UMHS Transplant Specialty Pharmacy Services

The University of Michigan (UM) Transplant Center is continually seeking opportunities to better serve transplant patients. In calendar year 2008, 407 kidney, pancreas, heart, liver and lung transplants were performed at the University of Michigan. Each transplant patient is dependent on immunosuppressive medications, which generally must be taken for the rest of their lives to prevent organ rejection. Along with immunosuppressive medications, patients typically require additional medications, such as anti-fungals, anti-virals, anti-hypertensives, diabetic medication and supplies, anti-coagulants, anti-platelets, hemostatics, and specialty compound medications for pediatric patients. The long term success of a transplant is tied to the patient having access to the medications they need.

Our patients face significant challenges related to their medication needs following transplantation, specifically in the areas of access and costs. Even with insurance coverage some patients spend hundreds of dollars each month in medication co-pays. Having access to transplant medications is also an issue for patients because transplant medications are needed by only a small percentage of the general public. For this reason, transplant medications are not always readily available at your corner drug store and take special arrangements, and a period of time, to obtain. Billing for transplant medications is significantly more complex than billing for routine medications. The
Letter from the Director

Dear Friends,

I am pleased to share with you the progress we have made in the past year. We continue to do as many transplants as ever, and we are gratified by our continued excellence in both patient survival rates and in patient satisfaction. The year was notable for many different reasons. In 2008 we performed our first paired donation kidney transplant. Paired donation allows two patients to receive kidney transplants that would otherwise have been unable to receive a transplant because they are incompatible with their donor. Incompatibility happens in as many as a quarter of donor-recipient pairs. The University of Michigan has developed a computer program that can pair incompatible donor-recipient pairs with a second donor-recipient pair that is also incompatible with each other, but are compatible with the first pair. The result is two patients receiving living donor kidney transplants, which were previously impossible. Not only does this benefit the two patients that were in need of kidney transplants, but it removes these two individuals from the ever growing waiting list for a kidney transplant from a deceased donor, providing opportunity for those remaining on the wait list.

In 2008 we also opened a new service for transplant patients. We now offer mail order pharmacy services to new transplant recipients. Our goal is to provide the best possible service to our patients by ensuring that medications are dispensed accurately and on time. To date, the newly organized mail order pharmacy has been offered to newly transplanted kidney patients and satisfaction rates have been exceptional. Read about the new UMHS Transplant Specialty Pharmacy Services in this newsletter.

Another wonderful development this year is the recruitment of a new medical director of kidney transplantation. Following a careful international search Milagros Samaniego, M.D. was recruited to fill this position. Dr. Samaniego is a dynamic individual with an impressive list of accomplishments. We are absolutely delighted that she is bringing her extraordinary ability together with her wonderful personality to our program.

Three endowed professorships have been awarded to Transplant Center faculty in the past year. Transplant Nephrologist Akinlolo Ojo, M.D. was named the Florence E. Bingham Research Professor of Nephrology, Francis Pagani, M.D. was named the Otto Gago Professor of Cardiac Surgery, and Jorge Marrero, M.D. was named the Keith S. Henley M.D. Collegiate Professor of Gastroenterology. Endowed professorships are vital to our mission because they allow the recruitment and retention of superstars, and they allow these brilliant individuals to spend some of their time working on research projects. These research projects will tend to lead to advances that improve and even save the lives of our patients. In the next decade, we hope to attract funding for additional endowed professorships in order to continue to further our mission.

Thank you all for your support of our Transplant programs and best wishes for a productive and fulfilling year.

Warmest regards,

Jeffrey D. Punch, M.D.
Director, Transplant Center
complexities can cause inaccurate and/or untimely billing. This often results in transplant patients paying higher out-of-pocket costs than they need to. The neighborhood pharmacist may have limited experience in the various medication combinations taken by transplant patients. Each of these situations can cause increased risk and needless frustration for our patients. To assist our patients in addressing their medications needs, the UM Transplant Center and the UM Pharmacy have joined to develop a UMHS Transplant Specialty Pharmacy.

