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Welcome from the transplant team
Welcome from the Transplant Team

The transplant team is your key to a successful transplant. The team is made up of your child and family and highly dedicated professionals. Each team member has a specific job to do.

**Important phone numbers**

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<thead>
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<th>Name</th>
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<tbody>
<tr>
<td>Main hospital</td>
<td>206-987-2000 or toll-free 1-866-987-2000</td>
</tr>
<tr>
<td>Transplant office</td>
<td>206-987-1800</td>
</tr>
<tr>
<td>Megan Clift, RN</td>
<td>206-987-4143</td>
</tr>
<tr>
<td>Transplant Coordinator (A-E)</td>
<td></td>
</tr>
<tr>
<td>Ellen Cella, RN</td>
<td>206-987-6045</td>
</tr>
<tr>
<td>Transplant Coordinator (F-N)</td>
<td></td>
</tr>
<tr>
<td>Rachel Page, RN, BSN, CCRN</td>
<td>206-987-5730</td>
</tr>
<tr>
<td>Transplant Coordinator (O-Z)</td>
<td></td>
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<tr>
<td>Appointment Scheduling:</td>
<td></td>
</tr>
<tr>
<td>Cindy Wright, Transplant Specialist (A-L)</td>
<td>206-987-6613</td>
</tr>
<tr>
<td>Michelle Moore, Transplant Specialist (M-Z)</td>
<td>206-987-2478</td>
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</table>
The Transplant Team

Transplant surgical attending physicians:
Patrick Healey, MD
Jorge Reyes, MD
Andre Dick, MD, MPH

Gastroenterology attending physicians:
Simon Horslen, MB ChB
Evelyn Hsu, MD
Karen Murray, MD
David Suskind, MD
Danielle Wendel, MD
Ghassan Wahbeh, MD
Niviann Blondet, MD

Nurses and nurse practitioners:
Megan Clift, RN (A-E)
Ellen Cella, RN (F-N)
Rachel Page, RN (O-Z)
Jessica Aslakson, ARNP (Inpatient care)
Nicole Broas, ARNP (Inpatient care)
Ronelle Caskey, ARNP (Inpatient care)
Christine Lundberg, ARNP (Inpatient care)

Transplant specialists:
Cindy Wright (A-L)
Michelle Moore (M-Z)

Pharmacists:
Shiho Fukasawa, PharmD
Beatrice Ho, PharmD
Gwen Nance, PharmD
Thomas Nemeth, PharmD
David Newland, PharmD
Jennifer Pak, PharmD
Hyacinth Wilson, PharmD

Dietitians:
Melissa Mortensen, R.D.
Nila Williamson, R.D.

Social worker:
Amal Muammar-Hastings, LICSW
Transplant coordinator

The coordinator is a registered nurse specially trained in caring for transplant patients and families. You will meet your transplant coordinator either during your first clinic visit or hospital stay. You will work with them closely throughout your child’s transplant process. They provide follow-up and care across the continuum from pre-transplant, during transplant and post-transplant. They collaborate with other members of the health care team to enhance patient care by acting as a liaison between families, patients and staff.

Your child’s transplant coordinator also monitors lab results, communicates concerns to your doctors, maintains your child’s medical information, and is the key contact person for your family. You will see them whenever you’re in clinic and throughout your hospital visits. Your coordinator is available to answer any questions you have throughout this process.

Transplant dietitians

The transplant dietitians are nutrition experts who will work with you and your child during the transplant process. They will:

• Help manage your child’s nutrition before and after transplantation
• Coordinate nutrition support plans with our multidisciplinary team and community providers
• Watch your child’s growth trends

Social worker

The social worker is part of the multidisciplinary transplant team at Seattle Children’s Hospital. The social worker provides psychosocial services to your child and family throughout the course of care. This includes initial diagnosis, clinic visits, the hospital stay, discharge to home and follow-up. Social workers provide supportive direction and discussion of problem-solving options with children and families to enhance continuity of care and partnership. These discussions may involve one or all of the following:

• Helping your child, family and others understand the complexities of the medical system
• Acting as a liaison with medical staff and community for psychosocial factors, which may impact your child’s and family’s adjustment
• Supporting your child and family in setting realistic goals
• Assisting with referrals to community resources
• Providing supportive follow-up therapy referrals
Why your child needs an organ transplant
Why your child needs an organ transplant

Liver disease
The liver is a vital organ to your body. You cannot live without it. The liver has many jobs to do, but here are a few:

• Clears wastes from the blood
• Helps digest and store the food that is used for energy (glycogen)
• Makes proteins to help the blood clot
• Helps use and store vitamins
• Breaks down many toxins and drugs

The liver also helps control the way the body uses food and it works with the body's defense system.
Can the liver heal itself?

When the liver is badly damaged it cannot grow enough new liver tissue to heal itself. Severe liver damage is called “cirrhosis.”

Cirrhosis results in two main problems:

- It cannot do the work it is supposed to do, as described above.
- The liver is so damaged that the blood cannot flow freely. High blood pressure builds up in the vein that feeds the liver causing portal hypertension. See the big portal vein labeled in the picture above.

The liver can hold up under a lot of damage. It only starts to fail when more than half of it is damaged. Once a person shows signs of liver failure, it means there is not much of the liver left for the body to rely on during sickness and in times of need.

What are the signs of liver disease?

Signs of liver failure may include:

- Yellow skin and eyes (jaundice)
- Forgetfulness, confusion, or even coma (encephalopathy)
- Feeling very tired (fatigue)
- Muscle wasting
- Itching
- Poor clotting of the blood

Other signs of liver disease include a build-up of fluid in the abdominal area (ascites – pronounced “a site eeze”), infections and bleeding in the stomach. There is no treatment that can help the liver do all of its jobs. Therefore, when a child reaches a certain stage of liver disease, a liver transplant may be the only way to prolong their life.
Before transplant:
Pre-transplant evaluation
and preparation
Medical tests your child will need to be considered for a transplant

Before any child can get a transplant, they need to go through several medical tests to make sure they are a good candidate. Most of the time these tests show that a patient needs a transplant, but sometimes a child is too sick, too well, or would benefit from another type of surgery.

The transplant coordinator will guide your family through the pre-transplant tests and medical exams. The tests listed below are a sample of what might be ordered. Your child may not need all the tests listed.

Your child will be seen by:

- Transplant GI (gastro-intestinal) doctor
- Transplant surgeon
- Anesthesiologist
- Dietitian
- Social worker

Lab tests

A number of laboratory tests are done to check your child’s liver and kidney function, blood type and nutritional status. For example, abnormalities in vitamin levels, glucose or protein can be a sign of severe liver disease that needs medicine or diet changes. Blood tests can tell us about previous exposure to infections and immunizations, such as hepatitis, HIV, Varicella (chicken pox), pneumococcal and meningococcal disease.
Liver Transplant Handbook

X-rays and radiology exams

Your child will have several pictures and sound recordings of their inside organs, like:

• Computed Tomography (CT or CAT scan)
  This X-ray film is used to look at the size of your child’s liver and other problems that would make it hard for your child to have a liver transplant. Cirrhosis can lead to liver cancer. A CT scan will help screen for this.

• Ultrasound
  This test uses sound waves from a microphone that is passed across the skin. It will give a picture of your child’s liver, bile ducts and the blood supply to and from the vessels to the liver.

Magnetic Resonance Image (MRI)

This is similar to the CT scan. It is another way of looking at the size and shape of your child’s liver. As with the CT scan, there is no pain during an MRI.

Chest X-ray

This study gives a black and white picture of the lungs, ribs, heart and diaphragm muscle.

Heart tests

Two tests are done on the heart.

Echocardiogram (ECHO)

Sound waves coming from a microphone are moved lightly across the skin of the chest to show how well the heart is pumping. The ECHO also checks the blood pressure in parts of the heart. Doctors will then know if you need more tests or treatments for your heart.

Electrocardiogram (EKG or ECG)

This is a record of the electrical action of the heart. It is used to find errors in heart rhythm.

Liver tests

Liver biopsy

A bit of liver tissue is taken out via a needle biopsy while your child is asleep. It will help to show what type of liver disease your child has and the severity of damage the liver has undergone.

Endoscopy

A flexible tube with a tiny camera is passed down the throat and into the stomach. We look for enlarged veins or ulcers that are caused by liver disease. Your child will be asleep during this test.
Sclerotherapy and rubber-band ligation – vein repair
Some children may have life-threatening bleeding from enlarged veins in their throat or stomach caused by liver disease. Depending on the size and location of the enlarged veins, they are treated with injections or small rubber bands. The injection of chemicals causes the enlarged veins to clot and harden. This is called sclerotherapy. Another treatment involves the doctors placing rubber bands on the enlarged veins that will make them shrink. This is done to prevent or stop bleeding.
Transjugular Intrahepatic Portosystemic Shunt (TIPS)

What is TIPS?

TIPS is an abbreviation for a procedure that helps correct blood flow problems in the liver. It stands for:

**Transjugular** Across the jugular vein (vein in the neck)

**Intrahepatic** Within the liver

**Portosystemic** From the portal vein to the general circulation (the portal vein is the main vein that carries blood from the stomach and intestines to the liver)

**Shunt** A channel for blood to flow through

When the liver has a lot of damage and there are blockages, blood cannot flow through it very easily. This procedure creates a new connection between two veins in your child’s liver. The new pathway allows blood to flow better through the liver. It can help stop bleeding and fluid backup.

How is the procedure done?

This is not a surgical procedure. It is done by a radiologist in the X-ray room using X-ray guidance. The radiologist uses X-ray to guide the insertion of a stent (tube) to connect the veins in the liver. This is done through a small puncture site through the skin into a vein in the neck. If TIPS is recommended for your child, we will give you more information on the procedure.
Nutrition and liver transplant

Good nutrition is important before and after liver transplant. A transplant dietitian will work closely with your child and family throughout the transplant process. Before transplant, your child may need a special diet, formula, tube feedings, or total parenteral nutrition (TPN). This is to optimize their growth and health and help prepare them for transplant. Over time, your child's nutrition plan may change based on changes in their liver function. After transplantation, good nutrition will help your child to heal, fight infection and achieve their desired weight. Your child’s transplant dietitian will help you learn about good nutrition both before and after transplant surgery.

