

# New York- Presbyterian

## The University Hospitals of Columbia and Cornell

# LIVER CONNECTION

Volume VI, Issue 2

THE NEWSLETTER FOR LIVER TRANSPLANT  
PATIENTS AND FAMILIES

Summer 2007

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### From The Editors

Happy Summer!

As you can see from all the events noted in the newsletter, it has been a busy Spring! A big thank you to Astellas Pharma! Astellas has awarded us a grant to translate the newsletter into Spanish. We're still working on the kinks but we're very excited to be able to offer this to our Spanish speaking patients! If you do not receive one, but would like one, please contact the SW office.

Just a few words for you all to keep in mind over the next few months:

- Wear sunscreen and a hat!
- Let us know if there are any changes to your insurance. If you are in a situation where you need to change your insurance carrier, please contact Sharifa Bailey, our financial coordinator, so you can choose the right plan.
- Stop smoking. If you are struggling with smoking cessation, please speak to your coordinator or Dr. Haflinger who can help work with you. Smoking is very dangerous to all patients but even more so after transplant.
- Fill out your health care proxy and submit it to your social worker.
- Attend the educational workshops. It is very important to learn as much as you can about liver disease and transplant. They are also required by the Center for Liver Disease and Transplantation!
- Happy Anniversary to all of our recipients celebrating their transplant anniversary this summer. We know there are a lot of you!

If you have any questions, please speak to your caregiving team. We're here to help. Enjoy the summer!

REMEMBER - We are very interested in receiving patient stories, pre and post-transplant. Also, if there is a transplant related organization or event that you think would be a good resource to other patients, please let us know. Email ([aim9003@nyp.org](mailto:aim9003@nyp.org)) or mail to the address below.

### Connections

In celebration of National Donate Life Month, volunteers from the CLDT, The Rogosin Institute, and the New York Organ Donor Network (NYODN) staffed an information table on organ donation at the Cornell campus. The groups enrolled 75 new organ donors to the New York Organ Donor Network list! We would like to thank the following CLDT volunteers who made this event such a great success: Selwyn Morgan, Jane Zash, Henny Brenner, John Maschi, Dennis Kubiak, John Rice, and John MacDonald. Many thanks also to Karen Cummings and the NYODN for providing the training and materials.



Ed Eggleton, one of our nurse practitioners, and his uncle, Jeff Downes, completed the Commerce Bank Five Boro Bike Tour on Sunday, May 6<sup>th</sup>. Mr. Downes had a kidney transplant in January 1989. The bike tour traveled through the five boroughs of New York City on traffic free roads. Congratulations Ed and Uncle Jeff for completing a total of 48.8 miles!



Speakers at the Circle of Life Celebration included: Dr. Robert Brown and Dr. Eric Rose; Dr. Herbert Pardes, NYPH President and CEO, and Senator Charles Rangel.



Tony, Jr. gave his father life by donating part of his liver over six years ago.



Small bowel recipient, Kyle Cramer, with his parents at the Circle of Life Celebration.

