Transplant Research in Ann Arbor: The Scientific Registry of Transplant Recipients

The U-M Transplant Center is well known as an excellent system that works hard to improve the lives of its patients. But few patients know that Ann Arbor is also home to another organization that works to improve transplantation all around the country. In downtown Ann Arbor, a non-profit research group called the Arbor Research Collaborative for Health runs the Scientific Registry of Transplant Recipients (SRTR). Together with many doctors and researchers from U-M, including doctors from the U-M Transplant Center, Arbor Research manages the SRTR for the Health Resources and Services Administration, a branch of the U.S. Department of Health and Human Services. Because donated organs are a scarce lifesaving resource, the nation’s transplant system is overseen by the federal government.

The SRTR works closely with the Organ Procurement and Transplantation Network on many of the technical details of the nation’s transplant system. They conduct research behind important questions of transplant policy and practice. One important area of research is allocation policy: how organs are distributed and given priority to different people on the “waiting list.” Because donated organs are a scarce lifesaving resource, the Federal government is interested in evaluating and updating the organ allocation system in order to make the best use the short supply of organs. The SRTR plays an important role in that process of evaluation. They look at recent and historical trends in transplantation, and present their research in medical journals and government committees. They also develop computer models to simulate the effect of different changes to allocation policy, identifying which changes would be both efficient and fair.

For example, SRTR research and computer simulation was recently the basis of a change to the lung allocation system. In 2005 the national policy was changed to give lungs to transplant candidates on the basis of their medical urgency. Before that, a candidate’s place on the waiting list depended on how long he or she had been waiting. Since that policy was changed, the SRTR’s predictions of lives saved by changing allocation rules have become a reality.
The above figure, taken from the 2006 OPTN/SRTR Annual Report, shows the number of days it took for one-quarter of the people waiting for a new lung to receive one. In 2004, it took 183 days; in 2005, it took only 54 days, the shortest time in a decade. Source: 2006 OPTN/SRTR Annual Report, Table 12.2.

Another large area of the SRTR’s research is of particular interest to patients waiting for an organ or just entering the transplant process: they evaluate the performance of every transplant center in the country. These program-specific reports (PSRs) are released publicly every six months on the SRTR’s website (www.ustransplant.org). The reports look at many features of each center’s transplant program, such as the number of transplants performed in recent years, how long patients wait for an organ transplant, and how well the patients do after transplantation. The statistics show how well each center does compared to a national average that takes into account many of the difference between patients treated at each center. The SRTR produces similar performance reports for organ procurement organizations, which obtain and distribute organs in specific geographic regions of the country.

Other topics the SRTR looks at include fair access to transplant waiting lists for different demographic groups (including racial and ethnic minorities), how different types of patients fare while waiting for an organ, and how healthy they remain after receiving different types of organs. The SRTR looks at these issues in regular public reports, at the request of government policymakers, and in collaboration with other researchers across the country. Because the SRTR database includes information on every organ transplant in the country, it is valuable for people looking for detailed and up-to-date information on how the US transplant system works – patients and families, as well as researchers and doctors.

Miles P. Finley
Arbor Research Collaborative for Health
Show Us Your Heart Campaign

A new organ donation campaign has begun in Michigan. Everyone adding their name to the organ donor registry will receive a heart sticker for their driver’s license or state identification card.

The heart sticker is placed on the front of the license or ID card where it is readily visible. It designates the person’s wish to be a donor and alerts law enforcement, emergency responders and hospital personnel of the choice. Michigan law supports residents’ rights to make their own donation decisions - no further consent is required once they enroll on the registry.

The Michigan Organ Donor Registry is a confidential database of residents who wish to be organ donors, which is maintained by the Department of State. Anyone wishing to add his or her name may do so online at www.michigan.gov/sos or at any Secretary of State branch office.