Specialty pharmacy services are unique from your neighborhood retail pharmacies in that they offer specialized mail order distribution along with other value-added clinical support, financial counseling and education services for patients. In addition to providing all these services, our patients have the advantage of enrolling in a pharmacy that is an extension of their transplant medical team. Using an in-house specialty pharmacy enhances patient care for our enrollees because the pharmacy has access to complete medical records allowing them to facilitate accurate and efficient coordination of the patient’s treatment plan. It also provides the foundation for the pharmacist to directly communicate with the medical team regarding medication changes and refill requests.

Our UMHS Transplant Specialty Pharmacy has pharmacists and customer service staff specializing in transplant medications; dedicated solely to assisting our patients through their treatment process. We approach patient care in a proactive manner; contacting patients directly to monitor their progress, reminding them of scheduled refills, and ensuring they are progressing with their treatment plan. We provide financial counseling and support services assisting patients in navigating the complexities of their insurance coverage, obtaining prior authorizations, exploring other payer options, and when needed responding to patient inquiries about insurance and financial concerns.

The program started in November 2008 by offering this service to UM patients with a newly transplanted kidney. The program is now beginning to expand enrollment to include all kidney patients previously transplanted at UM. The program will eventually be able to offer this service to all UM transplant patients.

Newly transplanted patients who enroll in the program will have their medications delivered to them in the hospital prior to discharge from their transplant event. Each enrolled patient will receive a transplant medication bag including a pill box, pill splitter, blood pressure monitor and thermometer. Having their medications available allows patients to leave the hospital without delay and prevents their family from needing to find a local pharmacy on the day they are discharged.

The patients are contacted a couple days after discharge to ensure they understand their medication regimen and to answer any questions they may have. Prior to the monthly refill due date, the pharmacy will contact the patient checking for changes in medication before processing the refill. Medications will be delivered monthly to the patients home, office, or other identified location at no additional cost.

Even with all these services available to transplant patients, occasionally patients experience periods of time where they cannot afford their medication co-pays and insurance premiums due to changes in health or job loss. When this occurs the financial impact to the patient’s family can be tremendous. If a patient makes the difficult choice to reduce or eliminate their medications due to financial concerns, it can have a grave impact on their transplant. To prevent such difficult choices, we try to utilize every
resource available to the patient, such as assistance programs, drug company programs, and charity care. Unfortunately, many patients will not meet the guidelines for these assistance programs. When all options are exhausted the patient still needs their medication to remain healthy. This is an area where additional resources would directly benefit the patient.

By making a donation to the Transplant Center Patient Emergency Fund, you will be helping transplant patients retain their health by financially making their medications available to them. The fund is not intended as a solution, but rather a temporary stopgap measure to assist patients in an urgent situation. Candidacy would be based on hardship determined by social work in collaboration with the transplant team. The team strives to ensure proper use of the funds to provide the most assistance to the greatest number of patients experiencing hardship. If you would like to assist patients in this way, please make a donation to the Transplant Center Patient Emergency Fund.

– Tammy Zukowski

A Vision for Success and a Love of Giving Back

To step into Jeffrey Cappo’s world is to step into the life of someone who knows that when he shares with others, he gives them an opportunity to realize their dreams. Having experienced personal success, he wants to help create opportunities for others, especially children. Jeffrey has supported our Camp Michitanki Golf Classic as the presenting sponsor for the past five years. The success of the event has made the dream of a week at summer camp a reality for many transplant children. Jeffrey knows that his generosity helps today, but he sees it just like he sees everything in his life: with vision for the future. He explains it like this:

Camp Michitanki is like an ice cream cone, and the kids start out way down in the bottom of the cone, in the smallest little corner. The camp lets them climb up, climb out, and get to the big scoops of ice cream on the top. When they get a chance to see bigger and better things, they begin to develop their own dreams for success.

