

Hopkins Surgeons Perform World's First "5-Way Kidney Swap" Transplant Operation

On November 14, 2006, surgeons with The Johns Hopkins Comprehensive Transplant Center performed what is believed to be the world's first "quintuple swap" kidney transplant operation. Five transplant candidates simultaneously received new kidneys in an operation that took 12 surgeons, six operating rooms, and five donors.

Johns Hopkins Director of the CTC, Robert Montgomery, MD, PhD called this "a triumph of the human spirit."

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Transplant "Gratitude" Quilt to Celebrate Donors and Families

On a quiet morning in April 2006, Carolyn Kramer, heart transplant recipient, stood at the "Donor Memorial Quilt" display outside the main cafeteria at the Johns Hopkins Hospital. She had come to Hopkins to volunteer her time, as she does almost every year, to raise awareness about organ and tissue donation during April. But this year was the first that the

quilt was on display at Hopkins and it affected Carolyn deeply.

"I was awestruck at the beauty and the sentiment involved," says Carolyn. As one of the many grateful recipients of the gift of organ donation, Carolyn's next thought was "Why can't we, as transplant recipients, create a quilt for our donors?" *(continued on p. 2)*

The creation of the "Donor Memorial Quilt" (pictured right) was coordinated by the Transplant Resource Center of Maryland. It inspired Carolyn Kramer, Marie Rogers (shown below) and other Hopkins volunteers to plan for a transplant "Gratitude Quilt."



("Quilt" continued from p.1)

Quilts have been powerful symbols of health crises, ever since the national AIDS Memorial Quilt was begun in 1987. Each panel in a memorial quilt is created to remember someone who has been affected by a health crisis. The U.S. is still facing a crisis in transplantation as thousands of people are awaiting a vital organ or tissue donation.

Having been inspired by the Donor Memorial Quilt, Carolyn, together with Hopkins transplant recipient volunteers, Maureen Thornton, Rose Stelmack and Patricia Barget, began to plan a "gratitude" quilt. They quickly joined up with an expert seamstress from the community, Marie Rogers, who has generously offered to sew the quilt. Their vision is to create a quilt to demonstrate transplant recipients' gratitude to donors. "We struggle with a way to express how grateful and respectful we are to our donors," says Carolyn, "and this quilt will be such a wonderful visual representation of our thanks to donors."

Bridges:

PATIENT NEWSLETTER OF THE JOHNS HOPKINS
COMPREHENSIVE TRANSPLANT CENTER

Bridges aims to provide support for patients and their caretakers, to connect the CTC to its transplant family, and to inform patients about news within the transplant community.

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The volunteers worked with the Johns Hopkins Comprehensive Transplant Center to ensure that funding would be available so that any Hopkins transplant patient who wished to contribute a square to the quilt could do so. They are providing instructions on making the quilt squares to organ recipients at the annual transplant events, such as the Holiday Party, the Springtime Conference, and the Fall Picnic. In addition, they have made instructions available through all the transplant coordinators offices and on some of the in-patient transplant floors, such as Nelson 4, 5, 6 and 7.

Like the other famous memorial quilts, the transplant "Gratitude Quilt" will never be complete. Marie, the quilt seamstress, will leave one seam open to be able to add more squares.



Volunteers, Pat Barget, Maureen Thornton, Carolyn Kramer and Rose Stelmack assemble packets of quilt materials with instructions for transplant recipients to make their own squares.

The Hopkins quilt volunteers hope to have the first sections of the quilt completed by next April, the period during the year that we celebrate national donate life month. This is when the "Donor Memorial Quilt" should be on display again at Hopkins. The quilt volunteers say that they hope to have the first squares of the transplant "Gratitude Quilt" right by its side.

If you are a Hopkins organ or tissue recipient and would like to know more about how to create a quilt square for the transplant "Gratitude Quilt" please visit www.hopkinsmedicine.org/transplant or leave a message at the Comprehensive Transplant Center Volunteer Desk at 410-614-5622, and someone will return your call within a couple of days.

