Pediatric Liver/Liver Transplant Program

Recanati/Miller Transplantation Institute

Pre Liver Transplant Education Manual

24 Hour Telephone Number
(212) 659-8060

Fax Number
(212) 241-2064

www.mountsinai.org/RMTI/pediatrics
**Pediatric Liver/Liver Transplant Program Mission Statement**

The mission of the Pediatric Liver/Liver Transplant Program is to provide state of the art care for children with liver disease. This mission is met through clinical and research activities in pediatric hepatology and pediatric liver transplantation.

**Program Statistics**

- The program is nationally recognized as one of the leading centers in the country.

- Number of Pediatric Transplants Performed:
  - Over 400, including cadaveric, living donor and split liver transplants

- Youngest transplant recipient, 16 days old

- Experienced Living Related Donor Program:
  - First pediatric living related liver transplantation in New York State
  - Available option for both end stage liver disease and fulminant hepatic failure
  - Living related liver/kidney transplant from the same donor

- Skilled split liver program which allows two recipients to be transplanted from one donor

- Numerous combined transplants including liver/kidney, liver/intestine and liver/bone marrow transplants.

- First pediatric combined liver-intestine transplantation in New York State

- State of the art liver transplant techniques including:
  - Domino liver transplantation: One liver saves three lives; this transplant procedure was featured in *New York Magazine’s Top Ten Medical Miracles*.
  - APOLT (auxiliary partial orthotopic liver transplantation): This procedure is performed in rare cases where the patient keeps part of his/her native liver and receives part of a cadaveric liver. In the event the cadaveric portion fails, this portion can be removed, allowing the native liver to regenerate.
WHO ARE THE PEDIATRIC LIVER/LIVER TRANSPLANT PROGRAM TEAM MEMBERS?

One of the keys to our programs success is the team concept, which includes YOUR FAMILY as an important member of the team.

The Pediatric Liver/Liver Transplant Program is made up of various members of a highly specialized multidisciplinary, professional team within the Recanati/Miller Transplantation Institute (RMTI) and the Maternal Child Health Care Center (MCHCC). During your visits to our office you will meet many members of the team.

The main telephone number for the Pediatric Liver/Liver Transplant Program is:
(212) 659 8060

The main fax number for the Pediatric Liver/Liver Transplant Program is:
(212) 241-2064
Program Directors –
  Kishore Iyer, M.D. - Surgical Director, Pediatric Liver/Liver Transplant Program
  Transplant Surgeon

  Nanda Kerkar, M.D. -Medical Director, Pediatric Liver/Liver Transplant Program
  Pediatric Hepatologist

RMTI Director – Sander Florman, M.D., - Director RMTI
  Transplant Surgeon

Attending Transplant Surgeons – Surgeons who specialize in pediatric liver transplantation:
  Kishore Iyer, M.D.
  Marcelo Facciuto, M.D.
  Alan Contreras-Saldivar, M.D.
  Juan Rocca, M.D.

Attending Pediatric Hepatologists – Physicians who specialize in the field of pediatric liver disease:
  Nanda Kerkar, M.D.
  Ronen Arnon, M.D.

Fellows – Physicians who have completed residency and are now in the final phase of specialty training:
  Surgical Fellows – fully trained general surgeons who are specializing in the field of liver transplantation.
  Pediatric Gastroenterology Fellows – fully trained medical physicians who are specializing in the field of Gastroenterology and liver disease.
  Pediatric Hepatology Fellows – fully trained medical physicians who are specializing in the field of hepatology and liver disease.

Pediatric Transplant Coordinators – RNs/NPs/PAs who specialize in the care of pediatric liver transplant candidates and recipients:
  Christina Dugan, MS, MPH, CPNP
  Senior Pediatric Transplant Coordinator
  Telephone number – (212) 659 8060
Fiona Henderling, RN, MSN  
In patient Transplant Coordinator  
Telephone number – (212) 659 8060

Tara Keegan, RNC  
Post Transplant Coordinator  
Telephone number – (212) 659-8060

Samantha Lee, MS, CPNP  
Pre Liver Transplant Coordinator  
Telephone number – (212) 659-8060

Social Worker – Specially trained in the needs of children undergoing transplantation. Can offer assistance in obtaining benefits and community services. Provides support and assistance to your family before, during and after the transplant:  
Aline Goodman  LCSW  
Telephone number – (212) 659-8983

