

## RESOURCES

### Want to Learn More or Share Resources With Your Family and Friends?

The Pediatric Liver Transplant Patient Education Guide (this book) can be found electronically on the University of Michigan Health website at [www.MottChildren.org/conditions-treatments/transplantation/ped-liver-transplant/resources](http://www.MottChildren.org/conditions-treatments/transplantation/ped-liver-transplant/resources).

For general information about the University of Michigan Transplant Center's pediatric programs, please visit [www.MottChildren.org/conditions-treatments/ped-transplant](http://www.MottChildren.org/conditions-treatments/ped-transplant).

### University of Michigan Health Patient Portal

#### *What is MyUofMHealth.org?*

**MyUofMHealth.org** offers patients personalized and secure online access to portions of their medical records. It enables you to securely use the Internet to help manage and receive information about your health. With **MyUofMHealth.org**, you can use the Internet to:

- Request medical appointments
- View your health summary from the **MyUofMHealth.org** electronic health record\*
- View test results
- Request prescription renewals
- Access trusted health information resources
- Communicate electronically and securely with your medical care team



#### *How Do I Sign Up?*

Patients who wish to participate will be issued a **MyUofMHealth.org** activation code. There are two ways to get an activation code. Patients can get an activation code after their clinic visit or they can request an activation code by completing the online request form located on the **MyUofMHealth.org** website. This code will enable you to login and create your own username and password.

#### *Who Do I Contact if I Have Further Questions?*

You may e-mail [HIM-PatientPortal@med.umich.edu](mailto:HIM-PatientPortal@med.umich.edu) or you can call the Health Information Management Department at (734) 615-0872 Monday-Friday, 8 a.m.-5 p.m.

*\* Please note, once patients are 11 years old, parents have limited access to their child's account.*

## Glossary of Terms

**Absorption** – The degree and speed at which a drug enters the bloodstream from the small intestine.

**Acute Hepatitis** – An inflammation in the liver that lasts less than six months.

**Acute Rejection** – The body’s attempt to destroy the transplanted organ. Acute rejection usually occurs in the first year after transplant.

**Acute Tubular Necrosis (ATN)** – Reversible kidney damage resulting in delayed kidney function. Among other factors, it may be caused by the quality of the donor organ, the time the organ was stored before transplantation, or medications used to prevent rejection.

**Administrative Fee** – An amount of money charged by an organization handling fundraising money.

**Adverse Reaction** – An unintended side effect from a drug.

**Advocacy Organization** – A group that helps someone get what they need or want, promotes a certain point of view, or pleads the case of another.

**Albumin** – A protein made by the liver.

**Alcoholic Hepatitis** – An inflammation of the liver caused by alcohol.

**Alkaline Phosphatase** – An enzyme that may be increased in some liver and bile duct diseases.

**Allocation** – The process of determining how organs are distributed. Allocation includes the system of policies and guidelines that are followed to ensure that organs are distributed fairly to those waiting for them.

**Allograft** – An organ or tissue that is transplanted from one creature to another of the same species, such as human to human. An example would be a transplanted kidney.

**Alpha-1 Antitrypsin Deficiency** – A hereditary disease that may lead to hepatitis and cirrhosis.

**Alphafetoprotein (AFP)** – An abnormal protein that may be found in liver cancer. AFP levels that are slightly abnormal may be in those with chronic hepatitis or cirrhosis.

**ALT (SGPT)** – The abbreviation for alanine aminotransferase, an enzyme found in high levels in the blood when the liver is inflamed.

**Anatomy** – The structure of the body and the relationship of the parts of the body.

**Anesthetic** – Medication that reduces pain by dulling sensations.

**Antibody** – A substance produced by the body in response to an infection. Antibodies help fight infections, thus producing immunity to the infecting organism. Some antibodies, like the hepatitis C antibody, are not effective in neutralizing the organism and are not markers of recovery.

**Antigen** – A foreign substance, such as a transplanted organ, that triggers the body to try to reject it.

**Anti-rejection Drugs (Immunosuppressive Drugs)** – Drugs that reduce the body's ability to reject the transplanted organ.

**Arteriogram** – An X-ray of an artery after a dye has been injected.

**Ascites** – Accumulation of fluid in the abdominal cavity, most commonly a result of cirrhosis.

**AST (SGOT)** – The abbreviation for aspartate aminotransferase, an enzyme found in high levels in the blood when the liver is inflamed.

**Asymptomatic** – Free of symptoms.

**Auto-immune Hepatitis (AIH)** – A form of liver inflammation in which the body's immune system attacks liver cells.

**Bacteria** – Small organisms (germs) that can cause disease.

**Beneficiary** – The person who receives the benefits of an insurance policy.

**Benefits** – Services that are paid for by an insurance policy.

**Benign** – Benign indicates not malignant; not recurrent; favorable for recovery.

**Bile** – A fluid produced by the liver, stored in the gall bladder, and released into the small intestine to help absorb dietary fats.

**Bile Ducts** – The tubes through which bile flows.

**Bile Leak** – A hole in the bile duct system causing bile to spill into the abdominal cavity.

**Biliary Atresia** – A disease of young children that prevents proper development of the main bile ducts connecting the liver to the intestinal tract – resulting in obstruction and cirrhosis of the liver usually within the first year of life.

**Biliary Stenosis** – The narrowing or constriction of a bile duct.

**Biliary Tree** – All passageways inside and outside the liver that carry bile to the intestines.

**Bilirubin** – Bile pigments. Increased bilirubin levels cause yellowing of the eyes and skin (jaundice) and may be a sign of liver disease or bile duct abnormalities.

**Bioavailability** – A measure of how much of an administered drug is absorbed into the bloodstream, actually reaching the intended site of action in the body. For example, medicine is absorbed from the GI tract, travels through the bloodstream, and reaches the organ tissues, where it works to fight infection, prevent rejection, etc.

**Biopsy** – A procedure where a sample of tissue is removed from the body by a needle so it can be examined under the microscope.

**Bladder** – The part of the urinary tract that receives urine from the kidneys and stores it until urination.

**Blood Urea Nitrogen** – A by-product of protein breakdown in the body.

**Blood Vessels** – The veins, arteries, and capillaries through which blood flows. Blood vessels can be donated and transplanted.

**Brain Death** – When the brain has permanently stopped working, as determined by the physician. Machines may maintain functions such as heartbeat and breathing for a few days, but not permanently.

**Budd-Chiari** – Clotting of the hepatic vein which is the main vein leaving the liver.

**BUN** – Stands for blood urea nitrogen, a waste product normally secreted by the kidney. BUN values represent how well the kidneys function.

**Carcinoma** – A malignant new growth; a type of cancer.

**Cardiac** – Having to do with the heart.

**Cessation** – The act of ceasing; halt.

**Cholangiocarcinoma** – A primary malignant tumor (cancer) of the liver originating in bile duct cells.

**Cholestasis** – A blockage of bile in the liver or bile ducts.

**Chronic** – A condition that develops slowly and lasts for a long time, even the rest of the patient's life, for example, kidney failure.

**Chronic Hepatitis** – Hepatitis infection that lasts longer than six months.

**Chronic Rejection** – Slow failure of the transplanted organ.

**Cirrhosis** – An advanced stage of liver disease in which functioning liver cells are reduced in numbers and surrounded by scar tissue. Cirrhosis may be caused by viruses, alcohol, inherited metabolic diseases or drugs.

**Cirrhotic** – Pertaining to or characterized by cirrhosis.

**CMV (Cytomegalovirus)** – A virus infection that is very common in transplant recipients; it can affect the lungs and other organs as well; a member of the family of herpes viruses.

**Coagulation** – Blood clotting.

**Coalition on Donation** – A non-profit alliance of health and science professionals, transplant patients, and voluntary health and transplant organizations. The Coalition works to increase public awareness of the critical organ shortage and to create a greater willingness and greater commitment to organ and tissue donation.