Jeffrey Cappo is a passionate man. He loves his work and he is very committed to causes he is passionate about. Today he owns twenty auto dealerships including Victory Honda and Victory Toyota but he started with little more than his vision for success. He hasn’t forgotten where he came from:

I started out selling Kirby vacuums door to door and I had a dream. Thirteen years ago I started out with myself and two suitcases. Now I have 1,000 employees because I had a dream. We’re the #3 dealership for Toyota in Michigan, and the #1 Honda dealership in Michigan and have been for years. The difference is that I have a vision. We want to be like the University of Michigan by being the best of the best in our field. My attitude is that we should always take care of our customers. I don’t have any patents or special ways of doing things. I don’t do anything except follow a script better than most. As an employer, I’m very strict and everybody knows the rules. At every dealership I own, the cars are sold the exact same way. We do our best to take care of our customers, knowing that repeat business is critical to our success.

When Jeffrey refers to the University of Michigan, he always speaks in superlatives. Besides supporting the Transplant Center’s Camp Michitanki, he values the University as a whole, recognizing the value of health as well as education:
Both my sons were born at the University of Michigan. Then, when they were ready for a college education, the University of Michigan turned these children into men. The Michigan Business School took my son from a child and turned him into a powerhouse, and I just watched it all develop. So here’s the way that I look at Michigan: in the area of academics they take people and they develop them mentally. In the health system, they help people develop physically so that they have a chance to be developed mentally. If more people looked at it that way, they would realize that you’re giving people chances that they would never have.

Jeffrey is no stranger to giving money to good causes. He sponsors youth hockey, youth foundations and other causes in Michigan and elsewhere. He knows that people give to charities that are meaningful to them because they love to see their money being put to good work:

The biggest reason that I encourage people to give money is that it will help today. There are family foundations that honor someone who has already died, but really if you don’t give any money, how are they supposed to do all this research? The thing that I want people to understand is that everybody has limited discretionary income that they can give, unless they see value. And what I want them to get from me is that I saw the value. For every dollar I’ve given away to anybody, I’ve seen five in returned value. Tell everybody that giving is win-win. They will feel good about it. They’re helping others to have vision and to achieve their dreams.

Jeffrey loves everything about Michigan from athletics to education and he appreciates the way the Health System fits in the equation:

The Transplant Center helps them live, gives them a new transplant and a new lease on life. When we help them get into school, we create more solid citizens to have a better world afterwards. I’m involved because I truly believe that the University of Michigan really shines when it comes to saving lives because they have a vision. For such a large organization, the hospital has a team who want to be there. Everybody’s got a good attitude. People at the University of Michigan have dreams, their sights are high, and they will always hit their target.

For the donations I gave to the University of Michigan, I received a great deal. I don’t feel bad about giving money as long as I can see a good return. I don’t know of any better charity than Michigan to give my money. I really don’t. Do I think they do a good job with the money? Yes. People need to know the Transplant Center needs donations to accomplish the vision you have of giving people the opportunity to get well, become better educated, to make this world a better place. Let’s help more children get to the ice cream on the top of the cone.

– Bob Garypie
The University of Michigan Transplant Center is fortunate to have a wonderful team of professionals who are tremendously dedicated to the patients they serve. Mary Ingalls is one example of such dedication. Mary has been an employee of the health system for twenty years and she was a liver transplant coordinator in 1998 when she was called upon to help a family with a sick baby named Jason. His liver was failing, which meant he may need a transplant. At that time he was in the care of foster parents and, at only 3 months of age, he had already undergone surgery on his liver which was unable to cure him. It was determined Jason would need a liver transplant to survive.

In the coming months, Jason was admitted to the hospital numerous times. Unfortunately the staff at the University of Michigan Health System began to notice signs that his foster parents weren’t providing him with the care he needed. Every time he was admitted to the hospital, he was there alone with no one from his foster family there to visit him. His only regular visitors were staff from the Transplant Center. After many months of waiting on the transplant list, the call finally came. The baby’s liver coordinator, Mary, got word that the donor liver was a perfect match and she immediately called the foster parents, as the baby was at home with them. That late Saturday night, she got the foster dad on the phone and told him the fantastic news: the baby’s lifesaving liver had become available and the baby needed to get to Ann Arbor just as soon as possible. The phone went dead. The foster father had simply hung up the phone. When she called back, the phone just rang and rang and Jason was not brought to Ann Arbor. Following protocol, after the appropriate time elapsed, the liver was given to the next patient on the list. Jason lost his opportunity for a perfectly matched liver. Mary was heartbroken.