The Michigan Secretary of State has revamped its organ donation web site, allowing users to enroll on the registry and request a replacement heart sticker if the original one is ever lost. It also provides several resources to help educate visitors about the critical need for donors, including such topics as myths, minority issues, statistics and links to state and federal donor advocates.

Public Acts 140-143 of 2005 authorize the department to place a heart insignia on the front of the driver’s license or state identification card of everyone who agrees to be an organ donor. The laws were enacted to enhance the state’s efforts at promoting organ donation awareness and increase the number of names on the donor registry.

It is important for anyone who has added his or her name to the registry in the past to re-enroll. This will ensure that their donor registration is current and that they receive the heart sticker. There are plans to eventually “brand” donors’ driver’s licenses and ID cards with a heart logo, dispensing with the need for stickers. This phase of the campaign is awaiting the completion of certain programming components.

Gift of Life Michigan, the state’s authorized organ recovery organization, accesses the donor registry to assist hospitals in the recovery and transplantation of organs and tissues. For more information about donation, visit its Web site at: www.giftoflifemichigan.org

To enroll on the registry or learn more about the department’s efforts, visit: www.Michigan.gov/sos

Mark Gravel, RN
Liver and Kidney Transplantation in Patients with HIV Infection

In the past, HIV infection was considered an absolute contraindication to transplantation. This was partly because patients with HIV infection were previously not expected to live long enough to benefit from transplantation. In addition, there was concern that the immunodeficiency caused by the HIV virus would be worsened by medications used to prevent rejection of the transplanted organs. While a cure still does not exist, the risk of dying from HIV or AIDS has significantly declined with the development of effective treatment known as highly-active antiretroviral therapy (HAART). In the HAART era, people with HIV infection are expected to live more than 20 years after the time of diagnosis.

People with HIV infection are at a higher risk of developing kidney or liver disease. The virus itself can cause injury to kidneys which is known as HIV-associated nephropathy. People with HIV infection are more likely to have hepatitis B or hepatitis C, both of which can lead to liver disease. Hepatitis C can also lead to kidney disease. Finally, the medications included in HAART can also cause injury to the liver, potentially leading to liver failure. Because people with HIV infection are living longer and are at a higher risk of kidney or liver failure, a greater number of patients with HIV have been presenting with need of either a liver or a kidney transplant.

While the total number of patients with HIV who have received either a liver or kidney transplant in the United States is still relatively small compared to all people transplanted, studies have demonstrated that HIV transplant recipients do as well as other liver and kidney recipients. In order to be a candidate for transplant, patients with HIV must meet certain criteria. These requirements include an adequate immune system which is measured by the CD4 cell count. In addition, people with HIV who would be eligible for transplant should not have had a history of certain opportunistic infections and should have an undetectable viral load on blood tests.

Over the past two years, patients with HIV infection and either liver or kidney failure have been evaluated for possible transplantation at the University of Michigan. This has required a multi-disciplinary team including transplant nephrologists, hepatologists, surgeons, and infectious disease doctors who specialize in the treatment of HIV. While patients with HIV infection can be successfully transplanted, they are at a higher risk for complications and need to be monitored even more closely than the average transplant recipient. It is important to know that the medications used to prevent rejection of the transplanted organ can have a strong interaction with the medications that are used to treat HIV infection. Therefore, the use of these medications must be monitored very closely and should only be changed under the direct supervision of an infectious disease doctor or transplant doctor at the transplant center.

While HIV was once thought to be an absolute contraindication to solid organ transplantation, HAART is now a very effective treatment which allows HIV transplant recipients the same expected survival as uninfected patients. In addition, this can be performed with only a small risk of HIV disease progression. At the University of Michigan, we are carefully screening those with HIV infection and end stage liver or renal disease and performing transplants when appropriate.

Shawn Pelletier, MD
The University of Michigan Transplant Center hosts a number of events every year to benefit Camp Michitanki, our patient emergency fund, research projects and more. This year we are pleased to announce that we’re planning two bowling events, two golf events, a family walk, skate and bike event, and our gala dinner and auction. All of our events are open to the public and we are always looking for ways to attract new participants.

