

Transplant Trends

Liver, Kidney and Pancreas Transplantation

‘There was no Doubt he would be my Donor’

Luggage. Matching bathrobes. Gold lamé boxer shorts. Sounds like the makings of a romantic get-away.

Not quite – although donating a kidney to his wife, Janice, could be considered the most loving thing Tommy Rowland ever did. Friends and family armed the twosome with

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– Janice Rowland

gifts for the trip, including the robes and boxers, a Scooby Doo pillow, chocolate adhesive strips and a supply of magazines and books.

Janice, principal of Cimarron Memorial High School in Las Vegas, was diagnosed with polycystic kidney disease several years ago. In August 2002, although she felt no symptoms, lab work indicated that it was time to consider dialysis or transplant. Janice had watched her father struggle



All in the family for Janice and Tommy

with the disease and knew that dialysis was not something she wanted to endure. So, she began the journey of working through insurance issues and finding a donor.

Tommy also works in the Clark County School District as a special education coordinator at the vocational school. He immediately looked into testing and was a perfect candidate.

“It was like a miracle,” says Janice. “Everything – his blood type, cells, tissues – just matched up. Tommy didn’t blink an eye. There was no doubt that he would be my donor.”

The couple traveled to Mayo Clinic in Scottsdale, armed with gifts from their students and staff members,

for the surgery on March 26, 2003. Tommy’s kidney was removed laparoscopically on a Wednesday and he was released on Friday. Janice confides that he was the “darling of the nursing staff” for the short time he was hospitalized.

“It was so amazing how smoothly this process went,” says Tommy. “By the third or fourth night, I was back to my normal sleep patterns. And it sure didn’t affect my appetite! I felt kind of guilty because I was doing so well, while Janice was still in the hospital.”

Janice, however, was doing well herself. She was in the hospital for

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'There was no Doubt,' *(continued from page 1)*

six days and then released to the Arizona Transplant House. There, Tommy became her caregiver, finding all the good take-out places and encouraging her to walk whenever possible. In fact, Janice and Tommy walked a mile her first day out of the hospital. After that, they walked at least once a day – sometimes twice – on the beautiful grounds and area surrounding the Transplant House. The two marveled at all the little critters out during the spring.

Both Janice and Tommy agree that the Transplant House was an amazing place. Says Janice, "I have to admit that at first I was hesitant about staying there. I just wasn't sure I wanted to share space that intimately with people, especially when I wasn't feeling well. But it was truly a wonderful experience. There was such a good feeling there. All of a sudden, we were really one big family, seeing things and going through things we'd never been through before."

The couple stayed at the Transplant House for three weeks. They returned home on Good Friday and were able to celebrate Easter with their family, complete

with Tommy's famous Easter ham.

Janice's goal was to be there for her school's high school graduation, just eight weeks after her surgery. She made it, and describes the ceremony as just perfect. Now, Janice is back working full-time and was

"Everyone wants to know when I'm going to start acting like Tommy. After all, I do have his kidney in me."

– Janice Rowland

looking forward to spending time this summer at their place in New Mexico, where she gets to feed the deer every day.

Tommy returned to work after only three weeks and is still stunned by the fact that he really feels no ill effects from his surgery. Both Janice and Tommy agree that if more people knew the ease of donating a kidney through the minimally invasive laparoscopic surgical process, perhaps more donors would come forward. In fact, of the 116 living donor kidney transplants, all but two were completed laparoscopically. Their son, Jason, has even told his

dad that if he ever needs a kidney now that he only has one, he'd be happy to donate.

"We just both felt so blessed to have been at Mayo Clinic," says Janice. "Everyone, from the physicians to the food servers, showed so much friendliness, caring and kindness. They all treated each other and us with so much respect. We'd also like to thank Tom Davie from the Transplant House for his sensitivity. Everyone was just exemplary."

Things are now getting back to normal for Janice and Tommy. A new school year will begin soon, and thus a new chapter in their lives, with this experience behind them. There's one question, though, that people still keep asking Janice.