From the Editor

Dear Friends: We are always grateful to see inspiring stories about transplantation in the media - such as the recent "5-Way Swap" described in the page 1 article of this issue. The national press' coverage of groundbreaking transplant events is always helpful in our goal to raise awareness of the need for organ and tissue donation.

This issue also highlights what can be done on an individual level to raise awareness about our personal experiences in transplantation. The "Gratitude Quilt" described on pages 1-2 and the Hohman family story on pages 6-8 are two such examples. These articles show how individuals can make a difference in the lives of their loved ones and in the community.

Making a difference in other people's lives can be extremely gratifying. But, the transplant team wants to encourage you to make a difference in your own life. As always, this issue provides readers with tips and resources on staying actively involved in your healthcare.

On behalf of the CTC, I hope that you have a happy, healthy holiday and a joyful new year. - Jeanni Barget, Transplant Outreach Coordinator

Medications: Compliance, Emergency and Financial Information

Of course patients who are facing chronic medical situations know the importance of taking the medications prescribed for them. The transplant team always encourages patients to take an active role in their healthcare by asking questions, gaining knowledge of their medications, and keeping track of their schedules. We let patients know that they each should also prepare for an emergency situation with adequate supplies.

Equally important is keeping prescription drug coverage. Without coverage, the cost of transplant medication may be too expensive.

Daily Compliance

The following may help you manage your prescribed medications:

- Know what each medication looks like.
- Read the pill bottle label; make sure you understand the directions.
- Try and use the same pharmacist for all of your prescriptions, ask questions, inform him of any concerns you may have.
- Keep a log of medications you are taking, dosages, and physical descriptions of the pills. Give a copy to a friend or family member for safe-keeping.
- Create a way to help yourself remember when to take your medication.

Ways you can remember to take your medication:

- It can be as simple as using the 'Medications Log' for making a check-mark every time you take a dosage.
- Pill boxes with AM/PM sections that can be filled weekly are effective.
- There are other pill boxes with alarms if you need an audible reminder.

To Keep in Mind...

If you miss a dose, check with your physician or nurse coordinator.

Over-the-counter medications may or may-not interact with your prescription medication – check with your physician. This is also true for herbal based products, including pills and teas.

In An Emergency...

We never know when an emergency may strike. It can be a hurricane, snowstorm or a man-made catastrophe. There are many items that should be on hand: food, water, light source, blankets, medications and much more. Call the Red Cross for their guide or visit www.redcross.org for a complete list. The U.S. Department of Health and Human Services: www.hhs.gov and The Center for Disease Control: www.cdc.gov both have useful emergency guides as well. If you

have trouble accessing this information on-line, ask for help at the information desk of your public library.

Ideally, you should have a month's supply of your medications on hand (at least have 7 days worth). This is not always possible due to prescription insurance limitations. Check with your prescriptions insurer to see if they can accommodate and cover an emergency supply.

Have important medical information in a waterproof container with duplicates given to a friend or family member.

Consider getting a medical bracelet which will reference your ID to important medical and prescription information.

Paying for Your Medication...

Ultimately, patients are responsible for paying for their prescriptions. This is either by having prescription coverage, and never letting the insurance lapse or by having adequate funds to pay for them personally "out-of-pocket."

If you have prescription coverage:
– Do not let it lapse. If you are shopping for a better plan, make sure you do not cancel your coverage until the next one is in effect.

If you find paying for medication is a problem with Medicare:
Signing up for a Medicare D prescription plan is extremely important.

(continued on p. 8)

Resources

Thinking About Your Choices in Healthcare: *The Latest Advance Directive Tool Available to You and Your Loved Ones*

Your transplant team, in particular your transplant social worker, has most likely encouraged you to take an active part in your healthcare. Planning for end-of-life care is an important piece of this.

Caregivers and family members, too, can learn about and plan for end-of-life care.

Taking an active part in your healthcare is not just for transplant patients. Everyone should do it.

One tool available to you is the "Living Will;" another tool is the "Advance Directive."

Healthcare advisors recognize that you should have some type of a plan about end-of-life care. They also recommend that you should identify a trusted person to carry out your wishes if there is a point when you are no longer able to do so. Both of these recommendations encourage many individuals to complete a living will or an all-inclusive advance directive.