Bowling is a great family activity, which is made even more fun when doing it for a great cause. Bowling For Camp Michitanki will take place on Friday, May 18th at 5-Star Lanes in Sterling Heights. It’s easy to reserve your space for this event and then every bowler is asked to bring at least $25 in donations to the event. The registration form includes a pledge form to get friends, family and colleagues to contribute to the cause. Bowlers who bring bigger total amounts of pledges to the event will be eligible for rewards such as embroidered shirts, tickets to a Tiger ball game, and a digital camera.

On June 2nd the Second Chance at Life Bowl-A-Rama will kick off at Woodland Lanes in Livonia. This event asks bowlers to bring at least $50 in pledges and traditionally enjoys a big crowd of very enthusiastic participants.
The Camp Michitanki Golf Classic is planned for Monday, July 9th at Polo Fields Golf and Country Club in Ann Arbor. This is a best-ball format competitive tournament that has quickly become a favorite, drawing golfers from Michigan, Ohio, Indiana and Ontario. The Polo Fields golf course is one of the finest courses in Michigan, challenging golfers with a variety of terrain features. This event is a great way for golfers to get out and play at this exclusive private club. Golfers enjoy a gourmet lunch before the shotgun start and a fabulous dinner and auction following golf.

The Second Chance at Life Golf Tournament is moving to a new home for 2007. Teeing off on July 15th, golfers will enjoy the course at The Woodlands of Van Buren course in Wayne. This is the third year for this fun and growing event.

One of the landmark events of the Transplant Center is the Second Chance at Life Walk, Skate and Bike at Hines Park in Westland on Saturday, August 11th. Being close to I-275, M-14, and I-96, this is an easy event to find and is designed to be fun and affordable for the whole family. Registration includes lunch and beverages throughout the day. This event draws hundreds of people of all abilities that come to run, walk, skate or ride bikes on the winding roads of Hines Park that are closed to all automobile traffic for safety. Every year the event provides a unique and fun experience that has included fire and police department demonstrations, clowns, face painters, and even a “drop in” visit from the University of Michigan’s Survival Flight helicopter. This year promises to be as fun and exciting as ever. Walkers are even encouraged to bring the family dog (on a leash) to join in the fun – doggy drinking water is provided!
The culmination of a great year of events to benefit the Transplant Center is the Vita Redita (“Life Restored”) gala on October 20th. This formal event attracts business and political leaders from Michigan and beyond as well as transplant recipients, donor families, and transplant professionals. The Vita Redita takes place at the Polo Fields Golf and Country Club of Ann Arbor and is truly an enjoyable and elegant evening out on the town. Guests consistently comment that it’s not like every other fundraising event; our auction is actually a lot of fun! The strolling dinner is a treat for the taste buds with an array of chef’s specialties from around the globe. Each guest receives true VIP treatment including valet parking, an open bar, a portrait photo upon arrival, and so much more. Special presentations are kept brief yet entertaining. Past guest speakers have included Michigan’s Secretary of State Terry Lynn Land, Amway founder and heart recipient Richard DeVos, and CNN medical correspondent Sanjay Gupta. Besides the fabulous food, open bar, and elegant surroundings, guests always look forward to the enthusiastic live auction. A wide range of items available for bid include private jet trips to New York with tickets to the Rachael Ray show, golf clubs, jewelry, works of art, flying lessons, private chef services, and dozens more.

Please contact the Transplant Center Events Office at 734-936-3460 to discuss how you would like to get involved. Everyone is invited and anyone can participate! Mark your calendars!

Call today!