Immunizations and required health check-ups

Immunizations

Children and adolescents who may get a liver transplant must get all the recommended immunizations before the transplant is done. Vaccines are more effective when given before transplant. This is because of the medicines that are given after transplant to suppress the immune system.

Other vaccines may be recommended for children who have chronic illnesses or will be immunosuppressed due to having a transplant. Pneumonia and meningitis are not always recommended for all kids, but they are for your child. Be sure to tell your doctor’s office.

Important facts about immunizations for transplant patients:

- Live vaccines – like measles, mumps and rubella (MMR), Varicella (chicken pox), oral polio, and Flumist – cannot be given to your child after transplant. There is a risk of getting the disease from the vaccine. If these vaccines are given pre-transplant, you must wait 4 to 6 weeks after the vaccine is given, before a patient can have a transplant.

- Routine immunizations should not be given for at least 6 months after transplant.

- Before getting any immunizations for your child, please discuss with the transplant team.

- To decrease the risk of exposure, it is important to keep siblings up to date on all their immunizations.

- Your child must get a flu shot every fall. Try to have this done in October or as soon as the vaccine comes out. Everyone who lives in your household should get this vaccine. Family members may get the live Flumist instead of the flu shot if they prefer.

- Schools may ask for a letter that explains why your child has not received some vaccines. You can get this letter from your pediatrician or the transplant team.

- See the immunization schedules in the Appendices section of this handbook.
Dental check-up
Your child must have a full dental check-up prior to being listed for transplant. Have your child’s teeth cleaned and all cavities filled. This is to ensure they do not have any areas of concern that could lead to infection once your child is on immunosuppressive medicines after transplant. During the time that your child is waiting for an organ, continue to take them to the dentist every 6 months for cleaning and evaluation.

How do we decide if your child is eligible for a transplant?
Once your child has completed all their tests, imaging and or procedures, their case will be reviewed by the transplant selection committee. This committee is made up of doctors, transplant coordinators, and the psychosocial team. Once in a while, a child is found to be too healthy for a transplant. These patients may then be followed closely for signs of more liver failure. If their liver gets worse, they will be re-tested. Other children are simply too sick to survive the transplant. In these cases, the committee will not approve a liver transplant procedure. If your child fits the criteria for a transplant, the committee then approves a transplant. Once your child is approved, they can be placed on the waiting list.

Sometimes more tests are needed before a decision can be made. Your child’s transplant coordinator will let you know what might be needed. Your transplant coordinator will contact you to notify you of the transplant committee’s decision. They will also share the information with your referring doctor.

Getting ready for home
From the time your child is first evaluated for a transplant, we start the plan and preparation for going home. This preparation is important for the success of the transplant. While in the hospital, we will spend a lot of time teaching you how to care for your child after you leave the hospital. You will learn what to expect when your child leaves the hospital so that you will feel confident and comfortable in caring for your child. You will get to know your child’s transplant nurse coordinator really well. Think of your coordinator as your primary source of information and support for your family.
Options for liver transplants: deceased or living donor

There are a variety of ways we now perform transplantation of an organ from a donor. Though sometimes livers can come from a living person (called a living donor), most liver transplants are from a deceased donor.

Deceased donor

Most of the time, a liver transplant is done with a liver from a brain-dead person who is called a deceased donor. The term “brain-dead” means the brain’s electrical signals have quit firing, so it can no longer support life in the body. At this time, other organs are still alive and functioning. A donor is chosen for the recipient based on their medical condition, size and blood-group match. The liver is taken and kept sterile until it is ready for transplant.

There are three types of deceased donor transplants:

Whole Liver
In this type of transplant, the entire liver from the donor is used.

Reduced-size liver graft
A piece of a liver that is otherwise too large for the recipient is taken from a deceased donor and trimmed to fit your child.

Split-liver transplant
A liver from a deceased donor is cut in two. A small piece can be used for transplant in a child and a larger piece is used to transplant into an adult.

Living-donor transplant

Recently, living-donor liver transplants have become more common. A smaller part of the liver (left side) is removed from a healthy living adult donor and given for transplant into a child.

This can be done because a healthy liver can regenerate (grow back). After the transplant, the liver parts of both the donor and person in need will grow and form a complete organ. Over the past 10 years, nearly 1000 of these transplants have been done throughout the world. They have been just as successful as transplants of whole organs. There are some risks of living donation that must be carefully considered. If this is something that you are interested in, it can be discussed with your transplant surgeon.

What are the advantages of a live donor transplant?
• Shortens the waiting time for the recipient
• Timing of the surgery can be planned
What a living donor needs to know

Who can become a donor?
Family members such as parents, siblings (over 18 years old), adult children or someone close may offer to give part of their healthy liver.

People who want to be live donors are carefully checked to choose those who can safely give a part of their liver without harm to themselves. The first concern is the safety of the donor as well as being sure that the graft will work for the person in need of a liver. The risk of death is real. Discuss this with your doctor, and ask for the statistics. In general, those who can be liver donors must:

• Be in good general health
• Have blood type that is compatible with the blood of the person in need
• Not have a selfish motive for donating: There should be no pressure of any kind on a person to donate part of their liver, nor should there be any money given or received. Federal law does not allow the sale of organs.

What are the risks to the donor?
Risks to the donor include bleeding, infection, leaking bile and possible death. A donor might also need a liver transplant if their piece of the liver is damaged. This is rare. Many donors have minor problems after surgery. Most have full recoveries and are alive and well. As with any major surgery, there will be some pain from the incision, but it will get better with time.

What is involved in the live donor evaluation process?
All appointments for donor evaluation are at the University of Washington Medical Center and include:

• Blood tests: The first test will find out if the donor’s blood type is compatible with that of the person in need. Blood tests are done to test the donor’s liver and kidneys. Others are done to check for viruses such as herpes and HIV.
• Physical examination: If the donor and recipient blood types are a close match, the donor will get a physical examination.
• Ultrasound: An ultrasound is done of the liver, other organs and blood vessels.
• MRI and CAT scans: help to give a complete view of the donor’s organs.
• Lungs and heart tests
• It takes 2 to 4 weeks for a donor to go through the tests. In an emergency situation, it can be done in as little as 48 hours.

What is donor surgery like?
• The donor’s liver is split into two parts. One part is removed for the transplant.
• The gallbladder is almost always removed, too.
• After the surgery, the donor’s liver begins to heal and grow new tissue. It takes about 6 to 8 weeks for the liver to grow back to its normal size.
How long does the donor need to stay in the hospital?
Donors stay in the hospital for 4 to 7 days after surgery. They may spend their first night after surgery in the ICU (Intensive Care Unit).

How long does it take the donor to recover?
It takes about 4 weeks to recover from surgery. In the month after leaving the hospital, donors will need to return to the clinic to be checked on a regular basis. Donors often get back to work within 3 to 6 weeks, but this will differ from person to person. The medical staff will say when it is safe to return to normal life. Federal employees can get a special leave for being organ donors. Other employers have such programs. You should ask if there is such a program in your company.

What are a donor’s healthcare costs?
The health insurance of the person who gets the transplant covers the donor’s healthcare costs. This includes the costs of check-up, doctor’s fees, hospital costs, and follow-up visits after surgery. The donor must have their own health insurance to cover any long-term medical needs.

If a person is interested in being a living liver donor, please contact your Seattle Children’s Transplant coordinator.
Waiting for an organ

The organ waiting list

Donated organs are given to people based on how urgent their need for an organ is or how severe their condition is. Your child will be given a score called a MELD or PELD score. The score is based on the results of their blood work. A higher score means your child is sicker and will be higher on the list to receive a liver. This process is done by computer and is monitored by UNOS.

What is UNOS?
UNOS stands for the United Network for Organ Sharing. UNOS is a private, nonprofit organization, which coordinates the nation’s organ transplant system.

What does UNOS do?
UNOS assists the transplant community in a number of ways:

• Raises public awareness of the critical need for donated organs and tissues
• Maintains the national organ transplant waitlist
• Coordinates the matching and distribution of donated organs
• Collects and reports data related to transplantation
• Provides information about transplantation to patients, the public, and the transplant community

Where can I learn more about UNOS?
The UNOS website (www.unos.org) provides a lot of data, resources, UNOS news and details on the process of organ donation and transplantation.

Where is “the list” stored?
UNOS has a computer-based network for matching donated organs and managing transplant data. Every organ-sharing institution is linked live at all times over the Internet so donated organs are placed as quickly as possible. Transplant centers can only view patients listed at their own center, not the whole list.
WHAT are MELD and PELD scores?
MELD stands for Model for End Stage Liver Disease score (it applies to adults and children age 12 years and older).

PELD stands for Pediatric End Stage Liver Disease score (it is used for children under age 12).

What do the MELD and PELD scores mean?
The MELD and PELD scores are based on the severity of your child’s liver disease. By using MELD and PELD scores, patients are ranked on the waiting list according to their need for a transplant. The higher the score, the more severe the liver disease is.

How is the MELD/PELD score calculated?
The PELD score is based on a child’s:
- Bilirubin count
- Albumin
- Growth failure
- INR (“International Normalized Ratio Test”) This is a test that shows how well your blood can clot.
- Age

PELD scores can range from a negative value (such as -10) to very high numbers (such as 50).

The MELD score is based on a child’s creatinine, bilirubin, and INR. MELD scores can range from 6 to 40.

