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SHARING THE *gift*

A NEWSLETTER OF GIFT OF LIFE TRANSPLANT HOUSE VOLUME 3 | NO. 2 | FALL 2004

The Faces of Caregiving

Submitted by Gift of Life Board Member Barbara Schroeder, Clinical Nurse Specialist, Mayo Clinic, Rochester

FOR MOST OF THE READERS OF THIS NEWSLETTER, NOVEMBER'S THANKSGIVING HOLIDAY HAS MORE MEANING THAN IT HAD IN YEARS PASSED. FOR SOME, IT HOLDS THANKS FOR A NEW ORGAN OR LEASE ON LIFE AFTER A BONE MARROW OR STEM CELL TRANSPLANT. THERE ARE DONORS AND DONOR FAMILIES TO THINK OF, AND THERE ARE THOUSANDS OF BLOOD DONORS TO CONSIDER. For too many families, the holiday holds prayers for a loved one who fought so valiantly before slipping away. And for almost every reader, there are thoughts of the dedicated souls who gave of themselves in a quieter manner, as the patient's caregiver. It is to honor those devoted friends and family members that November has been declared National Caregiver Month by the National Family Caregivers Association (www.nfcares.org).

There is hardly a more important responsibility than caring for others. Stories about caregiving speak of energy, commitment, intellect, and heart. There are long, physically draining hours, and the related emotional toll is often hidden from others (or so the caregiver thinks). If one is fortunate, the caregiver will have some respite when another caregiver takes over for a few hours or days. But often, this committed caregiver is in it for the long haul with nary a peep said about any concerns he or she may have.

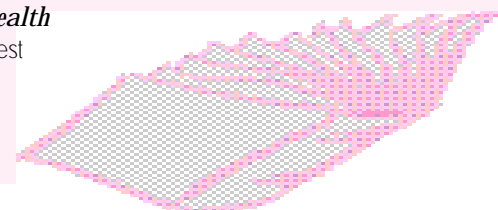
To assist those of you who still are caregiving or who have a caregiver, we offer the following reminder: knowledge is a powerful resource! Caregivers are encouraged to learn about the patient's disease, treatments, and medications, to know the names of the physicians and other professionals involved, and to know how to contact them. In addition, knowing where to find resources within the hospital, your community, or the Internet helps tremendously. There are reliable Internet sites that may be useful, including: <http://www.healthfinder.gov/>; <http://www.caregiving.org>; <http://www.wellspouse.org/>; and <http://www.nfcares.org/>.

Once the caregiver is well educated, the best thing she or he can do is "take care." Self-care is one of the most important and often forgotten aspects of caregiving. If you are a caregiver today, take time to go for a walk, listen to a CD, read a magazine, sleep in, or watch a video. Go to church or synagogue. Get a massage. And, you might even consider asking for help! Especially in November, celebrate caregivers and caregiving!

Stories about caregiving speak of energy, commitment, intellect, and heart.

Books that maybe helpful are listed here and are available for review in the Patients' Library at Rochester Methodist Hospital.

1. Houts, P. S. & Bucher, J. A. (2003), *Caregiving — A Step by Step Resource for Caring for the Person with Cancer at Home*, American Cancer Society
2. National Family Caregiver Association (1996), *The Resourceful Caregiver — Helping Family Caregivers Help Themselves*, Mosby Lifeline
3. Harper, L. R. (2002), *Give to Your Heart's Content Without Giving Yourself Away*, Innisfree Press
4. Hagen, P. T. (1999), *Guide to Self-Care — Answers for Everyday Health Problems*, Mayo Clinic Health Quest
5. Meyer, M. M. & Derr, P. (1998), *The Comfort of Home — An Illustrated Step-by-Step Guide for Caregiving*, CareTrust Publications



Support Group Finds Strong Following

*Margaret Gowan Mester,
Communications Manager*

Despite the fact that Gift of Life often has many new families each week, it seems the reputation has "gotten around" for a support group that holds bi-monthly meetings at the House.

Roshini (pronounced Rosh-nee) Sarah Abraham, Ph.D., a research scientist at Mayo Clinic, hosts the support group for patients and caregivers as a personal volunteer effort. Though she works primarily with amyloidosis and multiple myeloma in her research, the support group meetings are open to patients with any disease. The discussions vary, including spiritual health, the affect of a person's state of mind on the body's healing power, specific medical issues, and how to know when a caregiver should pull back to allow the patient more independence. Providing interested patients and caregivers with time for prayerful reflection and discussion is the support group's goal.