Jack Schwartz of the Maryland Attorney General's Office explains that a "living will" is a legal tool for you to write out your preferences about life-sustaining medical treatments. In other words, the living will is a statement from you about what you

want to have happen if specific conditions occur in your health. Once stated, it is final unless you revise it. If you decide to change your mind about how your health should be handled, you should make a revision to your living will.

An advanced directive is all inclusive – it has a section for your

*"It's important for everyone to complete a living will or advance directive, regardless of age, illness or financial status. It gives us a voice if we're in a position where we can't use our own."
- Angie Muir, LCSW-C, Social Worker*

"living will" where you can state your preferences about treatments and it has a section where you can name an individual who will carry out your wishes. In this section, you can provide guidance as to how that person is to decide specific issues.

The advance directive document also allows you to state your preferences about organ and tissue donation.

What if you have a living will and an advance directive? According to Mr. Schwartz, the criteria in the law states that it is the job of the healthcare provider to do what the patient would want if there is significant evidence. The living will most likely would be upheld first.

In his experience with the living will and the advance directive, the most important part of planning these documents is to talk to your

family and loved ones about it. Says Mr. Schwartz, "If the first time loved ones hear about a living will or advance directive is in the emergency room, sometimes, they are going to be shocked and rebel against it."

"One common misconception is that you have to go to a lawyer to have an advance directive or living will put in place. This is not the case. You can get forms online or from an office supply store - and while they have to be witnessed, they

do not have to be notarized or go thru a lawyer at all," says Angie Muir, LCSW-C, Johns Hopkins Transplant Social Worker.

A copy of the all-inclusive advance directive form is available free, online from the Attorney General's Office. There is a new (more user-friendly) form available now. To obtain a form, visit www.oag.state.md.us, call 410-576-7000, or write to Attorney General's Office, Health Policy Division, 200 St. Paul Place, Baltimore, MD 21202.

Your transplant social worker can help you understand more about these documents.

When you complete an advance directive, make sure it is available to others. Do not put it in a safety deposit box where only you can reach it. Give copies to your loved ones and your medical team.

Transplant Album



A Family's Lung Transplant Journey

You can tell when you first meet Christine ("Chris") Hohman that she is a woman with plenty of stories to share. This 37-year-old, wife and mother of two loves to tell visitors about the various antics of the small collection of farm animals who live in her backyard and the family's dog. But her stories take on a serious tone as she explains the level of gratitude she feels for the people who became her support after she knew she was seriously ill and would need a lung transplant. Initially diagnosed with emphysema in 1996, Chris tells her story of her declining health, her visit to Hopkins for transplant evaluation and then finally her transplant on August 20, 2005.

After the first diagnosis, Chris and her pulmonologist managed her health for a number of years until her condition required her to consult with the lung transplant team at Hopkins for specialized care. By July 2, 2003, the date she saw Hopkins pulmonologist, Dr. Girgis, she could tell that the emphysema was worsening her quality of life, little by little. It started out by creeping into her unconscious.

While she slept, panic would cross her mind and she would wake up suddenly to flee for the deck outside the kitchen door where she could take in the cold, brisk air available there. Her busy life of raising two small kids with her husband and working a job that required her to be pulled in many directions soon became overwhelming. What her body could accomplish in 1996, it could not in 2001. Her deteriorating health forced her decision to quit her job; it was sad for her to leave her position in graphic design and management that had allowed her to express the creativity she is well admired for. Then, her condition started to impact on her family's well-being, too, and this was distressing to Chris.

Stress on the Family

Dealing with chronic illness impacts each member of the family in different ways. As her condition declined, Chris wasn't able to do much more than sit in a chair in the living room, conserving her strength for her next task in the day. "It was my family, my two young boys, ultimately, who saw me at my worst and my best," she remembers. "If it

wasn't for my boys offering me hugs when my health was worsening it would have been unbearable." Her husband, too, found that he could help divert her for a brief moment from the confines of the chair in the living room. He



rigged the luggage container of his motorcycle to hold her oxygen tank and together, they would take on short rides around the community. Her family was able help her in ways that oxygen, nebulizers and medicine could not.

