

YOUR TRANSPLANT TEAM

Important Numbers

University of Michigan Pediatric Liver Transplant Office: (734) 615-2462
Monday – Friday, 8:00 AM – 4:30 PM (734) 615-2223 Fax

University of Michigan Paging (734) 936-6267
Ask for the on-call Pediatric GI physician
After hours, weekend and holiday calls

Your Pediatric Transplant Team

<u>Title/Position</u>	<u>Name</u>	<u>Phone</u>
Transplant Nurse Coordinator	Jessica Hollenbeck, RN, BSN Ceren Onsan, RN, BSN Brenda Shaw, RN, BSN	(734) 615-2462
Transplant Hepatologist	M. James Lopez, MD PhD (<i>Medical Director</i>) Frank DiPaola, MD Jacob Bilhartz, MD	(734) 615-2462
Transplant Surgeons	John Magee, MD (<i>Surgical Director</i>) Michael Englesbe, MD	(734) 936-9623
Social Worker	Tanya Smith, LMSW	(734) 232-8890
Dietitian	Kila Ahlijian, MD, RD, CSP	(734) 763-5702
Psychologist	Emily Fredericks, PhD	(734) 936-4220
Medical Assistant	Tammy Dorris	(734) 615-2462

Other Essential Team Members

Pediatric GI Attendings	Jeremy Adler, MD Vanessa Cardenas, MD Chris Dickinson, MD Grace Lee, MD Julia Mar, MD Haley Neef, MD Andrew Singer, MD Dana Steien, MD George Zacur, MD	(734) 763-9650
Transplant Surgeons	Jeff Punch, MD Chris Sonnenday, MD, MPH Randy Sung, MD	(734) 936-5816
Financial Coordinator	Anne Maskill (A-J) Frankie Mautone (K-Z)	(734) 647-0953 (734) 232-9984
Transplant Coordinator	Deb Westphal	(734) 615-1825

Team Mission and Team Structure

Pediatric Liver Transplant Team Mission

The mission of the Pediatric Liver Transplant Team is:

- Provide the best possible care for each child evaluated by our program
- Help families and patients in understanding a child's liver disease, its impact on his/her medical care, the steps involved in a liver transplant, and the care necessary after liver transplant

Our team is committed to providing care that is patient-centered and family-centered.

We provide care via a multidisciplinary team that focuses on the following issues:

- Patient evaluation and diagnosis
- Patient and family education



- Helping families find the support that they need for a transplant to be successful
- Listening to families' concerns and questions
- Emphasizing continual improvement in patient care and education through a constant process of self-assessment
- Creating opportunities for research with the goal of improving our care

Why Do We Have a Team and How Does the Team Work?

At a pre-transplant evaluation, you will meet the entire Pediatric Liver Transplant Team. This team consists of liver transplant surgeons, liver transplant physicians (hepatologist – liver doctor), a transplant nurse, a transplant dietitian, a transplant social worker, a transplant psychologist, and other members, such as financial specialists, if necessary.

