

## RESOURCES

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

The Pediatric Kidney Education Guide (this book) can be found electronically on the pediatric kidney transplant website at <https://www.mottchildren.org/conditions-treatments/ped-kidney-transplant/resources>.

For general information about the University of Michigan Pediatric Transplant Program, please visit <https://www.mottchildren.org/conditions-treatments/ped-transplant>.

### Michigan Medicine 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** or you can call the Health Information Management Department at **(734) 615-0872** Monday-Friday, 8 a.m.-5 p.m.

## Glossary of Terms

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

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

**Acute renal failure** – Reversible kidney damage.

**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.

**ADA** – Americans with Disabilities Act of 1990.

**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.

**Affordable Care Act** – A Healthcare Reform law that was passed in 2010 aimed at improving the quality of healthcare and health insurance and providing more Americans with affordable healthcare coverage. Provisions of the law include allowing children to stay on their parents' insurance until the age of 26, reducing the Part D coverage gap, eliminating pre-existing clauses and expanding Medicaid coverage. For those patients purchasing health coverage on the exchange (also called marketplace), premium assistance via tax credits is offered, as are cost-sharing subsidies for those who qualify.

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

**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 and tissues 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.

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

**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.

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

**Antigen match** – The process of comparing the blood from the donor and recipient to ensure they are compatible.

**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.

**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.

**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.

**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 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 a doctor. Machines may maintain functions such as heartbeat and breathing for a few days but not permanently.

**BUN** – BUN stands for Blood Urea Nitrogen, a waste product normally secreted by the kidney. BUN values represent how well the kidneys function.

**Cadaver** – A dead body.

**Cadaveric** – Refers to things about, or relating to, a dead body.

**Cadaveric donor (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.

**Calcium** – A silvery, moderately hard metallic element that is found in the earth's crust and is a basic component of most animals and plants.

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

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

**Cholesterol** – A pearly, fat-like substance found within the body.

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

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

**CMV (Cytomegalo Virus)** – A virus infection that is very common in transplant recipients. It can affect the lungs and other organs. 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, 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 insurance will cover. A typical amount is 20% (patients pay 20% of the doctor's bill and insurance pays 80%).

**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.

**Continuous Ambulatory Peritoneal Dialysis (CAPD)** – A form of dialysis using an abdominally placed catheter with a glucose solution the patient performs at home.

**Co-payment (co-pay)** – A flat fee that a person pays for healthcare 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.

**Crossmatch** – A test to see if the recipient has developed antibody against the donor to ensure the recipient's immune system would not attack the transplanted organ. The crossmatch must be negative for the transplant to be done.

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

**Delayed function** – A condition in which the transplanted organ does not work well right after the transplant. Many kidneys have a delay before they begin to function well. Kidneys can sometimes take as long as three weeks to "wake up." Sometimes a kidney recipient needs dialysis until the kidney starts to work.

**Department of Health and Human Services (HHS)** – The department of the federal government that 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.

**Dietitian** – An individual who has training in the areas of diet and nutrition.

**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.

**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 they are unable to speak for themselves.

**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** – Any of various ions, such as sodium, potassium or chloride required by cells to regulate the electric charge and flow of water molecules across the cell membrane.

**ELISA** – A blood test used to measure the presence of hepatitis C antibodies in blood.

**Encephalopathy** – Damage to the brain and central nervous system cause 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.

**End-stage renal disease (ESRD)** – kidney disease that is not reversible.

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

**Epivir HBV** – Also known as Lamivudine for treatment of hepatitis B.

**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.

**Focal Segmental Glomerulosclerosis (FSGS)** – A type of kidney disease where patients can present with edema (fluid retention), proteinuria (protein in the urine), low serum albumin and high serum cholesterol.

**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 these 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.

**Gender** – The particular sex of an individual; male or female.

**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.

**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 are 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.

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

**Hemoglobin** – The oxygen carrying the pigment in red blood cells.

**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; excessive bleeding.

**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 infections that can include serious infections, blindness, some types of cancers and neurological conditions such as senility.

**Hydronephrosis** – A back flow and accumulation of urine in the kidney.

**Hyperglycemia** – An abnormally increased content of sugar in the blood.

**Hypertension** – See high blood pressure.

**Hypoglycemia** – An abnormally diminished content of sugar in the blood.

**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), OKT3 and ALG, 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 infection 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 decisions 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.

