soon your child can start getting this after the transplant.
- Get other routine vaccines, including DPT, IPV (polio), pneumococcal, meningitis, hepatitis A and B, meningococcal, and HPV.

Household members

Anyone who lives with a transplant recipient should:

- Be up-to-date on their immunizations
- Get a yearly influenza virus vaccine if they're 6 months old or older. **They should NOT receive FluMist since it is a live virus that can be spread to the transplant recipient**
- Get the measles, mumps, and rubella (MMR) vaccines
- Get the varicella (chickenpox) vaccine if they have not had the virus and are at least 1 year old or older
- Get a hepatitis B vaccination
- Get a hepatitis A vaccination if they are at least 2 years old or older

Preventing Infection

You and everyone in your houldehold can help protect your child from colds, flu, diarrhea, and more serious diseases by following these best practices:

- Make sure all family members and your child wash their hands with soap or hand sanitizer for at least 20 seconds. Always wash:
  - Before and after meals
  - After blowing your nose
  - After going to the bathroom
  - After changing diapers
  - After playing with pets.
- Avoiding close contact with family members who are sick. Be sure to wash hands often, and do not share eating or drinking utensils.
- Avoid others who are sick. Ask friends and family to visit only when they are well.
- Don't submerge your child's incision site in standing water until the transplant team tells you it is okay to do so. If you use a shower, clean the shower head well with bleach or replace the shower head with a new one before bathing your child after transplant.
- Stay away from crowded places like malls, theaters, and churches, especially during cold and flu season and while your child's immunosuppression levels are high. This includes right after transplant for at least 2 to 3 months and if your child's medications were recently increased due to rejection or another complication.
- Avoid secondhand smoke. Smoke in the air makes colds, coughs, sinus infections, and asthma more severe.
- Don't touch animal waste, including cleaning litter boxes and cages.
- Avoid lakes and ponds.

- Avoid public swimming pools while immunosuppression is high. Your transplant team will tell you when it is safe to visit a public pool. When allowed to swim, avoid swallowing water.
- Use insect repellent to avoid mosquito bites.
- Wear shoes when outside, and cover all cuts and wounds with bandages immediately.
- If you're considering traveling overseas, please talk with the transplant team about extra precautions you may need to take.
- If there is a chickenpox outbreak at your child's school, call the liver transplant team to talk about potential risks and what steps to take to protect your child.
- Make sure your child receives regular dental care. They will be prescribed antibiotics before routine cleanings and any other dental procedures. You will need to call the transplant office and let us know before the dental appointment so we can send the prescription for antibiotics.

Signs of Liver Transplant Rejection

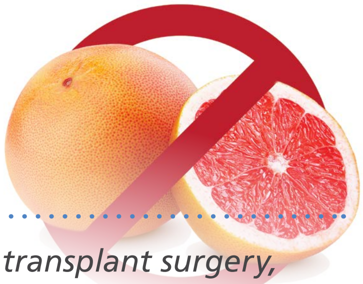
Rejection occurs when your child's immune system attacks the new organ because it sees it as a foreign object. About 1 in 20 of transplant patients will experience rejection. Signs of rejection include:

- Elevated liver function tests (this may be the earliest sign—labs will often let us know before your child shows any outward signs)
- Abdominal tenderness or distension, especially on the upper right side of the abdomen
- Fatigue
- Jaundice (yellowing of the whites of the eyes or skin)
- Light-colored stools (light tan or clay) or dark-colored urine (tea- or Coke-colored)
- Decreased appetite (not wanting to eat or drink much)
- Not feeling normal; seeming "off"
- Fever
- Itching

Liver rejection often happens with no outward symptoms. This is why it's so important to have labs checked regularly. You can help prevent rejection by:

- Giving your child all medications exactly as prescribed
- Coming to all follow-up appointments
- Calling the transplant office right away if you notice any signs of rejection

Your child may need a liver biopsy to diagnose rejection. The liver transplant team can treat rejection by changing or increasing medications. Your child may also need to be hospitalized to receive the best treatment.



Nutrition

When you child comes home after the transplant surgery, they will need to eat well to nourish their bodies and grow strong. But there are some foods that are better than others.