**Co-insurance** – A percentage of money insured persons must pay toward a service that insurance will cover. A typical amount is 20 percent – patients pay 20 percent of the doctor's bill and insurance pays 80 percent.

**Cold Ischemia Time** – The time an organ is without blood circulation – from the time of removal of the organ from the donor to the time the organ is transplanted into the recipient.

**Co-payment (co-pay)** – A flat fee that a person pays for health care services in addition to what the insurance company pays, for example, a \$10 co-payment for each visit to the doctor.

**Corticosteroid** – A hormone produced by the body but given as a synthetic (manufactured) medicine to suppress the body's normal reaction (immune response) to infection and foreign tissue, such as a transplanted organ. Prednisone is an example of a synthetic hormone.

**Coverage Date** – The day insurance benefits begin.

**Covered Benefit** – A service that an insurance company will provide payment toward.

**Creatinine** – A substance found in blood and urine; it results from normal body chemical reactions; high blood creatinine levels are a sign of depressed kidney function.

**Criteria (Medical Criteria)** – A set of standards or conditions that must be met.

**Cryptogenic Cirrhosis** – A cirrhosis of obscure or unknown origin.

**Deceased Donor** – An individual who has recently died of causes that do not affect the function of an organ to be transplanted. Either the person or the person's family has generously offered organs and/or tissues for transplantation.

**Deductible** – A fixed amount of money that must be paid for covered health care expenses before the insurance company starts to pay. This is usually a yearly amount of \$250, \$500, \$1,000 or more.

**Deficiency** – A lack or a defect.

**Delayed Function** – A condition in which the transplanted organ does not work well right after the transplant.

**Department of Health and Human Services (HHS)** – The department of the Federal Government is responsible for health-related programs and issues, including overseeing the OPTN and SRTR contracts and developing organ, tissue, and bone marrow donation programs.

**Dependents** – Those persons who also receive insurance benefits on an insurance policy, for instance, a spouse or child.

**Diabetes** – A disease in which patients have high levels of sugar in their blood.

**Dialysis** – The use of a machine to correct the balance of fluids and chemicals in the body and to remove wastes from the body when kidneys are failing. (See hemodialysis.)

**Diastolic Blood Pressure** – The bottom number in blood pressure (80 in a blood pressure of 120/80), which indicates the pressure in the arteries when the heart is at rest.

**Disability (Disabled)** – A considerable limitation in major life activity that cannot be helped with the use of a corrective device or medication. A disabled person is someone who is unable to perform the necessary functions of many jobs with or without reasonable modification.

**Disability Determination Service** – A State agency that reviews eligibility for vocational rehabilitation.

**Disability Insurance** – A type of insurance that provides an income if illness or injury prevents a person from being able to work for an extended period of time.

**Diuretic** – An agent that increases the output of urine.

**DNA** – The abbreviation for deoxyribonucleic acid, the substance that is the building block of all living things.

**Donor** – Someone from whom an organ or tissue is removed for transplantation.

**Donor Card** – A document that indicates a person's wish to be an organ donor.

**Donor Pool** – A group of people eligible to donate an organ.

**Durable Power of Attorney** – A legal document in which someone is named to make medical decisions for a person when he/she is unable to speak for him/herself.

**Edema** – Swelling caused when the body retains too much fluid, also called “water weight.”

**Electrocardiogram** – A recording of the electrical activity of the heart.

**Electrolyte** – Generally refers to the dissolved form of a mineral such as sodium, potassium, magnesium, chlorine, etc.

**Encephalopathy** – Damage to the brain and central nervous system caused by toxins not filtered out of the blood by the liver.

**End-stage Organ Disease** – A disease that leads to permanent failure of an organ.

**Enzyme** – Cellular proteins that begin or assist chemical reactions within the body.

**Evidence of Insurability** – Proof that a person is healthy enough for a particular insurance company to insure them.

**Exclusion** – Medical services that are not paid for by an insurance policy.

**Experimental** – New treatments, procedures or drugs that are being tested. Insurance companies usually do not pay for anything considered experimental.

**Federally Mandated** – Required by federal law.

**Fibrosis** – Scarring. Fibrosis in the liver is usually a result of long-standing injury and precedes cirrhosis.

**Foreign Body** – An entity that enters the body that is not supposed to be there, such as a germ, a piece of glass, a splinter, or a transplanted organ or tissue. The body normally attacks, or tries to reject, a foreign body to prevent further injury.

**Foundation** – An institution that provides funds for causes, issues, groups, people, etc. A foundation often has a particular interest or interests and solicits donations from those who support those interests. Some foundations help patients and their families with medical expenses.

**Fulminant** – Happening very quickly and with intensity, for example, fulminant liver failure or fulminant infection.

**Fungal Disease** – An infection that usually occurs in patients during treatment with steroids or immunosuppressants. Examples of fungal infections include candida, aspergillus, and histoplasmosis, which tend to be systemic infections.

**Gallbladder** – A muscular sac attached to the liver which stores bile.

**Gastroenterologist** – A physician who specializes in the treatment of diseases of the digestive tract, including the liver.

**Genetic** – Referring to heredity, birth or origin.

**Gingival Hypertrophy** – The enlargement of the gums, a common side effect of cyclosporine therapy, which can be managed with good oral hygiene.

**Glucose** – A type of sugar found in the blood.

**Glycogen** – The chief carbohydrate storage material.

**Graft** – A transplanted organ or tissue.

**Graft Survival Rate** – The percentage of patients who have functioning transplanted organs (grafts) at a certain point in time. The data is usually measured in one-, three- and five-year time periods.

**Grant** – An amount of money given as a gift, usually for a specific use.

**Group Insurance** – Typically offered through employers, although unions, professional associations and other organizations also offer group insurance. Most, if not all, of the premium is paid by the employer.

**Gynecology** – A medical specialty focusing on a woman's reproductive organs.

**HAV** – The abbreviation for the hepatitis A virus.

**HBV** – The abbreviation for the hepatitis B virus.

**HCV** – The abbreviation for the hepatitis C virus.

**HCV Genotype** – Hepatitis C can be divided into six genotypes (1 – 6). Each genotype can be divided into subtypes (a, b, c, etc.) Type 1 is most common and accounts for 70 percent of hepatitis C infections in the United States. Patients with genotype 1 have lower response to treatment than patients with genotypes 2 or 3.

**Health Maintenance Organization (HMO)** – An insurance plan where employers pay a fixed monthly fee for services, regardless of the level of care. Patients must usually see a primary care physician, then are referred to a specialist.

**Hematocrit** – A measure of the red blood cell content of blood.

**Hemodialysis** – A treatment for kidney failure whereby the patient's blood is passed through a machine to remove excess fluid and wastes. The procedure usually takes about three to four hours per session and is usually done three times per week.

**Hemorrhage** – A rapid loss of a large amount of blood or excessive bleeding.

**Hepatic** – Having to do with, or referring to, the liver.

**Hepatic Artery** – The hepatic artery is one of the primary blood vessels that supplies blood to the liver.

**Hepatic Encephalopathy** – A condition usually occurring secondarily to advanced disease of the liver which is marked by disturbances of consciousness and may progress to deep coma, psychiatric changes of varying degree, flapping tremor, and increased ammonia levels.

**Hepatitis** – Inflammation of the liver caused by viruses, infections, chemicals, or drugs.

**Hepatitis A** – A form of acute, self limiting hepatitis that is transmitted via contaminated food or water. Hepatitis A does not progress to chronic infection and will not lead to cirrhosis.

**Hepatitis B** – Inflammation in the liver caused by the Hepatitis B virus.

**Hepatitis B Surface Antibody (Anti-HBs)** – A marker of immunity to hepatitis B infection. Immunity can be acquired from vaccine or a previous hepatitis B infection.

**Hepatitis B e Antigen (HBeAg)** – A marker that can be detected through a blood test. Presence of HBeAg is an indication that the hepatitis B virus is actively multiplying.

**Hepatitis B Surface Antigen (HBsAg)** – A marker of hepatitis B infection. Test for HBsAg is used to screen for HBV infections. Further tests are needed to determine if the virus is active.