**Interventional Radiology** – An area in the hospital where certain procedures are done.

**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.

**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.

**Kidney Toxicity** – Pertains to substances that would be poisonous or damaging to the kidneys.

**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 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 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.

**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) and point-of-service (POS) plans and utilization review are all forms of managed care.

**Match** – The degree of compatibility, or likeliness, 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 healthcare service or supply that your insurance company has determined is required for your medical treatment and is also 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 aged 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.

**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 sale of human organs.

**Nephrectomy** – Surgical removal of a kidney.

**Nephrologist** – A medical doctor that specializes in kidney disease.

**Nephropathy** – Disease of the kidneys.

**Nephrotic syndrome** – A group of symptoms including protein in the urine, low blood protein levels and swelling.

**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 “wake up” (work) after being transplanted into a recipient. In the case of a kidney transplant, the recipient will return to dialysis and/or undergo another transplant.

**Non-Steroidal Anti-Inflammatory Drug (NSAID)** – A group of pain relievers that should not be used by kidney patients.

**OPO service area** – Each organ procurement organization (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 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 vary 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 1987, 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 healthcare 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 58 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 (e.g., a transplanted kidney).

**Osteoporosis** – A disorder in which the bones become increasingly porous, brittle and subject to fracture from the loss of calcium.

**Out-of-pocket expenses** – The portion of health costs that must be paid by the insured person per year, including deductibles, co-payments 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.

**Pancreas** – A large elongated internal organ situated behind the stomach which produces digestive enzymes and insulin.

**Pancreas After Kidney (PAK)** – This designation refers to receiving a pancreas transplant after the recipient has previously received a kidney transplant.

**Pancreas Transplant Alone (PTA)** – This designation refers to a patient receiving a pancreas transplant who is not planned to receive a kidney transplant.

**Peritoneal dialysis** – A method of purifying the blood by flushing the abdominal cavity with a prescribed solution.

**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 Kidney Disease** – An inherited disorder characterized by lesions throughout the kidney which can lead to kidney failure.

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

**Potassium** – An electrolyte that is essential to muscle and other cells in the body.

**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.

**PRA (panel reactive antibody)** – A panel reactive antibody screening test tells which antibodies a recipient has that would cause a reaction against certain donors.

**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 a provider (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 doctors 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.

**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** – Have 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 doctor or his or her designee, will determine the suitability for donation.

**Sarcoidosis** – A systemic disease of unknown origin; involves inflammation that produces lumps of cells in various organs of the body.

**Scientific Registry of Transplant Recipients (SRTR)** – In 1987, 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. URREA (University Renal Research and Education Association) operates the SRTR under contract with the federal government.

**Second opinion** – A medical opinion provided by a second doctor or medical expert after one doctor 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.

**Simultaneous Pancreas Kidney (SPK)** – This designation refers to a patient who is receiving a pancreas and a kidney transplant in the same surgical session.

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

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

**Spend down** – For disabled people who have higher incomes but cannot pay their medical bills. Under this program, a person pays part of his or her monthly medical expenses (the spend down), then Medicaid steps in and pays the rest. Eligibility is determined on a case by case basis.

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

**Stent** – A small expandable tube used for inserting into a blocked vessel or other part of the body.

**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 medicines.

**Survival rates** – Survival rates indicate what percentage of patients are still living or grafts (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 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.

**Tissue typing** – A blood test (performed before transplantation) to evaluate the closeness of tissue match between the kidney donor's organ and the kidney recipient's HLA antigens.

**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 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 doctor 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 doctor who provides surgical care to transplant patients.

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

**Ultrasound** – The use of ultrasonic waves for diagnostic or therapeutic purposes, specifically to image an internal body structure.

**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 policy.

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

**Usual and customary (U&C) fee** – The fee that providers, of similar training and experience, charge for a service in a particular geographical area. If a provider charges more than the U&C fee, insurance companies may limit their payment to the level of the U&C, leaving the patient responsible for the balance due.

**Vaccine** – A preparation that improves immunity to a particular disease.

**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.

**Wagener's Disease** – A form of vasculitis that affects the lungs, kidneys and other organs which can lead to kidney failure.