Medical Assistant – assists in office hours, schedules appointments, tests and procedures:  
Delia Hemingway  
Carmen Figueroa  
Telephone number – (212) 659- 8060

Administrative Assistants – Provide secretarial assistance to the physicians and clinical staff within the pediatric liver/liver transplant program:  
Dolores Rodriguez  
Milagros Gonzalez

Financial Coordinators – staff members who are responsible for screening insurance coverage and advising patients on possible financial options:  
Denise Campone  
Telephone number – (212) 241-8081

There are various other members of the Mount Sinai Hospital staff who work very closely with the pediatric liver/liver transplant team. Some of these members are listed below:

Pediatric Intensive Care Attendings: - Physicians who specialize in the medical management of children in the intensive care unit:  
Joann Hosjack M.D.  
Margret Satchell, M.D.
Child Life Specialists - Certified Child Life Specialists trained to help children and families cope with the hospital experience. They help young hospitalized patients cope with their fears and anxieties by offering therapeutic activities tailored to meet their social, emotional and educational needs. Therapists hope to enhance the understanding of medical experiences for children and families.

Telephone number – (212) 241-6797

Consultants – Physicians/Nurses who are specialists in their particular field of medicine, who we may request consult in your on-going care – these include (but are not limited to):

- Cardiologist – specializes in the treatment of heart disease
- Endocrinologist – specializes in the treatment of hormonal disorders
- Hematologist – specializes in the treatment of blood disorders
- Infectious Diseases specialist – specializes in the treatment and prevention of infections
- Intensivists - specialize in the treatment and care of critically ill children.
- Nephrologist – specializes in the treatment of kidney disease
- Pulmonologist – specializes in the treatment of lung disease
- Pediatric Pathologists – specializes in the evaluation of pediatric tissue
- Liver pathologists – specialize in the evaluation of liver tissue

Evaluation process for pediatric liver transplantation

You are here because your child’s pediatrician or gastroenterologist felt that your child needed to be evaluated for liver disease with the possibility that they may require a liver transplant. Although your child may not require a transplant at this time, early referral to our program is extremely important. This allows us to “get to know” your child and your family and also develop a relationship with your child’s pediatrician, gastroenterologist or hepatologist. This will also ensure that we have good insight into your child’s liver disease and allow us to optimize your child’s condition should a transplant be required. It also allows us to expedite the transplant process if your child’s condition deteriorates.

We encourage you whenever possible to bring various members of your family during the visits to the hospital. Evaluation for liver transplantation is extremely stressful and it is important that several members of the family are available to provide support. This also allows multiple questions to be raised by family members with regards to the transplant process.
Evaluation for liver transplantation is an ongoing process, which continues even after your child has been accepted onto the waiting list. The main goals of the evaluation process are:

- To find out if liver transplant is the best treatment of choice – on occasion transplantation may not be necessary as another type of surgery may be more appropriate due to your child’s disease process
- To find out if your child is a suitable candidate for liver transplantation
- To evaluate the timing of liver transplantation.
- To educate you about the following aspects of liver transplantation –
  - Waiting for liver transplantation
  - Organ allocation
  - Type of liver transplants performed
  - Potential post operative complications
  - Commonly used medications after liver transplantation.

We believe that education is an important factor in ensuring a successful outcome after liver transplantation. Education helps to foster a good working relationship between your family and our transplant team members.

Your child’s evaluation will include an initial consultation with:
- Pediatric Hepatologist
- Transplant Surgeon
- Transplant Coordinator
- Infectious Disease
- Registered Dietician
- Social Worker
- Financial Coordinator

Liver transplantation is a major undertaking and one key to successful liver transplant is commitment to health care. We have found that the presence of a positive support system to be very important to a successful outcome. The social worker will also be able to assist with insurance issues, which may arise as well as in other areas of psychosocial care.

Listed below are some of the “routine” tests that everyone must undergo in preparation for liver transplantation.

1. **Laboratory blood tests** – it is important that we find out your child’s blood type, your blood counts, blood chemistries and viral studies (this include checking for the hepatitis B, hepatitis C, Cytomegalovirus, Epstein Barr virus and HIV virus).
2. **Abdominal Ultrasound and Doppler** – this is a non-invasive imaging study that uses sound waves to create a picture of your liver and the surrounding organs. It also assesses the flow of blood into and out of the liver.