Social workers proceeded to contact social services to recommend that the foster family be investigated for neglect. It became clear that the foster family’s home was a very unstable environment. At the same time, Mary began to wonder about how difficult it might be to become a foster parent herself. She knew, if nothing else, she would do her very best to never let such a situation happen again. Mary began by having discussions with the director of the transplant center and the hospital’s legal department. With fierce determination Mary set out to become a foster parent for little Jason.

After three months of exhaustive preparation, red tape, paperwork, interviews, and hard work, Mary learned that she was approved to become Jason’s foster parent. On January 27, 2000, Jason with his failing liver was placed in Mary’s care. At 18 months of age Jason weighed just 15 pounds and he had a bald spot on the back of his head where he lay on his back in a crib all day long. He couldn’t sit up, and didn’t even respond to his own name. He showed up with only a pair of pajamas to his name. He was still on the transplant waiting list and was getting sicker by the day. In the coming months he was called more than once with an organ offer, only to learn that the donor liver wasn’t a perfect match and the surgery couldn’t proceed.

On June 15, 2000, the wondrous day finally came. Jason received the gift of life, a liver transplant, just a month before his second birthday. Jason began to get healthier right away and came home with Mary soon after the transplant. Mary began a quest to legally adopt Jason. Jason legally became Mary’s son a year later on August 11, 2001.
A Transplant Employee Makes a Difference  continued

Today, Jason is a happy and healthy young man – nearly eleven years old. Jason’s road to health has had its share of challenges. He faced a few health scares, medical procedures, Mary has been there through every phase, caring for him, guiding him, supporting him and loving him – as any mother would do. Although Jason was so young when he had his transplant he doesn’t recall it, that doesn’t prevent him from proudly showing his abdominal scar. Jason has begun to managing his own health by playing an active role in communicating with his medical team during visits and learning about the medications he needs to stay healthy. Jason has an avid interest in all types of cars, trucks and trains. He looks forward to driving – perhaps for a living when he gets older.

For three years Jason has attended Camp Michitanki, a week long summer camp experience for children who have had transplants. Jason enjoys his time away at camp, meeting new friends and participating in all the activities. In August 2008, he came home from his third trip to Camp Michitanki and he now asks every day how long it will be until he can go to camp again. Mary just smiles.

Mary continues her role as a full time liver transplant coordinator at the University of Michigan while raising her healthy young son. It is amazing how the little baby who was so sick and had such a treacherous journey has grown up to be a nearly eleven year old curious, good-natured and wonderful young man. Mary’s dedication to her son comes from knowing how sick he once was. Her joy of being his parent shows on her face when she speaks of him. Their experience has helped Mary to more fully understand the impact transplantation has on the patients she helps care for on a daily basis. Mary is a shining star among stars at the University of Michigan Transplant Center.

– Bob Garypie
Make 2009 the Year YOU Get Involved

The Transplant Center hosts a number of fundraising events every year. There are many ways to get involved. Whether you volunteer, sponsor an event, donate an auction item, help us seek event sponsors, or just show up to bowl, eat, or play golf - you are helping. Our events are a lot of fun and they are a great way to bring our “family” together: doctors, nurses, physician assistants, social workers, clerks, and countless others join our patients and families to help us reach our goals. Please plan to make at least one of our fundraising events YOUR event this year – there’s no better time than now to make a commitment to join in the fun!

Whole Foods Market 5% Donation Day on April 2, 2009
The Whole Foods Market selects four causes to support each year with a 5% Donation Day. The Transplant Center is fortunate to be the recipient of the 5% Day at the Whole Foods Market on Washtenaw Avenue in Ann Arbor on April 2, 2009. We will have staff and volunteers on site to promote organ and tissue donation as well as to provide education about our Transplant Center. Five percent (5%) of the day’s sales will be donated to the Transplant Center, so please consider stopping by to do your shopping!