How high will my child’s MELD or PELD score have to be before they can get a transplant?
Once a child is put on the list, getting a liver transplant depends on several factors. These include:
- Blood type
- The number of other patients listed within the local area
- The illness level of the other patients waiting in the local area
- The number of organs available in the local area or region

How will I know where my child is on the list?
We are not able to tell you where your child is in the list, only what their score or status is. Each time a new donor is added, a new match list is run. This is based on the donor’s blood type, size, weight, medical condition, and the recipient’s MELD/PELD score (see below), blood type, size, weight and other factors.
How do we get on the waiting list for a liver?

Only the patient’s transplant center team can decide when (or if) it is appropriate for a patient to be placed on the waiting list. While the MELD/PELD score determines a patient’s immediate need for a transplant, there are many other factors involved in the decision to list a patient for a liver transplant. The patient’s center will still need to make the final decision about putting your child on the list. Speak to your doctor about your specific medical circumstances and your MELD/PELD score.

Where can I find more information about MELD and PELD?

There are several documents describing the MELD/PELD system on the UNOS website (www.unos.org). You can also request a brochure about MELD/PELD by calling 1-888-894-6361.
Updating scores

Once your child is listed and we know what their MELD/PELD score is, we will know how often their score needs to be updated. The higher their score, the more often we will need to do lab tests. Each time your child has labs done we will calculate and update their score to get more points if they are eligible. Below is a table of scoring ranges and how often labs must be repeated. If your child is 12 or younger, a new height and weight must be done each time the labs are drawn.

### Pediatric Candidate Reassessment and Recertification Schedule

<table>
<thead>
<tr>
<th>PELD/MELD score 25 or greater (for patients 18 years and older)</th>
<th>New labs needed every 7 days</th>
<th>Laboratory values must be no older than 48 hours</th>
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<tbody>
<tr>
<td>PELD/MELD score 25 or greater (For children less than 18 years)</td>
<td>New labs needed every 14 days</td>
<td>Laboratory values must be no older than 72 hours</td>
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<td>Score less than or equal to 24 but greater than 18</td>
<td>New labs needed every 1 month</td>
<td>Laboratory values must be no older than 7 days</td>
</tr>
<tr>
<td>Score less than or equal to 18 but greater than or equal to 11</td>
<td>New labs needed every 3 months</td>
<td>Laboratory values must be no older than 14 days</td>
</tr>
<tr>
<td>Score less than or equal to 10</td>
<td>New labs needed every 12 months</td>
<td>Laboratory values must be no older than 30 days</td>
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It is extremely important you get your child’s lab tests done on schedule. If labs are not obtained by their due date, your child’s MELD or PELD score will be automatically adjusted to their previous lower score.

If your child’s condition worsens before they are due to be updated we can update their score at any time using their new labs and height and weight.

### For patients who are critically ill

For patients who are critically ill and meet certain criteria, there is a different scoring system. This scoring consists of Status 1A and Status 1B. Some metabolic liver diseases are also eligible for status 1B. We will talk about these criteria if they apply to your child.

<table>
<thead>
<tr>
<th>Status 1A or 1B</th>
<th>New labs required every 7 days</th>
<th>Laboratory values, including height and weight, must be no older than 48 hours</th>
</tr>
</thead>
</table>

### Multiple listing

All patients have the right to be listed at more than one transplant center. Depending on your child’s health status, it may benefit you to get on the list at more than one center to get an organ faster. If this is something your family would like to do, you will need to contact your insurance to find out if this is an option.
Also refer to the pamphlet “Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer.”

**Changes in listing status**

You and your family will get a written notice from the transplant center when your child is placed on the waiting list, if they need to be placed on hold, or if their status changes from a MELD/PELD to a Status 1 or from a Status 1 to a MELD/PELD.

Occasionally during the waiting period patients become ineligible to receive a transplant. This can be due to:

- An active infection
- Loss of insurance coverage
- Your child is too well or too sick

If this happens, your child will be placed in a “temporary hold” status on the waiting list; they will not be removed from the list. In order to reactivate your child on the list, new labs, height and weight must be completed.
The waiting period
Waiting for a donor organ is a stressful time for your child and family. Here are some helpful steps to prepare while you wait for an organ:

Make sure your child’s transplant coordinator can reach you at all times
The transplant nurse coordinators must be able to reach you immediately when an organ becomes available. Contact the coordinator if:
• There are any changes to your address or phone number as soon as they change
• You are going to be away on vacation

Update insurance information
Let your child’s transplant financial specialist know of any change in insurance coverage or changes in employment immediately. It is best to do this as soon as possible, before the change occurs, as it may affect your child’s transplant coverage.

Take good care of your child’s health
• Make sure your child takes all their medicines as prescribed.
• Contact your child’s transplant nurse coordinator if:
  • Any other medicines have been prescribed or changed
  • Your child is hospitalized for any reason or if they develop any new medical problems or infections, even if they can be treated out of the hospital

Learn all you can about the transplant
Wait time can be a good time to get to know the transplant team and to learn about the care that your child will need after the transplant.

Meet others or join a support group
Some families find it helpful to meet other transplant patients and their families. If you would like to do this, your social worker can help make arrangements.

Stay in touch with family and friends
Good company will take your minds off waiting and enhance your quality of life. There are patient websites that make it easy to keep family and friends up to date on your child’s condition and your family’s needs. Some examples are Caring Bridge at www.caringbridge.org and Care Pages at www.carepages.com.
Fundraising
Depending on your insurance and your financial situation, this may be a good time to start fundraising. Even with insurance there are many costs associated with transplant, such as some medications, travel, insurance co-pays and deductibles. The transplant social worker can help you with fundraising ideas. There are also websites to help with the process and they can be found in the resources section of this notebook.

Plan how you’ll get to the hospital
You must be able to get to the hospital as soon as you are told that an organ is available. Make travel plans in advance.

Read about hospital services
We welcome you to stay with your child overnight and have room for one parent or legal guardian. Siblings and visitors may not stay overnight. The Pediatric Intensive Care Unit (PICU) has limited sleeping rooms for parents in the Family Resource Center. The unit coordinator assigns these based on your child’s condition.

Make a list of what to pack
You must be ready to leave and get to the hospital as soon as the call comes. Be sure to pack an extra 24-hour supply of your child’s medicines. Include clothes and toiletries for you and your child, a few toys, books, videos and a favorite blanket—things that help pass time and soothe your child.

Relax
Take time to read with your child. Listen to music together. Watch funny movies. An older child can meditate or do light yoga. You can play games with a younger child. Focus on creating stress-free enjoyable times with your family.
The call: when the organ arrives

A nurse coordinator, transplant surgeon and doctor are on call 24 hours a day. When an organ becomes available, the coordinator and the transplant surgeon will review the history and condition of the donor to decide if the donor organ would be the best match for your child.

If the organ is a good match, the transplant nurse coordinator will contact you to see if your child is able to undergo the transplantation operation. The coordinator must make sure that your child does not have a cold, an infection, or any new health problems that might complicate the transplantation.

When an organ becomes available we are required to decide whether to accept or turn down the organ(s) within **one hour**. This is based on current UNOS policy.

We will make every effort to contact you. **You must answer all calls that come, even if you do not recognize the number.** The call to you may come from a blocked number, the coordinator’s home or cell phone number. We must also have a list of contacts (family, friends, school, work, etc.) to call in case we can’t reach you at the other numbers. We may even call the local police to help find you.

When we contact you, the coordinator will:

- Ask if your child is well, without fever or upper respiratory infection
- Ask how you will get to the hospital
- Ask how long it will take you to arrive
- Tell you when to have your child stop eating and drinking to prepare for surgery
- Tell you where to park and check in at the hospital when you arrive

**If we are unable to contact you within that hour, a very important opportunity for a transplant will be missed. The organ will be offered to the next person on the list, and your child will remain on the waiting list.**
During the transplant: Surgery and your child’s stay at Seattle Children’s Hospital
The Surgery

Checking into the hospital
Once an organ has been found, your child is admitted to the hospital. There might be a wait to go to the operating room or they might be taken to surgery right away. Waiting for a longer period of time does not mean there are problems. However, sometimes an organ that was thought to be good for your child can be found to be unacceptable. We want to provide your child with the best opportunity for a successful transplant. Sometimes, though rarely, a child is sent back home because the donor’s condition has deteriorated or an unsuitable organ arrived.

The surgery
Once your child is in the operating room and asleep under anesthesia, the transplant team will put several lines into your child’s veins (called “IV’s”). These IV lines help us to monitor heart and blood pressure, or give medicine, fluids and blood products. To do the transplant, the surgeon will make a long incision (cut) that goes along the bottom of both sides of the ribs. Sometimes, there is also a cut that goes up the stomach, making the whole cut look like the Mercedes-Benz sign. (See illustration below.)

Four blood vessels connect the liver to the rest of the body. When the liver is removed, the surgeon cuts and clamps these vessels shut. After getting the donor liver ready, the surgeon connects these vessels to the donor vessels. The bile duct (that drains the bile from the liver to the intestines) on the donor liver is then connected to your child’s bile duct (see illustration). Then the gall bladder, which acts as a holding area for bile, is removed.

In some cases, a small piece of the intestine is connected to the new donor bile duct. This connection is called Roux-en-Y. If your child has had a Kasai procedure for biliary atresia, this is the bile duct connection they will get.
How long does the surgery take?

Your child will be in the operating room for about 8 to 10 hours. This includes 6 to 8 hours for the surgery plus another 2 hours to prepare for surgery. After surgery, your child will go directly to the pediatric intensive care unit (PICU, pronounced “pick-you”).

Surgical complications

The transplant surgeon will discuss in detail any possible complications that can occur during and after the surgery including:

- Bleeding or clotting of blood vessels. Without proper blood flow to the liver it won’t function well. If there is a clot after surgery, this may require a second transplant.

- Bile duct problem. The bile duct or blood vessels of the liver could become too narrow. This may require surgery or a procedure by interventional radiology to open the duct or vessels with balloon dilation, or by placing a stent.

