

RESOURCES AND GLOSSARY

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

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

Questions

Where do Organ Donors Come From?

Hearts become available when a person suffers an accident or illness that causes the brain to die but leaves the heart undamaged. Without brain function, the donor is legally dead. Because a mechanical ventilator breathes for the donor, the heart continues to beat and the liver, kidneys and other vital organs continue to function.

The process of obtaining the heart for transplantation is coordinated by the Transplant Society of Michigan or Gift of Life. This agency is notified when a heart is available and makes arrangements for our medical team to obtain the heart.

Families of donors give permission for organ removal. They welcome the opportunity to pass on the gift of life to those in need.

How are Candidates and Donors Matched?

Heart transplant candidates are matched with available donor hearts based on the urgency of the candidate's condition, blood type and physical size. In adults, the donor and the recipient should be about the same weight. In children, the weight range is 1.5 to 2 times the weight of the child. The donor heart must easily fit into the transplant candidate and be capable of pumping enough blood to meet the candidate's needs.

Sex, race, religion, beliefs, or any other physical or nonphysical characteristics do not matter when matching the patient with a donor heart.

How Long is the Operation?

The actual operation lasts about five hours. The recipient will spend additional time in the operating room being prepared for surgery and waiting for the donor heart.

How Long are Transplant Patients Hospitalized?

Most recipients remain in the Pediatric Cardiothoracic Unit (PCTU) approximately two to three days and are then moved to a regular hospital room for about 10 days to two weeks. However, the length of the stay is patient specific and some stays are longer than others.

How Do Recipients Take Good Care of Their Heart Transplant?

Transplant recipients are expected to take medications as prescribed by the transplant team. They are also expected to attend transplant, primary care, and specialty care visits as scheduled. Recipients need to maintain a healthy lifestyle in physical, nutritional and emotional categories.

What is Life Like After a Transplant Operation?

Most heart transplant recipients rate their quality of life as good. The goal of transplantation is for the recipient to participate in an active, healthy lifestyle. Many heart transplant recipients resume a normal active life, including playing, attending school, participating in sports, earning a living or maintaining a household.

Becoming an Organ Donor

To find out more about organ, eye, and tissue donation and registration as a donor, contact one of the following:

Gift of Life Michigan Michigan

3861 Research Park Drive

Ann Arbor, MI 48108

Phone: (800) 482-4881

www.gifttolifemichigan.org

Donate Life America

5516 Falmouth St., Suite 302

Richmond, VA 23230

Phone: (804) 377-3580

www.donatelife.net



Other Reputable Online Resources:

American Society of Transplantation

Phone: (856) 439-9986

www.myast.org

United Network for Organ Sharing (UNOS)

www.unos.org

Transplant Living

www.transplantliving.org

For further resources, please contact either the social worker or transplant coordinator.

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 N. Radnor Corporate Center
100 Matsonford Road, Suite 100
Radnor, PA 19087
(800) 642-8399 toll-free
www.helphopelive.org
- **Children's Organ Transplant Association**
2501 West COTA Drive
Bloomington, Indiana 47403
(800) 366-2682 toll-free
www.cota.org
- **National Foundation for Transplants**
3249 W. Sarazen's Cir, Suite 100
Memphis, TN 38125
(800) 489-3863 toll-free
www.transplants.org

Transplant-Related Web sites

- **University of Michigan Transplant Center - 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**
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**

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**

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**

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**

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.

- **Transplant Families- <https://www.transplantfamilies.org/>**

Support and resources for patients, families, and caregivers of pediatric transplant recipients.

- **Enduring Hearts- <https://enduringhearts.org/research-for-families/>**

Support and resources, including financial resources, for pediatric heart transplant recipients and their families.

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) to plan routes for you. Our address is listed below:

**University of Michigan Health
C.S. Mott Children's Hospital
1540 East Hospital Drive
Ann Arbor, MI 48109**

Once you arrive at University of Michigan Health, you have the option for self-parking in a structure or valet parking. Both options have associated fees. If you are unable to afford the cost of the daily parking rates, discuss with your social worker whether you meet criteria for financial assistance. Free parking passes are available for the hospital structures for those who qualify. Please contact us if you have any questions.

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 Transit Authority (AATA) 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 Michigan Medicine Lodging [(800) 544-8684] staff to identify the hotels with this service.

Lodging

There are a number of places that parents, 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. Up to two parents/guardians can sleep at the bedside at night. Visitors under the age of 18 are allowed to stay until 9 p.m., at which time they will need to leave the hospital for the night. Please keep in mind that the hospital's waiting rooms are not private, and they do not have beds. While you are welcome to use the waiting areas as needed, they are not intended to serve as long term lodging for family members.

Michigan Medicine Lodging helps patients and families find overnight lodging during their time at Michigan Medicine. We know finding the right accommodations can be challenging, and the Michigan Medicine Lodging team is here to help. Michigan Medicine Lodging will handle your lodging needs so you can focus on the important things – providing support and care to your child while they are being treated at Michigan Medicine.

Reservation Services

Best Rates for Rooms that Meet Your Needs: Our team members will work with you to match your preferences with a local lodging option at the best rates possible. For example, if a complimentary breakfast, handicapped-accessibility, or a shuttle service is a priority for your family, we will work with you to find an option that meets your needs.

Onsite Reservations for Med Inn: We make all of the reservations for our 30-room on-site Med Inn hotel.