It was her oldest son (age 5 at the time) who was home with her on the day Chris collapsed in the shower. Her 5-year-old called 911. Chris instructed her son to also call his grandparents, and soon, Chris' brother-in-law arrived to make sure the children were safely away from the confusion while the paramedics did their work. "I just kept thinking, 'help me, I can't breathe' and I remember pulling at the paramedic's clothing in my panic," recalls Chris. Chris tells of a closed in, hot sensation when she speaks about the moments when she could not catch a breath. At the moment the paramedics took her out of the house on the stretcher, it began to drizzle. Cool rain helped calm her. Looking back, she expresses how much it means to have somebody there when she needed help – her sons, her family, the paramedic.

To help Chris recover from the collapse, the physician put her in a drug-induced coma and kept her at the hospital. She was uncon-



scious for more than a week. She hints at the difficulties her family faced during that time. Then, her family and her medical team knew that it was critical that she receive a transplant.

Coping with Difficulty

In August 2003, Chris and her husband met with the other members of the Hopkins transplant team, including the surgeon, the transplant coordinator, the social worker, etc. The idea of having a transplant was not shocking to the couple, as it is to some people. Chris' family just wanted Chris to be able to do the kinds of every day things that everyone takes for granted – taking a shower, walking to the mailbox, even doing the laundry. During their first meetings, the team members talked at length with the couple about all of the medical aspects of transplantation, including the evaluation testing, the waiting process, the surgery, recovery, and what life might be like after the transplant. The team would continue to meet with Chris every three months to help monitor her health and answer any questions.

At the beginning, some of the topics that came up during the appointments they had with the various team members surprised the couple. It is part of the transplant team's responsibility as healthcare providers to help patients understand some negative issues, and families sometimes do not expect this. The transplant team must discuss emotionally stressful

issues, including death, that patients and families may face when confronting chronic illness.

It is hoped that a conversation about some difficult aspects of illness might help families prepare themselves, no matter what would happen, good or bad. At the start of their transplant experience, Chris and her husband were coping with many emotions. The couple was not ready to accept that any of these



negative ideas might potentially become true for them. They occasionally walked away from a meeting with the team angry and determined that they would do what they could to ensure that everything would be ok.

Today, Chris appreciates the intent of these discussions. And Chris also tells how grateful she is to the various members of the team, such as the social worker who helped her sort through a lot of the repercussions of the stress that had laid heavy on her family during the experience.

In her regular appointments at Hopkins, the transplant team would have the opportunity to be a resource to Chris - as they are to

all transplant patients. For example, at one point, Chris and her family were worried when their insurance coverage changed. The stress of not knowing whether your insurance will be able to cover the cost of transplantation can be unbearable. The team immediately connected Chris to the resources available through the transplant business office so that she and her family would get the answers to their financial questions.

Tactics to Ease the Journey

Chris would follow through on her promise to do whatever she could to make the transplant a healthy experience. Her neighbor provided Chris with a treadmill that had been sitting unused in the basement and Chris walked on the treadmill religiously. She would start a walking program and continue to do tasks around the house in order to maintain her physical stamina, something she knew she would need for the transplant surgery and recovery.

Unlike many people who wish to isolate themselves when they are facing serious illness, Chris made a point to share her story with people in her community when asked. With her oxygen tank in tow, Chris still made trips to the local store to pick up household items. One day, a store worker offered to help Chris to take her bags to the car and in the process asked about her health. From then on, the same woman at the store would escort Chris to the car, load the bags and then take a moment of silence to pray with Chris for a healthy transplant. Her son's school "Cedarmere" pulled together and held a fundraiser campaign in a show of solidarity for the Hohman family. They collected gift certificates for meals and home

("Journey" continued from page7)

cleaning service to make it easier for the family when Chris would be admitted to the hospital.