BOWLING on April 18, 2009
Bowling for Camp Michitanki is moving to a new location in 2009. Bowlers will enjoy 3 games of bowling plus all-you-can-eat pizza, pop and salad for $25 per person ($15 for children 12 and under). Bowling shoe rental is also included. New this year is an optional competition for cash prizes. Teams of four may pay an additional $100 at the door to participate in the competitive bowling event. Cash prizes will be determined based on the number of teams that enter. Early registration is strongly suggested for this event. Register online at www.firstgiving.com/michigantransplant. Bowlers may register at the door if space is available.

GOLF on May 2, 2009
The Northern Michigan Transplant Golf Tournament returns to the Pinecraft Golf Plantation in Benzonia, Michigan on May 2, 2009. Scheduled tee times start early in the morning and continue throughout the day. Enjoy 18 holes of golf including cart and lunch for just $40 per person. The hilltop golf course for this event offers incredible scenic views making this an enjoyable kick off for the Michigan golf season.
Make 2009 the Year **YOU** Get Involved  

**GOLF on June 28, 2009**  
Hockey fans and golfers alike will enjoy the opportunity to meet the hosts of this year’s event: Ken Daniels, the television voice of the Detroit Red Wings, and Dan O’Halloran, NHL referee. Our Camp Michitanki Golf Classic, a favorite of golfers, is moving to a new location in 2009. The event will be on the Golden Fox course at Fox Hills of Plymouth, Michigan. This is a first-class event that draws golfers back year after year. The scramble format allows golfers of all abilities to come and enjoy the day on a pristine championship course. Registration includes lunch, golf with cart, dinner, beverages all day, driving range privileges, logo memento gifts, and more. All proceeds benefit our Camp Michitanki, sending transplant recipient children to summer camp this August, 2009. There are many opportunities for sponsorships of this event, and individual golfer registration is only $150. Non-golfers are welcome to come for the dinner and auction for only $50.

**DINNER on June 16, 2009**  
Would you enjoy seeing your doctor serve dinner to you? Join us on Tuesday, June 16, 2009 at Zingerman’s Roadhouse in Ann Arbor. Chef Alex Young is creating a special menu for the evening. In 2008 our waiters were all transplant surgeons. This year they will be transplant medicine doctors including Dr. Samaniego, Dr. Fontana, Dr. Leichtman, Dr. Aaronson, Dr. Marrero, Dr. Dyke and Dr. Chan. The cost is $85 per person ($65 tax deductible).

**VITA REDITA GALA DINNER AND AUCTION on November 14, 2009**  
The Vita Redita is Ann Arbor’s most elegant night out on the town each year. Thanks to the success of this event, we are looking forward to moving to a new, larger venue in 2009. The Vita Redita will be at the Fox Hills Conference Center in Plymouth on Saturday, November 14, 2009. Gourmet food, an extensive silent auction, and a fresh and entertaining live auction make this one of Ann Arbor’s best-attended events. Tickets are $175 per person, which includes valet parking, a strolling dinner, and an open bar.

For more information about any of our events, please contact the Transplant Center Events Office at 734-936-3460.

— Bob Garypie
Karen Morey – She Volunteers, She Donates, She Cares

Karen Morey is an outstanding volunteer for transplantation and the University of Michigan Transplant Center. Karen has seen transplantation from a variety of vantage points. Karen is a donor family member, since her husband became an organ donor in 1993. Karen is the chairperson of the Donate Life Coalition of Michigan. She is a team manager for Team Michigan for the U.S. Transplant Games and she is an active member of the Donor Family Council of Michigan. Karen received the 2006 Crusader Award from the Donate Life Coalition of Michigan and was recognized by the University of Michigan Transplant Center at the 2008 Vita Redita. In 2006 Karen took over the management of several fundraising events at the Transplant Center during staff absence due to medical leave. She has been a volunteer at Camp Michitanki for many years and looks forward to her role as primary golf cart driver. Day and night, Karen shuttles campers and staff with difficulties walking long distances.

Karen’s background is in education but when she became a pharmaceutical sales representative she began to learn about transplantation. Karen spent her childhood summers at camp as a camper and, later as a counselor. When she became a physical education teacher, she continued her love for physical activity and working with children encouraging their physical, social and emotional development. In 1989 she began working with transplant medications and learned about the shortage of donor organs. She knew that she was helping by working with the medications that are so critical to the lives of transplant recipients. She also knew there was more to do, and she became active in promoting organ, tissue and eye donation. She worked hard to dispel myths surrounding donation and transplantation, recognizing its value every time she saw another patient rebound from death’s door to get a second chance at life.