"Everyone wants to know when I'm going to start acting like Tommy. After all, I do have his kidney in me," reminds Janice. "Tommy's a big man, so I was really curious to find out just how big that kidney was! We joke about things like that, but I have to tell you that Tommy really is my hero – I just can't let him know that!"

HOLD THE DATE! 2003 Transplant Reunion

Please mark your calendars for Saturday, Nov. 8, 2003! That's the date set aside for the 2003 Celebration of Life reunion in Scottsdale for Mayo Clinic living donors and transplanted patients. More information about the time, place and particulars of the event will be sent to you in the coming weeks. We look forward to celebrating our successes, your health and the precious gift of life.

‘Down and Troubled,’ Liver Patient Finds a Friend/Donor

*When you're down and troubled
And you need a helping hand
And nothing, nothing is going right...
You just call out my name
And you know wherever I am
I'll come running...you've got a friend...*

So goes the James Taylor song, *You've Got a Friend*. But chances are, even Sweet Baby James couldn't have imagined a friendship as powerful as Dennis O'Dell and Robert Hickok, both from the Portland area. When Dennis needed more than just a helping hand – but part of a liver – Robert was right there to help out. And so it was that a 20-year friendship, built on seeing each other through good times and bad, brought the two men and their wives to Mayo Clinic Hospital in northeast Phoenix for a Valentine's Day transplant.

For Dennis, who will soon turn 55, it was the answer that probably came just in time, because his health was rapidly deteriorating. In 1998, he went in for a routine physical and found that some blood counts were off. Then came the surprising diagnosis of hepatitis C. Looking back on it, Dennis acknowledges some early signs, included a quick temper, a hangnail that wouldn't stop bleeding and difficulty sleeping.

"Pretty quickly, I started noticing some effects on my mental capacity," Dennis recalls. "One day, I was driving to the doctor's office and literally couldn't remember how to get there. When things like that happen, it starts getting pretty scary."

Dennis and his wife, Lisa, lived in the Phoenix area at the time, but Mayo Clinic Hospital had not yet opened and there were no local liver transplant programs. Ironically, the couple moved back home to Oregon to be closer to the Oregon Health and Sciences University program. But, although Dennis was



You've Got a Friend – Dennis and Robert have a special bond.

actually getting sicker, his MELD score was getting lower, putting him further and further away from the liver he needed.

After researching living liver donation, Lisa went to Mayo Clinic in Scottsdale to be tested, but was not a match. It was Christmas time and things were looking grim. Spirits were low, and Dennis had turned an ashen gray color and wasn't very alert. Then Robert and Debbie began researching what was involved in being a living liver donor. After discussing it with Lisa, they gave the news to Dennis one night at dinner – both Robert and Debbie planned to be tested. Robert, 46 at the time, was tested first and turned out to be a good match.

"I was definitely doing this for Dennis, but there was also a part of me that recognized the chance to do something truly significant with my life," says Robert. "In terms of my life's achievements, I'd have to say this ranks pretty high."

Following the surgery, Dennis showed immediate improvement, while Robert had a little rougher recovery. Robert progressively improved as the weeks went on, but Dennis developed complications

and ended up staying in the hospital for six weeks, two and a half of those in the ICU. Although recovery has been slow, Dennis has started back to work full-time from home and is starting to feel a bit more like himself. The process does take a toll on the caregiver, too, as Lisa can attest.

"One thing I wish I'd known more about was the effect of the medications, particularly the steroids, on the personality," says Lisa. "All in all, though, I'm just so grateful to Robert and Debbie for being there. It was a wonderful gift. Words can't really express our feelings."

Dennis and Robert, of course, had long been friends, but now share an even stronger life-long connection. And, although Lisa and Debbie had been friends before, the experience brought them even closer. The two relieved some of the stress in Phoenix by frequenting garage sales.

The gift of transplant has transformed more than just Dennis. It's made an indelible impact on these two couples – forging bonds that will last a lifetime.