Chris' health declined rapidly in 2005. She struggled with the idea that her sons were losing touch with who she had been as a vibrant young 30-year old, and that they might lose their mother altogether. She recalls the month of July 2005 as being the most dismal episode in her life. She gave in completely to the feeling of being "boxed in" and trapped by what life had presented to her. Then, in August, the transplant team called her to the hospital.

On August 20, 2005, Chris was told that there was a matching donor for her and she underwent a bi-lateral lung transplant. Chris describes it as re-birth.

Once on the recovery floor, her surgeon asked that she immediately start moving again to help

her new lungs recover from the surgery. He let Chris know that he expected her to walk laps around the in-patient floor, not one or two, but a dozen. She remembers her transplant nurse encouraging her to keep her head high and her buttocks out so that she would regain her posture and her strength. When she walks on the treadmill today, she smiles at the memory and checks her posture.



Putting it in Perspective

The experience was far from

normal for a young married couple with two small children. It was hard on their relationship. It was hard for their kids. "They were either going to be insane, or going to be doctors," she half-jokes. Today, she still marvels at what they all went through in the early part of their youth.

She is also awed by the donor family who, at a time of loss, was still able to help someone else. She took time to write them a letter to explain what this meant to Chris, her sons, her husband, and her entire community of loved ones and supporters.

She is still careful about spending too much time so early in her recovery in public areas with a lot of germs. However, when she is out, she will connect with anyone who is interested in hearing about lung transplantation. She thinks, "Anything I can do to honor the donor and all of those people who helped me along the way..."

("Medications.." continued from page3)

Some Medicare D plans may cover immunosuppressants, even if the transplant was not paid for by Medicare. There are significant differences in the plans. At a certain amount of coverage, a non-coverage gap occurs. This seems to be the hardest part for patients to handle. It can be up to \$3600 out-of-pocket before coverage resumes again.

There may be a better plan for you.

There are plans that cover formulary or generic drugs when the gap is reached. Call 1-800-633-4227 or visit www.medicare.gov for Medicare's Plan Finder.

Depending on your income, you may qualify for additional help from Social Security in paying for your Medicare D premiums. Call 1-800-772-1213 or visit www.socialsecurity.gov to see if you qualify.

If you find that you are without coverage, for whatever reason, there are pharmaceutical Patient Assistance Programs (PAPs) for those in need. Some medications are delivered at little or no charge. The easiest way to access these programs is through the Pharmaceutical Industry's 'Partnership for Prescription Assistance' website: www.pparx.org. You can search by medication and the links will lead you to an application and information. You may also call 1-888-477-

2669 for applications for the medications you are taking.

Don't forget to look into the various state programs that may be offered (for example, the Maryland Pharmacy Assistance Program "MPAP.")

If you find yourself in a situation where you cannot afford your medications – look into the above suggestions.

Need further help? Call your social worker immediately. Do not wait until you are almost out of your medications. It is crucial to your well-being that you continue on your prescribed meds.

-Joanne Kramer, Liver Transplant Office Manager

Hopkins Liver Researcher Aims to Increase Donor Organ Pool

Johns Hopkins is able to research and apply the latest advances in transplantation to its medical care for patients. The transplant team has recently focused one of their areas of research investigations on the goal of increasing the donor organ pool. In particular, Dr. Zhao Li Sun, liver transplant researcher has been working to identify more effective use of a special donor liver categorized as the "steatotic liver."

The success of liver transplantation has created an increasing imbalance between organs available for transplantation and the number of patients in need of transplantation. The number of people who have agreed to donate their organs - either while they are living or after they have passed away - is far less than the number of people needing organ transplantation. Each year, several thousand people face serious medical complications, and even death while awaiting a liver transplant. The gap between number of donor livers available and the number of people on the waiting list is further complicated because 13 percent to 50 percent of the donor livers show signs of steatosis. (This is also commonly referred to as "fatty liver" or a condition where there is an excessive amount of lipids in the cells of the liver.)