"Roshini has been a friend to Gift of Life for years," said Sister Margeen Hoffmann, O.S.F., executive director of the House. "She is a warm, intelligent, and compassion-

ate person, and our guests are very fortunate to be able to visit with her."

Having made many friends as the moderator of the support group, it's no surprise some of the House guests have kept in touch with Roshini after they've left Rochester. But Roshini is quick to say she's certain she gets as much, if not more, out of the visits than she gives. "As a scientist, these wonderful people remind me why my research is so important," she said. "And it's been my distinct pleasure to meet the guests." Those of us on staff know the feeling is mutual.



Roshini (second from left) and friends at Gift of Life — Mike Lanasa, Megan Lutz, and Linda Lanasa, far right



President's Letter

Dear Friends,

Could it be that fall is upon us again? Just as our guests are given moments to reflect on the passage of time and the meaningfulness of life, so, too, does fall give us reason to reflect. We will enter soon a season of dormancy, a time when life will prepare to regenerate. As always, we hope fall brings positive experiences, helping our guests move into a new season of health improvements as they journey through life's continual challenges.



The summer of '04 brought many special events to our home. We hosted an open house to celebrate our 20th anniversary and to thank the many benefactors who have made generous donations in recent years. The happy event was well attended and fellowship was enjoyed by past and current guests. The next day, our golf tournament was, again, a great success, and the day was capped by an excellent banquet and silent auction. (See photos on page three.) These activities are vital fundraisers for Gift of Life, as the proceeds support our operating fund. Much of the success can be attributed to the many volunteers, staff, and Board Members who gave countless hours to the house. Our debt of gratitude is enormous!

In this newsletter issue, you will see an article about what it means to be a caregiver. November is National Caregivers Month, so we hope you'll take this opportunity to thank those in your life who have supported you in ways large and small. As was said by Edwin Markam: "There is a destiny that makes us brothers; none goes his way alone; all that we send into the lives of others comes back into our own." We hope you will share your gratitude freely!

Here in Minnesota, nature's fall colors are breaking into glorious shades, and we are reveling in the cool days upon us. On behalf of the Board of Directors, staff, and volunteers, I wish you and your loved ones a healthy and happy fall and winter, full of love and prosperity.

Ron Kreinbring, President
Gift of Life Board of Directors

TRANSPLANT GAMES OFFERED SOMETHING FOR EVERYONE

Submitted by Danielle Peabody, LGSW, Medical Social Services, Kidney/Pancreas/Islet Transplant, Mayo Clinic, Rochester

Over 75 Mayo Clinic employees, friends, and family members volunteered their time and energies to the success of the 2004 U.S. Transplant Games held this summer in Minneapolis, Minnesota. Sponsored biennially by the National Kidney Foundation, the events offer transplant athletes an array of competitions in 12 sports, including swimming, bowling, and track and field. Throughout the week, special events were held as well, such as ceremonies to honor living donors and deceased donors' families.

Among the Mayo Clinic attendees were Gift of Life Board of Directors Vice President Thomas Schwab, M.D., and his wife Kathy Schwab, clinical manager in the William J. von Liebig Transplant Center. In addition, Drs. Stephen Textor and Mikel Prieto and Social Worker Danielle Peabody were proud to represent Mayo Clinic as speakers at a Clinic-sponsored conference, "Transitions in Transplantation." That educational forum was held for transplant professionals.

Gift of Life has heard from one guest, liver transplant patient Randel Anderson, who competed in the Games. He had his personal best in each of the events in which he participated. For the shot put, he threw 29 feet 8 inches, earning seventh place for 50-59 year olds. He won third place in the 1500 meter, running nearly a mile in 6 minutes, 50 seconds. And in the 5000 meter (just over three miles), he ran 26 minutes and 29 seconds and earned ninth place out of the 66 men in that race. Did we mention Randel did all of this just nine months post-op? *Amazing!*

Holiday Open House Will Razzle-Dazzle You!

We can't wait! "Gifts of Beauty and Leisure," a benefit open house offering hundreds of gifts and gift-giving ideas, will be hosted December 4th and 5th at Gift of Life.