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CENTER FOR LIVER DISEASE AND TRANSPLANTATION

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# TRANSPLANT NEWS

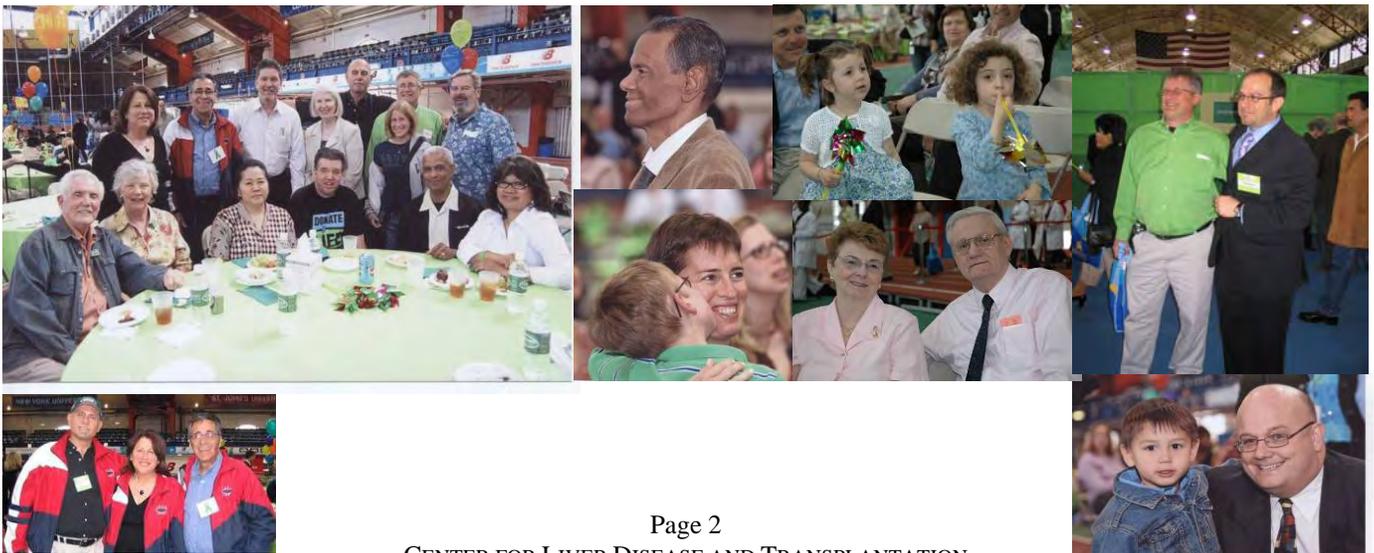


## Transplant Celebration – May 4<sup>th</sup>

On Friday, May 4, close to 1,000 organ transplantation patients from both the Columbia and Cornell campuses, donors and their families reunited with their medical teams to celebrate a second chance at life. The event, held in the West 168th Street Armory, was hosted by Dr. Herbert Pardes, NYPH's President and CEO, who noted that New York-Presbyterian has the nation's largest transplant program. The importance of research and organ donation was highlighted with transplant recipients, organ donors and clinical teams recognized. Speakers included Senator Charles Rangel, Dr. Lee Goldman, Dr. Robert Brown, Dr. Sandip Kapur, Dr. Eric Rose, the New York Organ Donor Network's Elaine Berg, and two transplant recipients, Mark LaRose and Joshua Lentin. The Eleanor Roosevelt Middle School Choir also entertained those in attendance with their beautiful voices!

Mark LaRose, the first recipient who spoke, is a 46-year-old account specialist from Queens Village, originally from Guyana. He has had diabetes for 31 years. Complications necessitated a kidney and pancreas transplant, which he received in 2005. A single father of a 15-year-old son, he feels his transplant has allowed him the opportunity to see his son grow up and to live a full, complete life. He and his son have traveled extensively. This summer, they plan on visiting Asia.

Three time heart transplant recipient, Joshua Lentin is a 17-year-old from Long Island with plans to attend Lynn University in Florida in the fall with a major in communications. He has received three heart transplants, the first when he was only 3 years old. He received the second heart transplant only one year later and the most recent in 2001, when he was 11.



# TRANSPLANT NEWS, continued

## TRANSPLANT NEWS, continued

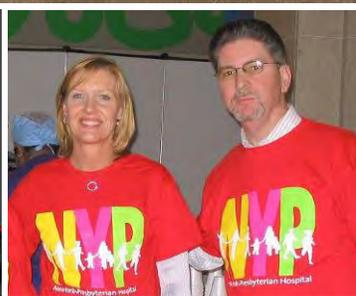


### ALF Liver Walk Kick-Off – April 17<sup>th</sup>

The American Liver Foundation (ALF) hosted a kick-off event for the 2007 Liver Walk in the Wintergarden of the Morgan Stanley Children's Hospital on April 17<sup>th</sup> for past walkers. New York Presbyterian Hospital's Team Gratitude was recognized as having the largest hospital affiliated team for the past two years. Last year's team captain, Regina Williams, and this year's captain, John Rice, were in attendance to build support and get everyone excited about the NYC walk June 10<sup>th</sup> in Battery Park.



### In our Team Shirts!



# LIVER WALKS, 2007

## LIVER WALKS, 2007

Long Island, May 20



Living related liver donor Tom Baker and his team 'Baker Family and Friends' along with liver transplant recipient Sylvia Caiola and her team, 'Team Caiola' took the Long Island Walk by storm. While final numbers have not been tallied for either team, ALF disclosed that the Baker Family and Friends team raised over \$32000! Tom's team celebrated the conclusion of the event with a catered picnic and live music. Unfortunately, they walked this year in memory of Tom's wife, liver transplant recipient, Debbie Baker, who died this past year from unrelated cancer.