How common is the presence of steatotic ("fatty") livers in the general population? "Although only about 11% of young people have steatosis, the prevalence exceeds 40% in people over 60 years of age," says Dr. Sun. Because of this, the transplant team's ability to successfully use fatty livers for transplantation

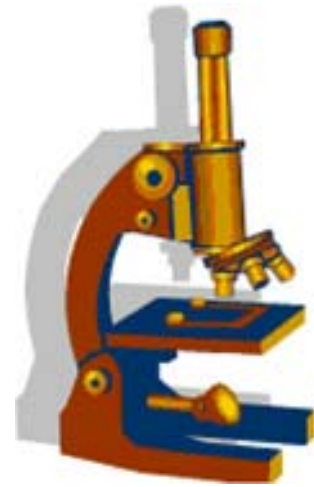
would significantly increase the organ pool. The hope is that in the future, it could increase the number of transplantable livers and shorten the time people are forced to wait on the transplant list.

More than three years ago, the Hopkins liver transplant team, including Dr. Sun, recognized the opportunity to address this problem. At that time, fatty livers were not commonly used in transplantation because prior experience showed that they would not perform well when transplanted. Dr. Sun and a team of Hopkins researchers wanted to see whether they could improve the fatty liver's performance once transplanted.

These past years of research at Hopkins provided hope for the successful use of fatty livers. Hopkins scientists found that they could treat fatty livers with a special protein (called "IL-6"), and that by doing this, they could increase the blood flow and the liver function of the liver when transplanted. This special treatment has not yet been fully tested in humans.

It is common practice for transplant specialists to use livers that have levels of steatosis no greater than 30%. At levels higher than that, steatosis of the liver is still a risk factor for poor liver performance.

Dr. Sun hopes to continue his research and uncover what exactly causes livers at higher levels of steatosis to perform differently from non-fatty livers. He recognizes that recent evidence suggests that there are different chemical reactions that occur within the cells of fatty versus non-fatty livers. Different types of cell death occur



following the cold preservation time for the two types of donor livers. Also, evidence shows

that strategies for improving regeneration in lean livers are not effective in the presence of fat deposits in liver cells. Thus, fatty livers not only poorly tolerate long periods of cold preservation time, but also develop different types of injury than those observed in lean organs. Dr. Sun seeks to define new insights into mechanisms of injury related to steatosis.

"Our long-term goal is to develop protective strategies for the safe use of steatotic liver allografts for transplantation. We first demonstrated that in vitro IL-6 treatment prevents mortality following fatty liver transplant in rats. Thus, we believe the regulation of IL-6 signal transduction pathways may be an appropriate target for improving of fatty liver graft function and improve outcomes following transplantation of steatotic liver allografts," says Dr. Sun.

Dr. Sun next seeks to define the mechanism of primary non-function following fatty liver transplantation and develop a novel therapeutic strategy for the safe use of fatty liver for transplantation.

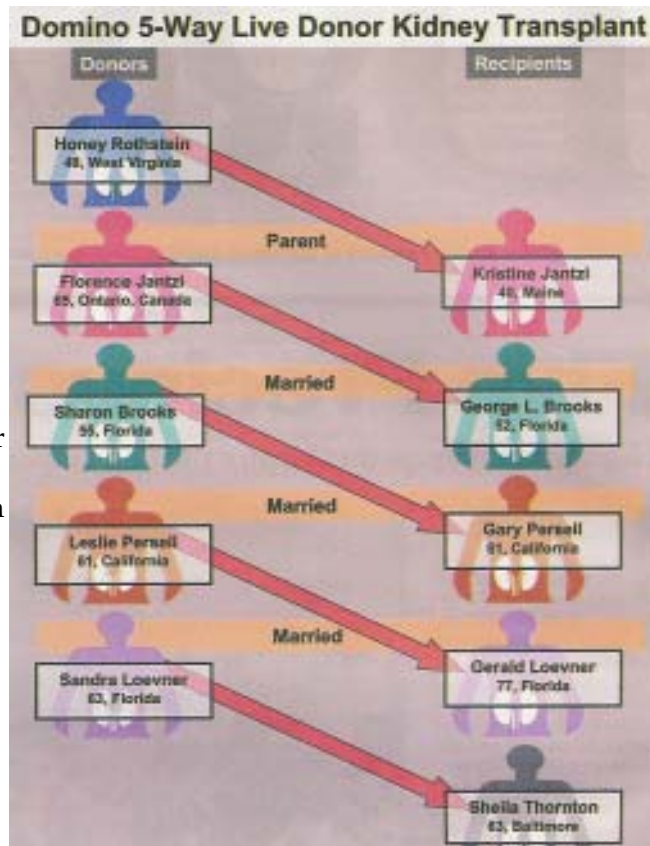
("Swap" continued from p.1)