Mary Kay beauty products, handmade soaps, and Partylite candles will be displayed this year. As always, we thank Sister Margeen Hoffmann's sister, Margie Balint, for bringing her Mary Kay products to the house. She'll offer free facials again, too. New this year, we'll have handmade soaps by one of our House volunteers, Amy Brooks, and Partylite candles sold by our Volunteer Program Manager, Denise Stegall.

Many of the gift items will be available gift-wrapped and ready to go — at no additional charge. Such a deal!

This open house will help Gift of Life and allow you to get great gifts for some of the men and women on your holiday list. Proceeds given to Gift of Life will support guest services at our home. Be sure to check your calendar and your holiday list so you'll know what you need when the sale comes up.



If you can't make it to our home for this special event, go to Margie's Web site, www.marykay.com/mbalint, and shop anytime between December 2nd and 15th. Note on the order page that your purchases should benefit Gift of Life. For candle and accessory ideas, check out www.partylite.com then e-mail Denise to order, denise@gift-of-life.org. And go to Amy's Web site, www.bubblesbybrooks.com, between November 15 and 29, to order soaps online using her e-mail link. Remember to note Gift of Life when you order.

Happy shopping!

OPEN HOUSE PROMPTS "THANKS"

Whether you attended or kept Gift of Life in your thoughts from afar, "thank you!" to all who participated in the 20th Anniversary Open House and Benefactor Recognition in July. Acquaintances were renewed and friendships continued to grow. Our thanks, as well, go to the house guests for letting us use "their space." It was an incredible day — fitting for an incredible organization, wouldn't you agree?

— Roger Erickson, Chairperson, and the 20th Anniversary Planning Committee

WISH LIST
All of these are current needs of the House.
Please help if you are able. Thank you.

- Four-packs of two-ply toilet paper
- Paper towels
- Wrapped candy, especially chocolates
- Liquid dishwashing detergent for kitchens
- Paper napkins
- Small bottles of liquid hand soap for bathrooms, preferably orange
- Post-card stamps for office use



RECIPE CORRECTION

On page 140 of Gift of Life's newer cookbook, *Recipes to Remember: More Good Things from Gift of Life*, we've heard from the chef that the recipe for Norwegian Macaroons needs a correction. There should be one (1) beaten egg added to the list of ingredients. As you make the recipe, just add the egg with the butter and vanilla. The rest of the recipe is correct.

We apologize for the error.
Bon appétit!

A Two-day Celebration Like No Other!

Margaret Gowan Mester, Communications Manager

Those of us working and volunteering at Gift of Life remember Sister Margeen's words all too clearly: "Well, let's just have the open house on the same weekend as the golf tournament. If we're going to work ourselves into a frenzy, let's do it all at once." Who could argue with that wisdom? (Who would argue with the boss anyway?)

Our celebrations certainly were fitting for a 20th anniversary year! The open house on Sunday, July 11, was picture perfect...after the downpouring we had early in the morning, that is. With two large white tents covering our front lawn, balloons and flowering pots everywhere one looked, a feast fit for royalty, and the media in attendance, it was quite a "thank you" event for the nearly 200 visitors we had. Many of our attendees were honored guests, those who have given so generously to the House in the three years since we last held a benefactors' reception. We were overwhelmed by the kindnesses many of our guests have shown. Of course, we know they are doing this in good part for you — for those who have followed in their footsteps at Gift of Life.



Top center: Executive Director Sister Margeen Hoffmann, O.S.F., thanks the family of Susan Powers for initiating the "Susan Powers Helping Hand Fund" at Gift of Life.

Second row, left to right: We're not sure about his stance, but it looks like this golfer was hoping for a long drive!

Sue Sands and Tim Kriese made beautiful music together for our open house.

Young-Ja Lee, who donates flowers for our annual golf event and open houses, told the crowd how meaningful her stay at the House was to her.

Keith Fahnhorst, a kidney recipient, was our featured speaker at the golf dinner.

Third row, left to right:

We can tell golf tournament Chairperson Jim Purvis really hates volunteering some days... He pauses to pose with three Minnesota Vikings cheerleaders who helped us celebrate:

Tournament volunteers Bob Shively (second from left) and Bob Groettum (second from right) played with Paul Brandrup, Ike Rogers, and Casey Groettum (lining up his shot):

Transplant recipient Tom Jorgenson, a professional pianist, and Sister Jane Frances Gregoire, O.S.F., facility manager, serenade the crowd before dinner.