- Primary graft non-function. Sometimes, because of how the graft is preserved, a new liver transplant may not work as it should. This is critical. It means going on the transplant list again and getting a new liver within days.
Your child’s stay in the hospital after the surgery

First stop: Pediatric Intensive Care Unit (PICU)

Your child will wake up from the surgery in the pediatric intensive care unit (PICU). One of the things you may notice most is how “puffy” your child looks after surgery. This will go away after the extra fluid from surgery is removed by the kidneys. During the wake-up period, your child will have a tube in their windpipe to help them breathe. It is removed when they are fully awake and strong enough to breathe on their own. They may have other tubes as well. These tubes will be removed as your child recovers.

Here are some of the tubes your child will have in place after their transplant, and their descriptions:

- Monitors that check heart rate, breathing rate, blood pressure and oxygen in the blood.
- An endotracheal tube (ET) is placed in your child’s windpipe during the surgery. It connects to a breathing machine (ventilator) to help with breathing. The doctors will remove the ET tube when your child no longer needs help breathing. While your child has the breathing tube in, they will be given medicine to make them sleepy.
- A nasogastric (NG) tube which passes through the nose and into the stomach, to help drain secretions from the stomach.
- Several abdominal drains in your child’s stomach area to help remove extra fluid from the surgical site.
- A catheter to drain urine from the bladder. It measures how much urine is being made and ensures the bladder is being emptied while your child is under anesthesia and sedation.
• Several IV lines will be used to give pain medicines, antibiotics and other fluids that your child will need.
• An arterial line to check blood pressure and provide blood samples. The arterial line looks like an IV, but it’s in an artery rather than a vein.
• A central venous catheter (a flexible tube placed in a large vein in the neck or chest) to give IV fluids and provide blood samples.

**Next stop: Recovering on the Surgical Unit**

When ready, your child will leave the PICU and be transferred to the Transplant Unit. This is a special area on our surgical floor. Now, the goal is to get your child walking, eating, and learning about medicines. During this recovery period, your child’s transplant team will:

• Make sure your child is getting enough calories for their body to heal.
• Adjust the medicines that suppress your child’s immune system to avoid rejection.
• Perform many checks for possible rejection or infection like X-rays, ultrasounds or liver biopsies as needed.

**Helping your child get stronger**

Some of the things you can help your child with at this time are:

• Walking. Help your child take short walks around the room, then into the hallways. This will build strength, and increase appetite and help them have bowel movements.
• Coughing and deep breathing exercises. Use the breathing exercises or aids your nurses give your child. These exercises help prevent fluid build up in the lungs.
• Relaxing and play. Read books, do crafts and play games to help your child feel better and get better.
• Eating. Your child can start eating when their intestine starts to move wastes normally. If your child is unable to eat enough calories to help with healing, tube feedings may be needed. A nasogastric (NG) feeding tube or total parenteral nutrition (TPN) is temporary and should not be seen as a setback in your child’s recovery. It may be required to aid the healing process.
• Working with Child Life specialists. Child Life specialists are here to assist your child in the recovery process. They can work with your child and family to help you adjust to being in the hospital.

**Nutrition after Transplant**

Right after their transplant, your child will not be able to have foods or fluid by mouth for many days. During this time your child will get intravenous nutrition called total parenteral nutrition (TPN). Once your child’s transplant surgeon determines that it is safe to eat and drink after transplant, your child can start taking clear liquids. They can then progress to solids as tolerated.
Many patients need additional tube feedings after transplant to meet their calorie, protein and fluid needs for healing and growth. The tube feedings may be needed for a few days to a few months, depending on your child’s feeding skills, appetite and intake. Your child may discharge home from the hospital after transplant with a feeding tube. These tube feedings will be reduced as your child can eat more by mouth.

**Regular tests**
During the hospital stay, your child will have routine tests to check how their organ is working before your child shows physical signs:

- Daily blood tests
- X-rays if your child needs them
- A liver biopsy is done if there is any thought that the new liver is being rejected. Rejection is common and does not mean your child is losing the liver.

**Rounds**
Rounds take place each morning. This is a term we use for the medical staff’s daily visit to your child’s room to check on your child’s progress and make a plan of care for the day. The transplant team is quite large, but each member has a role in providing care for your child. We encourage you and your family to join the team in rounds each morning to discuss how your child is doing. You know your child better than anyone else and we value your knowledge and observations.

**Before you leave the hospital**
You can expect to spend about 10 to 14 days in the hospital. For some, the stay may be shorter or longer. Before you go home, you will be taught:

- How to give the new medicines. A pharmacist will do extensive teaching with you over three days. At the end of the teaching you will be required to give all your child’s medications in a 24-hour period. This is a good time to practice what you have learned and ask questions.
- Signs of infection and rejection
- How to change your child’s dressings (surgery bandages)
- General health guidelines for living with a transplanted organ

For families that live outside the Seattle area, it will be required that you stay close to the hospital for a period of time for continued monitoring to avoid post-transplant complications. This way our team can identify early signs of rejection and move quickly to maintain your child’s health.
Complications

With any organ transplant, three main problems can happen: rejection of the organ, side effects from medicines, and infection. In this section we explain each complication and give tips for lowering your child’s risks. First you must understand the effects of the medicines your child will need to take after transplant, called “immunosuppression.”

Imunosuppression

The body uses a complex system to attack and kill invading organisms such as bacteria and viruses. This immune response involves many steps using the body’s white cells. These cells eat up the invading organisms or release toxic chemicals that kill them. There are two different types of cells: the T-cells and the B-cells.

The transplanted organ is a foreign substance to the body just like a splinter, bacteria or virus. Unfortunately, there is no way for the body to tell the difference between bacteria or viruses and the transplanted liver. Even with a perfect match, the normal response is for the B and T cells to attack and destroy. Children in particular have a “hyper” immune system. Their systems respond more quickly and vigorously to infection than adults. This is why you see more fevers in children than adults.

At the time of transplant, your child will receive an infusion of immunosuppressive drugs through an IV.

How long will my child take immunosuppressive drugs?

Your child will always take some type of immunosuppressive drugs such as Prednisone, Tacrolimus, Sirolimus, Cyclosporin, and MMF. These work to prevent this natural “attack and destroy” process of the immune system.

However, being on these immunosuppressive drugs results in fewer antibodies left to fight other germs and infections. Your child will need these medicines for the rest of their life (as long as the transplanted organ is in place). Think of immunosuppressive medicines as a gate held closed against the immune system, which is on the other side just waiting to get through.

Rejection

Organ rejection is a problem that can occur after transplantation. Because your child’s new organ comes from another person, their immune system will recognize it as foreign and it sends out the white blood cells (T-cells) to attack. If your child’s immune system damages the new organ, it is called rejection.

Rejection does not necessarily mean that your child will lose the organ.

If detected early, most rejection episodes can be treated successfully with medicine.
There are different types of rejection

1. **Acute rejection:** Acute rejection most often occurs within the first 6 months after transplant. It is not unusual to see a rejection episode 7 to 14 days after surgery. Most patients have a rejection episode in the first year post-transplant.
   Don’t get discouraged. This is why we check your child so closely with lab work and other tests. If rejection is diagnosed, we will start IV steroids for several days. Other medicines can be used if this therapy does not work.

2. **Chronic rejection:** Chronic rejection occurs slowly over time and causes permanent damage. Our care will focus on maintaining liver function for as long as possible. New medicines may be started, but chronic rejection can sometimes result in liver failure and the need for a second transplant, or in some cases, death.

Staying on top of the signs of rejection

For your child’s new organ to live successfully in their body, we must give medicines that suppress their immune response.

The possibility for rejection is greatest soon after transplant. But at any point, your child’s immune system may try to attack the organ. To prevent this from happening, your child will take medicines for as long as the transplanted organ is in place.

One of the challenges is that infection and rejection symptoms are similar but the treatments are quite different. We will need to perform tests to figure out the cause of the symptoms and choose the best treatment.

Every child is different and some or none of these symptoms may occur during a rejection episode. You must watch your child for any early signs of rejection and act promptly. Always call even if you are not sure!

Look for these signs of organ rejection:

- Flu-like symptoms: remember that the body is acting as if there is an infection. Your child may have general malaise, just not feel well, or be weak or lethargic with nothing specific. (As a parent, listen to your instinct. If you think something is wrong, call.)
- Fever greater than 101 F or 38.4 C
- Increased pain over the incision site
- Cold symptoms: runny nose, cough, sore throat
- Vomiting for more than 24 hours, especially if unable to keep medicines and liquids down
- Excessive diarrhea (more than 3 or 4 times in one day)

Normal liver function test values:

- ALT 5-41
- AST 5-40
- Alk Phos 95-380
- GGT 5-55
- Bilirubin:
  - conjugated 0.0-0.3
  - unconjugated 0.0-1.1
**Medicine side effects**

The key to managing a transplanted organ is a finding the balance of using immunosuppressive medicines to prevent rejection, without causing infection or medicine complications.

Immunosuppression medicines can cause side effects, which we will watch for carefully. These side effects include:

- **Elevated blood sugar**: Prednisone and Tacrolimus therapy may cause a mild form of diabetes (elevated blood sugar). A small number of children may require insulin or oral medicines to treat high blood sugar.

- **Cancer**: Immunosuppressive therapy may increase your child’s risk of cancer. Skin cancers are the most common types of cancers in transplant recipients. Patients are also at risk for lymphomas.

- **Hypertension (high blood pressure)**: Some of the medicines taken after transplant (Prednisone, Cyclosporine) may raise your child’s blood pressure. This may require that your child take blood pressure medicine (anti-hypertension drugs). Elevated blood pressure may be only a short-term or temporary condition. The blood pressure usually comes down after the drug doses are lowered.

- **Decreased kidney function**: Many of the immunosuppressive medicines used are filtered through the kidney. Over a long period of time this can put a stress on the kidneys, causing them to not function properly.