**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 cells** – 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.

## Travel and Parking

Planning in advance for your trip to Ann Arbor for your child's transplant might help cut down on your stress on the day of transplant. Although you may have a preferred route to the hospital, you might want to consider planning an alternate route in case weather, construction or a football game blocks your way. You may want to get a map to plan your routes or, if you have internet access, you might use a service like Google Maps ([www.googlemaps.com](http://www.googlemaps.com)) to plan routes for you. Our address is listed below:

**Michigan Medicine**  
**1540 East Hospital Drive**  
**Ann Arbor, MI 48109**

Once you arrive at the U-M, you can park in the P4 parking structure (enter C.S. Mott via the 3rd floor parking structure simpson connector). It is located on East Hospital Drive. There are hourly rates to park in this structure but you may obtain an in-patient day pass from the parking attendant and will only be charged \$2 a day. With this pass, you can enter and exit the structure as often as you would like each day. You might also want to keep an envelope in the car to save receipts for your parking costs as some insurance companies may reimburse you for your parking and travel expenses.

Once you are in Ann Arbor, you can make use of the public transportation systems. The Ann Arbor Area Transit Authority (AAATA) has a system of public buses that travel throughout Ann Arbor and Ypsilanti. You can pick up a schedule of the routes and costs in the Guest Assistance Program office (**734-764-6893**) on the second floor of University Hospital (near the cafeteria and gift shop).

Some of the local hotels offer free shuttles between their facilities and the hospital. The hours of operation are typically limited to daytime hours and may not run at all on the weekend. Please check with your hotel or with Patient and Visitor Accommodations (**800-544-8684**) staff to identify the hotels with this service.

## Lodging

There are a number of places that moms, dads, guardians, family and friends can stay overnight in and around the hospital. Please note that not all options are appropriate for children or adults with special needs.

Once your child has the transplant surgery, he or she will be admitted to an area in C.S. Mott Children's Hospital called the Pediatric Intensive Care Unit (PICU). In that area, each child has his or her own nurse around the clock. Two parents/guardians can sleep at the bedside at night. Other adult visitors are permitted to stay in the nearby family waiting rooms. Visitors under the age of 18 are allowed to stay until 9 p.m., at which time they will need to leave for the night. Please keep in mind that the waiting rooms are not private and they do not have beds. They are not the most comfortable accommodations but if you want to be as close to your child at night as possible while he or she is cared for in the PICU, then the waiting rooms are the place to stay.

### *Med Inn Hotel*

Limited accommodations are available at the Med Inn which is a 30-room hotel that is part of the hospital complex. The Med Inn is available to the families of both pediatric and adult patients. While preference is given to those families whose loved one is in an intensive care unit, it can still be very difficult to get a room. The Med Inn costs \$80 a night, and they do not accept Medicaid. They do take partial payment from Children's Special Health Care Services (CSHCS). Prices may change.

For reservations, contact the Patient and Visitor Accommodations Program at **(800) 544-8684** or **(734) 936-0135** or visit their website at **[www.med.umich.edu/hotels](http://www.med.umich.edu/hotels)**.

**Please note:** In the event that the Med Inn does not have a vacancy, the staff in the Patient and Visitor Accommodations Program can make reservations at other contracted off-site hotels in Ann Arbor. You can contact staff in the Guest Assistance Program at **(734) 764-6893** or go to their office on the second floor of University Hospital near the cafeteria between 9:00 a.m. and 5:00 p.m. Monday through Friday.

### *Ronald McDonald House*

Close to Mott Hospital is the Ronald McDonald House. It is on Washington Heights Street, and it is about a five minute walk to the hospital. The Ronald McDonald House is considered communal living which means that you and your family would have your own bedroom, but you would share a bathroom, a kitchen, and living area with other families whose children are staying with us in C.S. Mott Children's Hospital. You will also have a daily chore. The Ronald McDonald House costs \$10 a night, and rooms are reserved on a first-come, first-served basis.

Up to four family members can stay in the Ronald McDonald House, including children. The Ronald McDonald House is a popular place to stay for many families, so if you think you might want to stay there, you should call to see if they have any rooms available. If they do not have any rooms when you call, you can ask them to put your name on the waitlist for a room.

There is also a 10-room Ronald McDonald House within C.S. Mott Children's Hospital. Only two visitors age 18 and older are able to stay in these rooms. The rooms in the "Mott House" are reserved for families whose children are in the ICU, and are intended for brief, one- to two-night stays. You can make reservations at the Ronald McDonald House by calling **(734) 994-4442**.