**Hepatitis B DNA (HBV DNA)** – The marker of active hepatitis B infection.

**Hepatitis C** – Inflammation of the liver caused by the hepatitis C virus.

**Hepatitis C Antibody (anti-HCV)** – This is a marker of hepatitis C infection. Presence of Anti-HCV is usually an indication of active HCV infection. However, anti-HCV can also be detected in individuals who have recovered from hepatitis C.

**Hepatitis C RNA (HCV RNA)** – A marker of active hepatitis C infection.

**Hepatocellular Carcinoma (HCC)** – Liver cancer, which starts in the cells of the liver.

**Hepatologist** – A physician who specializes in the treatment of liver diseases.

**Hepatomegaly** – An enlarged liver.

**Herpes** – A family of viruses that infect humans; herpes simplex causes lip and genital sores; herpes zoster causes shingles.

**High Blood Pressure (Hypertension)** – High blood pressure occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller. High blood pressure causes the heart to pump harder to move blood through the body. High blood pressure can cause kidney failure and heart disease if not treated.

**Hirsutism** – An excessive increase in hair growth. It is a common side effect of some drugs and can be controlled with waxing, hair removal creams, or shaving.

**Human Immunodeficiency Virus (HIV)** – A virus that destroys cells in the immune system, resulting in the eventual inability of the body to fight off infections, toxins, poisons, or diseases. HIV causes AIDS (acquired immunodeficiency syndrome), a late stage of the HIV infection that can include serious infections, blindness, some types of cancers, and neurological conditions such as senility.

**Hypertension** – See high blood pressure.

**Illicit** – Forbidden by custom or law; unlawful.

**Immunity** – The ability of the body to recognize harmful or foreign substances and eliminate them without injury to itself.

**Immune System** – A system within the body that continually monitors for harmful or foreign substances that may damage the body.

**Immunosuppression** – The artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue. Drugs commonly used to suppress the immune system after transplant include Prednisone, azathioprine (Imuran), cyclosporine (Sandimmune, Neoral), mycophenolate mofetil (Cellcept), and tacrolimus (Prograf, FK506).

**Immunosuppressive** – Relating to the weakening or reducing of the immune system's response to foreign material. Immunosuppressive drugs reduce the immune system's ability to reject a transplanted organ.

**Infection** – A condition that occurs when a foreign substance enters the body, causing the immune system to fight the intruder. Transplant recipients can get infections more easily because their immune systems are suppressed. It is more difficult for them to recover from infections, such as a urinary tract infection, colds and the flu.

**Inflammation** – A tissue reaction to irritation, infections, or injury marked by localized heat, swelling, pain, redness, and sometimes loss of function.

**Informed Consent** – The process of reaching an agreement based on a full disclosure and full understanding of what will take place. Informed consent often refers to the process by which one makes decisions regarding medical procedures, including the decision to donate the organs of a loved one.

**Inpatient Treatment** – Treatment in the hospital involving at least one overnight stay.

**Insurance Benefits** – Services paid for by an insurance company.

**Intensive Care Unit (ICU)** – A unit in the hospital that has highly technical and sophisticated monitoring devices and equipment for seriously ill patients. The staff is specially trained to take care of these patients who are often critically ill or recovering from surgery.

**Intravenous (IV)** – Within a vein or veins, usually refers to medication or fluids that are infused into a vein through a plastic catheter (narrow tube) or “line” inserted into the vein.

**Investigational** – A drug or procedure that is in a research phase and has not yet been approved for patient use by the Federal Drug Administration (FDA). Insurance companies normally do not pay for investigational drugs or procedures.

**Jaundice** – A yellow discoloration of the skin caused by the buildup of bile pigments in the blood. Jaundice may be caused by liver diseases or obstruction of bile ducts. Rarely, jaundice may be caused by excessive breakdown of red blood cells.

**Kidneys** – A pair of organs that remove wastes from the body through the production of urine. The blood supply in the body passes through the kidneys about 20 times every hour. Kidneys can be donated from living or deceased donors and transplanted into patients with kidney failure.

**Lactulose/kristalose** – A medication used for hepatic encephalopathy. This medication changes bacteria in the gut and increases bowel movements.

**Leukocyte** – A white blood cell.

**Lifetime Maximum** – The total amount of money an insurance company will pay out for covered expenses during the insured’s lifetime. Typical amounts are \$150,000 up to \$5,000,000. Once the insured has reached the lifetime maximum, they no longer have insurance benefits. It is important for patients to know how their insurance dollars are being spent.

**Liver** – The liver is located in the upper right abdomen and is a spongy mass of wedge-shaped lobes. The liver secretes bile which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. The liver also removes wastes from the blood. The liver can be donated and transplanted. Living donors can give part of their liver.

**Liver Biopsy** – A procedure to remove a small piece of the liver by inserting a needle through the right upper abdomen. The liver tissue is examined under the microscope to assess the integrity of the liver cells.

**Liver Enzymes** – Substances produced by the liver and released into the blood; these are measured to assess liver function.

**Liver Failure** – A condition in which the liver no longer carries out, or adequately carries out, its functions in the body. Liver failure may present as fatigue, jaundice, swelling (retention of fluid in the legs and abdomen), bleeding from the stomach and mouth, confusion and decreased levels of consciousness (encephalopathy).

**Living Related Donor (LRD)** – A biological family member who donates a kidney or part of a lung, liver, or pancreas to another family member, such as a sister, or a parent to a child.

**Living Unrelated Donor** – A person who is not related by blood, who donates a kidney or part of a lung, liver, or pancreas to another person, such as a husband who donates to a wife.

**Malignant** – Malignant indicates the tendency of a cancer or tumor either to invade the surrounding tissues, to destroy or replace the tissues previously present, or to metastasize (spread to other parts of the body). Not all malignant tumors cause death in patients.

**Malignancy** – A growth that has become malignant. See “Malignant.”

**Managed Care** – A term used to describe insurance programs that try to control health costs by limiting unnecessary treatment. Health maintenance organizations (HMOs), preferred provider organizations (PPOs), point-of-service (POS) plans, and utilization review are all forms of managed care.

**Match** – The degree of compatibility, or likeness, between the donor and the recipient.

**Medicaid** – A partnership between the federal government and individual states to share the cost of medical coverage for welfare recipients and to allow states to provide the same coverage to low-income workers not eligible for welfare. Programs vary greatly from state to state.

**Medically Necessary** – A specific health care service or supply that your insurance company has determined is required for your medical treatment and also is the most efficient and economical way to provide that service. Examples would be having a minor surgical procedure performed in the doctor’s office instead of staying overnight in a hospital, or renting rather than buying a piece of medical equipment.

**Medicare** – The federal government program that provides hospital and medical insurance through Social Security taxes to people age 65 and over, those who have permanent kidney failure, and certain people with disabilities.

**Medicare-Approved Facility** – A facility that meets Medicare standards for the number of transplants they do and the quality of patient outcomes.

**Medigap Policy (MedSupp, Medicare Supplementary)** – Private insurance that helps cover some of the gaps in Medicare coverage.

**Metabolic Liver Disease** – Liver enzyme deficiencies that prevent carbohydrate, fat, protein and vitamin metabolism, which can lead to cirrhosis of the liver or result in serious diseases in other organs and tissues.

**Metabolism** – A general term applied to the chemical processes taking place in the body.

**Mortality** – Death (mortality rate = death rate).

**Multiple Listing** – Being on the organ transplant waiting list at more than one transplant center.

**National Organ Transplant Act (NOTA)** – Passed by Congress in 1984, NOTA initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data. It also outlawed the sales of human organs.

**Nonalcoholic Fatty Liver Disease (NAFLD)** – An accumulation of fat in the liver which can range from simple steatosis to NASH.

**Nonalcoholic Steatohepatitis (NASH)** – Inflammation of the liver associated with the accumulation of fat in the liver which causes damage to the liver.