These lovely ladies staked out one of the best tables at the Country Club for our post-tournament dinner!



Mary Davie, honorary lifetime Board Member, and her husband Tom told the open house visitors about their efforts to help launch an Arizona hospitality house.

Monday held just as much fun for golfers and every one else who came to Rochester Golf & Country Club. The tournament had more than 100 participants and nearly 200 dined with us that evening. Once again, we were blessed to have an incredible speaker — Keith Fahnhorst, a former lineman for the San Francisco '49ers, who had a kidney transplant in early 2003. Keith lives in the Twin Cities now and was more than happy to drive down to share his story and promote organ donation. After Keith's presentation, we revealed the winners of the silent auction, including the coveted Minnesota Timberwolves and Notre Dame tickets, and the raffle for two American Airlines tickets. Congratulations to all who participated in those activities, and "thank you" for being so generous on behalf of the House.

Already, we've begun to plan for the 2005 golf tournament. Keep a positive thought for us as we try to snag an incredible speaker we have in mind!

BOARD & STAFF PROFILES:

ED AND HELEN POMPEIAN

"When life gives you lemons, make lemonade." As we celebrate our 20th anniversary, it's appropriate to return to the beginning, when Ed Pompeian was 11 and became critically ill. It was the early '60s, when patients didn't question medical advice or care, not even simply to become better educated. Ed's diagnosis: first strep then lupus. Soon enough, he was taking upwards of 45 pills per day to treat whatever symptoms arose. After many hospitalizations, his parents, Helen and Edward, were told he had end-stage renal disease.

Ed was 12 and a patient at a Michigan hospital when he met Sam Leto, a kidney patient, and his wife, Mary. Sam told Helen and Ed that his treatment for kidney disease at Mayo Clinic, Rochester, saved his life. After more hospitalizations and opinions, and worsening health, Ed was inpatient again at 15 when his parents finally were told, "The nicest thing to do would be to take him home to die." Ed later said, "Mom, I'm not afraid to die, but I don't want to leave you and Sharon (his sister). Get me out of this hospital; they're killing me. Take me to Mayo like Sam said." And his parents did.

At Mayo Clinic, the doctors said the strep throat wasn't treated correctly, and the infection had gone to his kidneys. His condition wasn't caused by lupus; he had glumereal nephritis. By now, Ed was blind, had slurred speech, and couldn't walk. Quickly, he was put on a restricted diet, taken off the 45 pills per day, and told he would need dialysis then a transplant. Within weeks, his sight and speech returned, and months later therapy helped him walk again. Back in Michigan, at age 17 he began three-and-a-half years of dialysis, six hours per day, three days per week. He finally was ready for a Mayo transplant at 21 with his mother as his donor. The ingredients for lemonade were in sight.

Ed spent the next few years visiting kidney patients at Rochester Methodist Hospital, and he brought some of his new friends home for good cooking and extended stays. During one of his hospital visits, he met his future wife, Jayne, a nurse. By the time he was 34, married, and a Realtor, he found a perfect "transplant house" and began to scrape together a mortgage down payment.

Ed has said to his family, "The best things in my life happened to me in Rochester." With hindsight, we know his early experiences made him compassionate and that taught him about the need to make lemonade. Thank you, Ed and Helen, and all those who have worked with you, for making many good things happen for thousands of people in Rochester!



Ed Pompeian and two of his favorite ladies, wife Jayne (left), and mother Helen

Liver Transplantation as a Treatment for Hilar Cholangiocarcinoma

Submitted by Charles B. Rosen, M.D.,
Liver Transplant Surgical Director,
William J. von Liebig Transplant Center,
Mayo Clinic, Rochester

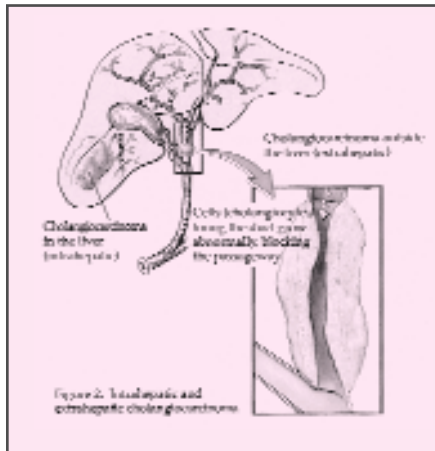


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CHOLANGIOCARCINOMA IS A RELATIVELY UNCOMMON MALIGNANT TUMOR that arises from the lining of the bile duct. In the United States, the most common risk factor is sclerosing cholangitis, a disease involving scarring of the bile ducts. But this cancer also is seen in patients with congenital bile duct cysts and bile duct stones. The most frequent location of these tumors is in the hilus of the liver, where the bile duct divides into the left and right hepatic ducts. Cholangiocarcinomas arising in this location are also referred to as Klatskin tumors, and they are notoriously difficult to treat. The tumor often extends deep into the liver such that it cannot be completely removed with a conventional operation.