Partnership with Area Hotels and Motels: Michigan Medicine Lodging also partners with more than 30 hotels and motels in the area (currently in Ann Arbor, Brighton and Livonia) to provide uniquely tailored services matched to your specific needs. We will take your information and preferences on accommodations, make your reservations at the best rate, provide you with information about hotel amenities, give directions to the hotel and answer any questions you may have. Michigan Medicine Lodging can help you make arrangements at many hotels and organizations, often at a better rate than what you might otherwise receive.

Contact Us: For assistance in making reservations for any of the lodgings above, contact Michigan Medicine Lodging at (800) 544-8684 or (734) 936-0100. You may also complete an reservation request form online at www.UofMHealth.org/patient-visitor-guide/michigan-medicine-lodging.

Ronald McDonald House

The Ronald McDonald House is located on Washington Heights Street and is about a five-minute walk to the hospital. The Ronald McDonald House is considered communal living, which means that you and your family have your own bedroom and bathroom and will have access to a shared kitchen and living area. The house is available for all families whose children are staying with us in C.S. Mott Children's Hospital. The Ronald McDonald House costs \$10 per night and rooms are reserved on a first-come, first-served basis.



Up to four family members (including children) can stay in a room at the Ronald McDonald House. The Ronald McDonald House is a popular place to stay. If you think you might want to stay there, ask your social worker to call to see if a room is available. Do this upon your arrival to the hospital. If no rooms are available, social work can ask them to put your name on a waitlist. 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 given priority to families whose children are in the ICU. You can make reservations at the Ronald McDonald House by calling **(734) 994-4442**.

Other Information

Meals

Caregivers of transplant patients may be assisted with the cost of meals during an inpatient admission if they have Medicaid or a Medicaid Health Plan, and meet guidelines set by the Department of Health and Human Services for distance from the hospital. If you are facing financial difficulty and need help with the cost of meals, contact your social worker.

Work or School Letters

Your employer or your child's school may require a note to verify the clinic visit or hospital stay. For clinic visits, these are available at checkout at the front desk. For inpatient stays, please contact your social worker or medical team and a letter can be provided to you to verify the dates of the admission.

Disability and Other Forms

Because of the complexity of the Transplant Clinic, disability and other forms may **NOT** be completed during your child's clinic visit. The forms will be reviewed after clinic, and if appropriate, our team will complete them and return to you either by fax, email, or mail 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 if needed.

Wish-granting Organizations:

Your child may be eligible to participate in receiving a wish through an organization such as the Make-a-Wish program or Rainbow Connection, based on his/her diagnosis and severity of disease. Contact your social worker regarding the referral process.

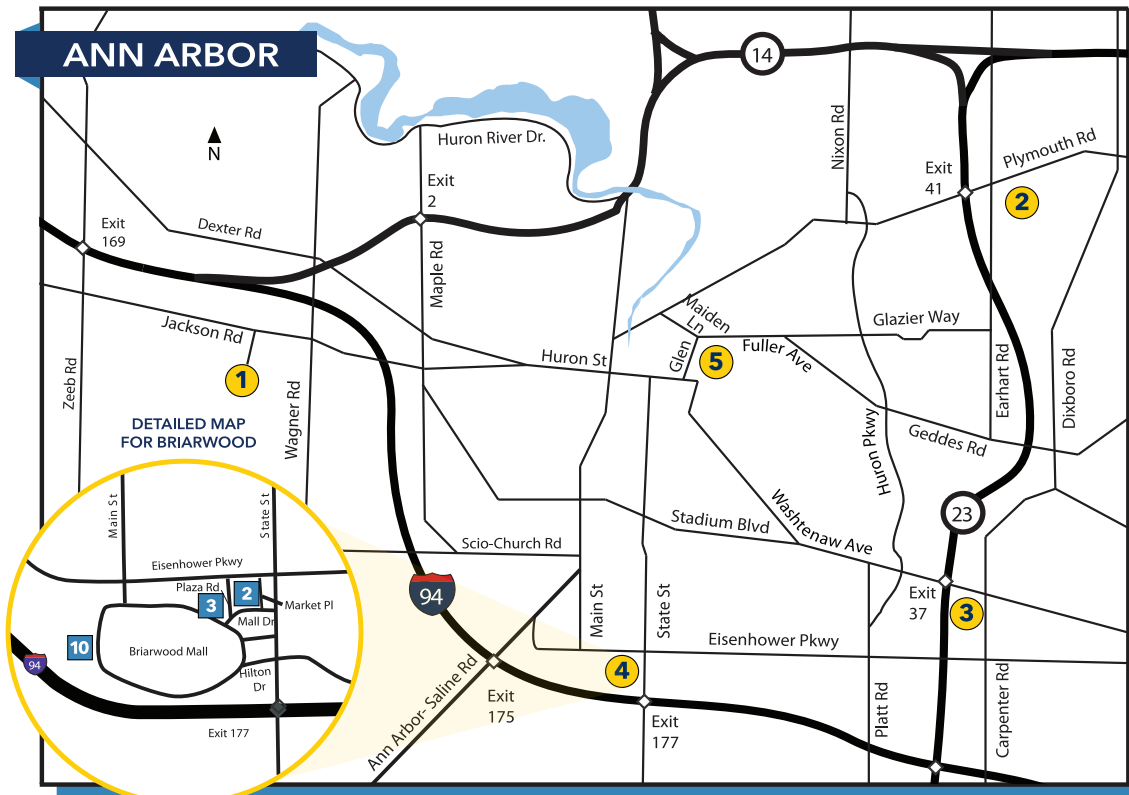
LABORATORY PATIENT SERVICE CENTERS



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
(Closed 2nd Wednesday of each month 8am - 1pm)