Coordinators Help Patients Navigate Tran

If you've been a transplant recipient, donor or caregiver, chances are you've met Kathy Hansen, R.N. and Diana Salerno, R.N. Both are Transplant Care Coordinators at Mayo Clinic Hospital. They help patients and family members navigate the complicated terrain they face before, during and after the transplant process. Both of them share advice they have to offer, based on their years of experience.

Tell us a bit about your background and experience.

Diana: I worked in telemetry and ICU nursing for six years before being introduced to transplant. I was working in Mayo Clinic Hospital's ICU when our liver transplant program was initiated. After taking care of my first post-op liver transplant patient, I was hooked. When there was an opening in kidney transplant, I jumped at the chance to work as a coordinator. I've been with Mayo for four years, the past two-and-a-half years as a renal/pancreas transplant coordinator.

Kathy: I have 30 years of nursing experience in labor and delivery, cardiac catheterization and radiology. I've been working with liver transplant patients for about six years, the past four at Mayo Clinic Hospital. I was thrilled to come to work for Mayo because of its world renowned reputation in research and education. I gravitated to this position when my best friend was waiting for a kidney transplant. I stay in this field because there is no other place in nursing that can give that sense of new life, other than labor and

delivery. It is like witnessing someone being pulled back from the brink of death. It is also wonderful working with such a wonderful team. The collaboration required to help the patient be successful through this struggle is huge, but very rewarding.

You're called a "coordinator", but we know that you do much more than "coordinate." What does your job entail?

Diana: The coordinator's job is to oversee patients' pre-transplant evaluations and to maintain them on the transplant list by staying up-to-date with their testing. I help introduce newly referred patients to transplantation. I also coordinate living donor evaluations, meet with potential kidney donors, and schedule surgeries once their evaluation is complete and donors are approved by the team.

Kathy: The coordinator's job is to help steer the patient through the process of transplant – from diagnosis of end-stage liver disease, through the actual transplant and on into recovery. Having a



Transplant coordinators Diana Salerno,

transplant is a life-long commitment, so you're going to have me, or someone like me, around for the rest of your life. I think my job is similar to the parenting process, in that the goal is to support the patients as they grow in knowledge about their illness and acceptance of transplant – and the requirements necessary to maintain their health. Although we have very close connections to the patients and seem to want to control their decisions in the early post-transplant period, this control is quickly relinquished as patients assume more and more responsibility and demonstrate healthy decision-making.

Transplant Journey — A Lifetime Commitment



(l) and Kathy Hansen, (r)

What is your favorite part of the job?

Diana: The transplant coordinators are the ones contacted by Donor Network when a deceased donor organ becomes available. I would say that is the most exciting part of the job – making those calls, which sometimes come in the middle of the night! I also love seeing patients come off dialysis and enjoy a better quality of life after transplant.

Kathy: I like educating patients as they prepare for transplant and when they are being discharged to go home after transplant. It is wonderful to see the rebirth as they recover and move on to a more normal life.

What advice do you have for someone awaiting a transplant?

Diana: It is easy to feel discouraged by having to wait so long for an organ. The best thing you can do for yourself while you are on the list is to work with your physician to stay as healthy as you can before your transplant. I would also add – stay up-to-date with your testing and make sure we are able to reach you – keep your coordinator informed of any phone number changes!

Kathy: Waiting is extremely tough — we get questions all the time about when we think a transplant will occur. It is very important that patients realize that the "when" of transplant is completely outside anyone's control. The best thing to do is to be prepared to wait and be prepared to go, whichever occurs. This takes patience and faith that transplantation will occur when the time is right. Letting go of the need to control the timing is critical, so that patients concentrate on staying healthy by doing what the physicians order regarding diet, medications, exercise and abstinence from alcohol and non-prescribed drugs. They need to continue to live their lives to the best of their abilities.

What advice do you have for someone moving into the role of caregiver of a transplant patient?