PATIENTS WITH CHOLANGIOCARCINOMA USUALLY PRESENT WITH OBSTRUCTIVE JAUNDICE, weight loss, and occasionally abdominal discomfort. Endoscopic retrograde cholangiopancreatography (ERCP), an X-ray study of the bile ducts done by passing a tube down the stomach, is usually able to demonstrate these tumors. However, to determine how far the tumor extends into the liver, transhepatic cholangiography often is necessary. This is an X-ray of the bile ducts done by placing a needle in the bile ducts within the liver.

UNTIL RECENTLY, TREATMENT OF PATIENTS WITH HILAR CHOLANGIOCARCINOMA HAS BEEN DISAPPOINTING. Few of these tumors can be completely removed since they often extend deep into the liver. Even with complete resection, patient survival at five years is only 20 to 50 percent.

CHOLANGIOCARCINOMA RESPONDS TO RADIATION THERAPY, which can significantly slow the progression of the disease and occasionally improve the long-term survival. When combined with surgery, the results are better than surgery alone. However, patients treated with surgery and radiotherapy may eventually succumb to liver failure due to radiation toxicity, even in the absence of tumor recurrence.

DURING THE 1980s, LIVER TRANSPLANTATION WAS USED FOR UNRESECTABLE TUMORS. Unfortunately, only 10 to 20 percent of transplanted patients survived beyond five years, and cholangiocarcinoma became widely accepted as a contraindication for liver transplantation.

IN AN ATTEMPT TO IMPROVE RESULTS OF LIVER TRANSPLANTATION for unresectable hilar cholangiocarcinoma, Mayo Clinic developed a treatment protocol combining radiation therapy, chemotherapy, and liver transplantation. Radiation treatment is with high-dose, external beam therapy, followed by high-dose irradiation with iridium administered through a catheter passing through the bile duct and tumor. 5-FU chemotherapy is given during radiation treatment and continued until the time of transplantation. Prior to transplantation, patients undergo an abdominal staging operation to look for any spread of tumor to lymph nodes or the abdomen that would preclude complete removal of tumor at the time of transplantation.

EARLY RESULTS ARE VERY ENCOURAGING. Five years' survival for 28 patients that received transplants as of December 2003 was projected to be 83 percent, and only four patients developed recurrent tumor. These results equal those achieved with liver transplantation for other chronic liver diseases and hepatocellular carcinoma.

THE MAYO CLINIC LIVER TRANSPLANT TEAM has treated more than 70 patients with hilar cholangiocarcinoma. Approximately one-third of the patients have findings at the staging operation that precludes subsequent transplantation, but this number may be decreasing with earlier diagnosis and referral for treatment. Forty-one patients have undergone liver transplantation, and the results remain superb.

LIVING-DONOR LIVER TRANSPLANTATION HAS ENABLED PATIENTS TO UNDERGO TRANSPLANTATION SOONER than would be possible with a deceased donor. Avoidance of waiting time reduces the chance of tumor progression and facilitates timing of the staging operation. Although living-donor recipients had more difficulty earlier in our experience, results now are similar to those achieved with deceased-donor livers.

PATIENTS TREATED IN THIS PROTOCOL HAVE HAD MORE COMPLICATIONS than other patients undergoing liver transplantation, but most of the complications are manageable. The risks of complications and tumor recurrence are greatly minimized

cholangiocarcinoma *continued on next page*

My Journey with Cholangiocarcinoma *Submitted by George Bollinger*

In May of 2001, I gave a blood donation at my place of work. Much to my surprise, three weeks later I received a letter from the American Red Cross alerting me of elevated liver enzymes. After many tests at my local hospital in November 2001, I learned I had PSC (primary sclerosing cholangitis). I decided to get a second opinion in April 2002; it, too, indicated PSC. At the same time as they tested for the second opinion, brushings were taken from suspicious-looking areas in my bile ducts. Two weeks later we found out I had cholangiocarcinoma (bile duct cancer). This ruled out any chances of a liver transplant. A year after my innocent blood donation, I came to the reality that I had been given a death sentence.