- **Weight gain**: Several factors may lead to weight gain in your child after their transplant:
  - They likely have fewer dietary restrictions now.
  - Food also tastes better because they are no longer sick.
  - Prednisone can increase their appetite.
  - Excessive weight gain can cause high blood pressure and put added stress on the heart, brain and kidneys. Try to follow the dietary plan prescribed for your child as closely as possible.
Infection

Immunosuppressive medicines keep the body from attacking the new organ. Because the immune system is weakened from these medicines, it cannot effectively attack common bacteria (such as Strep), fungus (such as candida), and viruses (such as CMV, EBV). The first month, when the dosages of medicines are at the highest, is when the threat of infection is the most serious.

Infections that the body would normally have been able to fight may seriously threaten your child and/or their liver. **Prevention and early detection is the key.**

The hepatologist, transplant coordinator and your primary care provider work closely together in the care of your child. **Keep the transplant nurse coordinator informed. Always call even if you are not sure!**

**Ways to prevent infection:**

- **Wash hands often.** This is the most effective way to stop the spread of germs and is the first line of defense! Have everyone in the household make handwashing a habit.
  - Remember: wash in warm water for at least 15 seconds and use soap. Get between fingers, under fingernails, the back of hand and the wrists.
  - Use instant hand sanitizer between washes.
- **Monitor visitors at the hospital.** When your child is in the hospital, they will be in a private room to help reduce infection. Ask visitors who are ill (even with a mild cold) to please stay away. All visitors are required to wash their hands or use hand sanitizer before entering the room.
- **Call the nurse coordinator whenever your child is sick.** When your child has a cold or flu (including the intestinal flu), call the nurse coordinator. You must watch your child for fever, worsening of symptoms, and the inability to keep medicines or liquids down. Your child will need extra liquids with a fever, vomiting or diarrhea. The transplant coordinator can give you instructions and decide if your child should be seen in clinic or the emergency room.
- **Keep your child away from people who are ill.** Preventing exposure is often hard because people often don’t know that they are ill until after the symptoms appear. For example, chicken pox can be spread by air borne particles and is most contagious before the rash appears. Tell us **immediately** if your child is exposed to a contagious illness. The most dangerous exposures to your child are chicken pox, measles, mononucleosis (mono), and hepatitis of any form. Let the transplant coordinator know of possible exposures, and if your child becomes ill.
- **Give your child the virus prevention medicines as prescribed.** CMV (Cytomegalovirus) can cause cold symptoms in a healthy person, but in an immunosuppressed person, it can be very dangerous. CMV attacks the liver and other organs and can trigger a rejection episode. Your child will be given Ganciclovir or Valganciclovir (to help prevent getting CMV) up to 90 days after transplant when the immunosuppression medications are at higher doses.

When your child is ill with things like a cold or ear infection you can see your regular primary care doctor.

Handwashing is the best way to stop the spread of germs. Wash hands often using soap and warm water for a full 15 seconds.

Let us know immediately if your child was possibly exposed to a contagious illness; especially chicken pox, measles, mono or hepatitis.
• **Be alert to signs of Epstein-Bar Virus or excessive tiredness in your child.** EBV (Epstein Barr Virus) is responsible for mononucleosis. As with the CMV virus, EBV may become more serious in the immunosuppressed child. We now know that the Epstein-Barr virus (EBV or mono virus) plays a role in **Post-transplant Lymphoproliferative Disease (PTLD)** or lymphoma. PTLD is an abnormal growth of cells, or cancer. We also know that the Epstein-Barr virus can remain silent in the body, and the virus may be passed onto the recipient through the transplanted organ. The risk of developing PTLD is higher when you do not have antibodies against the virus before transplant. Many children don’t have these antibodies because they have not been exposed to the EBV virus. Most adults have been exposed.

• **Monitor routinely for viruses.** We will continue to watch your child for any type of infection. Any time your child has a high fever, we will be checking blood work that will include tests for viruses such as CMV and EBV. If EBV is detected in the blood, further tests will be needed to look for signs of PTLD, including extra blood work and a CT scan to rule out PTLD or lymphoma (please refer to our CT Scan handout). Most people who test positive for EBV will never develop PTLD, and the EBV will go away on its own. Sometimes the transplant doctors may decrease the amount of immunosuppressive medicines so the body’s own immune system will fight the virus. If PTLD does develop, doctors who specialize in treating this disease (Hematologists/ Oncologists) will be consulted to participate in care.

• **Fungal infections:** There should be no flowers or plants in your child’s room after their transplant. For 6 to 12 months after the surgery they should avoid being around construction areas and digging in the dirt.

• **Watch for cold sores.** HSV (Herpes Simplex Virus). Many people have the herpes virus dormant (quietly sitting) within the body. When we are stressed (emotionally or physically such as with a cold), the virus pops up in the form of a cold sore. If your child develops a cold sore, they may need to be treated with Acyclovir. A sore may not be visible on their lips, but may develop inside the mouth. Call the transplant coordinator if your child complains of mouth pain or stops eating well.

• **Be aware of shingles.** Chicken pox or Herpes zoster (separate from HSV) also lays dormant (quiet) within the body. The virus may surface with stress in the form of a painful rash called shingles. Shingles will cause pain in one area about 1 to 2 days before a rash appears. If you see a rash, see your pediatrician and notify the transplant coordinator.
Enhancing success for your child

What you need to do

You can help the success of your child’s transplant by collaborating with your child’s transplant team and keeping your child healthy before and after transplant.

To promote good health and a mutually respectful experience to promote the success of transplanting a scarce organ, we ask the patients and their families to comply with the following expectations:

• Make sure your child takes the medicines properly. This is extremely important.
• Attend all pre- and post-transplant scheduled appointments on time.
• Get blood draw (labs) before your clinic appointments.
• Follow with nutritional diet as recommended by your child’s medical team members, including TPN and/or NG tube placement.
• Follow along with medical education as recommended by your child’s transplant team members. This includes going to teaching sessions before going home and having a consistent support system at home to assure success at home. This includes 1 day (24 hours) of bedside care for your child before going home.
• Your child must abstain completely from using alcohol and illicit substances. Illicit substances include cannabis (marijuana) in any form, cocaine, opiates, amphetamines, hallucinogens and any other controlled substance. Failure to abstain from these substances may prevent you from being a candidate for transplant or re-transplantation if needed.
• Let the staff at the transplant center know about any problems you may have that may prevent you from keeping your appointments or taking the medicines.
After the transplant surgery
Going home from the hospital

Recovering from a liver transplant is different for each child. Your family’s need for advice and support from your transplant team will vary in the months and years to come.

In this section, you will find information about the warning signs of problems and the basics of caring for your child in your first weeks back home.

Before discharge

Before you leave the hospital, you will meet with your child’s pharmacist, who will do all your medication education. You will also meet with your transplant coordinator, who will go over the material outlined in this handbook. You may also meet with a dietitian if your child is having difficulty with their nutrition.

After you leave the hospital

After leaving the hospital, your family will need to stay in the Seattle area for a while. This is so your child can come in for regular visits to the transplant clinic. The amount of time you will stay in Seattle depends on your child’s health. The time spent in Seattle will give you and your child time to ease into life after transplant and get comfortable with your new routines.

One of the most important parts of ensuring the health of your child’s transplant is giving careful attention to taking the immunosuppressant medicines. These are essential to avoid rejection and prevent infection. Your child’s medicines are reviewed at each clinic visit. Although your child will likely take immunosuppressants for the rest of their life, the doses and types of medicines may be changed by the transplant team.

Talk with your doctor about any problems or side effects your child is having. Most problems can be treated by adjusting medicines or starting new ones.
When to call us – warning signs of trouble

Study and get familiar with this list of warning signs. Share it with those who care for your child. Call us right away if your child is having any of these:

- Fever over 38.4 C (101 F)
- Flu-like symptoms (body aches and fever)
- Cold symptoms: runny nose, cough or sore throat
- Black, tar-colored, clay-colored or bloody stools
- Yellow-colored eyes or skin
- Itchy skin
- Unexplained bruising or bleeding
- Vomiting for more than 24 hours, especially if unable to keep medications and liquids down
- Headaches that are severe and sudden, and not helped by Tylenol and rest
- Vision changes (for example, changes in peripheral vision, flashes, floaters)
- Possible exposure to persons with contagious diseases (such as measles, mumps, rubella, chicken pox). We must know as soon as possible.
- Persistent joint or bone pain
- Excessive diarrhea (more than 3 or 4 times in one day)
- Missed immunosuppression medicines
- Increased pain over the incision site
- Increase in blood pressure (10 points of either systolic and/or diastolic over baseline that does not respond to regularly scheduled blood pressure medicine, or after taking one dose of blood pressure medicine that is prescribed “as needed”)
- Any time you are unsure or something does not seem right

Who to call

Call your transplant nurse coordinator during the week between 8 a.m. and 5 p.m. After hours, on weekends and holidays call the paging operator at 206-987-2000 and ask for the gastroenterologist on call.
The after-transplant diet

Have your child follow the transplant diet given by your dietitian. Your child will need extra calories while their body is healing from surgery. Many children require a formula supplement either by mouth or tube feeding after a liver transplant. Please feel free to call your dietitian at 206-987-5518 if you have any questions.

Protein

Getting enough protein in the diet is very important after transplant to support wound healing. Your child’s transplant dietitian will talk with you about how much protein your child needs each day. Please refer to our handout “Protein: Where Is Protein Found” for information on the protein content of many common foods. (See the Appendices section of this handbook.)

Food Safety

Your child’s immune system will be suppressed after transplant to prevent rejection. It will be important for your family to follow food safety guidelines to help prevent your child from getting sick from a contaminated food source (see the detailed “Food Safety” information near the end of this section). Please also refer to the handout “Immunosuppressed Patients’ Food Guide” for detailed food safety information in the Appendices section of this handbook. If needed, your child’s transplant dietitian can review this information with you and answer any questions.