There are other hotels and motels around the city of Ann Arbor. Some are a few miles from the hospital and can be reached by car, taxi, bus, and hotel shuttle, depending on the hotel or motel. Please request a list of the hotels in the U-M's Guest Assistance Program (GAP) Office at **(734) 764-6893**.

## Other Information

### *Meals*

Caregivers of transplant patients may be assisted with the cost of meals during an inpatient admission if they meet guidelines set by the Department of Social Work. If you are facing financial difficulty and need help with the cost of meals, contact your social worker.

### *Work or School Letters*

Many times your employer or your child's school will require a note to verify the clinic visit or hospital stay. Please inform the transplant team before leaving the clinic area, so this request can be completed or let staff know while you are in the hospital about this need.

### *Disability or Other Forms*

Because of the complexity of the Transplant Clinic, disability and other forms will **not** be completed during your child's clinic visit. The forms will be completed after clinic and then either faxed or mailed to you for processing.

### *FMLA (Family Medical Leave Act)*

If you must take time away from work to care for your child, ask your employer if you are eligible for FMLA. Your social worker can assist you with paperwork for this as needed.

### *Make-a-Wish*

Your child may be eligible to participate in the Make-a-Wish program based on his/her diagnosis and severity of disease. Contact your social worker regarding the referral process.

## 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 help 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, Pennsylvania 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**  
5350 Poplar Avenue, Suite 850  
Memphis, Tennessee 38119  
(800) 489-3863 toll-free  
(901) 684-1128 fax  
[www.transplants.org](http://www.transplants.org)

## Transplant-related Websites

- **University of Michigan Transplant Center**  
[www.uofmhealth.org/transplant](http://www.uofmhealth.org/transplant)  
The official website 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**  
**[www.giftoflifemichigan.org](http://www.giftoflifemichigan.org)**  
 Gift of Life (GOL) is the only non-profit, full-service organ and tissue recovery agency in Michigan since 1971. As an organization, Gift of Life 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 website 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.
- **National Kidney Foundation of Michigan**  
**[www.nkfm.org](http://www.nkfm.org)**  
 The National Kidney Foundation of Michigan is the local chapter of a national organization that exists to prevent kidney disease and to improve the quality of life for those living with kidney disease.
- **The Gift of a Lifetime; Organ and Tissue Transplantation in America**  
**[www.organtransplants.org](http://www.organtransplants.org)**  
 This site weaves together information about donation and transplantation with real world stories of transplant recipients, donors and healthcare professionals.