**Noncompliance** – Failure to follow the instructions of the medical team, such as not taking medicines properly or not attending clinic appointments. Noncompliance can lead to the failure of a transplanted organ.

**Nonfunction** – A condition in which a transplant organ fails to work after being transplanted into a recipient.

**OPO Service Area** – Each OPO provides organ procurement services for transplant centers throughout the United States. An OPO service area can include a portion of a city, a portion of a state or an entire state. OPOs distribute organs according to an established allocation policy.

**Orally** – By mouth.

**Organ** – A part of the body, made up of various types of tissues, that performs a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas, and intestines.

**Organ Donation** – To give an organ, such as a kidney, to someone in need of that organ, or to have organs removed for transplantation after death.

**Organ Preservation** – Donated organs require special methods of preservation to keep them viable between removal and transplantation. Without preservation, the organs will deteriorate. The length of time organs and tissues can be kept outside the body varies depending on the organ, the preservation solution, and the preservation method (pump or cold storage). Common preservation times vary from two to four hours for lungs to 48 hours for kidneys.

**Organ Procurement or Organ Recovery** – The act of surgically removing an organ from a donor for transplantation.

**Organ Procurement and Transplantation Network (OPTN)** – In 1984, Congress passed the National Organ Transplant Act (NOTA) that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the Nation’s organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. OPTN members include transplant centers, OPOs, histocompatibility laboratories, voluntary health care organizations, and the public. UNOS contracts with the Federal Government to operate OPTN.

**Organ Procurement Organization (OPO)** – OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors and the removal, preservation, and transportation of organs for transplantation. OPOs also collect data on deceased donors for the Scientific Registry. As a resource to the community, OPOs engage in public and professional education on the critical need for organ donation. Currently, there are 59 OPOs around the country. All are OPTN members.

**Organ Rejection** – An attempt by the immune system to reject or destroy what it recognizes to be a “foreign” presence (for example, a transplanted liver).

**Out-of-Pocket Expenses** – The portion of health costs that must be paid by the insured person per year, including deductibles, copayments, and co-insurance.

**Outpatient Care (Ambulatory Care)** – Medical testing or treatment done without an overnight hospital stay, performed in a hospital setting or doctor’s office.

**Placebo (Dummy)** – An inactive substance with no direct medical benefits. Often used in clinical trials to determine if the test drug is safe and effective.

**Platelet** – A small blood cell needed for normal blood clotting.

**Polycystic Liver Disease** – An inherited disorder characterized by lesions throughout the liver.

**Pool** – A group of people or objects with a similar characteristic or function.

**Portal Hypertension** – Higher than normal pressure within the vessels of the liver. Left untreated, this may result in development of collateral vessels in the esophagus, stomach and intestines, which may rupture, leading to bleeding (variceal bleeding) and ascites.

**Potassium** – A mineral essential for body function.

**Potential Transplant Recipient** – A transplant candidate who has been ranked by the OPTN computer match program as the person to whom an organ from a specific deceased organ donor is to be offered.

**Pre-Authorization (Pre-certification)** – The process of notifying and getting approval from your insurance company before you proceed with an elective (non-emergency) medical procedure. If the insurance plan requires pre-certification, and it is not obtained, the insured will be responsible for a larger portion of the cost.

**Pre-Existing Condition** – Any disease, illness, sickness or condition that was diagnosed or treated by an insurance company in the 12 months before the start date of insurance coverage; also, anything that caused symptoms in those 12 months that causes the insured to seek medical care.

**Preferred Provider Organization (PPO)** – A group of hospitals or physicians who have signed a contract with a particular insurance company to provide care to their members, usually at a discount. With a PPO plan, the cost of care is usually lower if the insured uses one of the designated providers.

**Premium** – Amount paid to an insurance company for providing medical or disability coverage under a contract.

**Primary Sclerosing Cholangitis (PSC)** – A disease in which the bile ducts inside and outside the liver become narrowed due to inflammation and scarring.

**Private Health Plan** – An insurance policy obtained by an individual, not through an employer.

**Procurement** – The surgical procedure of removing a donated organ or tissue.

**Prophylactic Medication** – Medication that helps prevent disease.

**Protein** – The fundamental building blocks of all living things.

**Pulmonary** – Having to do with, or pertaining to, the lungs.

**Recipient** – A person who has received a transplant.

**Recovery or Retrieval** – The surgical procedure of removing an organ or tissue from a donor.

**Rejection** – When the body attacks a transplanted organ or tissue because it reacts to the organ or tissue as a foreign object. Anti-rejection (immunosuppressive) drugs help prevent rejection.

**Renal** – Having to do with, or referring to, the kidneys.

**Re-Transplantation** – Due to rejection or failure of a transplant organ, some patients receive another transplant after having returned to the waiting list.

**Risk Pools** – High-risk health insurance plans, called risk pools, have become an important safety net for individuals who are denied health insurance because of a medical condition. About 30 states operate risk pools to provide health coverage for individuals who, because of their physical condition, are unable to purchase health insurance at any price.

**Routine Referral** – Hospitals are required on or before each death to call the OPO in order to determine suitability for organ, eye and tissue donation. The OPO, in consultation with the patient's attending physician or his or her designee, will determine the suitability for donation.

**Scientific Registry of Transplant Recipients (SRTR)** – In 1984, Congress passed the National Organ Transplant Act that mandated the establishment of the Organ Procurement and Transplantation Network and SRTR. The purpose of the SRTR is to provide ongoing research to evaluate information about donors, transplant candidates and recipients, as well as patient and graft survival rates. The SRTR contains historical data from October 1, 1987 to the present. The registry tracks all transplant patients from the time of transplant through hospital discharge, and then annually for up to three years or until graft failure or death. MMFR (Minneapolis Medical Research Foundation) operates the SRTR under contract with the Federal Government.

**Second Opinion** – A medical opinion provided by a second physician or medical expert after one physician has provided a diagnosis or recommended treatment to an individual.

**Sensitized** – Being immunized, or able to mount an immune response, against an antigen by previous exposure to that antigen.

**Seroconversion** – The loss of an antigen and the development of detectable antibodies to the antigen.

**Shingles** – A herpes infection (Herpes Zoster) that usually affects a nerve, causing pain in one area of the body.

**Side Effect** – An unintended reaction to a drug.

**Social Security Administration** – A federal government program best known for its retirement benefits. The monthly benefit is determined by the salary of the individual and the number of years covered by the program. The Social Security Administration also administers disability benefits.

**Sodium** – A component of table salt (sodium chloride); an electrolyte that is the main salt in blood.

**Status** – The degree of medical urgency for patients on the waiting list for a liver transplant.

**Steatosis** – Accumulation of fat in the liver; known as fatty liver.

**Steatohepatitis** – Fat in the liver (steatosis) with the presence of inflammation or hepatitis.

**Stricture or Stenosis** – A narrowing of passage in the body.

**Supplemental Policy (Medigap policy)** – An insurance policy offered by private insurance companies, not the government, designated to pay for some of the costs that Medicare does not cover. These policies have limited coverage for medications.

**Survival Rates** – Survival rates indicate what percentage of patients are still living or transplanted organs still functioning after a certain amount of time. Survival rates are used in developing organ allocation policy. Because survival rates improve with technological and scientific advances, policies that reflect and respond to these advances are expected to improve survival rates.

**Systolic Blood Pressure** – The top number in blood pressure readings; the 120 in a blood pressure of 120/80. It measures the maximum pressure exerted when the heart contracts.

**Termination of Benefits** – Health insurance benefits stop when an individual has reached the lifetime maximum amount or when an individual is no longer eligible for the plan due to nonpayment of premiums or leaving his or her job.

**Thoracic** – Referring to the heart, lungs, or chest.

**Thrush** – A fungus infection in the mouth.

**Tissue** – An organization of similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bones, corneas, heart valves, ligaments, veins, and tendons.

**Transmission** – The transfer of an infection from one person to another.

**Transplant, Transplantation** – To transfer a section of tissue or complete organ from its original position to a new position, for example to transfer to a healthy organ from one person's body to the body of a person in need of a new organ.