Potassium Intake

Tacrolimus, one of the immunosuppressive medications used after transplant, can cause the potassium level in your child’s blood to increase above normal levels. Your child’s potassium levels will be watched closely by the transplant team during your child’s hospitalization and in transplant clinic. If your child’s potassium level goes up after transplant, we will need to limit the potassium in your child’s diet. Patients on tube feedings or oral formula after transplant may need a special low potassium formula. Your child’s transplant dietitian will teach you about low potassium food choices. Please refer to the handout “Your Potassium Guide” in the Appendices section of this handbook.

Magnesium

Tacrolimus, one of the immunosuppressive medications used after liver transplant, can also cause the magnesium level in the blood to decrease below normal levels. Most patients will need to take a supplement to keep their magnesium levels in a safe range. Choosing high magnesium foods can also help boost magnesium intake. Please refer to the handout “Magnesium Food Sources” for more information in the Appendices section of this handbook.
**Weight Gain and Growth after Transplant**

Every child will have different needs for growth after transplant. Your transplant dietitian will work with your family to establish a plan that is best for your child. Over time, that plan will change as your child’s needs change from healing and recovery to normal growth for their age. Establishing good nutrition habits after transplant will help your child learn lifelong healthy eating habits.
Liver Transplant Handbook

Clinic visits, tests and labs after transplant

Clinic visits

You will have a number of clinic visits in the weeks after your child’s transplant. These visits allow doctors to check on the function of the new organ, so they can detect any problems right away. Clinic is also a good time for you to ask all your questions.

At a typical clinic visit, your child’s doctor and nurse will:

• Discuss your child’s current health with you.
• Check your child’s weight and blood pressure.
• Perform a physical examination.
• Check for any signs of rejection or infection as well as side effects from medicines.
• Look at your child’s incisions to see if they are healing properly.

Doctor visits will be needed the rest of your child’s life, but these visits will become fewer and further apart. Your child’s follow-up schedule will depend on how they are doing and also the distance you have to travel to the hospital.

All these follow-up visits can be demanding on your family. They are a big responsibility the first 6 months after your child’s transplant. It is normal to feel frustrated, but there is light at the end of the tunnel. These demands will decrease as your child’s new organ stabilizes, as follow-up visits decrease, and most importantly, as your child’s quality of life improves.

The clinic appointments are from 1 to 4 p.m., Tuesday and Thursday afternoons. They take place on level 8, Ocean zone.

Labs

Blood work will be done to check your child’s blood counts (a look at the number and types of blood cells in the blood), and liver function. If your child is taking certain medicines such as Tacrolimus, Sirolimus or Cyclosporine, blood work is also used to measure and monitor the level or amount of medicine in your child’s bloodstream.

Blood work is done more often in the first weeks and months following your child’s transplant. They may have blood drawn two or more times per week in the beginning. This number will lessen over time.

If your child’s blood results are abnormal, the transplant coordinator may call you to change the dose of your medicine or to have your child re-admitted to the hospital for more tests or treatment.

If your child is taking Tacrolimus, Sirolimus or Cyclosporine, we will need to take lab tests ½ hour to 1 hour prior to their scheduled dose. This is called a “trough” level. Some lab draws will be able to be done with a finger stick, while others may require blood drawn from a vein. If your child has a hard time with blood draws, we can prescribe a numbing cream to put on the skin before the poke to lessen the pain. Please let us know ahead of time if this is something you would like to try.

You may need to bring your child’s medicine to the lab with you if it’s to be given after the blood has been drawn.
Blood draws, except from central lines, are done on level 8, Ocean zone at the main hospital campus.

Where do we go for blood draws?

Labs are done on level 8, Ocean zone at Children’s main hospital. The lab is open:

Monday – Friday 7 a.m. to 10 p.m.
Saturday, Sunday and holidays, 8 a.m. to 8 p.m.

If your child needs a central line draw, these are scheduled with home care services. Please contact your home care nurse to set up blood draw times at the appropriate time for drug levels.

Due to the risk of infection, central lines are not left in place just for blood draws. Please discuss this with your transplant team.

As your child stabilizes after transplant and lab draw frequency decreases, you can work with your coordinator to find a lab closer to your home.
Caring for your child at home

Care of the wound

• Keep area clean and dry.
• Have your child shower or bathe daily and wear fresh, clean clothes each day.
• Have your child wear loose clothing to prevent unnecessary rubbing that can cause irritation.
• Report any fever, redness, swelling or drainage from the wound.

Infection prevention:

• Have everyone in the house wash their hands often. Use sani-wipes or hand sanitizing gel or foam often between soap and water handwashing.
• Have your child avoid gardening and digging in the dirt the first year after transplant. Soil contains organisms like fungus that can be released and inhaled into the lungs.
• Have your child brush their teeth at least twice a day. Plan to see a dentist every 6 months.
• Transplant patients should not receive live vaccines, which include MMR and Varicella (chicken pox).
• Do not allow your child to receive any immunizations until 6 months after transplant.

Medicines:

• Have your child take all medicines as prescribed at the correct time.
• Always keep a supply on hand for times when you are unable to get to the pharmacy. Families can get stranded at home due to bad weather, illness or transportation problems.
• Know the name, purpose and appearance of each medicine.
• Do not wait until you have run out of a medicine to call for refills.
• Bring your medicine bottles to the first clinic appointment, and always bring an updated list of the medicines you are giving.

Activity:

• Increase your child’s activity slowly.
• Avoid heavy lifting and strenuous exercise for 6 weeks after discharge. By one year post-transplant your child should be able to return to most regular sports.
• Remind your child to keep both feet on the ground until 8 weeks after transplant. This means no climbing, jungle gyms or bike riding.
• Continue to wear seat belts. Your child’s life is more important than potentially bruising the new transplanted organ.
Avoid being in the sun. Some of the medicines could make your child’s skin more susceptible to sun damage and skin cancer. Wear hats and sunscreen with an SPF of 30 or above. Remember to apply all over before getting dressed and reapply often.

If your child gets sudden pain or shortness of breath during an activity, they should stop right away. Contact your doctor if pain persists.

**Food safety**

People who are immunosuppressed are at a greater risk for developing a food-borne illness. Since most food-borne illnesses result from improper handling of food, it will be important that you and your family follow basic food safety practices to avoid unnecessary exposures for your child.

**Shopping**

- All milk and cheese products should have the word “pasteurized” on the label.
- Avoid all products that contain any raw or uncooked meat or dairy products.
- Avoid products with a “sell by” or “best used by” date that has passed.
- Place packaged meat, poultry or fish into plastic bags before placing it in the shopping cart. This prevents drippings from coming into contact with the other foods. This reduces the risk of cross-contamination (bacteria from one food contaminating another food).
- After shopping, put chilled and frozen foods into the refrigerator or freezer as soon as possible.

**At home**

- Keep shelves, countertops, refrigerators, freezers, utensils, sponges and towels clean. This is one of the best ways to prevent bacterial contamination of food at home.
- Wash all utensils and your hands with soap and hot water after handling one food before handling another.
- Don’t use wooden cutting boards for cutting raw meat, poultry or fish. Use plastic boards. They are easy to clean and sanitize.
- Fresh fruits and vegetables should be washed well with water and refrigerated to reduce spoiling.
- Cook red meat until it is well done and poultry until the juices run clear. Reheat leftovers to 165 degrees Fahrenheit.
- Never eat raw eggs or foods that contain them.

**Eating out**

- Avoid raw seafood such as sushi.
- Order foods well-done to ensure they have been cooked to the proper temperature.
- Avoid salad bars or buffets where the food has been sitting out for long periods of time.
Well water

Microorganisms, bacteria and viruses can be found in well water. Your child must avoid well water in the first year after the transplant.
**Home health care services**
Hospital staff will help you make arrangements for any home health care and services needed when you return home. This may include nursing care, physical therapy, occupational therapy and speech therapy.

**Lines and tube care**
Your home care company will show you how to care for lines and tubes placed in your child. These may include a Broviac catheter, PICC line, and nasogastric or gastrostomy tube.

**Broviac catheter**
The Broviac catheter is an IV line placed in a major vein in your child’s chest. It is used to give fluids and medicines and to draw labs without the pain of a needle stick.

**PICC line**
A PICC line is a “peripherally inserted central catheter” placed in a vein in your child's arm or leg. It is used to give fluids and medicines, and sometimes to draw labs without a needle stick.

**NG or G-tubes**
A nasogastric (NG) or a gastrostomy tube (or G-tube) is used for feeding. The NG tube is placed through the nose and into the stomach. The G-tube is surgically placed in the stomach. Both tubes are used to supplement food taken by mouth to meet your child’s caloric and nutritional needs. Each of these devices is reversible and may be temporary or used for a longer term. The ultimate goal is to remove all of them.
Contacting your transplant nurse coordinator
Keep in touch with your child’s transplant nurse coordinator. They are here to help you with home care issues, medicine questions and refills, and to answer or address any general questions or concerns you may have. Your coordinator will provide you with a follow-up routine and continue to be your link to the transplant team, as well as your child’s local primary care provider. Don’t hesitate to call at any time, for any reason.
Life after transplant
Life after transplant

Follow-up care continues

After leaving the hospital, your child’s transplant will continue to be managed by the healthcare team made up of your pediatric liver specialist (gastroenterologist or hepatologist), the nurse coordinator, the dietitian, a pharmacist, and your child’s local family doctor. Your child will continue to be followed by a transplant center for the life of their transplant.

If you have a local gastroenterologist, much of your child’s routine care can be provided by them along with your pediatrician. It is important for your local providers to be in contact with staff at the transplant center, especially when your child is ill.