Diana: The best thing a caregiver can do for a transplant patient is to help them with their transplant medications. Yes, there are a lot of

them, and it is easy for a patient to feel overwhelmed going home from the hospital and having to deal with all of these new meds, as well as recuperating from surgery. But the best way to protect the new organ is to take your medications exactly as prescribed. Just remember to call your coordinator if you are not sure what to do. That's why we're here.

Kathy: The decision to be a caregiver is a big one. It requires being willing to be available to that patient 24 hours a day, seven days a week, for at least a month after transplant. This means that they learn everything that the patient learns and take responsibility to see that patients go to appointments, take their meds and do what is ordered. Caregivers need to be completely dedicated to the necessary responsibilities and able to put their lives on hold for the duration needed – whatever that is. If a patient does not have a strong support system, he or she can't be transplanted, because they cannot do this job without support--emotional and physical.

Kathy also offers one other important piece of advice: "Don't forget to say thank you to your donor family. They deserve it and it is the best way to increase donation. Imagine giving a priceless gift to an anonymous person and never hearing a word from them. It would take a special person to do it again, or to recommend it to their friends and family. That's my soapbox!"

Gift of Life Touches Mayo Employees, Too

There's no doubt that transplantation transforms the lives of patients, families, friends and their support people. At Mayo Clinic in Scottsdale, several employees have found themselves touched personally by the tremendous power of transplant. A few of these employees who were touched by the "gift of life" recently shared their stories.



Rebecca Frantz, Perioperative Services/Endoscopy
(These are the words of Rebecca's daughter, Reve, regarding her kidney transplant.)

"Years of having diabetes and a difficult pregnancy had taken a toll on my kidneys. I was fighting an uphill battle. I was only 27 and had to use a walker and a wheelchair. My friend, Serenia, was tested to be my donor. She was a perfect match. My donor came in the form of an angel who was in my life all along. On Aug. 1, 2001, I received the gift of a new start and a second chance."



Connie Weber, Dietetics
"My husband, Dennis, went for a routine check-up which led to his diagnosis of polycystic kidney disease, a genetic

disorder. Gradually, his kidneys failed and by December 2002, we were told to look for a kidney donor. As it turned out, I had the same

blood type and was accepted to be my husband's kidney donor. On Feb. 26, 2003, we went in for the dual transplant surgeries here at Mayo Clinic Hospital. Dennis is doing well and feels he truly has a new lease on life."



Raymond Heilman, M.D., chair, Division of Nephrology
"As a clinician caring for transplant recipients, we are usually

caught up in the technical aspects of the patients' care. But for me, personally, the most rewarding aspect of my practice is to witness the tremendous impact transplant has not only on the recipient, but also on their family and friends who get their loved ones back. Each organ donation has an amazing impact on many, many people.



Judith Sommer, Medical Transcription
"In 1994, I received the phone call every parent fears. My nine year-old daughter, Sheila,

had been in a horrible accident and was in a coma. Doctors exhausted all possibilities before I was approached to make a decision regarding discontinuation of life support and possible donation of organs. I did not hesitate for a second. It seemed pointless to bury her organs if they could help someone else. A few months later, I received several letters that were forwarded to me by the Wisconsin Donor Network. Several recipients

had written to thank me for donating Sheila's organs. One recipient, just 14 months old, was born with a congenital defect and now had her first opportunity for a normal life. Two people received her kidneys and no longer had to be on dialysis. Soon after Sheila's death, I joined Compassionate Friends, a support group for parents whose children had died. One parent said that, because her son was hit by a train, organ donation was not possible. Had they been able to donate his organs, she said, it would have made his death seem much less senseless. I think that one statement says it all."