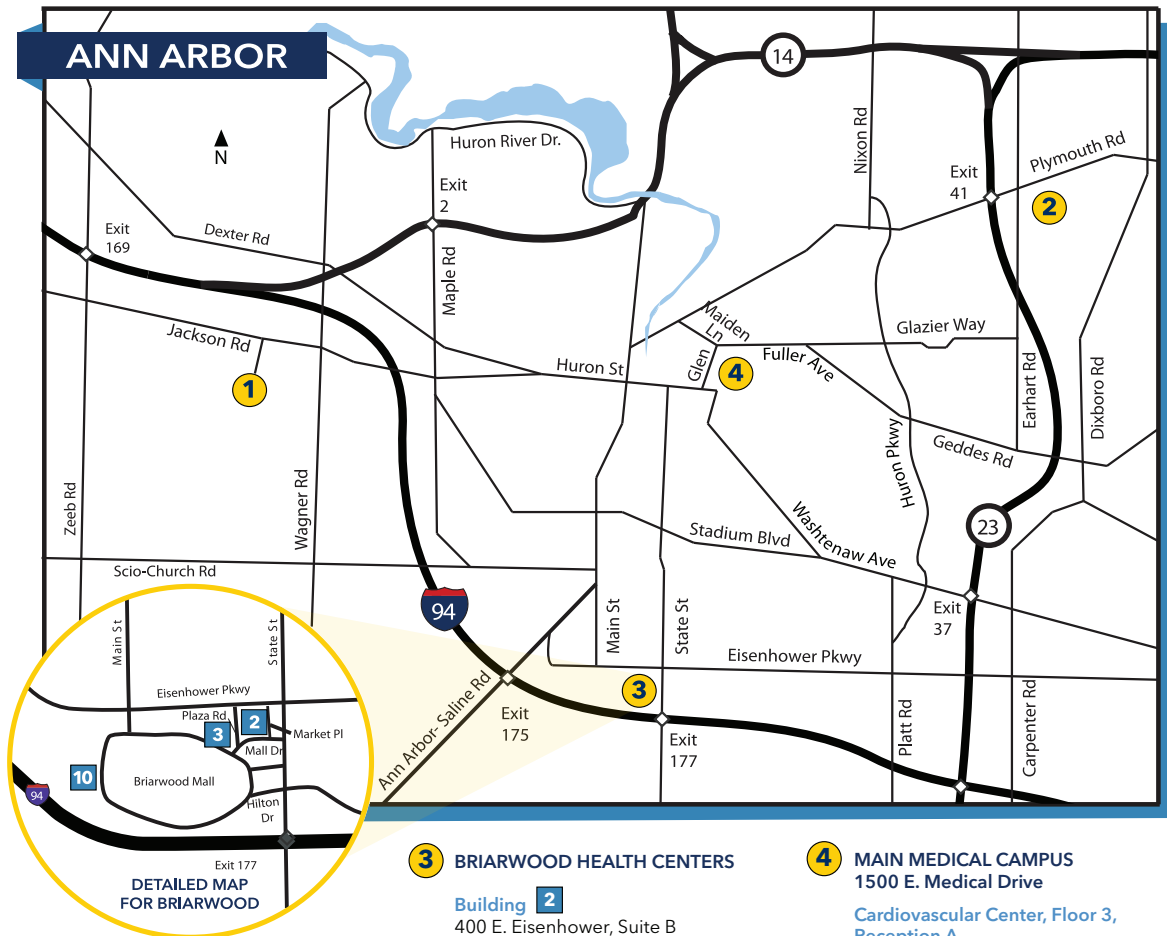


## MLABS BLOOD DRAWING LOCATIONS

Rev. Mar 2018



MLabs offers adult and pediatric blood drawing services through Michigan Medicine. No appointment is necessary for routine services; please call ahead to schedule glucose tolerance testing. Hours are subject to change without notice. Please do not contact the specimen collection facility or blood drawing station for test result information. Questions? Call 800.862.7284 or visit [mlabs.umich.edu](http://mlabs.umich.edu)



- 1 WEST ANN ARBOR HEALTH CENTER**  
380 Parkland Plaza, Suite 130  
**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.  
**Ph:** 734.647.5685 **Fax:** 734.647.6457

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

### 3 BRIARWOOD HEALTH CENTERS

**Building 2**  
400 E. Eisenhower, Suite B

**Ph:** 734.998.4413 **Fax:** 734.647.3718  
Mon, Tue 8am - 6pm  
Wed-Fri 8am - 5pm

**Building 3**  
375 Briarwood Circle  
**Ph:** 734.998.0284 **Fax:** 734.998.6502

Mon, Tue, Th 7am - 5pm  
Wed 7am - 7pm  
Fri 7am - 4:30pm  
(Closed 1st Tuesday of each month 8am - 10:30am)

**Building 10**  
1801 Briarwood Circle  
**Ph:** 734.913.0167 **Fax:** 734.998.4489  
Mon, Wed 8am - 7pm  
Tue, Th, Fri 8am - 5pm  
Sat 8am - Noon  
(Closed 2nd Wednesday of each month 8am - 1pm)

### 4 MAIN MEDICAL CAMPUS 1500 E. Medical Drive

**Cardiovascular Center, Floor 3,  
Reception A**

**Ph:** 734.232.5111 **Fax:** 734.232.5130  
Mon-Fri 7am - 6pm

**Children's & Women's Hospital,  
Reception B**

**Ph:** 734.232.5672 **Fax:** 734.232.5682  
Mon-Fri 7am - 6pm

**Cancer Center, Floor B2**

**Ph:** 734.647.8913 **Fax:** 734.647.8937  
Mon-Fri 7am - 6pm

**Taubman Center, Floor 1, Reception D**

**Ph:** 734.647.6304 **Fax:** 734.647.6779  
Mon-Fri 7am - 6pm

**Taubman Center, Floor 2, Reception H**

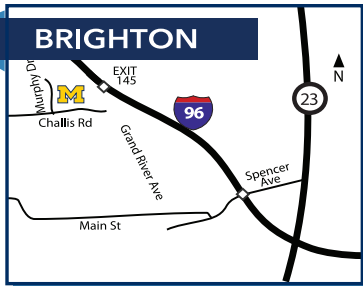
**Ph:** 734.936.6781 **Fax:** 734.764.3225  
Mon-Fri 8:30am - 3:30pm