Regular clinic visits

At first, your child will come to the transplant clinic twice a week for laboratory work and exams by the doctors. As your child recovers, these visits become less frequent depending upon how well they are doing. Use the chart below as a guideline for how often you will need to come in:

Clinic and lab frequency

<table>
<thead>
<tr>
<th>Date due</th>
<th>Clinic visits</th>
<th>Labs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month 1</td>
<td>2 times a week</td>
<td>2 times a week</td>
</tr>
<tr>
<td>Month 2-3</td>
<td>Once a week to every other week</td>
<td>1 to 2 times a week</td>
</tr>
<tr>
<td>Month 4-6</td>
<td>Once a month</td>
<td>2 times a month</td>
</tr>
<tr>
<td>Month 6-12</td>
<td>Monthly</td>
<td>Monthly</td>
</tr>
<tr>
<td>Year 1</td>
<td>Quarterly*</td>
<td>Quarterly*</td>
</tr>
<tr>
<td>Year 2</td>
<td>Every 6 months</td>
<td>Quarterly*</td>
</tr>
<tr>
<td>After 24 months</td>
<td>Annual</td>
<td>Quarterly*</td>
</tr>
</tbody>
</table>

*Once every 3 months
Labs
Blood draws are done regularly after transplant. Through these labs we can check on how your child’s new organ is functioning; monitor for any side effects, rejection, new viral illnesses; and check drug levels. Labs must always be done before clinic visits and drawn at the appropriate time for drug levels.

School and social activities
Most children may return to school 6 weeks after transplant. Check with your child’s doctor for any special reasons to delay your child’s return to school.

Regular attendance at school is important for your child. You might want to use a tutor for your child during extended times of missed school. If you do not feel good about sending your child to school for health or other reasons, please call and talk with your transplant team.

Once in school, children with transplants should take part as fully as possible in school activities and P.E. class. There are very few limits on physical activities.

Use the list below as a guide. In general, aerobic (cardio) exercises are good for children with transplants. No one can guarantee that any of these activities are totally safe and will not injure the transplanted organ. Use good common sense when choosing activities for your child. Please discuss this with your transplant team.

Activity choices for your child

<table>
<thead>
<tr>
<th>Sports to be avoided:</th>
<th>Sports that are encouraged:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• American football</td>
<td>• Badminton</td>
</tr>
<tr>
<td>• Boxing</td>
<td>• Basketball</td>
</tr>
<tr>
<td>• Field hockey</td>
<td>• Canoeing</td>
</tr>
<tr>
<td>• Rugby football</td>
<td>• Golf</td>
</tr>
<tr>
<td>• Jump rope</td>
<td>• Running</td>
</tr>
<tr>
<td>• Swimming*</td>
<td>• Swimming*</td>
</tr>
<tr>
<td>• Volleyball</td>
<td>• Weight lifting</td>
</tr>
<tr>
<td>• Weight lifting</td>
<td>• Aerobics</td>
</tr>
<tr>
<td></td>
<td>• Cross-country skiing</td>
</tr>
<tr>
<td></td>
<td>• Cycling</td>
</tr>
<tr>
<td></td>
<td>• Rowing</td>
</tr>
<tr>
<td></td>
<td>• Skating</td>
</tr>
<tr>
<td></td>
<td>• Sledding</td>
</tr>
<tr>
<td></td>
<td>• Soccer</td>
</tr>
<tr>
<td></td>
<td>• Tennis</td>
</tr>
</tbody>
</table>

*Swimming in chlorinated pools is OK but your child should avoid swimming in lakes, oceans or rivers for 3 to 6 months after their transplant. Check with your child’s transplant coordinator before swimming in these types of water.

Pets
Pets are not off limits, but need to be handled with caution. Animals do pose some risks to a person with a transplanted organ because of some diseases they may carry. Have your child wash their hands well after handling any pet. Keep the family pets’ immunizations up to date.

Wild and or sick animals carry illnesses that may be potentially dangerous to the immunosuppressed patient.

New puppies and kittens are not recommended within the first year after transplant.
Cats
Your child should not clean a cat box, because cat feces may contain toxoplasmosis. This is especially important with outdoor cats. Keep in mind that neighborhood cats may use your yard and your child’s sand box for their bathroom needs. Cat scratches can transmit bacteria and should be washed well with soap and water. Call the transplant coordinator and your child’s primary care provider for scratches that get red and inflamed, have drainage, or do not heal, or if lymph nodes near the scratch become swollen.

Birds
Have your child avoid contact with birds. They spread bacteria in the dust that is given off from their feathers and feces.

Plants and gardening
Tell friends and family not to send flowers or live plants to the hospital after transplant, as the dirt or water may carry bacteria, spores and fungus. They may send artificial plants or Mylar (non-latex) balloons.

Aspergillus and other fungi live in the dirt and are potentially fatal to the transplant patient. Spores from these fungi can be released during construction, or if dirt and dust are stirred up in your home (a major cleaning project, a furnace replacement, etc.). Spores become airborne and can cause pneumonia when inhaled. In the first 6 to 12 months after transplant, your child should not dig in the dirt or be around any construction within your home or at school that might release spores.

Routine screenings and self-care needed after transplant

Primary care doctor or pediatrician
Although your child will be seen often by the transplant team, it is important that your child continue to be seen by their local family doctor or other primary care provider. Please make an appointment with your primary provider soon after your return home so that your child can be seen when they are well. If your child has an acute illness like a cold, cough, or ear infection unrelated to their transplant, your primary care doctor should see them. It is also important for your child to be seen for their routine well-child checks to ensure they are growing and developing, receiving immunizations and getting referred for special services they may need.

Dental care
Your child should have regular dentist visits after transplant. There are some special dental issues to consider after your child has an organ transplant.

The mouth has a large number of bacteria in it. The use of transplant medicines after transplantation makes it harder for the body to fight infection. For instance, a bad dental cavity may turn into a tooth abscess if the immune system is low. Also, some of the drugs used after transplant may cause gum swelling. This, in turn, leads to bad gum disease.
**Answers to common questions about dental care**

**What can I do at home to keep my child’s teeth healthy?**

Have your child brush and floss their teeth regularly. Your child should have a dental check-up every 6 months after transplant.

**Does my child need antibiotics before dental procedures?**

No, antibiotics before dental procedures are not required for liver transplant patients. They are only required for people with prosthetic cardiac valves, previous endocarditis, or unrepaired cyanotic congenital heart disease. If you are unsure, ask your child’s cardiologist.

**What about the use of braces after transplant?**

Many children and teens get braces after transplant without problem.

**For any dental care:**

- Make an appointment with your dentist.
- Tell your dentist that your child has a transplant and is on immunosuppressive medicine.

**Skin care**

**Skin cancer**

Transplant patients have a higher risk of developing skin cancer as adults. It is very important that children with transplants and their families know how to protect themselves from the sun. To help prevent skin cancer:

- Use a sunscreen with a sun protection factor (SPF) of 30 or more daily.
- Wear clothing with long sleeves and a tight fabric weave and a broad-brimmed hat when outdoors.
- Stay out of the direct sun between 10 a.m. and 4 p.m. as much as possible.
- Do not use tanning beds.

**Warts**

Your child could have problems with warts. This is because the transplant medicines might make it harder for your child to fight off the virus that causes warts. They may have more and larger warts that last longer and are harder to treat. If warts become a problem, see a dermatologist who has skill in dealing with warts in children.

**Taking medicines**

**Taking medicine on schedule (adherence)**

Transplants can fail when patients do not take medicines as directed. This is considered “medical non-adherence.” You and your child must be committed to taking these medicines daily and on schedule. While it is important to learn responsibility, you, as the adult, must remember that children and adolescents will forget and procrastinate and you must continually supervise. The loss of the transplant will affect everyone.
Adolescence is the most challenging time for transplant patients due to busy schedules, the desire to fit in with their peers and be “normal,” and the teen’s increasing independence. The transplant team will work with you to help prepare for this period of your child’s life. We can help with ways to prevent rejection and other complications of non-adherence.

**General rules about your child’s medicines**

Follow these safety rules about your child’s medicines:

- If your child needs relief from symptoms, **never** treat them for anything without first contacting the transplant team.
- Store all medicine at room temperature, unless it says something else on the medicine bottle or package.
- Your child must take medicine as part of their daily routine, just like eating and sleeping.
- It is your job to call the pharmacist or transplant coordinator before any new medicines are started. This could include any new medicines that are prescribed by anyone other than your transplant team at Seattle Children’s, including your local pediatrician, family doctor or even over-the-counter medicines.
- If your child is vomiting or has diarrhea, it can keep them from absorbing their medicines. Call your doctor, transplant doctor or transplant coordinator.

**Avoid herbal medications**

The government does not require herbal medications to be tested for purity, safety or efficacy. Some herbal medications (like St. John’s Wort) could interfere with your child’s immunosuppressant medicines.

**Abstaining from all illicit substances**

You should not use any alcohol or illicit substances including cannabis (marijuana) in any form, cocaine, opiates, amphetamines, hallucinogens and any other controlled substance after transplant. This is very important to keep you healthy after your transplant. Failure to abstain from these substances may prevent you from being a candidate for re-transplantation if needed.

**Pregnancy**

When it’s time to plan a family, it is possible for your daughter to become pregnant and have a child after receiving a transplant. But, there are special concerns and considerations. To lessen risks and make sure that the transplant and the baby all do well during and after a pregnancy, it is very important to plan ahead with your doctor and transplant team. Some transplant medicines can cause serious birth defects and should not be taken during pregnancy.