Foods to Avoid

Liver transplant patients have some dietary rules that are important to follow. They need to avoid grapefruits, pomegranates, and acai berries and their juices because they can increase tacrolimus levels. Some sports drinks, juices, and other fruit snacks have these juices in them, so remember to check all food labels and read the ingredient lists.

Food Safety

Because your child's immune system is weak, they have a higher risk of food poisoning, especially right after transplant when medication doses are high. Your child should avoid:

- Raw or cooked shellfish, including oysters, clams, mussels, and scallops
- Raw or unpasteurized milk or cheeses
- Soft cheeses such as feta, Brie, Camembert, blue-veined, and Mexican-style cheese
- Raw or undercooked eggs and foods with raw or lightly cooked eggs (certain salad dressings, cookie and cake batter, sauces, and eggnog)
- Raw or undercooked meat or poultry
- Raw sprouts (alfalfa, clover, and radish)
- Unpasteurized fruit or vegetable juices (these have warning labels)

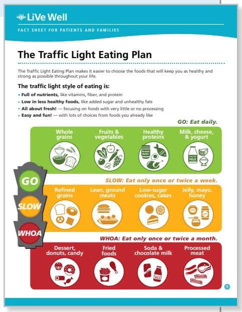
Note: Your child CAN eat hard cheese, processed cheese, cream cheese, cottage cheese, and yogurt.

To keep your child safe while preparing meals:

- Sanitize cutting boards after each use.
- Use a separate cutting board for meats to avoid cross-contamination.
- Carefully wash and peel all fruits and vegetables.
- Keep hot foods hot and cold foods cold.

Ask your child’s dietitian if you have any questions about food safety.

How to Treat Side Effects from Medication:

Possible problems	What you can do
Unwanted weight gain	• Give your child smaller portions. • Limit "junk" or processed foods and choose more fruits and vegetables. Ask your healthcare team for a copy of the Traffic Light Eating Plan for ideas. • Cook low-fat meals. • Help your child exercise regularly. • Avoid juices and sugary drinks.  LiVe Well FACT SHEET FOR PATIENTS AND FAMILIES **The Traffic Light Eating Plan** The Traffic Light Eating Plan makes it easier to choose the foods that will keep you as healthy and strong as possible throughout your life. **The traffic light style of eating is:** • **Full of nutrients,** like vitamins, fiber, and protein • **Low in less healthy foods,** like added sugar and unhealthy fats • **All about fresh!** — focusing on foods with very little or no processing • **Easy and fun!** — with lots of choices from foods you already like *GO: Eat daily.* Whole grains · Fruits & vegetables · Healthy proteins · Milk, cheese, & yogurt *SLOW: Eat only once or twice a week.* Refined grains · Lean, ground meats · Low-sugar cookies, cakes · Jelly, mayo, honey *WHOA: Eat only once or twice a month.* Dessert, donuts, candy · Fried foods · Soda & chocolate milk · Processed meat GO SLOW WHOA 1
Low blood phosphorus	• Give your child low-fat, high-phosphorus foods, such as: – skim or low-fat milk – yogurt – low-fat cheese – extra-lean meats, chicken, and turkey – dried beans
High cholesterol and triglycerides	• Give your child low-fat foods. • Encourage your child to get regular exercise.. • Help your child lose weight safely, if recommended by their doctor. • Give your child more fiber.
High blood sugar	• Space out meals and limit snacking. • Limit sugar. • Make sure your child exercises regularly. • Help your child lose weight safely, if recommended by their doctor.
High blood pressure	• Help your child lose weight safely, if recommended by their doctor. • Limit salt in your child's diet. • Make sure your child gets enough calcium through their diet or supplements. • Encourage your child to get regular exercise.
Low blood magnesium (may cause leg cramps)	• Give your child high-magnesium foods such as bananas, potatoes with the skin, almonds, and fortified cereal. • Your child may need a magnesium supplement.
Stomach irritation	• Space meals and snacks throughout the day. • Avoid foods with caffeine and spicy foods. • Give prednisone with food.

After surgery, your child must get enough calcium and protein for healthy bones and muscles. We will discuss ways to make sure they are getting enough of both of these during your clinic visits.