3. **Chest x-ray** – to ensure there are no lung infections present

4. **Echocardiogram** – this is a non-invasive imaging study of the heart to create a picture of the heart. This allows us to assess how well the heart is functioning.

5. **Psychosocial evaluation** – this allows us to find out the individual needs of every patient and family member and help them deal with the stresses of transplant.

Occasionally there are additional consultations or procedures that may be required prior to completion of the evaluation process. Pending clearance from your insurance company you will hear from our scheduler notifying you of the various appointments.

After completion of the evaluation your child will be discussed at our Pediatric Recipient Review Committee Meeting. The committee is a group of professionals from the various departments that are involved with the transplant team to see if a transplant is needed. If your child is accepted as a candidate you will be notified and they will be placed on the UNOS waiting list.

**Remember** - the transplant evaluation period also gives you and your family a chance to meet us and decide if you want to pursue transplantation at Mount Sinai Hospital.

### Research Activities

Mount Sinai Hospital is a large teaching hospital and participates in the many different multi-center and worldwide research studies and protocols. Research is important for the advancement of future medical care throughout the world. During your child’s hospitalization you may be asked to participate in one of these studies. You will be given complete information with regards to the type of study, reason for the study and potential outcomes as well as any potential complications and side effects of participating in the study. If you wish to participate you will be asked to sign a consent form stating that you agree to participation.

You are **NOT** required to enroll your child in any study protocols.

### Psychosocial Care

**Psychosocial evaluation:**

Children who had a transplant or are listed for a transplant and their families often face many financial, psychological and social challenges. Our team is committed to finding
out about the individual needs of every patient and family and helping them deal with any aspect of the illness.

We have specific resources and expertise to help in this process. As part of the standard care in the outpatient office and in the inpatient units, we perform comprehensive psychological assessments supervised by our dedicated psychiatrist, social worker and psychologist. This assessment includes interviews and questionnaires, which will be used to inform you about the potential needs or problems as well as guide you through the recovery process and assist in finding specific help if it is needed.

**Types of Liver Transplant**

There are various options for liver transplant that may be offered to your family and your child. The type of transplant offered will depend on the height and weight of your child.

- **Whole liver transplant** – A liver is obtained from a cadaveric donor (donor who is brain dead) and the whole liver is transplanted. This is currently the most common type of transplant for adults although not the most common for children (due to the scarcity of organs).

- **Split liver transplant** – A whole cadaveric liver is “split” into two smaller pieces for transplantation into two recipients. Usually the right lobe is transplanted into an adult recipient and the left lobe or left lateral segment is transplanted into a child. This is a technique that allows two lives to be saved with one organ.

- **Reduced size liver transplant** – a cadaveric liver is “cut down” for size but due to the use of the attached blood vessels for one recipient, part of the liver must be discarded.

- **Living donor liver transplant** – The Recanati/Miller Transplantation Institute has the largest living donor transplant program in the United States. This is where a potential donor (usually a family member) volunteers to donate a portion of his/her liver for transplant. A living donor can either donate the right lobe (largest lobe), the left lobe or the left lateral segment (smallest portion of liver that can be transplanted). This will be determined by the size of the donor and the size of the recipient. A living donor transplant allows for the surgery to be scheduled while your child remains medically “stable”. Prior to acceptance for donation there are multiple tests that must be completed. The first step is to evaluate the size of the potential donor in relation to the size of the recipient. We then check blood types to
ensure that they are compatible. If after the initial evaluation the decision is to proceed with donor evaluation then we schedule the remainder of the donor’s required tests and procedures. These include (but are not limited to):

- Appointment with the Adult Hepatologist to ensure medical clearance for surgery.
- Laboratory blood tests – includes liver function tests, screening for Hepatitis B. Hepatitis C, Cytomegalovirus, Epstein Barr Virus and HIV.
- Appointment with a Transplant Surgeon who will explain the surgical procedure as well as the associated risks of surgery.
- Meeting with the Transplant Coordinator – discuss the evaluation process living donor transplant.
- Social Worker – to assess social supports and financial concerns.
- Cardiologist – to assess the function of the heart.
- MRI of abdomen – to assess liver volume to ensure that adequate liver tissue will remain for the donor after donation.
- Chest X-ray – to ensure that there are no lung infections present.