A few weeks later, my wife, Carla, and I met with the head of the liver transplant unit of one of Pennsylvania's major medical centers. She took an interest in my case and would not accept the idea that nothing could be done. Through research she discovered Mayo Clinic had a protocol to treat my disease. In July of 2002, we met with Dr.

Gregory Gores. Many tests were done, and it was confirmed that I had PSC with cholangiocarcinoma (primary cancer of the biliary system). I was accepted into the protocol, which consisted of radiation/chemotherapy and brachytherapy (the placement of isotopes on the tumor). Later, I learned that only a small percentage of patients get this second chance at life. I finished radiation/chemo in September of 2002, was placed on the liver transplant list, and went home to take oral chemotherapy as I waited for a liver. Every three months we went to the Clinic for a checkup and had the good fortune to stay at Gift of Life Transplant House.

Finally, in August of 2003, I underwent exploratory surgery and was found to be cancer free! What a joyous day that was! My joy was overshadowed, however, during the winter of 2003/2004. It was a tough time with one episode after another of cholangitis. In February I nearly died; a blood infection, jaundice, and a 105-degree temperature had me in the hospital. Back at Mayo in March,



George and Carla Bollinger
are all smiles as George
recovers beautifully from his
liver transplant.

Dr. Gores decided to put stents in my liver. I was put on antibiotics and sent home again to wait. Several weeks later I was doing much better. On May 14, we finally got the call to go to Rochester to wait for a liver. We arrived on the 19th, our 31st wedding anniversary, and five weeks later, on June 25, 2004, we finally received the call we had been waiting for!

Throughout this journey, we always had a home at Gift of Life Transplant House. What an incredible place of encouragement, comfort, and healing! The friendships you make there leave footprints on your heart forever. I thank God for leading me to Mayo Clinic and Gift of Life. If it weren't for the Clinic, Dr. Gores and his protocol, all the wonderful medical staff, and especially my donor, I would not be here today to tell this story. God has truly blessed me with a second chance at life!

An Experience with Cholangiocarcinoma and Liver Transplant Submitted by Peter Han, M.D.

love, support, and care

At 59 years old, I considered myself to be healthy and active for my age, working from 8 a.m. to 5 p.m. daily, maintaining a healthy diet, and exercising vigorously for many years. As a physician, I was mindful of aging and related diseases, so after I turned 50, I started having yearly blood screening and urine tests, periodic physical examination and an electrocardiogram. Everything had always been normal except for a slightly high PSA (prostate-specific antigen level). The prostate workups (including biopsies) showed no cancer, and the colonoscopies, which had been done almost every 2-3 years, were normal. I was glad to be free of any serious medical problems and decided to skip all tests in 2001.

For about six months that year, I had slight, occasional itching of my legs and back, but I attributed that to my twice daily warm showers. I assumed that my 3-5 pound weight loss was thanks to eating more fruits, vegetables, and salads. And I completely dismissed how easily I felt chilled in the evenings. But then, on a February morning in 2002 as I looked in the rearview mirror during the drive to work, I realized my eyes were noticeably yellow. I brushed it off and hurried to the office since it was going to be a long day. That afternoon, I was again surprised when I saw the bright orange color of my urine. The following morning, when my entire body was yellow, it was obvious something was seriously wrong.

My wife, Sirilaksana, and I rushed to a hospital in Los Angeles. The endoscopy showed my bile ducts were completely blocked. Surgery to place drainage tubes relieved the obstruction, but a few days later I began to vomit blood and had low blood pressure from intestinal bleeding, warranting blood transfusions. Two weeks later, a fever developed from infection of the drainage tubes, so new tubes were placed. That cycle of infection and new tubes happened every few weeks for a total of ten occurrences.