Fluids

After the liver transplant, your child must drink enough fluids to stay well-hydrated and limit stress on the kidneys from medication. Their doctor will give your child a **fluid goal** (how much fluid is needed each day). It is very important for your child to stay well hydrated. They can have a special water bottle to take to school to help make sure they reach this goal.

Dehydration

Dehydration, or the loss of body fluids, can happen if your child vomits a lot, has diarrhea, or doesn't drink enough. Signs of dehydration include:

- Not urinating for 12 hours (children younger than 6 months may still urinate even if they're dehydrated)
- Dark circles under the eyes
- Sunken eyes
- Being tired, weak, and lethargic
- Sticky mouth
- Increased thirst or hunger
- Sunken soft spot (in infants)
- Decreased weight
- Loose skin
- Suddenly looking "skinny"
- Fast heart rate
- Low blood pressure

Dehydration is serious when your child has received a transplant. It increases your child's tacrolimus level, which can cause injury to the kidneys. Dehydration also makes the blood thicker and increases your child's risk for blood clots to form in the blood vessels to the liver. If your child is dehydrated, call the transplant team or on-call GI physician right away.

Exercise

Your child can begin exercising soon after the transplant surgery. Encourage walking when your child is able. They might also work closely with a physical therapist to help regain strength. Physical therapy may continue after discharge.

After surgery, your child's muscles may feel weak because of inactivity or as a side effect of prednisone. Regular exercise — including walking every day after discharge — will help your child regain and increase muscle strength. After 6 weeks, your child can usually begin bicycling, taking exercise classes, and playing sports. **Please check with your child's liver doctor before resuming these activities.**

After recovering from surgery, your child should exercise for 30 to 45 minutes 4 to 5 times per week. Ask your child's liver doctor or transplant coordinator if you have questions about their activities or exercise.

For the first 3 months after transplant surgery, your child should avoid:

- Pulling or straining the abdominal muscles (no heavy lifting or sit-ups)
- Contact sports
- Jolting activities like horseback riding or snowmobiling
- Gymnastics, trampoline
- Swimming

After 3 months, your child should be able to participate in most activities, but ask their transplant coordinator or doctor first.

Help your child choose exercise they enjoy and can do daily so they'll continue doing it. For example, your child might enjoy walking several miles each day combined with biking or sports. Talk to the transplant team about safe swimming options. If your child has bone or joint pain, tell your child's doctor or transplant coordinator. This may be a side effect of a medication, and your child may need additoinal tests.

Infection Risks After Transplant

Cytomegalovirus (CMV)

Cytomegalovirus [sigh-tow-MAY-gah-low-vy-ruhs] is a common virus that can damage the liver and cause rejection in patients with weakened immune systems. Signs of CMV may include:

- Sore throat
- Swollen lymph nodes
- Fever
- Headache
- Fatigue
- Weakness
- Muscle aches
- Loss of appetite
- Blindness and vision problems
- Pneumonia

CMV is usually detected by lab tests. This virus is checked frequently after transplant. CMV is usually treated with antiviral medications and by decreasing immunosuppression medications.

Epstein-Barr virus (EBV)

Epstein-Barr virus is a common virus that causes **mononucleosis** [mah-noh-nu-klee-OH-sis] (often called **mono**). Signs and symptoms may include:

- Unexplained fever
- Lethargy or tiredness
- Fatigue
- Swollen lymph nodes
- Sore throat with enlarged tonsils
- Enlarged spleen
- Pneumonia, cough, or rapid breathing

The transplant team will watch your child closely for EBV for the first year after transplant and then every 6 months. Epstein-Barr virus is diagnosed with lab tests and a physical exam. If your child has EBV, they may need to have their immunosuppression medications decreased, and sometimes an antiviral medication is prescribed.

Post-Transplant Lymphoproliferative Disease (PTLD)

Post-transplant lymphoproliferative [lim-foh-pro-LIF-fer-ah-tive] **disease** is a pre-cancer condition than can occur with Epstein-Barr virus. We will watch your child very closely for any signs of this virus.

Non-Melanoma Skin Cancer

When your child takes immunosupressive medications for a lifetime, the suppressed immune system may not notice abnormal cells, like cancer, which can spread. Your child also has a higher risk of getting viral infections, which can cause certain types of cancer.