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

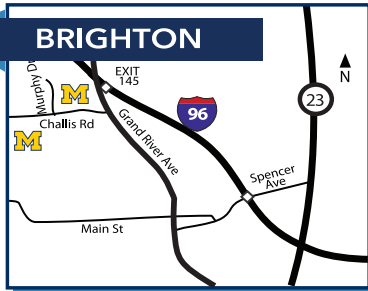
Cancer Center, Fl. B2, Recep. E
Ph: 734.647.8913 **Fax:** 734.647.8937
Mon-Fri 7am - 6pm

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

Taubman Center, Fl. 3
Ph: 734.936.6760 **Fax:** 734.936.7419
Mon-Fri 7am - 6pm

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 Specialty Care

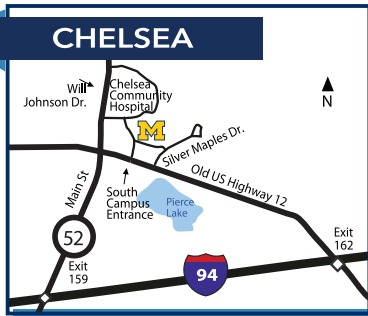
BRIGHTON CENTER FOR SPECIALTY CARE

7500 Challis Road
Brighton, MI 48116

P: 810.263.4087
F: 810.263.4090

Mon - Fri 7am - 6pm
Sat 7am - 4pm

CHELSEA



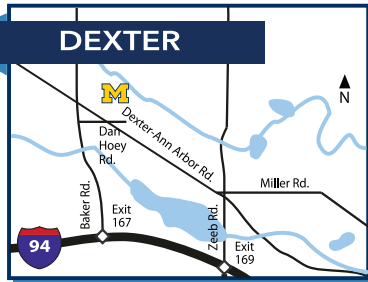
CHELSEA HEALTH CENTER

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

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 8am - Noon
(Starting 3/5/22) 8:30am-12:30pm

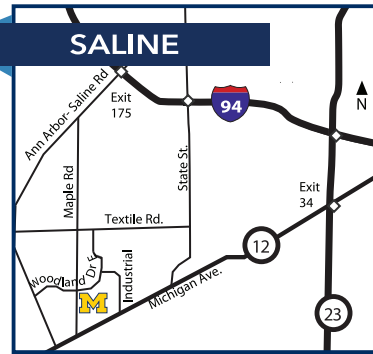
CANTON HEALTH CENTER

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



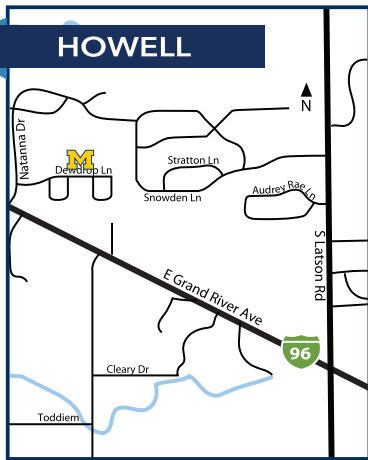
SALINE HEALTH CENTER

700 Woodland Dr E
Saline, MI 48176

P: 734.295.0022
F: 734.429.1156

Mon - Fri 8am - 3:30pm

HOWELL

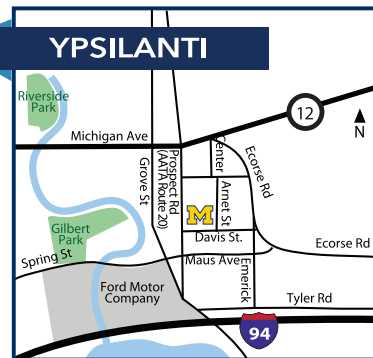


HOWELL HEALTH CENTER

3399 E Grand River Ave
Howell, MI 48843

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 - 5pm

Closed daily for lunch
between 12:30-1:00pm



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

Glossary of Terms

Aneurysm: A ballooning of the wall of a vein or an artery or the heart itself due to weakening of the wall by disease, traumatic injury or an abnormality present at birth.

Angiocardiology: A diagnostic method of involving injection of dye into the bloodstream. Chest x-rays taken after the injection show the inside dimensions of the heart and great vessels, as outlined by the dye.

Anoxia: Literally, no oxygen. This condition most frequently occurs when the oxygen supply to a part of the body is critically diminished. This may result in the death of the affected tissue.

Antiarrhythmic Drugs: Drugs that are used to treat disorders of the heart rate and rhythm, such as lidocaine, procaine amide, quinidine, digitalis, propranolol atropine and isoproterenol.

Anticoagulant: A drug that delays clotting (coagulation) of the blood. When given in cases where a blood vessel has been plugged by a clot, an anticoagulant tends to prevent new clots from forming, or the existing clots from enlarging, but does not dissolve an existing clot. Anticoagulants are also used to prevent clots from forming on artificial material, such as artificial valves.