### NYC, June 10

Color the day RED. The sky was grey, the sun in hiding, but the prevailing winds blew in smiles. All those red NYP shirts on the Team Gratitude walkers brightened spirits and made us very visible. The 5K walk started at the north end of Battery Park, went up along the Hudson with perfect views of Lady Liberty and came back down West Street, passing Ground Zero, and back to the start.

The Long Island, New Jersey and NYC walks raised a combined \$275,000 for the American Liver Foundation. The May 20<sup>th</sup> Long Island Walk raised \$145,000 with the June 10<sup>th</sup> NYC Walk raising \$80,000 and the June 17<sup>th</sup> NJ Walk \$50,000.



Steve shows off his NYP shirt, while the rest of the team huddles for a pep talk and the Financial District towers over Battery Park.



Ready, rain or shine



Social Worker Kim Morse



NPs Dianne and Margie walk with their daughters (both named Isabella!) and Steve's caregiver and spouse, Denise.

# LIVER WALKS, continued

## LIVER WALKS, continued



# SILVIA'S CORNER

## SILVIA'S CORNER

### Important Facts about Cirrhosis and Liver Disease

*Silvia Hafliger, MD*



Almost 75% of patients who are referred for liver transplantation suffer from liver cirrhosis. The remaining patients who need a new liver have either acute liver failure (complete shutdown/ necrosis/cell death) due to Wilson's disease or other toxic injury, or have developed liver cancer.

**Cirrhosis** simply means **scarring of the liver**. It is the end result of *years of injury, inflammation and ultimately scar tissue formation* throughout the liver. Some common reasons of liver injury are viruses Hepatitis C and B, alcohol, fat accumulation or autoimmune processes, meaning the body not recognizing the liver or bile ducts as its own. *Scars prevent the liver from functioning normally* and are the reason for most of the symptoms that patients experience. These symptoms include ascites and edema (accumulation of fluid in the abdomen or legs), encephalopathy (confusion and memory difficulties), bleeding from enlarged veins in the esophagus, fatigue, cold intolerance, muscle loss and weakness.

The most common reason for injury to the liver in the U.S. is due to the Hepatitis C virus. This virus prefers to grow and live in the liver. The majority of patients who have Hepatitis C infection will never develop liver disease, but in 20% of patients their immune system attacks the virus in the liver cells, leading to inflammation and eventually scarring.

Unfortunately, getting a new liver does not mean that the virus is eliminated. The virus will infect the new liver, and in time lead to cirrhosis again. Your doctors and nurses will monitor you closely after a transplant to detect any damage done by the virus and offer treatment with Interferon injections and/or Ribavirin pills.

Some of you were treated in the past with Interferon and have bad memories about the side effects. Interferon stimulates the immune system and, as a result, can cause flu-like symptoms, fatigue, generalized body aches, irritability, sadness and depression. The more scarring the liver had when you were treated prior to transplant the worst the side effects were. In patients with a new liver, Interferon seems to be tolerated better. Some patients who were not able to eliminate the virus before transplant will be able to do so after transplant. Even if we are not able to achieve a negative viral load (no virus particle in the blood), Interferon *can slow the progression of scar formation* and may even prevent cancer cells from developing.

With teamwork, help from your nurse practitioner, family, psychiatrist (to help with depression, insomnia, irritability and/or pain), patients are able to tolerate Interferon for 1-2 years after transplant. By controlling your weight, not smoking tobacco or ingesting any alcohol you can improve your chances of keeping a healthy liver. It is hard work, and requires long-term commitment to care - frequent

blood tests, medical follow-up, and supplemental injections to boost the bone marrow to make red and white cells.

Some patients need a new liver due to **cancer** cells growing in the liver. Many patients do not feel ill from the cancer and have trouble accepting the idea of needing a transplant.