Four organ recipients had come to Johns Hopkins separately for evaluation, each with a willing donor who was not of a compatible blood or tissue type.

The Hopkins "Incompatible Kidney Transplant Program" provides a way to swap kidneys among the pairs, if patients are willing to exchange their donor's kidney for a kidney from another donor. This would allow all to receive a compatible kidney from someone they had never met.

There was a special element to this story: the gift of a kidney from an altruistic donor, Ms. Honore ("Honey") Rothstein.

An altruistic donor is somebody who is willing to give a kidney to anyone who needs it. While four



recipients already had (incompatible) donors, the fifth recipient was waiting on the national organ list for a deceased donor kidney and was able to be transplanted because Honey stepped forward.

All five were paired with a compatible donor through a "domino" process (see chart at left). Honey donated to Kristine, a young woman from Maine, and Kristine's original donor (her adopted mother) donated to the next recipient, and so on. See related article on swap participants below.

Heroes of All Types Involved in the "5-Way" Kidney Swap, Including Mothers and Daughters

Donor #1 was Honore "Honey" Rothstein, 48 of West Virginia. Honey (pictured right) had lost her first husband and her daughter early in life. Both had signed up to be organ donors, but her daughter was not able to donate. Honey said that she had felt great peace of mind when she received letters from transplant recipients who had lived on through the gift of organ donation from her husband. She wanted to donate a kidney as a way to honor her daughter, who had been unable to do so. "I'm thankful. [Kristine, my recipient] has a piece of me and a piece of my daughter to live on," she said when she met Kristine Jantzi, the recipient of her kidney, pictured left. Honey's daughter whom she honored through her altruistic donation is pictured in the photo on the table.



Because the Hopkins team is sensitive about protecting patients' privacy, donors and recipients were asked if they wanted to meet. All replied they would and a meeting was set up about one week after the surgery day.

At the first meeting of the swap patients, Kristine was asked how she felt initially when she heard about the potential of the kidney swap. Kristine replied, "My reaction was wonderful, but don't get too excited yet. Even after the transplant I tried to hold back from hoping too, too much. But this morning that changed because I met Honey whose daughter [and] whose story made this all possible."



Donor #2 was Florence Jantzi, 65 of Ontario, Canada. She wanted to donate to her adopted daughter, Kristine, but they were not a compatible match. During their meeting, Florence and Honey exchanged sentiments about their similar need to help their daughters. Through the swap, Florence was able to be donate a compatible kidney to George Brooks of Florida. (Pictured in left corner, this page, Florence Jantzi listens proudly to comments from jubilant daughter, Kristine Jantzi.)

("Heroes" continued from p.10)

Donor #3 was Sharon Brooks, from Florida who was thrilled at the opportunity. "Not only did I get a kidney for [my husband, George], but I got to give a kidney to somebody else. So, it's just a great, great, wonderful thing." Sharon donated to Gary Persell, 61 of California.

Donor #4 was Leslie Persell who was not a match for her husband, but who was a match with Gerald Loevner, 76 of Florida. Looking back, Leslie spoke with eloquence of the need for more opportunities for living kidney donation.

Donor #5 was Sandra Loevner who wanted to help her husband resume a normal life. "When you watch someone on dialysis and you see they can't even go for icecream with their grandchild, you realize what a [different path] their life has taken." While not a match with her husband, Gerald, Sandra was able to donate to Sheila Thornton, 63 of Baltimore who had been waiting for years on the national kidney list and who had no living donor.

At their meeting, Sheila spoke of her feeling toward Sandra's and all donors' kindness in saying, "How do you thank someone who saved your life?"