Two months later, in April 2002, I was referred to Mayo Clinic. After a series of tests, evaluations, consultations, and counseling, I was diagnosed as having cholangiocarcinoma (cancer of the bile duct). I had chemotherapy and radiation treatment and was sent home with continuous IV chemotherapy to be followed by my local oncologist. While on chemo, I developed massive intestinal bleeding, which required transfusion of 18 units of blood. I also had bile leaking into the abdomen during replacement of the drainage tubes, causing intense cramping and pain. Finally, in October 2002, I was transferred to Mayo's Methodist Hospital for treatment. Siri and I were emotionally exhausted. We decided to stay in Rochester to wait for a liver transplant. The next month, exploratory abdominal surgery (a laparotomy), done to determine transplant eligibility, showed a tumor of 3x3 centimeters involving the bile ducts near the liver. Fortunately, there was no metastasis, so we continued our wait.

While we waited, we lived at Gift of Life Transplant House, where we greatly appreciated the warmth, friendliness, and comfort of the home, the guests, and the people working there. We got to know many patients and families who brought us good friendship, encouragement, and support. And yet, after nine months of waiting and a weight loss from my usual 138 to 116, we began to consider going home.

Then it happened. On the morning of March 12, 2003, the phone rang, and our nurse coordinator told us to get to the hospital. We were overwhelmed with relief and anxiety. My liver transplant went well. And though the postoperative period was complicated with septicemia and low blood pressure, I recovered readily. We continued to stay at Gift of Life until mid-April 2003, when we flew back to our home in California.

My sense of well being and appetite rapidly returned. I re-gained my weight in a few months, and I was able to resume vigorous exercise. At both the four-month and one-year checkups, I was cancer free. I've had no side effects from the anti-rejection medications. I feel quite healthy and plan to return to work soon.

I was able to go through all of this with the love, support, and care of my wife. We both are very grateful to the donor and his or her family and to our Mayo Clinic physicians and staff for making my transplant possible. Our thanks extend as well to the Gift of Life Transplant House staff, volunteers, and guests who made our time away from home so meaningful!



Dr. Peter Han and his wife, Sirilaksana, celebrate their daughter Iris's college graduation in May 2003 — a celebration that may not have occurred were it not for the kindness of a donor family.

Hilar cholangiocarcinoma has re-emerged as an indication for *liver transplantation*.

cholangiocarcinoma *continued*

by avoiding surgery, biopsy, and placement of permanent stents prior to protocol enrollment. Cholangiocarcinoma patients are candidates for this treatment protocol if they have no evidence of extrahepatic disease, active infection, or a medical condition that would preclude preoperative adjuvant therapy or liver transplantation.

COMBINED PREOPERATIVE RADIOTHERAPY AND 5-FU CHEMOSENSITIZATION WITH SUBSEQUENT LIVER TRANSPLANTATION ACHIEVES EXCELLENT RESULTS for highly selected patients with hilar cholangiocarcinoma. Initial results exceed those reported with conventional resection and compare favorably with the results of liver transplantation for other indications. Hilar cholangiocarcinoma – once a transplant contraindication – has re-emerged as an indication for liver transplantation when combined with effective preoperative adjuvant therapy.

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Finding a New Way to Walk Through Life

Submitted by Betty Anderson

Editor's note: *No matter your age or disease, there's no disputing the impact a medical crisis has on one's life. The physical, spiritual, psychological, social, and financial ramifications can be mind numbing (and occasionally simultaneously rewarding). In particular, many of our guests have faced loss of employment after what are often months away from home and work. Either they are forced to resign due to poor health before moving to Rochester or they realize upon return they won't have the stamina to continue the work they once did so proficiently. For one recent guest, Randel Anderson of Norfolk, Nebraska, the surprise of his disease moved his dream of a new career in art to the forefront of his life.*

Randel was diagnosed with islet cell carcinoma, a rare neuroendocrine tumor, in May of 2002. There is no cure for this slow-growing cancer, but sandostatin shots seemed to hold the tumors in his liver in check. In January 2003, he was told transplants for his condition were a new treatment. Randel and his wife, Betty, were interested, to say the least, and headed for Rochester.

As a pre-requisite for a liver transplant, in March 2003 Randel had a portion of his pancreas removed — the origin of his cancer. Complications caused a three-week hospital stay and long recovery at home. It was during this time Randel decided to leave his financial services business of 20 years and pursue a career in art. This was a love he'd pursued earlier in his life only to drop when his financial career became all-encompassing.

"I was recovering from the pancreas resection when I read a life-changing line in a book: 'If He has called you to this work, then you can give it all you have to give. If He has not called you, then you are stealing time from God.' Those words hit me like flashing lights."