A potential donor may be asked to see other members of our multidisciplinary team prior to clearance to become a donor or undergo further testing. These may include:

- Meeting with the transplant Psychiatrist - to assess for psychosocial issues.
- A liver biopsy may be required to assess for any signs of liver damage or fat in the liver.

Living donor donation is a personal decision. You MUST NOT feel pressured into volunteering to become a living donor. It is important that you feel comfortable with the decision that you have made in regards to living donation.

Please inform us if you wish to discuss living donor transplant in more detail with us. We have an information package available for any potential living donors.

**Listing for Liver Transplant**

Once your child has been accepted as a candidate for liver transplantation, the search begins for a suitable organ donor. Livers are matched by compatible blood type and organ size. All patients are listed on a national waiting list, which is maintained by the United Network for Organ Sharing (UNOS). UNOS is a non-profit, private (non-government) organization. UNOS is responsible for the matching and distribution of
What is the PELD (Pediatric End Stage Liver Disease) scoring system?

The PELD scoring system gives liver transplant candidates a “score” based on how urgently they need a liver transplant within the next three months. The PELD score is also based on objective (non-biased) medical criteria. This is a precise method of ranking patients so that those most at need will be given highest priority for donated livers.

Both pediatric and adult Status 1 patients are the most critical as they have a life expectancy of less than 7 days without a transplant.

Candidates under the age of 12 years are ranked according to the PELD scoring system. This system is similar to MELD (Model for End Stage Liver Disease – adult scoring system for organ allocation) but recognizes the specific needs of children. The pediatric scoring system is calculated by including:

- Age if less than 1 year old
- Albumin
- Total Bilirubin
- INR
- Growth failure (if less than 2 standard deviations from normal).

The result of this scoring system will allow pediatric and adult patients to be ranked for liver offers based on the same risks of death within a three-month period. It will remove waiting time as a factor in determining who is offered a donated liver. As your child’s laboratory blood test results change so will the PELD score therefore the PELD score will change as your child awaits the transplant. As they become more in need of a transplant the PELD score will increase and they will move up on the UNOS list therefore receiving greater priority for organ offers.

(Information obtained from www.unos.org)

We have included further information about UNOS and the PELD scoring system in your information package that you received during your first visit. Please ask your transplant coordinator if you have any further questions.

Waiting on the list

As well as receiving follow up from your pediatrician, the pediatric transplant team will also continue to see you in our office on a regular basis. This is a regular visit with the opportunity to talk more with the Transplant Hepatologist, Transplant Surgeon,
Transplant Coordinator and Social Worker. We use this time to continue education and answer questions with regards to transplantation.

Immunizations

- It is important to keep up to date with the recommended immunization regimen. Please ensure that we are aware of any changes to your child’s immunization record. For patients awaiting liver transplantation, immunization schedules may have to be altered. Our team will contact your pediatrician to discuss this issue.

- It is important that your child and your family receive their annual flu shot prior to transplantation. Please contact us if you require further information.

School

- Attendance at school is encouraged. Please discuss schooling options with us. If your child is attending school please inform us if you have any concerns. We can discuss any limitations on your child’s activity directly with the school staff.

Changes in condition

- If there are any major changes in your child’s condition or if he or she is hospitalized because of the liver disease, it is important to inform us. This may affect your child’s status on the UNOS waiting list.

Preventing Infections

- Good hand washing is very important to prevent the spread of germs. The use of gloves may be necessary when handling soiled diapers.

- Your child can become ill when he or she is exposed to children or adults who are sick with colds or other viruses. You should prevent your child from being exposed to people who you know are ill.

- Remember to communicate any concerns to the school nurse and the transplant team.

- Please notify the transplant team if your child comes in contact with anyone who has chickenpox, tuberculosis or any other contagious diseases.

Skin Integrity
• While bathing your child check the skin for any rashes, petecchiae (little purple spots), bruising, and skin irritation from scratching and diaper rash.

• Rashes can happen from some viral infections and from allergic reactions to medications or soaps and detergents used to wash your child’s clothing.

• If your child’s skin and tissue of the eye is yellow or jaundiced:
  - Your child may be itchy and will scratch the skin especially around the eyes, ears, and face.
  - Keep your child’s nails short and filed to prevent any irritation to the skin.
  - A lukewarm bath using Aveeno ® oatmeal bath can help to soothe the skin. There are medications that can be ordered to help control the itching. Please discuss these issues with our team.