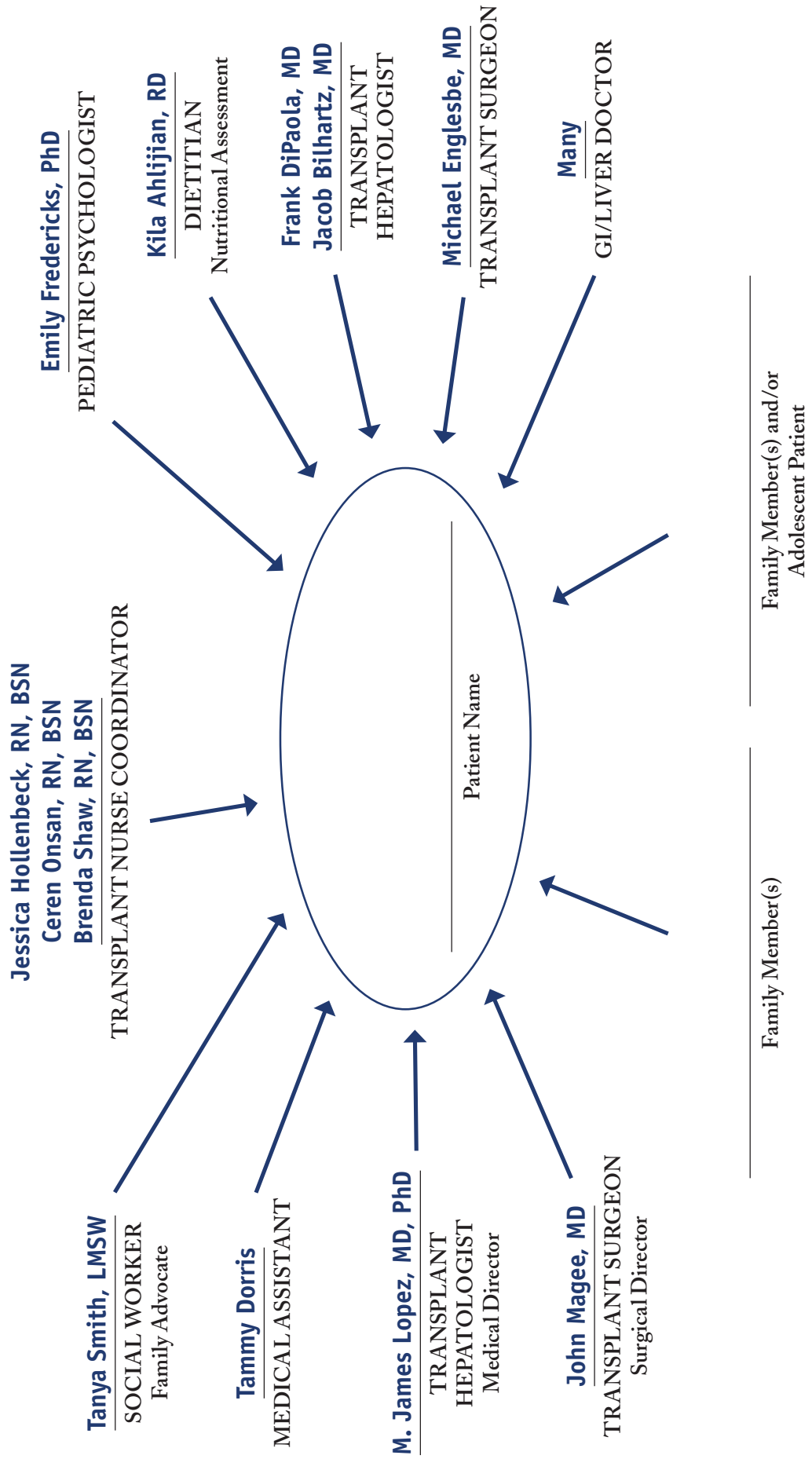
We believe that the best care is patient and family-centered. This means that communication between all members of the transplant team (including the family and referring physician) is important for the success of a liver transplant. We believe that creating an environment that is open to both asking questions and sharing concerns or problems is key to providing the best care to each child.

Communication is always a two-way street. We are here to listen to families and their concerns as well as to provide education regarding liver disease and transplant.

We believe that families need to be involved in all areas of their child's care and understand as much as possible about their care. In addition, we understand that having chronic liver disease (before transplant), and undergoing a liver transplant, are both very disruptive and stressful. The stress and disruption caused by medical issues often creates a need for support from members of the transplant team. Because the main concern of the team is a child's long-term outcome, we often will spend time discussing emotional and developmental issues with families and patients. We believe these issues to be just as important for long-term outcomes as any liver related medical issues. Finally, we believe adolescents should be viewed as team members and not just as patients. This helps adolescents develop more responsibility for their medical care, understand their health-related issues, and live a healthy lifestyle. Thus, we spend a considerable amount of time involved in education, discussion, and questions with families and adolescents to help them gain the knowledge and skills necessary for long-term success in caring for their liver transplants, and by extension, their whole body.

To illustrate our view of what a liver transplant team looks like we have included a diagram.

Pediatric Liver Transplant Team



Members of the Pediatric Liver Transplant Team

Dietitian

The dietitian works with the medical team to maintain and improve your child's nutritional health. They provide information and education about how impaired liver function and liver disease impact nutritional health and growth. The dietitian provides support when special interventions are needed before or after transplant.

Liver Transplant Coordinator

The coordinator is responsible for communication with families and referring physicians regarding initial listing status, communication with UNOS (United Network for Organ Sharing), and contacting families when an organ becomes available.