Bob Garypie

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Details</th>
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<tbody>
<tr>
<td>May 18, 2007</td>
<td>Bowling for Camp Michitanki, 5-Star Lanes, Sterling Heights</td>
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<tr>
<td>June 2, 2007</td>
<td>Second Chance at Life Bowl-a-Rama, Woodland Lanes, Livonia</td>
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<tr>
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<td>October 20, 2007</td>
<td>Vita Redita, Polo Fields Golf &amp; Country Club, Ann Arbor</td>
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In January 2007 a new comprehensive Patient Education Guide for adult liver transplant patients was introduced. This guide is the patient’s road map to navigating through the transplant process successfully.

Liver transplant patients come to the Transplant Center with many questions swirling in their heads. Serious liver disease and a referral for a transplant evaluation can create much stress for the patient and their family. To understand transplantation a tremendous amount of information must be shared with the patient and the family. Since anxiety reduces a person’s ability to learn and to remember, there was a need to provide information to liver transplant patients in an easy to understand written format.

The Patient Education Guide for adult liver transplant patients was developed over the past two years by the Transplant Center Patient Education Committee. It contains specific information patients need during each phase of the transplant process.

Some information changes as a patient moves through the phases of transplant, such as nutritional needs, medications, insurance, and steps to remain healthy. Therefore some topics are covered in multiple sections giving patients the information they need at each phase of treatment.

The committee would be interested in feedback on this new educational tool. Please send your comments to mckruger@umich.edu.

The sections of the guide include:
- Your Team
- Your Medical Evaluation
- Transplant Class (Social Work, Nursing, Finance & Insurance)
- Post Transplant
- Resources
- Living Donor Livers

What is MELD?
What is my MELD score?
What happens after surgery?
The operation – how long?
Does insurance cover?
Costs... How much?
Employee of the Year for 2007

Each year in the springtime, the Transplant Center solicits nominations and selects one employee to honor as Transplant Center Employee of the Year. Many staff were nominated for the honor of being Transplant Center Employee of the Year 2007. While only one can be selected for the highest honor, the others have earned recognition as well. The nominations in alphabetical order, with brief excerpts, were:

**Kolette Allen**
nicest, most fair supervisor I've ever had, friendly, makes the job get done

**Nathan Bates, MSW**
a ‘natural’ social worker, very steady voice and contributor, calm, effective style

**Linda Carver, RN**
‘very best’ to each and every patient, caring, excellent nursing skills, team player

**Mary Jean Essenmacher, RN**
extremely efficient, shows great deal of patience & compassion for patients, encourages others

**Jessica Fetterman, PA**
compassionate care giver, team player, very highly valued colleague, willing, a quick learner

**Diane Hilfinger**
advocate for accuracy, collaborative, dedicated and committed to Transplant

**Michele Kinney**
projects a positive image, accurate and timely, the go-to person, treats all with utmost respect

**Scharry Milne**
very helpful and positive, makes time to help, goes the extra mile

**Robert Rousseau, Jr.**
strives for perfection, very professional and caring, pleasure to work with, promotes teamwork

**Crystal Sprang, MBA**
covered development events, positive attitude, team player, highest level of customer service

**Tonya Travis**
dedicated, caring, hardworking, diligent, easy to work with, intelligent

**Karen Walker**
williness to take on new projects, interest in developing new systems, does a great job

(continued on next page)
After careful consideration, Bernie Mathews, RN was selected as the 2007 Transplant Center Employee of the Year. Bernie is a nurse serving the post transplant kidney and pancreas patients. Excerpts from the nomination submissions are:

- Bernie agreed to ‘swap’ positions, not just once, but multiple times to help other teams
- shows her knowledge and flexibility and her strong commitment to the Transplant Center
- she quietly goes about supporting the transplant center
- gives her every attention to every aspect of the transplant center with professional grace
- her work ethics are consistently the highest.
- rarely misses work and has a positive attitude
- has a positive attitude as evidenced by her readily available smile and infectious laugh
- rotates through all areas of kidney transplant. She does this with grace, elegant style and insight.
- participates in Christmas family gift program and basket raffle for Camp Michitanki

Congratulations!
Two Valentines Day Fundraisers

Basket Drawing

Once again Linda Carver, RN filled a wonderful large basket full of Valentine goodies to solicit donations to assist in sending children to Camp Michitanki. The red basket was filled with all things heart shaped and red – including Godiva chocolates – with a chance to win a diamond, Cupid Crunch, Starbucks’ coffee, Thai chips, and specialty candies. As staff made donations to Camp Michitanki, their names were placed in a basket. When one name was drawn – the lucky person was Anne Murphy, our Transplant Center Administrator! Congratulations to Anne!