Sleep and rest

• For children with liver disease, sleep can sometimes be difficult if they are jaundiced as they may scratch their skin to try to relieve the itching. If this is a problem for your child let us know so that we can make suggestions about skin care products to help with the itching and to help them sleep.

• Please inform us if your child has a change in his/her usual sleeping pattern and becomes more sleepy or difficult to wake up. When the liver is not working effectively it is unable to clear waste products from the blood stream and this can result in unusual sleepiness and confusion.

• Caring for a child with a chronic illness can be exhausting for the caregivers. Try to look after yourself and ask for support from family members and friends as necessary. Please inform the transplant team if you are having difficulty. There are organizations that may be able to help with the care of your child.

Stress and Coping

• Your child will be referred to child life for pre-operative preparation for surgery – this will involve age-appropriate information through:
  • Play - with the medical equipment that will be used to help your child to prepare for the transplant surgery.
• Education - through books, handouts and medical equipment (stethoscope) for adolescents.

• Emotional support and information for parents/primary care giver - in collaboration with the transplant coordinator families will receive information on the process of transplant in relation to their child’s needs. Therapeutic coping techniques will be provided.

**Optimizing Your Child’s Nutrition before Transplant**

As part of the evaluation process, your child will meet with a Registered Dietician for a comprehensive nutritional assessment. The goal of this assessment is to make changes in your child’s diet, vitamin supplements or even way of eating to improve growth and development while waiting for a transplant. Furthermore, it has been shown to help the healing process after transplant.

The following are some of the specific issues that the Registered Dietitian may discuss with you:

• **Growth and weight gain** – it is very important that your child continues to gain weight and grow at a steady rate. This is a sign that your child is developing physically. Sickness can make it harder for children to gain weight and grow. The transplant team will closely follow your child’s height and weight. If your child has difficulty gaining weight and growing, special formulas and advice will be offered to you.

• **Calorie intake** – Calories come from formula and food that your child eats. Calories give your child energy to gain weight, grow and perform activities. If your child has trouble gaining weight or growing it may mean that more calories are needed. The Registered Dietician will ask you questions about your child’s daily diet – this will allow for an assessment of your child’s calorie intake.

• **Special formulas for infants and children: need for oral nutritional supplements** – there are many different needs that your child may have before transplant that may not be necessary for other children. Infants are usually given specialized formulas to meet the needs of the specific disease. These formulas are designed to provide your child with the proper type of nutrients. The transplant team will explain which formula to give and what makes it special. Older children (over 1 year old) may also require formula. This may be prescribed in addition to a usual diet to increase the calories. There are also many nutritional supplements on the market – these supplements may be helpful to your child if his/her usual calorie is too low.
• **Vitamin supplements** – some children will need special vitamin supplements before transplant. These will be prescribed by the transplant team based upon your child’s needs. There are specific vitamin needs for each disease state. It is very important for your child’s to receive the supplement to prevent deficiencies. Children with liver disease need fat-soluble vitamins – this is because they cannot absorb the fat-soluble vitamins in their food.

• **The possibility of your child requiring tube feeding to meet the estimated nutritional requirements** – some of our patients are not able to meet their calorie and nutritional needs by eating by mouth alone. If this is true for your child, the transplant team will discuss the need for tube feeding. Tube feeding is a safe way of providing additional formula. Often children receive supplemental tube feeding at night and are encouraged to eat by mouth during the day. This will help your child gain weight, grow and prepare for the stress of the actual surgery.

**As a team we are all dedicated to promoting the best therapies that can help to improve our child’s nutrition before transplant.**

**Family Responsibilities**

**Contact Information**

• If you have any change to your home address or telephone number please contact us so that we may keep our record up to date. Please ensure that we have as many contact telephone numbers as possible including home and work telephone numbers, cell phone and pager numbers. This will ensure that if a liver becomes available we will have accurate records with which to contact you. If you are going out of town, especially if your child is higher on the list, please be sure to notify us of a contact number and the dates that you will be away.