Timothy Bleach, R.N., Hematology/Oncology
"Less than two years ago, my wife suffered a major myocardial infarction that eventually

took her life. While she was in the ICU, I went home to get some information I knew was in her purse. After removing the cards I needed, I put her purse back to where it had always been, but it fell to the floor. Her organ donation card fell out into plain view. I had forgotten what we had talked about many times – donation. Because recovery was not possible for my wife, I passed the information about donation along to her caregivers. I truly felt a sense of completion. Since that time, I have been notified that two people can now see who otherwise could not. My daughters and I relish the news that we received from Donor Network. These people share my wife's ultimate gift so they can enjoy life to the fullest."

Be Patient! Listen! Prepare! So Say Caregivers

You can read voraciously, research the Internet and seek advice from professionals. But nothing quite prepares you for what it means to take care of someone who's recently had a solid organ transplant. Recent patient caregivers offer a few words of wisdom:

Mary Jac Neal, from Prescott, Ariz., has been a caregiver twice – for her husband, Gil, following his liver transplant, and then for a friend the couple met at the Arizona Transplant House, Sherry Behrens of Phoenix. Sherry, a transplant patient, recently had a follow-up surgery at Mayo Clinic Hospital. Even though Mary Jac had been an R.N. all her life, it was still an amazing process for her to witness. Her words of advice:

- Read and research. One book that was helpful was *Hepatitis and Liver Disease – What You Need to Know*, by Melissa Palmer, M.D. Although the book does focus on hepatitis, there's still a lot of good information, regardless of the disease process.
- Get comfortable with driving. You're going to be the chauffeur for a while. If you've come into the Phoenix area from a smaller town, it can be frustrating to deal with the traffic and the amount of time it can take to get around.
- Take advantage of support groups – but remember that not everyone's experience is the same. Be wary of getting bogged down with other people's situations.
- Be patient with the patient!

Isabel Russell took care of her brother-in-law, Robert Espinoza. A retired nurse, Isabel flew in from Cibolo, Tex., following Robert's liver transplant in January 2003. She stayed for seven weeks until her sister, Eleanor, was on spring break from her workplace and able to care for Robert herself. Robert made history in Arizona when he was the recipient of the state's first "domino transplant." Here are Isabel's words of advice:

- Be prepared. Study all the discharge information. Timing medication and meals can be overwhelming, particularly if there's a complication like diabetes or another medical condition.
- Go to medical appointments with the patient. Sometimes it's tough for the patient to gather his or her thoughts to ask the right questions. It's better if the caregiver can take on the role of note-taker and question-asker.
- Attitude is everything. Stay rested and help the patient stay positive.

Peggy Turner, of Oklahoma City, was visiting her sister, Nancy Stone, Mesa, Ariz., when the beeper went off that a liver had arrived. A dietician, Peggy had been researching and studying in anticipation of this moment. When the time came, she became Nancy's caregiver 24/7. Peggy even slept in Nancy's hospital room and stayed "glued to her" until she was discharged. She stayed with her another week until Nancy's cousin, and later her mother, came to fill in as caregivers. Reminds Peggy:

- Ask lots of questions. This is important for the patient, but also for the caregiver. I found out ahead of time about the potential effects of the steroids, including hallucinations and personality changes. Since I knew what to expect ahead of time, it wasn't so scary.
- Be there and listen. That may sound simplistic, but that can become a top priority.
- Go with the flow – you never know what it's going to be like until you go through it. Expect the unexpected.

Outcome Statistics: Kidney Transplantation	
Total Transplants 6/99 - 6/30/03	162
Living Donor Transplants	116
Current 1-year graft survival rate	89.03%*
Current 1-year patient survival rate	93.30%*
Current 30-day patient survival rate	98.59%*
Median length of hospitalization	4 days
*www.ustransplant.org	

Outcome Statistics: Liver Transplantation	
Total Transplants 6/99 - 6/30/03	147
Living Donor Transplants	21
Current 1-year graft survival rate	88.24%*
Current 1-year patient survival rate	90.24%*
Current 30-day patient survival rate	98.78%*
Median length of hospitalization	7 days
*www.ustransplant.org	

Attention Physicians – 24-Hour Physician Referral Line: 1-800-344-6296 or 1-800-446-2279



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