Liver Transplant Nurse (Pre- and Post-transplant Care Coordinator)

The Liver Transplant Nurse is the person you will communicate with most before your child has his or her liver transplant. The nurse provides assistance with medical issues in the pre-transplant phase of care. He/she works in collaboration with your referring physician and the Pediatric Liver Transplant Team to meet the health care needs of your child. The Liver Transplant Nurse is your case manager and your main contact person before and after transplant. When your child is in the hospital, the Liver Transplant Nurse helps your family with the education needed to care for your child after the transplant, helps obtain medications, and oversees discharge planning. The nurse arranges home health care following discharge and sees your child for follow-up visits with the physician and other members of the team. The nurse also discusses your child's laboratory test results and any medication changes the doctor has prescribed.

Transplant Hepatologist (Liver Physician)

The transplant physician is the Pediatric Transplant Hepatologist or Pediatric Gastroenterologist who, together with the transplant surgeon, directs your child's medical care before and after transplant, both in and out of the hospital. Throughout all phases of care, beginning with transplant listing, the goal of the transplant physician is to ensure the best function of your child's liver and to help your child reach the best quality of life possible. The transplant physician will review your child's health-related concerns and make assessment and treatment plans with you after physical examination, laboratory evaluation, and imaging assessment of your child.

Liver Transplant Surgeon

The transplant surgeon is the physician who transplants your child's liver. The surgeon operates on your child and directs all of your child's care immediately after the transplant, when your child is in the intensive care unit, and on the liver transplant floor (12 East Mott). The surgeon also performs any additional operations your child may need and will stay active in your child's care as long as your child is followed at the University of Michigan.

Medical Assistant

The medical assistant oversees the transplant office's daily routine and is usually the first person you speak to when calling the transplant office. She can answer many of your questions, help make clinic appointments, and direct your phone calls to the best person on the Pediatric Liver Transplant team.

Psychologist

A pediatric psychologist is someone who has a PhD or PsyD in clinical or counseling psychology, but has specialized training in working with children with chronic or acute medical conditions. Pediatric psychologists provide assessment and interventions to patients and families and also consult with medical teams and hospitals. They often provide intervention in the areas of treatment adherence, adjustment to illness, coping, and health promotion.

Why is There a Psychologist in the Pediatric Transplant Clinic?

Although liver transplant offers children and families the possibility of increased quality and quantity of life, there are a number of individual and family-related psychological and social problems that arise during the transplant process. It is important to address the psychosocial needs, as well as the medical needs, of the child and his/her family throughout the transplant process in order to promote the best health outcomes.

The level of involvement by the transplant psychologist will likely vary across families. There are many aspects of the transplant process that may require psychological assistance including adjustment and coping of the child, sibling and family, parenting challenges, regimen adherence, and school-based issues. Some of these issues include:

Adjustment and Coping of the Child/Adolescent

- Depression
- Anxiety
- Behavior Problems
- Coping with Stress
- Body Image
- Developmental Issues
- Sleep Disturbances
- Transition to Adulthood

Adjustment and Coping of the Family

- Family Communication
- Siblings
- Parenting Challenges
- Trauma Reactions

Regimen Adherence

- Medication
- Pill Swallowing
- Diet & Exercise
- Attendance at Clinic
- Lab Draws

School Functioning

- Section 504 Plan/IEP (Individualized Education Plan)
- Homebound Services
- School Re-entry
- Cognitive Functioning
- Peer Relationships

What Can a Pediatric Psychologist Do?

- Evaluate psychological symptoms (e.g., anxiety, depression, eating disorder, etc), diagnose psychiatric disorders, and provide treatment recommendations.
- Evaluate treatment adherence and provide interventions to improve adherence.
- Evaluate family dynamics and structure, and provide brief family therapy interventions.
- Complete screening or evaluation of cognitive and academic abilities (e.g., IQ, learning disability).
- Provide parent training and behavior modification to families to manage behavioral or other concerns.
- Teach relaxation and pain management strategies to young children and adolescents.
- Teach problem-solving to patients and/or families to increase independence and promote active coping.
- Assist in developing a plan of care or care contract with families who are having difficulty following the treatment needs of the patient (e.g., missed appointments, not taking medications, not getting labs drawn).
- Provide psychological intervention to assist with major life transitions or changes.
- Provide support and interventions to facilitate decision-making with families.
- Facilitate communication between patient and peers, medical team, or family through teaching appropriate communication skills.
- Provide referrals for ongoing outpatient psychotherapy when that is most appropriate.
- Coordinate access to multi-disciplinary services based on the needs of the patient and family.