The most common cancer after a transplant is non-melanoma skin cancer. Transplant patients have a 20- to 60-times-higher risk of getting skin cancer.

To prevent skin cancer:

- Use a broad-spectrum sunscreen with SPF 30 or higher on all exposed skin, even on cloudy days.
- Reapply sunscreen if your child has been in the sun longer than 80 minutes.
- Buy new sunscreen yearly and check the expiration dates.
- Don't lay out in the sun, especially between 10 a.m. to 3 p.m.
- Have your child use a water-resistant sunscreen if swimming or sweating.
- Give your child a lip protection cream with SPF 15 or higher if they're outside for more than an hour.
- Don't let your child use indoor tanning booths (they have the same harmful rays as the sun).
- Have your child wear protective clothing in the sun (a long-sleeved shirt and long pants when possible).
- Have your child stay out of the sun as much as they can.
- Inspect your child's skin regularly, and teach them to look at it too.
- Take your child to the dermatologist for any skin changes, including dry patches, moles, growths, and non-healing sores.
- Do not smoke, and have your child avoid secondhand smoke.

- Give your child a diet that is rich in fruits and vegetables and low in saturated fats.
- Make sure your child exercises regularly.
- Take your child to a yearly physical exam with their primary care doctor.
- Tell your child's doctors if they have any new symptoms or complaints.

General Health Guidelines

Your child should have a primary care doctor to help with medical problems like ear infections, the flu, and respiratory infections. Your primary care doctor will monitor growth, overall health, and give advice based on your child's age. If your child doesn't have a primary care doctor, the liver transplant team can help you find one. The transplant doctors are not primary care doctors.

Skin Care

The skin protects the body from infection, so keep any cuts clean and covered. Your child may not need special skin care unless they have acne or dry skin. However, daily baths or showers help prevent infection. Teach your child to look for moles that change color or get bigger and sores that don't heal or become larger. Tell the transplant team if your child has any skin infections.

Acne

Acne is caused by the build up of dirt and bacterian in the pores that are traped by dead skin cells and oil on the skin. Some immunosuppressive medicines can also cause acne breakouts on the face, chest, shoulders, and back. To reduce acne, washing the face regularly to get rid of extra skin oils and prevent whiteheads and blackheads from forming. In addition:

- Don't use lotions with lanolin or petroleum jelly on acne areas.
- Wash affected areas gently several times a day without rubbing.
- Buy cleansers that remove oil and dirt but don't dry the skin (like Cetaphil).
- Use a topical, non-prescription cream with 5% to 10% benzyl peroxide.
- Wash hair every day or every other day to control oil. Don't use baby shampoo, which can have extra oils.
- Avoid touching the face and squeezing or picking at pimples.
- Change the pillowcase regularly and disinfect their cell phone to avoid bacteria on the skin.
- Buy a water-based makeup. Avoid oil-based, medicated, or hypoallergenic makeups.
- Consider seeing a dermatologist if acne doesn't get better. **Contact our office before starting any medications prescribed by your dermatologist.**

Stretch Marks

Prednisone can cause stretch marks. Some feel that using vitamin E cream on the skin may help.

Warts

Warts are caused by the papilloma [pap-puh-LOW-muh] virus and are easily spread. An over-the-counter wart-removal medication can be used to treat your child's warts, but it may not work. Treating warts can be hard, and your child may need to see a dermatologist. If your child has a caregiver with warts, have them keep the warts covered and wash their hands well.

Dry Skin

Prednisone sometimes causes the skin to be thin and dry. If your child has dry skin, bathe with mild bath soap and apply lotion, moisturizing creams, or baby oil after to help treat extremely dry skin. Do not use these products on areas with acne as they will make it worse.

Swimming

Your child can get diarrhea, rashes, ear infections, and respiratory infections from swimming pools, which can lead to more serious infections. Ask your team about the risks and recommendations before going swimming. Avoid ponds, rivers, oceans, and lakes for the first year after transplant.