• When your child is higher on the list we recommend that you obtain a pager. This enables you to go about your everyday life as much as possible without being tied to the telephone at home.
Insurance Coverage

- Please contact our financial coordinators with any changes to your insurance coverage as this may affect your transplant coverage. This is also required as we schedule appointments and routine tests may of which require pre-certification from the insurance company.

Transportation Arrangements

- In preparation for travel to Mount Sinai for transplant, please ensure that you have a transportation plan in place. The Pediatric Transplant Coordinator and Social Worker can help you with these arrangements.

Housing Arrangements

- If necessary the Transplant Coordinator and Social Worker can assist you with housing arrangements. The hospital is associated with the Transplant Living Center, which is located a short distance from Mount Sinai Medical Center. A brochure has been included with this manual. Please make arrangements for other family members in your family. One family member can remain at the bedside of your child at all times. There are no facilities for siblings to stay at Mount Sinai during the transplant and post transplant hospitalization.

Miscellaneous Costs of Transplant

- Most medical insurance plans will pay most of the costs of a liver transplant. There are other expenses after the transplant – such as lodging near the hospital, travel expenses etc. which are not covered under medical insurance plans. Please speak with the Pediatric Transplant Social Worker about organizations that can help you plan for these expenses.

When the Call Comes

When a suitable donor has been identified, you will receive a call from a Clinical Nurse Coordinator (Transplant Coordinator) to bring your child into the hospital to be admitted. We will attempt to call your home telephone number first and then we will activate your pager. Please return this call as soon as possible. At that time, please inform us if your child has been unwell within the past few weeks or if they currently have a fever or cold symptoms.
It is a good idea to have your belongings ready. As your child will be admitted to the Pediatric Intensive Care Unit after the transplant, bring as little with you as you can (except for toiletries). It is common to be called in the middle of the night therefore it is important to be prepared. Please ensure that you have transportation arranged.

Although it is important that you try to get to the hospital as soon as possible after you receive the telephone call it is important that you drive safely. You will have a few hours notice before the scheduled surgery.

Instructions on where to come will be given to you at the time you are called in. You will be instructed not to allow your child to eat or drink anything.

*Don’t panic if your child has just eaten!*

Once you arrive at the hospital for surgery, your child will have more tests in preparation to go the Operating Room. They will have a chest X-ray, urinalysis and blood tests to assess their current health status. An intravenous line will be started in their arm and intravenous fluids may be started.

Sometimes, although it is not a frequent occurrence, the donor liver may be found to be unsuitable for transplant and the surgery may have to be cancelled. Although this is disappointing, please do not be discouraged if this happens. Your place on the waiting list will not have been affected.

The transplant operation usually lasts between six to ten hours. You will be kept informed of the progress of the transplant by one of the transplant team. Your transplant surgeon will look for you after the operation is finished.

**Pediatric Intensive Care Unit**

When the surgery is over your child will be taken to the Pediatric Intensive Care Unit, which is located in 1184 5th Avenue on the 3rd floor. Visiting hours are open for parents with all other family members allowed between the hours of 9am and 9pm. You may occasionally be asked to leave the PICU while the multidisciplinary team is making rounds. Your child may be “groggy” for several days following the surgery while the new liver metabolizes the anesthesia. Your child’s heart rate, blood pressure and breathing will be closely monitored.

While in the intensive care unit your child will be monitored very closely. Once they are awake enough the breathing tube will be removed and they will be able to breath on their own. While the breathing tube is in place they will not be able to talk or make any sounds.
They will have several intravenous lines, which will allow for the administration of medications and fluids.

A tube known as a nasogastric tube will be placed through the nose into the stomach in order to drain the secretions from the stomach and will also allow for medications to be given. The NG tube will probably be removed within a couple of days after surgery.

A foley catheter will be placed into your child’s bladder to drain the urine. It is very important to measure the urine output closely in order to determine how well the kidneys are functioning and to determine your child’s fluid status.

The abdominal incision will be in the shape of an inverted “Y”. Small drains will be placed near the incision to drain blood and fluid from around the liver. These drains are known as Jackson Pratt drains (JP’s) and will collect fluid and will be emptied frequently by the nursing staff. These may remain in for several days after the surgery.

Your child may look “puffy” after transplant – this is called edema. This is common due to the amount of intravenous fluid that is required during the surgery.