**Transplant Candidate** – An individual who has been identified as medically suited to benefit from an organ transplant and has been placed on the waiting list by the transplant program.

**Transplant Physician** – A physician who provides non-surgical care and treatment to transplant patients before and after transplant.

**Transplant Program** – A component within a transplant hospital which provides transplantation of a particular type of organ.

**Transplant Recipient** – A person who has received an organ transplant.

**Transplant Surgeon** – A physician who provides surgical care to transplant recipients.

**Triglycerides** – A form of fat that the body makes from sugar, alcohol, and excess calories.

**T-Tube** – A tube placed in the bile duct that allows bile to drain into a bag outside the body.

**United Network for Organ Sharing (UNOS)** – A nationwide umbrella for the transplant community; a non-profit organization that administers and 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. Located in Richmond, Virginia, UNOS also brings together medical professionals, transplant recipients, and donor families to develop organ transplantation policies.

**Urinary Tract Infection (UTI)** – An infection of one or more parts of the urinary tract.

**Vaccine** – A preparation given to stimulate immunity to infections, organisms (such as bacteria), and viruses.

**Varices (Esophageal)** – Swollen veins at the bottom of the esophagus, near the stomach – a common condition caused by increased pressure in the liver. Varices can ulcerate and bleed.

**Vascular** – Referring to blood vessels and circulation.

**Ventilator** – A machine that forces air into the patient’s respiratory system when the patient is not able to breathe properly.

**Virus** – A microscopic particle that can only survive by invading other living things, usually causing illness.

**Waiting List (Waiting Pool)** – After evaluation at the Transplant Center, a patient is added to the national waiting list by the transplant center or organ procurement organization. Lists are specific to each organ type: heart, lung, kidney, liver, pancreas, intestines. Each time a donor organ becomes available, the UNOS computer generates a new list of potential recipients.

**White Blood Cell** – White blood cells are the basic building blocks of the body’s immune system.

**Wilson’s Disease** – An inherited disorder in which excessive amounts of copper accumulate in the body.

## Raising Funds to Cover Medical Expenses

If the out-of-pocket costs seem to be more than you would be able to afford, you may wish to consider raising funds to help cover the medical costs. Organizations are available to assist you and your family with fundraising for medical treatments. They often have information designed to help families with the process. The contact information for some of the organizations that work with transplant patients and families is shown below.

- **Help Hope Live**  
Two Radnor Corporate Center  
100 Matsonford Road, Suite 100  
Radnor, PA 19087  
(800) 642-8399 toll-free  
(610) 535-6106 fax  
[www.HelpHopeLive.org](http://www.HelpHopeLive.org)
- **Children's Organ Transplant Association**  
2501 West COTA Drive  
Bloomington, Indiana 47403  
(800) 366-2682 toll-free  
(812) 336-8885 fax  
[www.COTA.org](http://www.COTA.org)
- **National Foundation for Transplants**  
3249 W. Sarazen's Cir, Suite 100  
Memphis, Tennessee 38125  
(800) 489-3863 toll-free  
(901) 684-1128 fax  
[www.Transplants.org](http://www.Transplants.org)



## Transplant-related Web Sites

- **University of Michigan Transplant Center**  
[www.UofMHealth.org/transplant](http://www.UofMHealth.org/transplant)

The official web site of the University of Michigan Transplant Center geared to provide patients with information regarding the Transplant Center and the transplant process for all solid organ programs.

- **Scientific Registry of Transplant Recipients (SRTR)**

**[www.SRTR.org](http://www.SRTR.org)**

The Scientific Registry of Transplant Recipients (SRTR) provides ongoing research to evaluate information and tracks all transplant patients from the time of transplant through discharge, then annually, until graft failure or death.

- **United Network for Organ Sharing (UNOS)**

**[www.UNOS.org](http://www.UNOS.org)**

United Network for Organ Sharing is a non-profit, scientific, and educational organization that administers the Organ Procurement and Transplantation Network (OPTN) collects and maintains its data and serves the transplant community.

- **Gift of Life Michigan**

**[www.GiftOfLifeMichigan.org](http://www.GiftOfLifeMichigan.org)**

Gift of Life Michigan (GOLM) is the only non-profit full-service organ and tissue recovery agency in Michigan since 1971. As an organization, Gift of Life Michigan acts as an intermediary between the donor hospital and the recipient transplant center, providing all the services necessary for organ, tissue, and eye donation.

- **Transplant Living**

**[www.TransplantLiving.org](http://www.TransplantLiving.org)**

Transplant Living is a web site supported by the United Network for Organ Sharing and is promoted as your prescription for transplant information.

- **Organ Procurement and Transplantation Network (OPTN)**

**[www.OPTN.Transplant.hrsa.gov](http://www.OPTN.Transplant.hrsa.gov)**

The Organ Procurement and Transplantation Network (OPTN) is a unique public-private partnership that is committed to improving the effectiveness of the nation's organ procurement, donation, and transplantation system.

- **Society of Pediatric Liver Transplantation: Pediatric Families and Engaged Partners**

**<https://www.TTS.org/initiatives/split-pfep2>**

Society of Pediatric Liver Transplantation (SPLIT): PFEP bridges the gap between patients, families, doctors, and the community to help improve the outcome of pediatric liver transplantation.

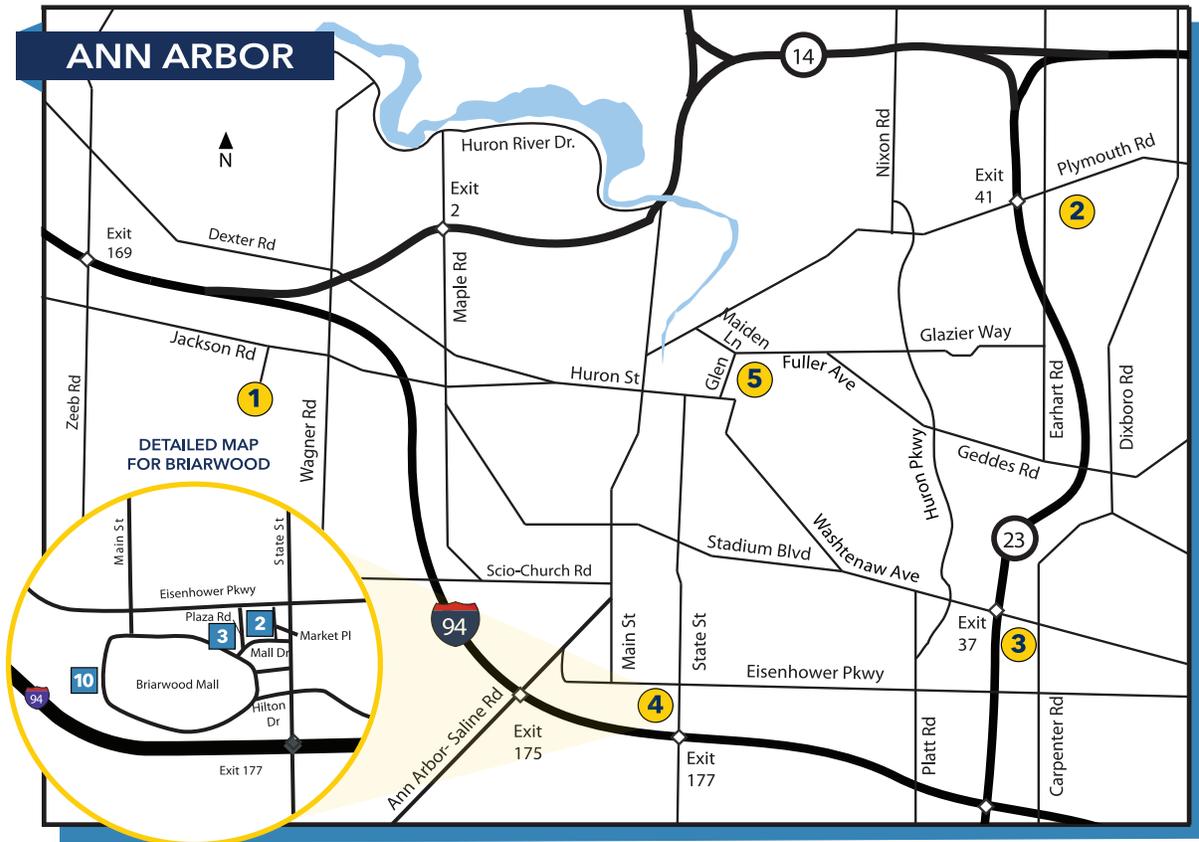
# LABORATORY PATIENT SERVICE CENTERS



MLabs Patient Service Centers offer collection of specimens such as blood and urine for laboratory testing.