Aorta: The main artery to the body, originating from the base of the heart, arching up over the heart like a cane handle, and passing down through the chest and abdomen near the spine. The aorta normally receives blood from the left ventricle of the heart and moves into the many lesser arteries that conduct blood to all parts of the body, except the lungs.

Aortic Stenosis: A narrowing at the valve opening, or just above or below the valve, between the left ventricle of the heart and the large artery called the aorta.

Arrhythmia: Any variation from the normal rhythm of the heartbeat.

Arterial Blood: Blood that picks up oxygen in the lungs and normally passes from the lungs to the left side of the heart via the pulmonary veins. This blood is then pumped by the left side of the heart into the arteries that carry it to all parts of the body.

Artery: Any blood vessel that carries blood away from the heart to the various parts of the body. Arteries usually carry oxygenated blood, except for the pulmonary artery, which carries un-oxygenated blood from the heart to the lungs, where it picks up oxygen.

Asymptomatic: Without symptoms, a person is considered asymptomatic when he does not exhibit functional evidence of a disease or condition.

Atresia: The absence of a normal opening.

Atrial Septal Defect: An opening in the wall, or septum, that normally divides the left and right upper heart chambers, called the atria.

Atrium: Sometimes referred to as the auricle. The atrium is one of the two upper chambers of the heart. The right atrium receives un-oxygenated blood from the body. The left atrium receives oxygenated blood from the lungs.

Bacterial Endocarditis: An inflammation of the inner layer of the heart caused by bacteria, sometimes resulting as a complication of another infectious disease, an operation or injury. The lining of the heart valves is most frequently affected, especially valves with previous damage from rheumatic disease or congenital abnormality.

Balloon Angioplasty: A technique accomplished during cardiac catheterization or surgery using a balloon tipped catheter inserted into a vessel, usually to dilate a narrowing or to open a blockage. This is a fairly new procedure.

Bicuspid Valve: Any valve with two leaflets. The term may refer to a normal mitral valve or an abnormal aortic or pulmonary valve, which normally has three leaflets.

Blood Pressure: The force that flowing blood exerts against the artery walls. Two blood pressures are usually measured: 1) The upper, or systolic, pressure occurs each time the heart contracts to pump blood into the aorta. This part of the heartbeat is called systole; and 2) The lower, or diastolic, pressure occurs when the heart relaxes and refills with blood. This part of the heartbeat is called diastole. The blood pressure is expressed by two numbers, with the upper one written over the lower one (systolic/diastolic).

Blue Babies: Babies having a blue color of skin, called cyanosis, caused by insufficient oxygen in the arterial blood. This often indicates a heart defect, but may have other causes, such as premature birth or impaired respiration.

Bradycardia: An abnormally slow heart rate. Generally, anything below 60 beats per minute is considered bradycardia.

Bundle of His: Also called the atrioventricular bundle or A-V bundle. This bundle of microscopic specialized fibers lies between the atria and ventricles and is the only known normal direct connection between the atria and the ventricles, serving to conduct impulses to the ventricular heart muscle. It is named after German anatomist Wilhelm His.

Cardiac: Pertaining to the heart. Sometimes refers to a person who has heart disease.

Cardiac Arrest: The cessation of the heartbeat. As a result, blood pressure drops abruptly and circulation of blood ceases.

Cardiologist: A specialist in the diagnosis and treatment of heart disease.

Cardiology: The study of the heart and its functions in health and disease.

Cardiopulmonary Resuscitation (CPR): An emergency measure used by one or two people to artificially maintain another person's breathing and circulation if these functions suddenly stop. CPR is done by keeping the airway open, performing rescue breathing and external cardiac compression, or heart massage, to keep oxygenated blood circulating through the vital organs of the body.

Cardiovascular: Pertaining to the heart and blood vessels.

Carditis: Inflammation of the heart.

Catheter: A thin, flexible tube that can be guided into body organs. A cardiac catheter is made of woven plastic, or other material to which blood will not adhere, and is inserted into a vein or artery, usually an arm or leg, and gently threaded into the heart. Its progress can be watched on a fluoroscope.

Cineangiocardiology: A diagnostic method similar to angiocardiology, except that instead of still x-ray pictures, motion pictures of the heart are made by fluoroscope as an injected opaque liquid is carried through the heart and blood vessels.

Clubbed Fingers: Fingers with a short broad tip and overhanging nail, somewhat resembling a drumstick. This condition is sometimes seen in children born with certain kinds of cyanotic heart defects and in adults with heart, lung or gastrointestinal diseases. It may also be hereditary and insignificant.

Coarctation of the Aorta: A congenital narrowing of the aorta, the main artery that conducts blood from the heart to the body.

Congenital Anomaly: An abnormality present at birth.

Congenital Heart Defect: Malformation of the heart or of its major blood vessels present at birth.

Congestive Heart Failure: Heart failure is a condition in which the heart is unable to pump the amount of needed blood to the body. This results from an anatomic or chemical abnormality that leads to congestion in the body and/or lung tissues. Congestive heart failure usually develops gradually over several years, although it can be acute (short and severe). It can be treated by drugs and/or, in some cases, by surgery.

Coronary Arteries: The two arteries that arise from the aorta, then arch down over the top of the heart and branch out to provide blood to the working heart muscle.