**Taubman Center, Floor 3**

**Ph:** 734.936.6760 **Fax:** 734.936.7419  
Mon-Fri 7am - 6pm

## MLABS BLOOD DRAWING LOCATIONS

### BRIGHTON



#### BRIGHTON HEALTH CENTER

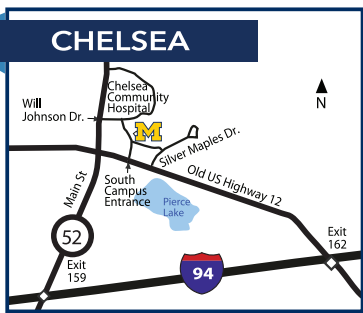
8001 Challis Road

**P:** 810.494.2649

**F:** 810.494.2645

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

### CHELSEA



#### CHELSEA HEALTH CENTER

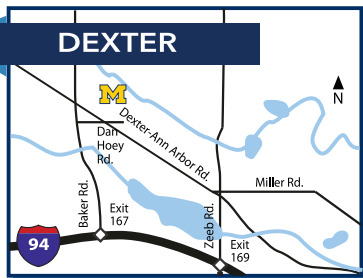
14700 E. Old U.S. 12

**P:** 734.475.4483

**F:** 734.433.4246

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

### DEXTER



#### DEXTER HEALTH CENTER

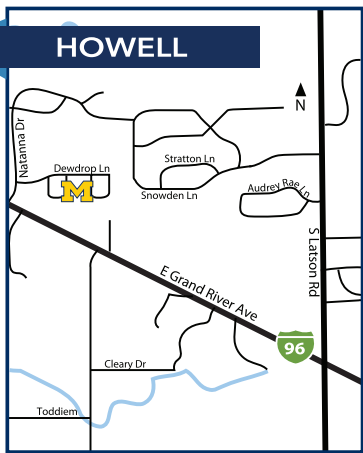
7300 Dexter-Ann Arbor Rd

**P:** 734.426.1724

**F:** 734.426.2707

Mon 8am - 7pm  
Tue 8am - 5pm  
Wed 8am - 7pm  
Th 8am - 5pm  
Fri 8am - 5pm  
Sat 8am - Noon

### HOWELL



#### HOWELL HEALTH CENTER

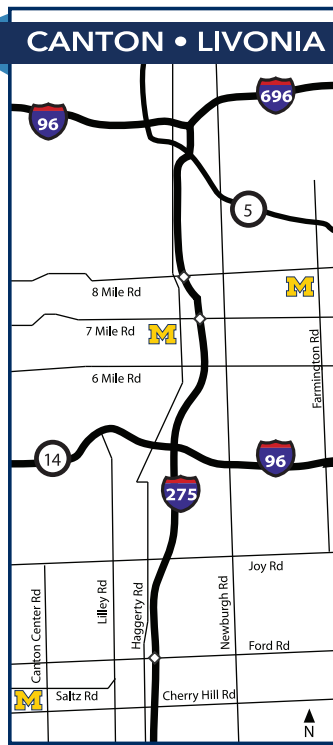
3399 E Grand River Ave

**P:** 517.338.2058

**F:** 517.540.0203

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

### CANTON • LIVONIA • NORTHVILLE



#### LIVONIA HEALTH CENTER

20321 Farmington Rd

**P:** 248-473-4350

**F:** 248-888-1390

Mon, Wed, Th 8am - 6pm  
Tue, Fri 8am - 5pm  
Sat 8am - Noon

#### NORTHVILLE HEALTH CENTER

39901 Traditions Dr  
(at 7 Mile & Haggerty)

**P:** 248-305-4640

**F:** 248-305-4642

Mon - Th 7am - 6pm  
Fri 7am - 5pm  
Sat 8am - Noon

#### CANTON HEALTH CENTER

1051 North Canton Center Rd

**P:** 734.844.5280

**F:** 734.844.5288

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

### SALINE



#### SALINE HEALTH CENTER

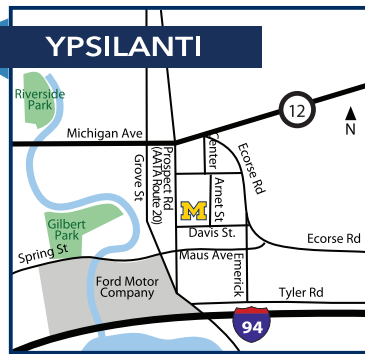
700 Woodland Dr E

**P:** 734.429.2302 x235

**F:** 734.429.1156

Mon 8:30am - 6pm  
Tue 8:30am - 7pm  
Wed 8am - 5pm  
Th 7:30am - 5pm  
Fri 7:30am - 4:30pm