No appointment is necessary, but we recommend to call ahead to confirm current hours of operation and to schedule glucose tolerance testing.

Test results are available from your physician or the Michigan Medicine patient portal at <https://www.myuofmhealth.org>



**1 WEST ANN ARBOR HEALTH CENTER**  
380 Parkland Plaza, Suite 130  
Ann Arbor, MI 48103  
**Ph:** 734.232.9720 **Fax:** 734.232.9772  
Mon-Th 7am - 7pm  
Fri 7am - 5pm  
Sat 8am - Noon

**2 EAST ANN ARBOR HEALTH CENTER**  
4260 Plymouth Rd., Ann Arbor, MI 48109  
**Ph:** 734.647.5685 **Fax:** 734.647.6457  
Mon-Th 7am - 7:30pm  
Fri 7am - 5:30pm  
Sat 8am - 12:30pm

**3 CARPENTER ROAD (Ann Arbor/Ypsi)**  
Packard Health Center  
2650 Carpenter Rd., Ann Arbor, MI 48108  
**Ph:** 734.998.0725 **Fax:** 734.998.0726  
Mon-Fri 8am - 5:00pm

**4 BRIARWOOD HEALTH CENTERS**  
**Building 2**  
400 E. Eisenhower, Suite B.  
Ann Arbor, MI 48108  
**Ph:** 734.998.4413 **Fax:** 734.647.3718  
Mon- Fri 8am - 3:30pm

**Building 3**  
375 Briarwood Circle  
Ann Arbor, MI 48108  
**Ph:** 734.998.0284 **Fax:** 734.998.6502  
Mon-Fri 7am - 2:30pm  
(Closed 1st Tuesday of each month 8am - 10:30am)

**Building 10**  
1801 Briarwood Circle  
Ann Arbor, MI 48108  
**Ph:** 734.913.0167 **Fax:** 734.998.4489  
Mon-Fri 9:30am - 5:00pm  
Sat 8:00am - Noon

**5 MAIN MEDICAL CAMPUS**  
1500 E. Medical Drive, Ann Arbor, MI  
**Cardiovascular Center, Fl. 3, Recep. A**  
**Ph:** 734.232.5111 **Fax:** 734.232.5130  
Mon-Fri 7am - 3pm

**Children's & Women's Hospital, Fl. 2, Recep. B**  
**Ph:** 734.232.5672 **Fax:** 734.232.5682  
Mon-Fri 7am - 6pm

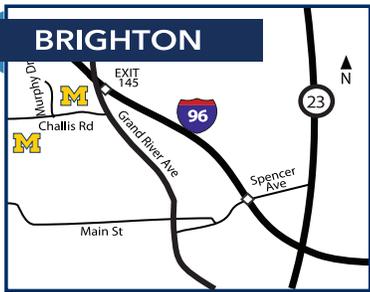
**Cancer Center, Fl. B2, Recep. E**  
**Ph:** 734.647.8913 **Fax:** 734.647.8937  
Mon-Fri 7am - 6pm

**Taubman Center, Fl.1, Recep. D**  
**Ph:** 734.647.6304 **Fax:** 734.647.6779  
Mon-Fri 7am - 6pm

**Taubman Center, Fl. 3**

## LABORATORY PATIENT SERVICE CENTERS

### BRIGHTON



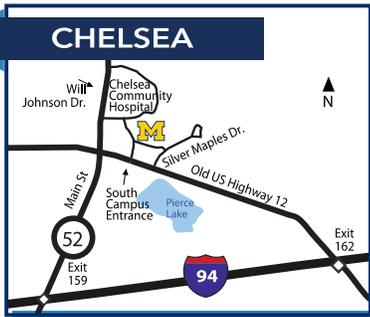
**BRIGHTON HEALTH CENTER**  
8001 Challis Road  
Brighton, MI 48116

**P:** 810.494.2649  
**F:** 810.494.2645  
Mon - Fri 7am - 3pm  
Sat: Visit Bright Center  
For Speciality Care

**BRIGHTON CENTER FOR SPECIALTY CARE**  
7500 Challis Road  
Brighton, MI 48116

**P:** 810.263.4087  
**F:** 810.263.4090  
Mon - Fri 7am - 6pm  
Sat 7am - 4pm

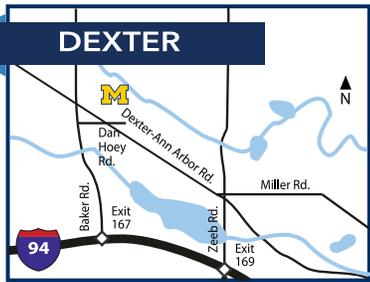
### CHELSEA



**CHELSEA HEALTH CENTER**  
14700 E. Old U.S. 12  
Chelsea, MI 48118

**P:** 734.475.4483  
**F:** 734.433.4246  
Mon - Fri 8am - 3:30pm  
Sat 8am - Noon

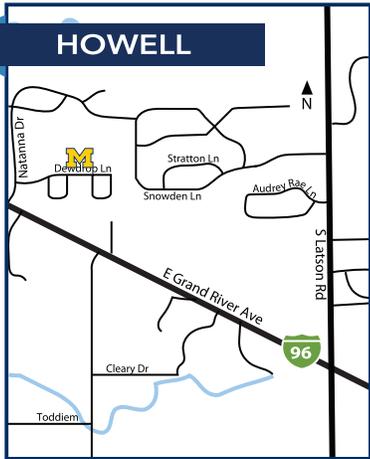
### DEXTER



**DEXTER HEALTH CENTER**  
7300 Dexter-Ann Arbor Rd  
Dexter, MI 48130

**TEMPORARILY CLOSED**

### HOWELL



**HOWELL HEALTH CENTER**  
3399 E Grand River Ave  
Howell, MI 48843

**TEMPORARILY CLOSED**

### CANTON • LIVONIA • NORTHVILLE



**LIVONIA HEALTH CENTER**  
20321 Farmington Rd  
Livonia, MI 48152  
**P:** 248.473.4350  
**F:** 248.888.1390

Mon - Fri 8am - 3:30pm

**NORTHVILLE HEALTH CENTER**  
39901 Traditions Dr  
Northville, MI 48168  
(at 7 Mile & Haggerty)

**P:** 248-305-4640  
**F:** 248-305-4642

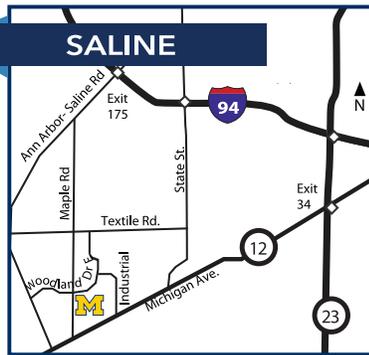
Mon - Th 7am - 6:30pm  
Fri 7am - 5pm  
Sat 8:30am - 12:30pm