Young women who are sexually active or may become sexually active need to discuss an appropriate birth control method with their transplant team. Should your child become pregnant when they are still being cared for at Seattle Children’s, we will transfer their care to an adult transplant center. These facilities are better equipped because they can provide for both their obstetric needs and transplant management.
Transitioning to adult care

Your child can be followed at Seattle Children’s until the age of 21, but we will begin the transition to an adult transplant center between ages 18 and 21. Starting around age 12 your child should begin to learn about their medical history, names of their medicines, and medical treatments. By the time your child transitions to adult care we like to see your child take on all parts of their transplant care on their own, including:

- Taking all medicines
- Calling the pharmacy for refills
- Making appointments for clinic visits and labs
- Asking and answering questions during clinic visits
- Calling the transplant coordinator with questions or concerns

The transplant team will work closely with you and your child to ensure they are well prepared, but much of the work will be done by you and your child.
Resources
Glossary

Alanine aminotransferase (ALT)
ALT is an enzyme produced in hepatocytes, the major cell type in the liver. ALT increases in conditions where hepatocytes are damaged or die.

Anemia
A condition in which the blood is deficient in red blood cells or oxygen-carrying proteins.

Antibody
Part of the immune system that helps the body fight infection and foreign substances.

Antigen
The “marker” that stimulates antibody production.

Arteriogram
An X-ray of the arteries taken with the aid of a dye. A kidney or mesenteric arteriogram gives a picture of the blood vessels of the organ.

Amylase
A type of enzyme made by the pancreas (it is also in saliva).

Ascites
Fluid accumulation in the abdominal cavity, often as a result of severe liver disease.

Aspartate aminotransferase (AST)
AST is an enzyme similar to ALT (see above). It is not just measured for liver disease as it is also produced in muscle and can be elevated in other conditions.

Bile
A yellowish or greenish fluid secreted by the liver. It helps the body digest and absorb fats.

Bilirubin
The orange or yellowish pigment produced by the breakdown of red blood cells. It is excreted by the gallbladder in the bile. It may build up in the blood of patients with severe liver disease.

Biopsy
A procedure in which a small sample of a tissue or organ is removed. It is then examined under a microscopic to check for diseases or conditions such as rejection.

Blood Urea Nitrogen (BUN)
Used along with creatinine to measure kidney function.
Catheter
A plastic or rubber tube put into the body. One type may be used to drain urine from the bladder. Another type may be inserted into a blood vessel to access the circulatory system.

Cholestasis
Any condition in which bile excretion is stopped.

Cirrhosis
Progressive scarring disease of the liver.

Creatinine
Is excreted by the kidney, and is directly related to how well the kidneys are working (renal function).

Crossmatching
A test of compatibility between the potential donor’s and prospective recipient’s blood.

Deceased donor
An individual who has recently died from causes that do not affect organ function. Either the person or their family has generously offered organs and tissues for transplantation.

Diastolic
The bottom of two blood pressure numbers. It measures the force of the heart when it is at rest. This is when it expands and refills with blood.

Encephalopathy
Accumulation of toxic substances causes metabolic abnormalities that lead to damage in the nervous system (brain and spinal cord). Characterized by confusion and changes in consciousness, behavior and personality.

Endotracheal tube
An airway tube inserted through the mouth into the windpipe to help with breathing during surgery.

Gallbladder
The pear-shaped organ that lies behind and slightly below the liver on the right side of the abdomen. It holds the body’s bile.

Gamma-glutamyltranspeptidase (GGT)
An enzyme produced in the bile ducts that may be elevated in the serum of patients with bile duct diseases.

Glucose
A type of sugar found in the blood.

Graft
The “new” organ.
Hepatic
Having to do with the liver.

Hepatitis
Inflammation of the liver, usually caused by a viral infection.

Hepatologist
A doctor who is specially trained in the diagnosis and treatment of diseases of the liver.

Hypertension
Another word for high blood pressure.

International Normalized Ratio (INR)
A conversion unit that takes into account the different sensitivities of thromboplastins. It is widely accepted as the standard unit for reporting PT results (see “PT” below).

Jaundice
A condition caused by the buildup of excess bile (bilirubin) in the body. It is characterized by yellowness of skin, eyes and body fluids.

Immunosuppressive
A drug that is taken daily by the transplant recipient. It helps prevent the recipient’s own immune system from struggling against and rejecting the new organ.

Intravenous (IV)
Into or within a vein; also refers to fluids and medications that are injected into a vein through a needle or catheter.

Noncompliance
Not taking medicine as prescribed, or making decisions that may shorten the lifetime of the transplant. Also called non-adherence.

Partial thromboplastin time (PTT)
Blood test that measures the time it takes blood to clot. This test can be used to screen for bleeding abnormalities.

Portal hypertension
Elevated blood pressure in the portal vein, which carries blood and nutrients to the liver. It is a common complication of cirrhosis of the liver.

Prednisone
A steroid hormone taken by transplant recipients to help prevent rejection.

Prothrombin Time (PT)
Blood test that measures the time it takes blood to clot.
Pruritus
Severe itching due to the buildup of bile in the skin.

Systolic
The top blood pressure number, which measures the force of the contraction of the heart muscle as blood is pumped out of the heart chambers.

T-cell
A specialized white blood cell that is involved in the rejection process (also known as T-lymphocytes).

Tacrolimus
A potent immunosuppressant drug that inhibits T-cell activation.

Thrombosis
The formation or presence of a blood clot.

Varices
Dilated veins caused by portal hypertension. These vessels are easily damaged and can have severe bleeding.

Vena Cava (also called IVC, for inferior vena cava)
The largest vein in the body. It returns blood to the heart.
Websites for liver transplant patients and their families

If you’re unable to pull these websites up directly, try looking them up on a search engine.

Websites for kids and/or teens and have chat rooms:

classkids.org
Children’s Liver Association for Support Services: Provides information, support and services to families coping with pediatric liver disease and transplantation. This site has a library with descriptions of liver diseases and treatments, including biliary atresia, cirrhosis and Alagille Syndrome.

Information about organ donation and transplantation

transweb.org
A resource for transplant patients and families with information specifically dealing with transplant issues and problems. Includes an index of sources for transplant-related information and provides information about donation and transplantation to the general public.

cota.org
Children’s Organ Transplant Association: Works to make life-saving organ transplants accessible to all. COTA works with individuals of all ages to arrange the necessary funding for transplant expenses.

unos.org
The United Network for Organ Sharing (UNOS): A nonprofit charitable organization; maintains the nation’s organ transplant waiting list under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. This site has an area just for patients with links to numerous sites.

shareyourlife.org
Coalition on Donation: An alliance of national organizations and local coalitions dedicated to educating the public about organ and tissue donation.

trioweb.org
Transplant Recipients International Organization (TRIO): An independent, nonprofit organization committed to improving the quality of life of transplant candidates, recipients, and their families; and donor families.

transplants.org
Reaches out to help those who seek a new life through transplantation, by providing a program of healthcare and financial support services and patient advocacy for transplant candidates, recipients and their families nationwide.
Information about liver diseases
alagille.org
The Alagille Syndrome Alliance: A worldwide support network for people who care about people with Alagille Syndrome.
liverfoundation.org
American Liver Foundation: A national, voluntary, non-profit health agency dedicated to preventing, treating, and curing hepatitis and all liver disease through research, education and support groups.
alpha1.org
Alpha-1 National Association: Provides support, education, advocacy and research information to those affected by alpha-1-antitrypsin deficiency.

For parents
fathersnetwork.org
The Washington State Fathers Network advocates for and provides support and resources for all men and their families who have children with special needs.

U.S. Government agencies
nih.gov
National Institutes of Health (NIH) U.S. government health agency under Department of Health and Human Services.
nlm.nih.gov
U.S. National Library of Medicine (NLM) is the world’s largest biomedical library.
organdonor.gov Division of Transplantation (DOT)
The Division provides federal oversight and funding support for the nation’s organ procurement, allocation and transplantation system; coordinates national organ and tissue donation activities, funds research and administers the national bone marrow registry program.
dhhs.gov
The U.S. Department of Health and Human Services.
ssa.gov
The Social Security Administration: The Social Security Office locator uses your U.S. Postal Service zip code to locate the Social Security office nearest you.
## Normal lab values

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Normal Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>AST (SGOT)</td>
<td>3 - 74 U/L</td>
</tr>
<tr>
<td>ALT (SGPT)</td>
<td>3 - 60 U/L</td>
</tr>
<tr>
<td>GGT</td>
<td>5 - 55 U/L</td>
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<tr>
<td>Bilirubin - conjugated</td>
<td>0.0 - 0.3 mg/dl</td>
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<tr>
<td>Bilirubin - unconjugated</td>
<td>0.0 - 1.1 mg/dl</td>
</tr>
<tr>
<td>Cr (Creatinine)</td>
<td>0.1 - 1.0 mg/dl</td>
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<tr>
<td>BUN (Blood Urea Nitrogen)</td>
<td>6 - 20 mg/dl</td>
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<tr>
<td>WBC (White Blood Cell)</td>
<td>5.0 - 11.0 (thousand)</td>
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<tr>
<td>Hct (Hematocrit)</td>
<td>35 - 45%</td>
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<tr>
<td>Plt (Platelets)</td>
<td>200 - 450 (thousand)</td>
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<tr>
<td>Glucose (blood)</td>
<td>60 - 105 mg/dl</td>
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<tr>
<td>Na (Sodium)</td>
<td>135 - 145 mEq/L</td>
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<tr>
<td>K (Potassium)</td>
<td>3.5 - 5.5 mEq/L</td>
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<tr>
<td>HC03 (Bicarbonate)</td>
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<tr>
<td>Magnesium</td>
<td>1.8 - 2.4 mg/dl</td>
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<tr>
<td>PO4 (Phosphorus)</td>
<td>4.0 - 6.0 mg/d</td>
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<tr>
<td>Calcium</td>
<td>8.7 - 10.7 mg/dl</td>
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## Pounds to kilograms conversion chart

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<thead>
<tr>
<th>Pounds</th>
<th>Kilograms</th>
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Appendices
Seattle Children’s offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children’s will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children’s. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s healthcare provider.

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**To Learn More**
- Transplant Center
  206-987-1800
- Ask your child’s healthcare provider
- www.seattlechildrens.org

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