### YPSILANTI



#### YPSILANTI HEALTH CENTER

200 Arnet St  
(entry drive off Davis St)

**P:** 734.544.3277

**F:** 734.544.3272

Mon - Fri 8am - 5pm  
Sat 8am - Noon

# SPECIALTY PHARMACY SERVICES: TRANSPLANT

## What is Specialty Pharmacy Services: Transplant?

We specialize in providing outstanding customer service. As a comprehensive pharmacy program developed by the University of Michigan, the Specialty 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 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 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.

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 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 Pharmacy specializes in transplant medications and is able to provide patients with commonly prescribed medications as well as those used less often. The Specialty Pharmacy coordinates the efforts of professionals from across the medical center, including the Michigan Medicine 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 Pharmacy Services: Transplant?

The Specialty Pharmacy is an extension of your Michigan Medicine 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.



- On-call pharmacists 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 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 / 734-232-3408 Fax / [www.pharm.med.umich.edu/specialty\\_pharmacy](http://www.pharm.med.umich.edu/specialty_pharmacy)

# Authorization for Transplant Mailings

New federal regulations became effective in April 2003 which are intended to protect the uses of a patient’s medical information. We need your written permission to send you general mailings from the University of Michigan Transplant Center. The mailings may include newsletters, information on upcoming events, articles of interest to the transplant community and development information. If you wish to receive our general mailings, please provide your consent below.



I authorize the University of Michigan Transplant Center to add my name to its mailing list so I may receive Transplant Center newsletters and other mailings.

Patient Name: \_\_\_\_\_ CPI:\_\_\_\_\_

Patient Email Address: \_\_\_\_\_

Patient Signature:\_\_\_\_\_ Date:\_\_\_\_\_

## Medical Emergency ID Tag

It is recommended that you wear a Medical Alert Tag in the form of a necklace or bracelet. You are free to buy them from whomever you please. The National Kidney Foundation of Michigan has them at a low cost to transplant patients. Ask your nurse for an order form (see example below).



## Medical Emergency ID Tag Program

Patient Name: \_\_\_\_\_

Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone Number: (\_\_\_\_) \_\_\_\_\_ County: \_\_\_\_\_ Email: \_\_\_\_\_

### Please Select:

- ☐ Bracelet \$8.00  
☐ Necklace \$8.00

Bracelet is 8" long. Please provide additional length required \_\_\_\_\_

### Ship to:

- ☐ Patient  
☐ Facility

Social Worker Name: \_\_\_\_\_

Unit Name: Pediatric Kidney Transplant

Unit Address: 1540 E. Hospital Dr.

City: Ann Arbor State: MI Zip: 48109

Phone Number: (877) 543-7789

*One letter per box*

Patient's Name																		
Modality*	K	I	D	N	E	Y		T	R	A	N	S	P	L	A	N	T	
Misc. Information**																		
Emergency Contact 1st Name & Phone	8	7	7	-	5	4	3	-	7	7	8	9						
Doctor's Last Name & Phone																		

\* Hemodialysis, Peritoneal Dialysis, Transplant

\*\* Drugs, Dyes, Diabetes, Heart Disease, Allergies, etc.

**We cannot include DNR information**

Do you receive Medicaid?

(e.g. mihealth card, Healthy Michigan Plan, MICHild, etc.)

☐ Yes

☐ No

Return completed form with payment to the:

National Kidney Foundation of Michigan  
1169 Oak Valley Drive | Ann Arbor MI 48108  
PHONE 734.222.9800 | FAX 833.292.6778

**www.nkfm.org**

Updated: 2/15/2022

### OFFICE USE ONLY

Check Number \_\_\_\_\_ Cash \_\_\_\_\_ Money Order \_\_\_\_\_

Date on Check \_\_\_\_\_ Date Received \_\_\_\_\_ Date Entered \_\_\_\_\_

Client # \_\_\_\_\_ Date Sent to Engraver \_\_\_\_\_

## 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**.

## Notes

[illegible]



[illegible]

## Notes

[illegible]

## Notes

[illegible]

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## Notes

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