Dental Care

Make sure your child brushes their teeth at least twice a day and flosses daily. **Keep in mind that they should visit the dentist every 6 months and take an antibiotic 1 hour before any dental procedure.** Tell the dentist your child is a liver transplant patient and list their medications. Your dentist can always contact our team with any questions or concerns, especially before any procedures.

Oral Care

Medications may cause thrush, a yeast infection that looks like a white coating on the tongue and in the back of the throat. If thrush isn't treated with medication, your child's mouth can develop sores. Contact the transplant team if you notice white patches or a white coating in your child's mouth, or if they are complaining of pain in their mouth.

Eye Care

Your child may need yearly eye exams. Some medications can cause eye changes like cataracts and glaucoma, a condition that can cause blindness over time. The transplant team will tell you if your child needs yearly eye exams.

Bone Health

Several immunosuppressive medicines have been linked to osteoporosis (thin and weak bones), including tacrolimus. There is an increased risk for osteoporosis if prednisone is taken for a long time. Avoid osteoporosis and osteopenia (lower bone mineral density) by:

- Walking, weight-lifting, dancing, doing aerobics, playing soccer, or doing simple leg lifts to increase muscle mass and protect bones
- Maintaining a healthy weight to decrease pressure on joints and bones
- Not smoking or drinking alcohol
- Eating 3 to 4 servings of high-calcium, low-fat foods with vitamin D each day
- Taking calcium supplements if needed
- Monitoring bone health through bone density scans (if your liver doctor orders them)

Bowel care

Constipation

Constipation may be a problem immediately after surgery until your child goes back to their normal diet and activities. Diets low in fiber and fluids can also cause constipation. Prevent constipation by:

- Remaining active
- Drinking plenty of water and other fluids
- Eating more fiber, especially through fresh fruits, vegetables, and whole-grain breads and cereals

Diarrhea

Diarrhea is a side effect of mycophenolate and sometimes tacrolimus. To reduce diarrhea:

- Avoid foods like prunes, bran, and beans
- Limit dairy, fruit, and juices

Do NOT give anti-diarrheals unless the transplant team instructs you to. Contact the liver team if your child has persistent diarrhea that lasts longer than 48 hours; dark, tarry stools; bloody stools; or a fever higher than 101° F.

Emotional and Social Concerns

Our transplant team social worker works exclusively with pediatric transplant patients and their families to help them manage emotional, social, and financial concerns. They can:

- Provide emotional support
- Help you find travel benefits and housing
- Assist with Medicaid, medical grants, and prescription copay help
- Answer questions about social security income, insurance, and medical bills
- Find resources for neuropsychological testing and behavioral health issues
- Coordinate with the Make-A-Wish program
- Work with schools and education services
- Serve as your advocate, and help you solve problems
- Connect with the Intermountain Donor Services social worker
- Work with you on writing a letter to the donor family if this is something you are interested in

The social worker will support your family before and after your child's transplant and answer any of your questions. They will be available to meet with you during clinic visits or you can call them directly.

Financial Considerations

How Do I Pay for My Child's Medical Expenses?

Employer Group Insurance

You may have insurance that helps cover the costs of your child's transplant. Most insurance companies cover minor children and may extend coverage until your child is 26. You will need to know:

- The name of your insurance company
- The policy and group numbers
- How long the insurance will cover your child and when they will no longer be on your policy

Carry a copy of the insurance card with this information in your wallet.

Medicaid

Some people are eligible for Medicaid, a state program for people with low income or a disability. If you have supplemental security income (SSI) from Social Security, you can probably also receive Medicaid. It pays bills after group insurance and Medicare. SSI and Medicaid can end one year after transplant because this is when your child may no longer be considered disabled.

Health Insurance Marketplace

The marketplace is a set of U.S. government-regulated and standardized healthcare plans. It is also called the health insurance exchange. Open enrollment starts in November and coverage starts as soon as January 1. Some people qualify for premium tax credits that lower the cost of coverage. Some also qualify for savings on deductibles, copayments, and other costs.

All plans cover:

- Essential health benefits
- Pre-existing conditions
- Preventive care

Aging Out of Parents' Insurance

Your child may face a time when your insurance no longer covers them or they are no longer considered disabled and eligible for Medicaid. It may happen before your child has finished their education or has a job that provides them with health insurance. This is a difficult time because your child will always need coverage for medications, labs, and doctor visits. If this occurs, ask your child's transplant social worker for ways to pay for the needed medical care.