Cyanosis: Blueness of skin caused by insufficient oxygen in the blood. When hemoglobin is not carrying oxygen, it is dark burgundy and is called “reduced hemoglobin.” The blueness of the skin occurs when critical amounts of reduced hemoglobin are present.

Dextrocardia: Abnormal position of the heart within the chest. The heart normally is in the left chest. When dextrocardia is present, the heart is on the right side. This occurs frequently when a congenital heart defect is present.

Diastolic Blood Pressure: The blood pressure inside the arteries when the heart muscle is relaxed.

Digoxin (Digitalis): A drug that causes the heart muscle to pump more effectively, thereby improving the circulation of the blood, and promoting the normal elimination of excess fluid. This drug is often used to treat heart failure. It is also used to certain arrhythmias.

Diuretic: A medicine that promotes the excretion of urine. These drugs are often used to treat conditions involving excess body fluid, hypertension and congestive heart failure. One important class of diuretics is the thiazides.

Ductus Arteriosus: A connection outside the heart of a fetus between the pulmonary artery and body of the fetus. Normally this connection closes soon after birth. If it does not close, the condition is known as patent or open ductus arteriosus.

Dysrhythmia (Arrhythmia): An abnormal rhythm of the heart.

Echocardiography: A diagnostic method in which pulses of high-frequency sound, called ultrasound, are transmitted into the body and the echoes returning from the heart and other structures are made into an electronic picture. These pictures are then studied for diagnostic purposes.

Echo: A picture of the heart and vessels made by echocardiography.

Edema: Abnormally large amounts of fluid in the tissues of the body.

Eisenmenger's Syndrome: A condition in which a large congenital shunting defect is complicated by a pulmonary hypertension, or high blood pressure in the blood vessels of the lungs. A shunting defect is an abnormal opening between the heart chambers, called a septal defect, or between the great arteries, such as patent ductus arteriosus. Some oxygen-poor blood gets pumped to the body and results in cyanosis of the lips, fingernails and toenails.

Electrocardiogram: Often referred to as ECG or EKG. A graphic record of the electric currents generated by the heart. The word “electrocardiogram” most often refers to a resting electrocardiogram, that is, the patient is lying at rest while the recording is being made. The recording can also be made during exercise or when the patient is walking.

Endocardial Cushion Defect: A complex congenital heart malformation involving the septum, or wall, between the upper chambers of the heart, called the atria, and the septum, or wall, between the lower chambers of the heart, called the ventricles. The valves between the upper and lower chambers are also malformed.

Endocarditis: An inflammation of the inner lining of the heart or heart valves.

Enlarged Heart: A state in which the heart is larger than normal, most often related to birth defect or underlying disease. Rarely may represent a normal variant.

Extra Beats/Skipped Beats: Single or multiple irregular beats, or palpitations, usually felt as a skip or momentary cessation of the heartbeat.

Fluoroscope: An instrument for observing the internal body organs at work. X-rays are passed through the body onto a fluorescent screen, where the shadows of the beating heart and other organs can be seen and studied.

Foramen Ovale: A hole between the left and right upper chambers of the heart that normally closes after birth.

Heart Attack: The death of a portion of heart muscle, which may result in disability or death of the individual, depending on the extent of muscle damage. A heart attack occurs when an obstruction in one of the coronary arteries prevents an adequate oxygen supply to the heart. Symptoms may be none, mild or severe, and may include: chest pain, sometimes radiating to the shoulder; arm, neck or jaw; nausea; cold sweat, and shortness of breath or syncope (fainting).

Heart Block: A condition in which the electrical impulse that travels through the heart's specialized conduction system to trigger the events of the heartbeat is slowed or blocked along its pathway. This can result in a dissociation of the rhythms of the upper and lower heart chambers, and is the major disorder for which artificial pacemakers are used.

Heart Disease: A general term used to mean ailments of the heart of blood vessels related to structure or function. May be present at birth (congenital) or developed after birth (functional).

Heart Failure: See Congestive Heart Failure.

Heart-Lung Machine: A special instrument used to provide circulation to the body during open-heart surgery.

Heparin: A type of anticoagulant that is given by injection.

High Blood Pressure: An unstable or persistent elevation of blood pressure above the normal range.

Holter Monitoring: A process by which the ECG can be tape recorded for 14 hours. The patient wears a small tape recorder connected to electrocardiographic leads placed on the chest for 24 hours. A written diary is kept during that period to record symptoms.

Hypertension: Commonly called high blood pressure. It is blood pressure above the normal range.

Hypertrophy: Enlargement of a tissue or organ due to increase in the size of its cells. This may result from a demand for increase work.

Hypotension: Blood pressure below the normal range. Most commonly used to describe an acute fall in blood pressure as occurs in shock syncope (fainting). It is often called low blood pressure.

Hypoxia: Less than normal content of oxygen in the organs and tissues of the body. At very high altitudes, healthy people experience hypoxia because of the decreased amount of oxygen in the air.

Isoproterenol: A drug that can be used as a cardiac stimulant to treat an abnormally slow heartbeat and to increase the strength of the heart's pumping.

Lanoxin: See Digoxin.

Mitral Valve: The heart valve between the left atrium and left ventricle. It has two flaps, or cusps.

Mitral Valve Insufficiency: An incomplete closing of the mitral valve, which is situated between the upper and lower chambers on the left side of the heart. The mitral valve normally prevents a backflow, or leak, of blood in the wrong direction. Mitral valve insufficiency is sometimes the result of scar tissue that forms after rheumatic heart disease. It can also be caused by a congenital heart defect.