**CANTON HEALTH CENTER**  
1051 North Canton Center Rd  
Canton, MI 48187

**P:** 734.844.5280  
**F:** 734.844.5288

Mon - Th 7am - 7:30pm  
Fri 7am - 5pm  
Sat 8am - Noon

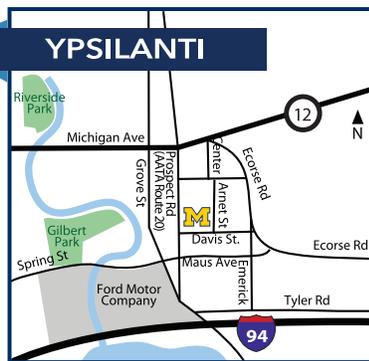
### SALINE



**SALINE HEALTH CENTER**  
700 Woodland Dr E  
Saline, MI 48176

**TEMPORARILY CLOSED**

### YPSILANTI



**YPSILANTI HEALTH CENTER**  
200 Arnet St.  
Ypsilanti, MI 48198  
(entry drive off Davis St)

**P:** 734.544.3277  
**F:** 734.544.3272

Mon - Fri 9am - 4:30pm



# SPECIALTY PHARMACY SERVICES: TRANSPLANT

## What is Specialty/Transplant Pharmacy Services?

We specialize in providing outstanding customer service. As a comprehensive pharmacy program developed by the University of Michigan, the Specialty/Transplant Pharmacy ensures timely and continuous access to your critical transplant medications. We recognize the challenges transplant patients face with their medications and our experienced team is committed to supporting you with comprehensive care throughout the entire treatment process.

The Specialty/Transplant Pharmacy Services are unique from your neighborhood retail and mail-order pharmacies. We offer specialized mail-order distribution as well as clinical support, financial counseling and education services. In addition to all these services, our transplant patients have the advantage of enrolling in a pharmacy that is an extension of their specialized Michigan Medicine medical team. Using the Specialty/Transplant Pharmacy enhances patient care because we have access to complete medical records enabling accurate and efficient facilitation of your treatment plan. Our pharmacists are directly linked to your transplant care team, and we are dedicated to personally serving you.

Transplant patients can face significant challenges paying for their medications. Even with insurance coverage, some patients spend hundreds of dollars in medication co-pays each month. Due to the complexities of billing for specialty transplant medications, we offer financial counseling and insurance support services to help you navigate the details of your insurance, ensuring you are maximizing all available resources.

Patients can also face obstacles to acquiring their medication. Transplant medications are only needed by a small percentage of the population, so they are not always readily available at your local pharmacy. Specialty/Transplant Pharmacy specializes in transplant medications and is able to provide patients with commonly prescribed medications as well as those used less often. The Specialty/Transplant Pharmacy coordinates the efforts of professionals from across the medical center, including the University of Michigan Transplant Center and the Department of Pharmacy, to ensure prompt access to medications. Patients may also easily obtain answers about medication regimens and side effects.

## Why Should I Use Specialty/Transplant Pharmacy Services?

The Specialty/Transplant Pharmacy is an extension of your Michigan Medicine transplant patient care team. We offer:

- Personalized service for all of your medication needs from a dedicated pharmacy care team of pharmacists, certified technicians, financial coordinators, and billing specialists.



- Direct access to pharmacists who specialize in transplant medications.
- Pharmacists on call 24 hours a day, seven days a week.
- Your choice of telephone or e-mail refill reminders to ensure you don't run out of your medication.
- Financial and insurance coverage counseling focused on minimizing your out-of-pocket expense.
- The medications you need after transplant will be delivered to you before you leave the hospital.
- Delivery of medications in unmarked, temperature-appropriate shipping containers to your home, office, or alternative location within Michigan at no extra charge.
- Care kits for specialty transplant prescriptions that includes comprehensive educational materials and medical supplies to help you manage the daily challenges of your transplant medication regimen.

## Two Locations to Serve You

- East Ann Arbor Pharmacy
- Taubman Center Pharmacy

## CONTACT US

Call 1-866-946-7695 for more info or to enroll with Michigan Medicine Specialty Pharmacy Services: Transplant  
4260 Plymouth Road, Ann Arbor / 866-946-7695 / [www.uofmhealth.org/specialty-pharmacy](http://www.uofmhealth.org/specialty-pharmacy)



## Communicating With Your Donor Family

A transplant is a major surgical procedure and may take time before the person feels healthy again. It may take months and even years before someone is ready to send and/or receive correspondence from the donor family. It is normal to experience a wide range of feelings when communicating with or receiving information from a donor family. Those feelings may include excitement, guilt, anxiety or fear. We support you and whatever decision you and your child make about communicating with his/her donor family. Some recipients may feel very happy to receive the correspondence from the donor family. Others may feel overwhelmed and find it difficult to express their thanks. Writing to your donor family does not mean you will get a response back. Some donor families may feel that writing about their loved one and their decision to donate helps them in their grieving process. Others choose not to write to the organ recipient.

If the donor family chooses to write they will send a letter to the Organ Procurement Organization. The OPO will then forward the letter to your child's transplant social worker. Your child's social worker will call you or see you in clinic before the letter is sent to you. Please know that often donor families include a photograph of the donor. Your child's social worker will talk with you and your child about whether a photo is included. It is common for recipients to imagine what their donor looked like, how old they were and how they died. Often the reality is different from what is imagined. Your child's transplant social worker is available to talk with you and your child about your feelings regarding this sometimes emotional experience.

When the transplant recipient is a child, these issues can become more challenging for the child, parents/guardians and siblings. The information regarding the donor may be more difficult to process if the donor was also a child. It may impact each member of the family differently. Children have unique coping and adjustment needs. This process of learning about their organ donor may impact their behavior, sleep, school performance and other social needs, depending on their age. Your child's social worker can talk with you and your child to make sure that you help your child learn about this information in developmentally appropriate ways. They can also provide the parents/guardians with adequate support about the process.

## Writing to Your Donor Family

### **Have you ever wondered how you could thank the family that made your transplant possible?**

The decision to write to your donor family is a personal choice. It may help you to know that donor families consistently express gratitude by hearing from their loved one's recipients. Some recipients will choose to write to their donor family and others will not. There is no time limit to write to your donor family but requires thoughtful consideration. Your child's transplant social worker is available to talk to you if you are having difficulty with your feelings. If you do not wish to write at this time, feel free to wait or have a family member write on your behalf. You may also consider sending a Thank You or Thinking of You card. Writing to your donor family does not mean you will get a response back as some donor families never write.

### **Suggestions:**

- Write about your child – his/her hobbies, family, friends, interests, etc. Please consider carefully about including religious comments in your letter, as the religious background of the donor family is unknown.
- Write about your child's personal transplant experience – how long he/she waited, how the transplant affected his/her life.
- Thank the family for your child's gift of life and express your sympathy to them for their loss.
- Sign only your first name and do not include any identifying information.

### **Sending your correspondence:**

- Place your card or letter in an envelope, unsealed.
- On a separate piece of paper write your child's full name, date of transplant and organ he/she received.
- Place all in an envelope and mail to:  
Gift of Life Michigan  
3861 Research Park Drive  
Ann Arbor, MI 48108

As time passes and if the donor family and recipient both agree, they can correspond directly and/or meet in person. These arrangements are made through Gift of Life and both parties must sign a release of information form.

Please contact Gift of Life Michigan if you or your child have any questions at **(734) 922-1028**.

# Durable Power of Attorney for Health Care (DPOA-HC)

## CHOOSE A PATIENT ADVOCATE

I, ..... (print your name),  
living at....., and being of sound  
mind, voluntarily choose a Patient Advocate to make care, custody, and medical treatment decisions for me. This durable  
power of attorney for health care is only effective when I am unable to make my own medical decisions. I understand I  
may change my mind at any time by communicating in any manner that this designation does not reflect my wishes.

I want the person named below to be my Patient Advocate and to be able to make medical decisions for me when I cannot  
make them myself. I have talked to my advocate(s) and have provided them with a copy of this directive.

### PATIENT ADVOCATE

Name..... Relationship.....

Address..... City..... State..... Zip.....

Telephone Number.....

If that person is not available, or cannot serve, I want this person to be my **FIRST ALTERNATE PATIENT ADVOCATE.**

Name..... Relationship.....

Address..... City..... State.....