- See if you can extend your child's coverage for as long as possible. If your child stays in school and carries a full-time schedule of classes, this may be an option.
- Encourage your child to get an education or training that will help them get a job with good health insurance.
- Apply for coverage through the Health Insurance Marketplace.
- Look into student health insurance while your child is in college.
- Contact drug companies and apply for special help with medications.
- Meet with financial counselors at the hospital to see if your child is eligible for hospital support.

Transition to an Adult Liver Program

Our team will work with you and your child to prepare you for when it is time to transition their care to an adult transplant program. We work closely with the local adult programs and offer a transition clinic so you can meet with adult liver doctors and nurse coordinators before you officially transition your care to their offices.

We will also discuss your transition during clinic visits to help prepare your child for more responsibility and independence as they get older. We will begin these discussions when your child is about 12 years old so they will feel prepared and confident about taking charge of their care when they graduate from high school.

Financial Information

Ask yourself these important questions before your child has a liver transplant:

1 What is your insurance company's name and policy number?

  a Insurance Company: ____________________

  b Policy Number: ____________________

2 How long can your child stay on your insurance? ____________________

3 Do you have Medicaid? __________

What month is your yearly review? ____________________

4 If you have more than one source of coverage, who pays first, second, third? (In other words, which policy counts as your primary insurance, secondary insurance, and so on?)

  1 ____________________

  2 ____________________

  3 ____________________

5 What can you do after your insurance, Medicare, or Medicaid end?

____

____

____

6 Do you keep a copy of your insurance card in your wallet? ____________________

Who's On Your Healthcare Team?

You and your child will interact with a lot of healthcare professionals during your transplant journey. This team will work together to provide the best possible care to your child and your family. See the brief descriptions below to find out each person's role in your child's care.

Child life specialist: An expert in child development who supports patients and families; helps your child be as comfortable as possible in the hospital; and encourages play

Dietitian: Evaluates your child's nutrition and works with other team members and your family to create the best diet for your child

Discharge coordinator / Case manager: A nurse who coordinates your child's transition from the hospital to your home; works with your insurance company to provide home nursing care, dressing changes, lab tests, medications, and rehabilitation therapy; works closely with your child's transplant coordinator during discharge from the hospital

Financial transplant coordinator: Helps you understand how your insurance covers the costs of transplantation evaluation, surgery, and follow-up care; contacts your child's insurance company to determine transplant benefits; helps with pre-approval for transplant surgery and hospitalization

Independent living donor advocate: A social worker who represents and advises possible living donors; advocates for the donor; and helps them make an informed decision without pressure from others

Pediatric gastroenterologist: A doctor who treats digestive system diseases and may also care for liver transplant patients ("GI doctor").

Pediatric hepatologist (liver doctor): Doctor who treats children with liver disease before transplant, during hospitalization for transplant surgery, and throughout their long-term follow-up care.

Pharmacist: Monitors your child's transplant medications and their effect on your child's body; teaches you about your child's medications, including how to give them and possible side effects.

Social worker: Helps families that come to our transplant clinic cope with challenges; offers counseling and family support; and helps you find financial and housing resources.

Transplant / transplantation: Taking an organ from one individual and placing it in another individual whose organ is diseased or not functioning well enough.

Transplant assistant: The first person you speak with on the phone; gathers information to best help your needs (including sick symptoms, medication names and doses, etc.); helps direct you to the correct person who can answer your questions or provide the assistance you need; arranges your child's transplant evaluation and follow-up testing; and schedules your clinic appointments.

Transplant coordinator: A nurse who answers questions before, during, and after transplant; records your child's condition while they wait for their transplant; provides family education; notifies you when a donor organ becomes available; and continues coordinating your child's care after their transplant.

Transplant surgeon: A doctor who performs liver transplant surgery and watches your child carefully before, during, and after the surgery.

You can reach our team by calling our main office at **(801) 213-3599** (or by calling **801–662–1000** after hours and asking for the on-call gastroenterologist or "GI doctor").

Intermountain
Primary Children's Hospital
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