The psychologists in our clinic are also involved in research, which is designed to help us learn ways to improve the long-term health of pediatric liver transplant recipients. Research projects focus on medication adherence, self-management, quality of life, and the transition to adulthood.

Social Worker

The primary role of the transplant social worker is to provide support to the patient and family and to act as a resource for the transplant team. The amount and type of involvement by the social worker varies widely depending upon each family situation and a family's specific needs. In many cases, assistance begins with the transplant evaluation to help you and your family prepare for your family's unique requirements and to reduce problems before transplant.

The social worker may:

- Help you and your child with adjustment to hospitalization and transplant,
- Offer supportive counseling for family members,
- Help to get resources during your hospital stay,
- Connect you to ongoing resources at discharge, and/or
- Act as an advocate to ensure you have services or to clarify your particular needs and views.

Considerable effort is made to work with you in determining what resources might best assist your family and how to continue and develop the relationship in the weeks and months ahead. Like other members of the transplant team, the social worker works collaboratively with team members to help provide continuity and high quality care for your child. The social worker devotes attention to listening to families and helping tailor aspects of your child's care to your family's particular needs with the goal of having the best possible family- and patient-centered-care.

Transplant Financial Specialist

The financial specialist works with you to help understand the various financial issues related to the transplant and hospital care your child receives. The cost of treatment may be one of your biggest concerns, next to the health of your child. Our transplant financial specialist addresses many of your concerns before the transplant and assists your insurance company with coverage issues.

Parents/Family/Patients

Parents and family members are part of the Pediatric Liver Transplant Team. Parents' and patients' contributions to the success of liver transplant are important but often are not specifically recognized for this. We believe that only with the help of patients and families in monitoring for illness, monitoring for side effects of medications, regularly giving and taking medications, and obtaining laboratory tests can a liver transplant ever be successful. Patients and their families are the "eyes and ears" of the pediatric liver transplant team. They are expected to ask questions to help make sure that they understand both transplant and the underlying disease process and its complications.

Other Health Care Members Important to Transplant

Attending Pediatric Intensive Care Physicians

These physicians are specially trained doctors who direct the medical care while your child is in the intensive care unit. These doctors work together with the liver transplant physicians in helping make medical decisions for your child.

Attending Pediatric Gastroenterology Physicians

These physicians are specially trained doctors who specialize in the care of patients with gastrointestinal and liver diseases. They may act as the primary attending or help with diagnostic tests or procedures both before and after transplant (i.e., if endoscopy or a liver biopsy is necessary).

Chaplains

Chaplains from many denominations are available to you and your child for spiritual support.

HOSTS (Health Unit Coordinators)

Health unit coordinators greet you as you enter the unit. They can be a resource to answer many of your questions.

Pediatric Gastroenterology Fellows

Gastroenterology fellows are physicians who have completed their residency in pediatrics and are completing further training to specialize in the care of patients with gastrointestinal and liver diseases.

Pediatric Intensive Care Fellows

PICU fellows are physicians who have completed their residency in pediatrics and are completing further training to specialize in the care of patients requiring the services of an intensive care unit.

Occupational Therapists/Physical Therapists (OT/PT)

OTs/PTs are specially trained staff who help your child work on strengthening muscles needed for feeding and development.

Patient Representative

This individual serves as a link between you and your child and the hospital staff. The patient representative can inform you about patient rights and responsibilities, hospital procedures, policies, resources and services.

Pediatric Nurses

Pediatric nurses are Registered Nurses (RNs) who are prepared to give you and your child the specialized care you need. These nurses will be assigned to your child to coordinate his or her care with the health care team and to help meet your needs as parents. These nurses work throughout C.S. Mott Children's Hospital.

Pharmacists

Pharmacists are specially trained and licensed to prepare medications for your child. We have both transplant pharmacists and pediatric pharmacists on staff as part of the program.

Resident Physicians

Residents (house officers) are physicians who come to the University of Michigan to receive training in the care of children. They work closely with the attending physician to care for your child.

Research Coordinator

The research coordinator is a specially trained nurse or other health care professional who may talk to you about special research studies at the University of Michigan for which your child may be eligible.

Respiratory Therapists (RT)

Respiratory therapists are specially trained members of the health care team who work with children to prevent complications and to help children who are having trouble breathing.

Child & Family Life Professionals

Child & family life professionals may be part of your child's healthcare team during inpatient hospital stays. They coordinate programs and services designed to lessen the impact of hospitalization on children and can help provide support to your child through therapeutic play activities and peer interactions.