Transfer to the General Pediatric Floor

The length of stay in the Pediatric Intensive Care Unit varies depending upon blood pressure, liver function and general status. Following discharge from the PICU your child will be transferred to the pediatric floor – usually P5. Hospital length of stay is usually between 2 and 3 weeks.

Post Transplant Regimen

Medication regimen

- Receiving a new liver means that your child will need to take medications for the rest of his/her life. Our immune system functions to protect us from invading bacteria. Unfortunately the body cannot determine that the newly transplanted liver is there to help us. It simply recognizes that it is something foreign and sets out to destroy it. Without immunosuppressive drugs, the body would reject the newly transplanted liver. However, immunosuppressive drugs can also suppress the immune system. This means that transplant patients are more susceptible to certain infections. To prevent infections we give prophylactic (preventative) medications. The medications can seem overwhelming at first. It is during the first six months after transplant that your child will require the most medications. After that time medications will be reduced.
The nursing staff will administer the medications after surgery. However, during this time they will teach you the names, dosages, side effects and reasons for taking the medications. Please ask questions with regards to the medication regimen. You will also receive intensive teaching from the Pediatric Transplant Coordinators. This will include ordering of medications from the pharmacy, administration of medication and discharge planning.

**REMEMBER – THERE ARE NO SILLY QUESTIONS!!!**

It is extremely important that before you go home you understand the medication regimen.

**Follow up office visits**

- Follow up in the outpatient office is an important part of the recovery period. During outpatient visits we monitor laboratory blood tests and perform a complete physical examination. It also allows you an opportunity to ask any further questions with regards to post transplant medical care and follow up.

- Below is an example of the frequency of outpatient visits for the first 3 months after transplant although this may change depending on laboratory blood test and physical examination results:

  - Twice per week (Monday and Wednesday) for one month.
  - Once per week for one month.
  - Every two weeks until three months post transplant or until stable.

Please do not hesitate to contact us at (212) 659-8060 with any further questions. Further discussions will take place whenever you come to visit us in the office.

**Possible Post Transplant Complications**

It is possible that a transplant recipient to have a transplant and not experience any complications. More, realistically at least one complication is likely arise. The Transplant Team will be closely monitoring for signs and symptoms of complications and initiate appropriate treatment. The most common complications that arise after liver transplantation:

- Rejection
- Infection
- Acute Hepatitis in the graft
- Thrombosis of a major vein or artery going into or coming out of the liver.
Biliary tract obstructions.
- Perforations – opening in the intestine made during surgery that may need to be closed by surgery.

Rejection

Without special drugs known as immunosuppressive medications your child’s body would try to reject the transplanted liver. This is because the body has a defense system that works to destroy foreign protein substances – such as viruses and bacteria – that invade the body and make you feel unwell. Unfortunately, the body cannot distinguish between an unwelcome invader (infection) and the new liver. This means that the immune system treats the new liver like it would any foreign substance and it attacks the new liver. A successful attack is called a rejection.

- Rejection can happen even although your child is taking medications to stop their body from fighting the new liver.
- Rejection can occur at any time after transplant, but it is extremely common in the first three months after transplant.
- We will closely monitor your child’s liver function tests (liver enzymes). If there is noted to be an elevation in the liver functions tests, we will perform an abdominal sonogram to ensure that there is adequate blood flow to and from the liver. This will also allow us to evaluate the bile ducts inside and outside the liver for potential complications.
- A liver biopsy will be required if the blood tests remain elevated.
- If rejection is confirmed by the liver biopsy – treatment will be required.

Rejection can be treated!

- Initially, rejection is treated with high doses of steroids. Your child will probably have to be admitted to the hospital for several days while undergoing treatment.
- During the hospital stay, blood tests will be checked every day.
- A repeat liver biopsy may be required if the liver function tests do not improve.
- If the liver function does not improve stronger medication may be required.
- In a very few cases, some recipients may need another liver – This is very uncommon.

Post Transplant Infections

The immunosuppressive medications which your child will be taking post transplant make it hard for the body to fight infections. Some of the more common infections are:

Viral infections: Signs and symptoms of viral disease include, fatigue, fever, irritability and loss of appetite:
- **Cytomegalovirus (CMV)** – one of the most common viral infections that occur in transplant recipients. The risk of CMV is highest in the first 3 months after transplant.
- **Epstein-Barr Virus** - frequently occurs in transplant recipients who receive immunosuppressive medications.
- **Herpes infections** – these viruses usually infect the skin. Although Herpes cannot be cured, it can be treated. Treatment is either by mouth, application to the skin or given by intravenous infusion.
- **Varicella Zoster (Chicken Pox)** – may appear as a rash or small blisters. If your family are in contact with anyone who develops chicken pox please contact your Pediatrician, Transplant Coordinator or Nurse Practitioner immediately for further information.