Telephone Number.....

If that person is not available, or cannot serve, I want this person to be my **SECOND ALTERNATE PATIENT ADVOCATE.**

Name..... Relationship.....

Address..... City..... State..... Zip.....

Telephone Number.....

**PROVIDERS: PLEASE RETAIN A COPY OF ALL PAGES FOR THE MEDICAL RECORD.**

## GUIDELINES WORKSHEET

### *Life Support*

Some people want to decide what types of life support treatments and medicines they get from doctors to help them live longer when they are sick. Read through all six choices and initial the one that best fits what you want or do not want to happen if you are very sick.

- ..... I want doctors to do everything they think might help me. Even if I am very sick and I have little hope of getting better, *I want them to keep me alive for as long as they can.*
- ..... I want doctors to do everything they think might help me, but, if I am very sick and I have little hope of getting better, *I do NOT want to stay on life support.*
- ..... I want doctors to do everything they think might help me, but (*initial all that apply*):
  - ..... I don't want doctors to restart my heart if it stops by using CPR.
  - ..... I don't want a ventilator to pump air into my lungs if I cannot breathe on my own.
  - ..... I don't want a dialysis machine to clean my blood if my kidneys stop working.
  - ..... I don't want a feeding tube if I can't swallow.
  - ..... I don't want a blood transfusion if I need blood.
- ..... I don't want any life support treatment.
- ..... I want my Patient Advocate to decide for me.
- ..... I am not sure.
- ..... Other .....

### *What Makes Life Worth Living?*

Think about what makes life worth living for you. For example, being able to talk to your loved ones, being able to take care of yourself, or being able to live without being hooked up to machines. Under what circumstances would you say life is NOT worth living? (*initial all that apply*)

- ..... If I will most likely not wake up from a coma.
- ..... If I can't take care of myself.
- ..... If I am in pain.
- ..... If I cannot live without being hooked up to machines.
- ..... I am not sure.
- ..... Other .....

**PROVIDERS: PLEASE RETAIN A COPY OF ALL PAGES FOR THE MEDICAL RECORD.**

**You must read and SIGN the following statement if you want to give your Patient Advocate the power to make medical decisions that might let you die when you are very sick:**

I want my Patient Advocate named in this form to make decisions about life support and treatments that would allow me to die when I am very sick. When making those decisions, I want my Patient Advocate to follow the guidelines I have provided.

.....  
Your Signature

.....  
Date

## **POWER REGARDING MENTAL HEALTH TREATMENT (OPTIONAL)**

I expressly authorize my Patient Advocate to make decisions concerning the following treatments if a physician and a mental health professional determine I cannot give informed consent for mental health care (*check one or more consistent with your wishes*):

- Outpatient therapy
- My admission as a formal voluntary patient to a hospital to receive inpatient mental health services. I have the right to give three days' notice of my intent to leave the hospital.
- My admission to a hospital to receive inpatient mental health services
- Psychotropic medication
- Electro-convulsive therapy (ECT)
- I give up my right to have a revocation effective immediately. If I revoke my designation, the revocation is effective 30 days from the date I communicate my intent to revoke. Even if I choose this option, I still have the right to give three days' notice of my intent to leave a hospital if I am a formal voluntary patient.

**You must read and SIGN the following statement if you want to give your Patient Advocate the power to make decisions about your mental health care and treatment:**

I want my Patient Advocate named in this form to make decisions about my mental health care and treatment. When making those decisions, I want my Patient Advocate to follow the guidelines I have provided.

.....  
Your Signature

.....  
Date

**PROVIDERS: PLEASE RETAIN A COPY OF ALL PAGES FOR THE MEDICAL RECORD.**

## END OF LIFE PLANS

If you are dying, where would you like to be? At home? In the hospital? With only your family? With a religious or spiritual leader?

.....  
.....  
.....  
.....

### What Happens to Your Body After Death?

You may choose to donate your organs. If you let your Patient Advocate donate your organs, he or she will be able to make that decision only after your death.

..... I want to donate ALL of my organs.

..... I want to donate ONLY THESE organs:

.....  
.....

..... I do NOT want to donate any of my organs.

..... I want my Patient Advocate to decide.

..... I am not sure.

### Religion

Some religions do not allow certain treatments or medicines. If there are treatments that you do not want to have because of your religion, please write them down here.

.....  
.....  
.....  
.....

### Other Guidelines

Write down any other guidelines or thoughts you think might help you Patient Advocate or doctor decide what kind of health care you want.

.....  
.....  
.....  
.....

**PROVIDERS: PLEASE RETAIN A COPY OF ALL PAGES FOR THE MEDICAL RECORD.**



# DURABLE POWER OF ATTORNEY FOR HEALTH CARE

## ACCEPTANCE BY PATIENT ADVOCATE

I, .....(insert Patient Advocate's Name),  
agree to be the Patient Advocate for .....(insert Patient's Name).

*I accept the patient naming me Patient Advocate and I understand and agree to take reasonable steps to follow the desires and instructions of the patient. I also understand and agree that:*

- (A) **This designation is not effective unless** the patient is unable to participate in medical or mental health treatment decisions.
- (B) **A Patient Advocate shall not exercise powers** concerning the patient's care, custody, and medical or mental health treatment that the patient, if the patient were able to participate in the decision, could not have exercised on his or her own behalf.
- (C) **A Patient Advocate CANNOT exercise powers for a pregnant patient** to withhold or withdraw treatment or make medical treatment decisions that would result in the pregnant patient's death.
- (D) **A Patient Advocate may make a decision to withhold or withdraw treatment** that would allow a patient to die only if the patient has expressed in a clear and convincing manner that the Patient Advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.
- (E) **A Patient Advocate shall not receive compensation** for the performance of his or her authority, rights, and responsibilities, but a Patient Advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights, and responsibilities.
- (F) **A Patient Advocate shall act in accordance with the standards of care** applicable to fiduciaries when acting for the patient and shall act consistent with the patient's best interests. The known desires of the patient expressed or evidenced while the patient is able to participate in medical or mental health treatment decisions are presumed to be in the patient's best interests.
- (G) **A patient may revoke his or her designation** at any time and in any manner sufficient to communicate an intent to revoke.
- (H) **A patient may waive his or her right to revoke the designation** as to the power to make mental health treatment decisions and, if such a waiver is made, his or her ability to revoke as to certain treatment will be delayed for up to 30 days.
- (I) **A Patient Advocate may revoke his or her acceptance** to the designation at any time and in any manner sufficient to communicate an intent to revoke.
- (J) **A patient admitted to a health facility or agency has the rights** enumerated in Section 20201 of the Public Health Code, Act No. 368 of the Public Acts of 1978, being section 333.20201 of the Michigan Compiled Laws.
- (K) **If the patient has designated the Patient Advocate to make an organ or body donation**, that authority will remain after the patient's death.

.....  
Patient Advocate's Signature

.....  
Date

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# C.S. Mott Children's Hospital Floor Plans



- 50 Chapel
- 51 Family Center
- 52 Gift Shop
- 53 ATM
- 54 Café
- 55 Children's Emergency Services
- A Reception A  
Otolaryngology/  
Audiology Clinic
- B Reception B  
Outpatient Blood Draw



## Floor 2

### Map Legend

- information Welcome Center
- parking
- valet parking/patient drop off
- entry/exit
- elevator
- stairs
- restroom

# Floor 3

## Map Legend

- ▶ Entry/Exit
- Public Pathway
- Elevators
- Stairs
- Information
- Restrooms



**C.S. MOTT**  
**CHILDREN'S HOSPITAL**  
MICHIGAN MEDICINE



# Floor 8

## Map Legend

- ▶ Entry/Exit
- Public Pathway
- ☑ Elevators
- ↗ Stairs
- ❓ Information
- ♿ Restrooms
- 👤 Lactation Room



# Floor 10

## Map Legend

-  Entry/Exit
-  Public Pathway
-  Elevators
-  Stairs
-  Information
-  Restrooms
-  Lactation Room



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