Thank you to Linda for creating the basket! Thanks to all who donated to Camp Michitanki! The basket generated $163 in donations!

Candy-Grams

Tiffany Peters developed a new fundraiser idea that was very positive and a lot of fun! The idea was for employees to show their appreciation to other employees in a tangible way. For a donation to Camp Michitanki employees could write out a personal note on a ‘candy-gram’ and select the ‘treat’ they would like the recipient to receive with the candy-gram. They could choose M&Ms, Peanut M&Ms, Twizzlers, or a carnation. Tiffany prepared a bag for each recipient and delivered them to the unsuspecting co-workers! Everyone loved this!

Thank you to Tiffany Peters for her creativity and initiative in bringing this idea to life! Candy-grams generated $175 in donations!
Transplant Center’s Mission

The Transplant Center’s clinical mission is to provide our patients with the best possible medical care in a setting that emphasizes excellence, compassion, accessibility, responsiveness and prompt delivery of care.

University of Michigan Transplant Center Contact Information

Liver Transplant Programs

Adult
Liver Transplant Clinic - Gastroenterology Division
1500 E. Medical Center Drive
3868 Taubman Center, Box 0391
Ann Arbor, Michigan 48109-0391
Phone: 734-936-7491 (Local)
Phone: 800-395-6431 (Toll Free)
TTY: 800-649-3777
Fax: 734-936-2464

Pediatric
Liver Transplant Program - Pediatric
Medical Professional Building
1500 E. Medical Center Drive
Room D3256, Box 0718
Ann Arbor, Michigan 48109-0718
Phone: 734-615-2462 (Local)
Phone: 877-543-7789 (Toll Free)
Fax: 734-763-7359

Heart Transplant Programs

Adult and Pediatric
Cardiovascular Center
200 North Ingalls Building, 8B02
Ann Arbor, Michigan 48109-0477
Phone: 888-287-1082

Kidney and/or Pancreas Transplant Programs

Adult
Kidney and Pancreas Transplant Program
1500 E. Medical Center Drive
3868 Taubman Center, Box 0391
Ann Arbor, Michigan 48109-0391
Phone: 734-936-7491 (Local)
Phone: 800-333-9013 (Toll Free)
Fax: 734-647-3417

Pediatric
Kidney Transplant Program - Pediatric
C. S. Mott Children’s Hospital
1500 E. Medical Center Drive
Room F6865, Box 0297
Ann Arbor, MI 48109-0297
Phone: 734-615-2040 (Local)
Phone: 877-543-7789 (Toll Free)
Fax: 734-615-2042

Lung Transplant Program

Adult
Lung Transplant Program
1500 E. Medical Center Drive
3862 Taubman Center, Box 0391
Ann Arbor, Michigan 48109-0391
Phone: 734-936-7491 (Local)
Phone: 800-333-9013 (Toll Free)
Fax: 734-936-6671

United Network for Organ Sharing (UNOS)

The United Network for Organ Sharing provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.
WHAT DO YOU THINK?

We welcome your feedback. Please share with us your thoughts on the Transplant Center Newsletter. Whether you wish to share your thoughts on a published article, make a suggestion, share news of your area, tell us what subjects you find interesting or valuable, we are interested in hearing from you!

Send your thoughts to Mary Kruger at mckruger@umich.edu. Please include your name and telephone number so we can explore potential stories.

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