Back in Rochester, the liver transplant in October 2003 was deemed a great success. As he recovered at Gift of Life, he pursued his newly rediscovered love with gusto, crawling on the ground to get a good photography angle on the front door, an image he would later draw in pencil for a more dramatic affect. Two other images of the House were drawn after Randel and Betty returned to their own home in November. There he has also taken to teaching art at the local arts center, in schools, and at the local site of a national hobby store. His greatest satisfaction, he reports, is watercolor or pencil commissioned work.

"I feel like a teenager again, starting life all over with a new joy and confidence in doing what I believe is God's purpose for me," Randel explains. "God is good!" he says.

If you are interested in purchasing prints of Randel's Gift of Life art or in pursuing his commissioned art work, check his Web site: www.randelandersonart.com. You also may contact him via e-mail at randerson@conpoint.com. A portion of the proceeds from each sale of a Gift of Life image will be donated to the Transplant House.



Randel and Betty Anderson and the Judd House Front Door drawing by Randel, ©2004 by Randel Anderson



How Do I Explain?

When Don Bryan tried to tell his eight-year-old daughter about his newly diagnosed disease, amyloidosis, words were hard to find. Then Don remembered why the beloved storytelling of "Dr. Seuss" (AKA Theodor Seuss Geisel) worked magic. Enjoy!

"The Dad in the Hat"

The Dad loved sports,
He loved to play,
He'd run and lift weights,
And do it all day.

His lungs were good,
His muscles so strong,
Hard to believe,
That something was wrong.

His muscles did tire,
His legs did swell,
His heart beat faster,
His body wasn't well.

The Dad went to Mayo,
He left for the day,
He went to the doctors,
To see what they'd say.

The symptoms say Amyloid,
It's what the docs see,
They'd run some tests,
To ensure what it be.

It's an abnormal protein,
A disease so rare,
Strikes eight in a million,
It's maybe not fair.

Gertz is the doc,
The man with the plan,
He will treat the Dad,
The best that he can.

Treatment for the Dad,
He'll have to stay here,
The prognosis is quite good,
He's little to fear.

A transplant is needed,
Stem cells from the bone,
No donor required,
He can use his own.

Blast him with chemo,
And see how he feels,
Infuse new stem cells,
And wait till he heals.

Yep, spray on Round-up,
And clear the terrain,
Plant the new seeds,
And pray for some rain.

He'll get so fatigued,
He'll stay in bed,
It will hit him so hard,
He'll wish he were dead.

His mouth will be sore,
His stomach queasy,
He won't want to eat,
Nothing will be easy.

Long hair,
Short hair,
Brown hair,
Gray hair.

Two hairs,
One hair,
Uh-oh,
No hair!

With hair so short,
He needs no comb,
A hat would be better,
It would warm his dome.

His head is so clean,
It shines like glass,
No hair on his head,
It looks like his...back.

Bald in the morning,
Bald at night,
He's bald all day,
It's quite a sight.

His ears are so big,
He surely can fly,
Flap 'em in the wind,
Just give it a try.

The Dad looks funny,
He has no hair,
The daughters can laugh,
But do they dare?

Of course they can,
It's all in fun,
They'll buy him a hat,
When this is all done.

Infection's a risk,
Keep everything clean,
The Dad will be cranky,
But surely not mean.

The Mom is so dear,
The love of Dad's life,
A wonderful mother,
And Dad's beautiful wife.

The Mom will be busy,
A servant so fine,
She's aging with grace,
Just like a good wine.

The Dad will feel puny,
It's two weeks of hell,
He'll begin to recover,
And soon he'll feel well.

The tide will turn,
As blood counts rise,
And a smile will show,
In Dad's steel blue eyes.

With support from his friends,
And by the grace of God,
The Dad will recover,
Let's give him the nod.

Soon to be done,
No time to be sad,
The Dad will get better,
His girls will be glad.

In time for the fall,
With his fuzzy white dome,
It won't be long... 'til
The Dad in the Hat comes home!!

Love, Dad

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GIFT OF LIFE TRANSPLANT HOUSE MISSION STATEMENT

The mission of Gift of Life Transplant House is to provide transplant patients and their caregivers with high quality, affordable accommodations in a supportive, home-like environment.

Gift of Life Transplant House is a proud member of



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Rochester, Minnesota 55902

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