Mitral Valve Stenosis: A narrowing of the mitral valve situated between the upper and lower chambers on the left side of the heart. Sometimes the result of a congenital heart defect.

Murmur: Noise made by blood flow, which may or may not be abnormal.

Open-Heart Surgery: Surgery performed inside the heart with the aid of a heart-lung machine.

Organic Heart Disease: A structural abnormality of the heart or great vessels.

Pacemaker: A small mass of specialized cells in the right atrium of the heart, which gives rise to the electrical impulses that initiate contractions of the heart. This is also called the sinoatrial node, or SA node. Under certain circumstances (normal or abnormal), other cardiac tissues may assume the pacemaker role by initiating electrical impulses to stimulate contraction. The term “artificial pacemaker” is applied to an electrical device, which substitutes for a defective natural pacemaker to control the beating of the heart by a series of rhythmic electrical discharges. If the electrodes that deliver the discharges to the heart are placed on the outside of the chest, it is called an “external pacemaker.” If they are placed within the chest wall, it is called an “internal pacemaker.”

Palpitations: A single or multiple irregular beat usually felt as a skip or momentary cessation of the heartbeat.

Patent Ductus Arteriosus: A congenital heart defect in which a small duct, or tube, between the artery leaving the left side of the heart, the aorta, and the artery leaving the right side of the heart, the pulmonary artery, which normally closes soon after birth, remains open. As a result of its failure to close, blood from the left side of the heart is also pumped into the pulmonary artery and thereby into the lungs. This defect is sometimes called simply patent or open, ductus.

Patent Foramen Ovale: An oval hole, called the foramen ovale, between the left and right upper chambers of the heart, which normally closes shortly after birth, remains open.

Pericarditis: Inflammation of the membrane sac, the pericardium, which surrounds the heart.

Persistent Truncus Arteriosus: A congenital cardiac defect, characterized by a single arterial trunk arising from the heart receiving blood from both pumping chambers, the ventricles, and the pulmonary artery.

Prostaglandins: Hormone-like substances made from fatty acids, which are found throughout the body tissues. They are thought to have important roles in tissue metabolism and blood flow.

Pulmonary: Pertaining to the lungs.

Pulmonary Artery: The large artery that normally conveys un-oxygenated blood from the lower right chamber of the heart to the lungs. This is the only artery in the body which normally carries un-oxygenated blood; all others carrying oxygenated blood to the body.

Pulmonary Edema: Congestion of lung tissues often resulting from critical, congenital, or acquired heart or lung disease.

Pulmonary Hypertension: High blood pressure, or hypertension, in the blood vessels of the lungs. The most common causes are congenital heart defects.

Pulmonary Valve Stenosis: A congenital heart defect in which there is a narrowing of the pulmonary valve, which is situated between the right lower chamber; or the ventricle, and the pulmonary artery.

Pulmonic (Pulmonary) Valve: The heart valve between the right ventricle and pulmonary artery. It has three flaps, or cusps.

Radioisotopic Scanning: A diagnostic technique involving radioactive labeling of tissues and organs by the injection of radioisotopes (minimally radioactive material) into the bloodstream. The emitted radioactivity is detected by a scanner and the resulting record of the scan is used to evaluate structural defects or functions.

Regurgitation: The abnormal backward flowing of blood through a valve of the heart.

Rheumatic Heart Disease: A complication of rheumatic fever in which damage results to all layers of the heart, particularly the valves.

Rubella: Commonly known as German measles.

Septa: The muscular walls dividing the two chambers on the left side of the heart from the two chambers on the right. The atrial septum separates the top chambers and the ventricular septum separates the bottom chambers.

SBE: See Bacterial Endocarditis.

Shock: Collapse of the circulation related to a congenital heart defect or acquired heart disease or loss of blood volume.

Shunt: A passage between two blood vessels or between the two sides of the heart, as in cases where an opening exists in the wall that normally separates them. In surgery, a shunt is the operation of forming a passage between blood vessels to divert blood from one part of the body to another.

Sphygmomanometer: An instrument for measuring blood pressure in the arteries.

Stenosis: A narrowing or stricture of an opening. Mitral stenosis, aortic stenosis, etc. means that the valve indicated has become so narrowed that it does not function normally. Also refers to narrowing of a blood vessel.

Stress Test: A diagnostic method used to determine the body's response to physical stress. Usually involves monitoring an EKG and other physiological parameters, such as breathing rate and blood pressure, while the patient is exercising – jogging on a treadmill, walking up and down a short set of stairs, or pedaling on a stationary bicycle.

Subvalvar: Below a valve.

Symptomatic: A person is considered symptomatic when he exhibits functional evidence of a disease or condition.

Systolic Blood Pressure: Pressure inside the arteries when the heart contracts with each beat.

Tachycardia: Abnormally fast heart rate. What is considered tachycardia varies with age.

Tetralogy of Fallot: A complex congenital heart malformation consisting of: 1) an opening in the wall between the lower heart chambers (ventricular septal defect), 2) a narrowing of the pulmonary valve (stenosis) and the muscular area just beneath it, 3) thickening (hypertrophy) of the right ventricle and 4) abnormal position of the great artery (aorta). These children are cyanotic.