Photo: (seated, left to right) Sheila Thornton, George Brooks, Sandra Loevner, and Leslie Persell (standing, left to right) Dr. Montgomery, Janet Hiller and Katie Stegner.



Transplant News

New Guidelines for Heart Transplantation Recently Published

Elderly patients with heart failure and men with treated prostate cancer are among those who have been historically denied heart transplantation. Now, under new guidelines co-authored by the Johns Hopkins Medical Director for Heart Transplantation and issued in September by the International Society for Heart and Lung Transplantation (ISHLT), they should be considered.

"People who once would die because they did not qualify now have a chance to get a new heart," says Stuart Russell, M.D., who served on the ISHLT committee revising the guidelines. "Research now suggests they are actually good candidates," he adds.

ISHLT guidelines, which date back to 1992 and were last updated in 1997, restricted access for cancer patients who have been tumor free for less than five years or had weakened immune systems from cancer therapy that precluded them from taking anti-rejection drugs for a transplanted organ. The new recommendations allow some people with slow-growing or treated cancers to qualify, and they raise the qualifying age cap from 65 to 70.

Support for the new criteria comes from research confirming that transplant recipients over age 65 have an 85 percent survival rate one year post-transplant. After 10 years, he says, 50 percent are still alive.

"Too often, people suffering from heart failure and cancer give up on the prospect of a long, productive life, thinking they have exhausted all treatment options possible, and

even their primary physicians are not aware that transplantation is a viable option," says Russell.

The updated criteria follow changes in 2002 guidelines for organ donation, which permitted transplantation of hearts from those over 50, even when the hearts were enlarged or the arteries feeding it were clogged, provided the clot was removed. And they are likely to increase demand for already scarce donor organs.

As of Sept. 1, at least 2,885 Americans were on the national waiting list for a heart transplant, according to the United Network for Organ Sharing. Up to 20 percent of those on the list will die while waiting, Russell notes.

The guidelines reaffirm ISHLT's view that demand for transplantation is unlikely to ever be fully met and that more resources are needed to slow down the progression of heart failure and prevent the need for transplant surgery in the first place.

Russell says new drugs, implantable defibrillators and pacemakers, and smaller heart pumps can assist a weakened heart for longer periods, or until a new donor organ becomes available.

He estimates that the relaxed guidelines could result in up to 15 more heart transplants for patients served by Hopkins in southeastern Pennsylvania, Maryland and northern Virginia, none of whom would have qualified for an organ under the old restrictions. Nationally, he estimates, up to 400 more patients could now qualify and receive a new heart.

Comprehensive Transplant Center Patient Events 2007 Calendar

Feb. 27	Multi-Organ Educational Session. 7 p.m., Information about 2007 Multi-Organ Educational Sessions will be mailed out in mid-January 2007. Call 410-614-5622 after January 31st if information has not arrived.	July 24	Multi-Organ Educational Session. Session details will be mailed out after Jan 15th.
Mar. 27	Multi-Organ Educational Session. Session details will be mailed out after Jan 15th.	Aug. 1	Minority Donor Awareness Day. This is a national observance designed to raise awareness of the need for more organ and tissue donors among minority communities.
Apr. 1-30	National Donate Life Month. Communities around the nation observe this opportunity to discuss organ and tissue donation.	Sept. 16	Annual Transplant Fall Picnic. Details to be announced.
Apr. 24	Multi-Organ Educational Session. Session details will be mailed after out Jan 15th.	Oct. 23	Multi-Organ Educational Session. Session details will be mailed out after Jan 15th.
May 12	Annual Transplant Patient Conference. 8am - 3pm. More details to come.	July 24	Multi-Organ Educational Session. Session details will be mailed out after Jan 15th.
June 26	Multi-Organ Educational Session. Session details will be mailed after out Jan 15th.	Nov. 9 -11	National Donor Sabbath. Faith communities around the nation observe this opportunity to discuss organ and tissue donation

To receive updates about CTC's events via email, please send your request to CTCOutreach@jhmi.edu



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