**Fungal infections:**

- **Candida** – is a fungus that can cause a variety of infections in transplant recipients. If there is infection in the mouth or throat it is called thrush. Thrush causes white raw areas, pain or tenderness, a white film on the tongue and difficulty swallowing. Candida can also infect the esophagus (the “tube” that goes from the throat to the stomach). If a fungal infection develops this will be treated with either intravenous or oral medications

**Common Signs and Symptoms of Rejection and Infection**

Below are some of the common signs and symptoms of rejection and infection:

- Increasing irritability
- Shortness of breath
- Fever greater than 100.4 F or 38 C
- Chills fever and sore throat
- Loss of appetite
- Dizziness or light-headedness
- Nausea or vomiting
- Fatigue

* Please contact the Transplant Team immediately if there are any changes to your child’s condition

**Glossary**
Acute – sudden and severe onset (i.e. acute liver failure).

Albumin – a protein that is produced in the liver.

Anesthetic – a general anesthetic is given to “put you to sleep” so that you do not feel the pain of surgery.

Ascites – fluid, which develops in the abdomen when the liver is not functioning properly.

Bacteria – germs that cause diseases.

Bile – a yellowish or greenish fluid made by the liver and stored in the gallbladder. Bile coats the fatty foods we eat making them easier to digest.

Bilirubin – the breakdown product of old blood cells in the body. These cells are converted by the liver into a substance that can be used and excreted by the body.

Cholangitis – inflammation of the bile ducts caused by bacteria from the intestines.

Cholestasis – stoppage or slowing of bile flow through the bile ducts.

Cirrhosis – progressive scarring of the liver that affects the way in which the liver works.

CT scan – a special type of X-ray that uses a computer to show a cross section of the body.

Donor – the person who gives one of their own organs to help others.

Edema – build up of fluid in the tissues causing swelling.

Encephalopathy – when liver disease has caused a build up of toxins that affected the brain causing tiredness, irritability and personality changes.

Fulminant Hepatic Failure – sudden development of acute liver injury with rapid clinical deterioration within 8 weeks of onset of symptoms.

Gastroenterologist – A doctor who specializes in diseases of the gastrointestinal tract.

Graft – an organ for transplantation.

Hepatic – relating to the liver.
Hepatitis – inflammation of the liver caused by a virus or other insult to the liver.

Hepatologist – a doctor who specializes in the diseases of the liver.

Immunosuppressive Medications – drugs that help to prevent the recipients’ own immune system from attacking and rejecting the new liver.

Intravenous (IV) – a small catheter that goes into a vein to give fluids, medications and blood products.

Jaundice – a yellow appearance of the skin and sclera (whites of the eyes) caused by the build up bilirubin in the bloodstream.

Liver – internal organ that stores and filters blood, excretes toxic substances from other parts of the body, secretes bile and aids in metabolism. The liver is located in the right side of the abdomen.

Liver Biopsy – a procedure in which a small piece of liver tissue is removed using a thin needle for examination under a microscope, to detect diseases or conditions such as rejection.

Liver Function tests – blood tests that show how well the liver is working.

Living-Related Liver Transplant – may also know as “living donor transplant”. This is when parent (or other family member) donates part of their own liver to be transplanted into their child.

Portal Hypertension – increased blood pressure within the portal vein, which carries blood and nutrients to the liver. This is a common complication of cirrhosis.

Rejection – occurs when antibodies are produced against the transplanted liver and it is attacked by the immune system.

Thrombosis – formation of a clot within a blood vessel.

Ultrasound – a non-invasive imaging study that uses sound waves to create a picture of the liver and surrounding organs. It is also used to assess the patency of the blood vessels that carry blood to and from the liver.

UNOS – United Network for Organ Sharing. UNOS is responsible for the fair distribution of organs for transplantation.
Variceal Bleed – high blood pressure in the veins within the esophagus (food pipe) and stomach. This causes “bursting” of the veins leading to severe bleeding.