Transplantation, Heart: The replacement of a healthy heart from a recently deceased donor into the chest of a person whose own heart can no longer function adequately. The donor's heart then replaces the failing heart.

Transposition of the Great Vessels: A congenital heart defect in which the aorta arises from the right, rather than left, ventricle and the pulmonary artery arises from the left, rather than the right, ventricle. Thus the right heart pumps un-oxygenated blood from the body through the aorta and back to the body, and the left heart pumps oxygenated blood from the lungs back to the lungs. Only if there is a sizeable hole between the right and left chambers, called a septal defect, or a channel between the aorta and pulmonary artery, patent ductus arteriosus, will enough oxygenated blood get pumped to the body to sustain life. Babies with this condition are critically ill and cyanotic and require surgical correction in the first years of life.

Tricuspid Atresia: A severe congenital heart defect in which the valve between the upper right chamber; the atrium, and the lower right chamber; the ventricle, failed to form. Other associated defects are required for life to persist. These children are cyanotic.

Tricuspid Valve: The heart valve between the right atrium and right ventricle, comprised of three flaps or cusps.

Ultrasound: High frequency sound vibrations, not audible to the human ear. In a sonar-like application, ultrasound can be used by a cardiologist as a diagnostic tool, usually echocardiography.

Valve: An opening covered by membranous flaps between two chambers of the heart or between a chamber of the heart and a blood vessel. When it is closed, blood normally does not pass through.

Valve Conduit: An artificial tubing with an artificial valve used in some congenital heart surgeries.

Valvular Insufficiency: Valves that close improperly and permit a backflow of blood. Valvular insufficiency may result from either congenital or acquired heart disease.

Vascular: Pertaining to the blood vessels.

Vectorcardiography: A special type of EKG

Vein: Any one of a series of vessels of the vascular system, which carries blood from various parts of the body back to the heart.

Venous Blood: Refers to blood returning to the heart. It is un-oxygenated when returning from the body and oxygenated when returning from the lungs.

Ventricle: One of the two main pumping chambers of the heart. The left ventricle pumps oxygenated blood through the arteries to the body. The right ventricle pumps un-oxygenated blood through the pulmonary artery to the lungs. Capacity of each ventricle in an adult averages 85 cc. or about 3 ounces.

Ventricular Septal Defect: A congenital cardiac defect in which there is an abnormal opening in the wall, or septum, that divides the right and left lower heart chambers.



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 Heart Transplant

Unit Address: 1540 E. Hospital Dr.

City: Ann Arbor State: MI Zip: 48109

Phone Number: (734) 764-5172

One letter per box

Patient's Name																			
Modality*	H	E	A	R	T		T	R	A	N	S	P	L	A	N	T			
Misc. Information**																			
Emergency Contact 1st Name & Phone	7	3	4	-	7	6	4	-	5	1	7	2							
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**.

Donor Family

CONTACTING THE DONOR FAMILY

The Following Information is for Children Over 18 Years of Age

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 your Patient Advocate or doctor decide what kind of health care you want.

.....

.....

.....

.....

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It is my intent that no one involved in my care shall be liable for honoring my wishes as expressed in this designation or for following the directions of my Patient Advocate. Photocopies of this form can be relied upon as though they were originals.

I want the people I selected in the “Choose a Patient Advocate” section to be my Patient Advocate and Alternate Patient Advocate(s). I understand that this will let them make medical decisions for me when I cannot. I am making this decision because this is what I want, **NOT** because anyone forced me to.

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

I have chosen two adult witnesses who are not my spouse, parent, child, grandchild, brother or sister, and are not my presumptive heir or beneficiary at the time of witnessing. My witnesses are not my Patient Advocate(s). They are not my physician, or an employee of a health facility that is treating me; not an employee of my life or health insurance provider, or of a home for the aged where I reside, nor of a community mental health services program or hospital that is providing mental health services to me.

We sign below as witnesses. This Declaration was signed in our presence. The **PERSON SIGNING APPEARS** to be of sound mind, and to be making this designation voluntarily, without duress, fraud, or undue influence.

Witness's telephone number

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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

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

**UNIVERSITY OF MICHIGAN
HOSPITALS & HEALTH CENTERS**

**Temporary Delegation Of Parental Rights
And Limited Power Of Attorney
For Consent To Medical Treatment Of Your Child**

Birth Date

Name

REG No.

Name of Minor: _____ Date of Birth: _____ (mm/dd/yyyy)

Known Allergies/Drug Sensitivities: _____

Known Medical Conditions: _____

Any Limitations to Delegation: _____

HMO/Insurance/Health Benefits and Physician Information:

Company/Government Program Name: _____ Member I.D.: _____

Minor's Physician Name: _____ Phone: _____

Minor's Dentist Name: _____ Phone: _____

I/we are the parent(s) or legal guardian(s) of the above named minor. We appoint (in order of appearance):

Name: _____ Phone: _____

Address: _____ DL or State ID #: _____

Name: _____ Phone: _____

Address: _____ DL or State ID #: _____

To act on my/our behalf to consent to: ☐ medical care ☐ dental care ☐ surgical care ☐ hospitalization for the above-named minor during period(s) of my/our absence from _____ through _____ (or until the 31st day following my return from deployment overseas, if I am an active duty member of the military). I understand this delegation includes receiving health information about the minor necessary to make health care decisions. **IN NO EVENT IS THIS DELEGATION OF PARENTAL RIGHTS EFFECTIVE FOR MORE THAN SIX (6) MONTHS FROM THE SIGNATURE DATE BELOW (OR LONGER, FOR UP TO 30 DAYS FOLLOWING RETURN FROM OVERSEAS DEPLOYMENT OF ACTIVE MILITARY PERSONNEL). THIS FORM DOES NOT DELEGATE POWER TO CONSENT TO MARRIAGE OR ADOPTION.**

This Delegation of Parental Powers is given under MCLA § 700.5103. I/we have signed and delivered this document on the date(s) listed below.