Karen says “if you have this passion in your heart, you just have to keep working hard.” She has seen the complete circle – knowing donor families and transplant recipients. Karen continues her work on the annual Betty Buckley Donor Family Ceremony and with the Gift of Life Michigan’s Donor Family Advisory Council. She is also an active member of the Transplant Center’s Vita Redita gala planning committee, frequently hosting committee meetings at her home.

Karen is a tireless worker on behalf of organ and tissue donation and transplantation. When she is called upon, she is always willing to step up and do whatever it takes to help. Her hard work, persistence, and passion for helping donation and transplantation have had a profound impact on the patients and families of the University of Michigan Transplant Center. Thank you, Karen!

– Bob Garypie
You Can Make a Difference

**Transplant Center Patient Emergency Fund**

The Transplant Center Patient Emergency Fund was established with donations from University of Michigan Transplant Center supporters. The fund is designed as a temporary stopgap measure to assist transplant patients in an urgent situation. For transplant patients to be eligible they must have been transplanted, be in the process of being transplanted, be listed waiting for a transplant, or being evaluated for transplant and likely to be listed.

The fund is accessed only in urgent situations and when it is clear that the patient and/or family simply cannot meet the immediate financial need. Transplant Social Workers work with patients to assess the need and make funding requests as appropriate. To the degree funds are available the Patient Emergency fund may be appropriate to assist patients with:

- **Medications.** Some funding may be available to provide coverage for medications to act as a short term bridge until other coverage or resources are identified.
- **Lodging.** Patients unexpectedly need to stay in Ann Arbor after a procedure; or the family must stay locally in support of an emergently hospitalized patient.
- **Retain Shelter.** Patients may be facing eviction from their home and need short term assistance.
- **Food.** Patients occasionally find their cupboard is bare, their monthly check is not expected for a while, and the patient’s dietary needs are not being met.
- **Utility bills.** The patient’s health or their access to Transplant team may be threatened by imminent shutoff of heat, light or telephone
- **Transportation.** The patient must get to an emergent medical appointment or their family must get to the medical center for an emergent meeting.

In 2008, the Transplant Patient Emergency Fund provided $29,000 in support of transplant patients and their families during times of hardship. The funds were as shown below.

With the challenging economic environment we are all facing, the requests for assistance and the degree of hardship are increasing. We can only offer support with the funds that are donated. We appreciate the generosity of the many Transplant Center supporters who have given in the past. We hope you will continue to support our patients by making a donation to the Transplant Patient Emergency Fund.

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**2008 Patient Emergency Fund**

- Lodging: 14%
- Food: 29%
- Transportation: 34%
- Medication: 9%
- Home/Utilities: 14%
You Can Make a Difference  

Other Opportunities to Make a Difference
There are many opportunities for you to Make a Difference in the lives of a patient or in the future of transplantation. Please consider making a donation today.

Transplant Center General Fund
Fund is used to provide support for transplant related initiatives, such as patient and staff education, new program development, surveys, recruitments, and communications.

Camp Michitanki
Fund is used to provide an exciting summer camp experience for children who have had a transplant.

Transplant Center Patient Emergency Fund
Fund is used to provide short term assistance to eligible patients and families with urgent needs.

Liver Transplant Program
Fund is used to support and to continue to develop the adult and pediatric liver transplant programs.

Kidney Transplant Program
Fund is used to support and to continue to develop the adult and pediatric kidney transplant programs.

Lung Transplant Program
Fund is used to support and to continue to develop the adult lung transplant program.

Organ Donation Outreach
Fund is used to provide community education and on-going discussions on organ donation.

Basic Science Research
Funds are used to support scientific research related to transplantation, such as understanding the process of graft rejection, preventing rejection, and graft intolerance.

– Crystal Sprang

To learn more about giving to the Transplant Center, please contact:

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