INSTRUCTIONS TO PARENT(S): At least one parent or legal guardian must sign this form below. The signature(s) should be witnessed by a person who is not an employee or contractor of the University of Michigan Health System and is not related by blood or marriage to the family, OR by a Notary Public.

**Parent/
Guardian** _____
Printed Name Signature

_____ Date
Contact Phone(s)

**Parent/
Guardian** _____
Printed Name Signature

_____ Date
Contact Phone(s)

CLINICAL STAFF: Please initial here after giving a copy of this signed form back to the parent or if the parent declines a copy: _____ (initial)

OPTION 1:

Witness _____

Printed Name Signature

Contact Phone(s) Date

or OPTION 2:

On this day, before me, the undersigned Notary Public, the parent(s)/ guardian(s) herein named personally appeared and freely executed this document. He/she/they [] is/are personally known to me or [] has/have provided satisfactory evidence of their identity.

Notary Public _____

Signature Date

34-10000

VER: A/11
HIM: 08/11

Original – Medical Record
Copy - Parent/Guardian



Temporary Delegation of Parental Rights and Limited Power of Attorney for Consent to Medical Treatment For Your Child

Guide to and Instructions for form:
**Temporary Delegation of Parental Rights and Limited Power of Attorney
for Consent to Medical Treatment of Your Child**

Are you planning a trip? Away for the day? Are your children in school?

If your child needs non-emergency medical, dental, or surgical services, whether in a doctor's office or in the hospital, you as a parent must give permission.

What about times when you cannot be reached for permission?

In an emergency, your child may be treated without your consent if a physician determines that your child needs immediate medical care and further delay would increase the risk to your child's life or health. In situations that are not emergencies, your child may need unexpected care. In these cases, contacting parents for permission can delay treatment and create unnecessary anxiety or discomfort for your child.

How can you prepare for the unexpected care your children might need when you are away?

- Make sure the person who is caring for your children knows how to reach you at all times.
- When you can't come with your children to medical appointments, or know you will be hard to reach, you may legally delegate your authority to give permission to other adults to authorize medical care for your children.

The form, Temporary Delegation of Parental Rights and Limited Power of Attorney for Consent to Treatment of Your Child, is a legal document. Under Michigan law, MCLA § 700.5103(2005):

- A parent or guardian of a minor or a guardian of a legally incapacitated adult may delegate to another person, for **up to 6 months**, any of the parent's or guardian's powers regarding care, custody, or property of the minor child or ward, except the power to consent to marriage or adoption of a minor ward or to release of a minor ward for adoption.
- If a parent or guardian is serving in the armed forces of the United States and is deployed to a foreign nation, a delegation under this law may be effective longer than 6 months, until the thirty-first day after the end of the deployment, if the delegation letter specifically permits the longer period.
- The following applies only if a parent is not signing the form: if a legal guardian for a minor or legally incapacitated adult delegates any power under this law, the guardian must notify the court that approved the guardianship within 7 days and provide the court the name, address, and telephone number of the new "attorney-in-fact."

The form's purpose is to allow your child to receive necessary health care services when you, the parent or guardian, are unavailable to give written informed consent.

- Fill out this form carefully. With it, you may appoint relatives, friends, teachers, neighbors or anyone you know and trust who is legally competent and over 18 years of age to authorize treatment in your absence.
- After you complete the form, give it to the adults you have designated and explain its use. Make sure they know that they must take the form with them to the physician's or dentist's office, or to the hospital or other health care facility.
- The form will be entered into your child's medical chart so that it is available to other UMHC providers and administrators with a need to know.

In order to be effective, the form must be signed by at least one parent and either a witness (not related to patient's family and not affiliated with UMHS) or a notary public. The following additional guidelines are suggested to help ensure the form is used appropriately.

- Print neatly to ensure that all information is legible. Use a blue or black ball point pen to ensure that information will not run, smear or smudge.
- Print the full name of the minor as written in the minor's birth certificate, insurance card and medical record.
- List all known allergies (e.g., medicines, insects, foods, etc.) and medical conditions (e.g., asthma, diabetes, etc.)
- Either initial or line-out "... [] medical, [] dental, [] surgical care, and/or [] hospitalization..." as you deem appropriate.
- Print all limitations to the general delegation of parental powers to consent to medical, dental, surgical care, and/or hospitalization. Ensure that the limitations are clear and specific (e.g., necessary surgery ok but no cosmetic procedures).
Note: It is essential that you trust the person you are appointing to make the decisions you would make under similar circumstances.
- Complete all blanks (e.g., if there are no known allergies, write "none"). Draw a line through any extra space at the end of each entry to ensure that nothing may be added at a later date.
- Have at least one (preferably both) parents sign the form and have a separate person - not the parent(s), not a relative, and not affiliated with UMHS - witness the signature.

Notes

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