Viral infections with Hepatitis B or C, fatty liver, hemochromatosis (excessive iron deposition) or alcohol, usually cause liver cancer. Liver cancer is a leading cause of death worldwide and treatment in the past has been poor. If the cancer is contained in the liver and not too extensive (smaller than 2 or 3 inches and has not spread to the lungs, bones, or other parts of the body), transplantation offers a chance of treatment. Patients with cancer cannot wait until they feel sick before they accept a new liver. They have to trust the medical team that transplantation offers a chance of survival. Untreated liver cancer usually leads to death in 6-9 months after initial diagnosis. After a transplant we monitor for recurrence of cancer by MRI/CT scan and monitoring of a cancer marker called alpha fetoprotein.

Teamwork and knowledge can lead to a successful outcome in transplantation. We encourage you to learn as much as you can about your illness, come to the workshops, and speak to others who have gone through this process.

Enjoy your summer and see you in the workshops!



# PEDIATRICS



## Transitioning to the Adult Service

*Kara Ventura*

Children with chronic illness are living longer due to advances in medical technology and science. Often, children with chronic illness become attached to their specialty providers, such as their transplant team. The specialty provider usually has known the child and the family since diagnosis and has supported, treated and been consistently available to the family through some very difficult times in the child's illness. There comes a period when the child has grown to a young adult and requires transitioning to an adult team. This is a process which needs preparation and much thought in order to include the desires of all involved: the child, the parents and the providers.

Many pediatric patients have difficulty leaving their pediatric providers. There are also challenges that the providers face during this transition including abrupt transfers, insufficient communication between pediatric and adult specialty providers, and fear the patient will become "lost to follow-up." When young adult patients were asked how they would like to be treated, they stated they preferred being treated as adults, wanting healthcare staff addressing them instead of their parents, wanting to be spoken to in an adult manner, and wanting to be responsible for their own care. Patients have also requested age at the time of transfer to be around 20 years old with a smooth movement within the same hospital, agreement of patients and their parents, prior personal contact with the adult physician, pediatric providers' attendance at the first visit at the adult service, and the availability of the same physician at out-patient clinic visits.

When transitioning, adolescents seem to be most concerned and fearful of poor communication and transfer of information relating to their transition to adult care, fear of leaving the healthcare provider with whom they were already familiar, fear that adult care providers might not understand their needs, fear that they won't have enough information about the adult care program, questions about how they will meet adult care providers, and concerns about how to help new healthcare providers to understand their needs.

In order to improve services and care, it is important to identify not only the needs of the patient but the perception and views of the health care professional who are (and will be) caring for this client. Here at our Center we have had conversations about what the best way is to start transitioning our adolescent patients. Currently, we are developing a clear transfer plan, good dialogue between staff and patients, and education and training for caring for this population with set protocols. Further suggestions include joint hand-over clinics with adult and pediatric care providers, a care conference for families with complex needs, and pediatric and adult teams meeting together to plan each individual transfer.

Our goal for transitioning is to use the principles of multidimensional, multidisciplinary care to address the medical needs of adolescents as they move from childhood services to adult services while still addressing their psychosocial, educational and vocational

needs. We hope that the development of a clear transition program can overcome problems, including fear and anxiety, which may arise when moving from pediatric to adult care.

We plan to start discussion of transition at all visits after age seventeen. The patient and their parents must continually be made aware that inevitably a transfer will occur and they will know when their transition is expected at age twenty. There will be flexibility around this transfer period in instances where the adolescent may be ill at time of anticipated transition. Our hope is not to increase stress on the family during times of medical instability by having all new providers. On the other hand, if the adolescent's life changes earlier than the age of twenty, such as getting married or becoming pregnant, the transfer to the adult service will occur sooner.

Pediatric patients will have a DrNP coordinating their transfer from the start of discussion. Part of this coordination will include training for the adolescent in communication skills, shared decision making, creative problem solving, assertiveness, self-care, self-determination and self advocacy. Psychosocial services will be consulted during this period as needed. Each family will be provided the opportunity to have a family meeting with the adult and pediatric service. Pediatric providers will be present at the first transition visit. Patients and their families will be made aware of the collaborative communication between the adult and pediatric service and continued availability to the family but must clearly understand that the pediatric service will not change the medical plan set by the adult team. The patient may provide input as to what their personal long term needs and concerns medically and socially are. This plan along with a medical summary will be given to the patient and adult provider upon transition.

For the providers, a written transition policy between the adult and pediatric services will be followed. The referring physicians will be made aware of the transfer by the pediatric service and the adult providers will continue to seek their involvement for primary and preventative care. The pediatric team will remain consistently available to the adult team for whatever issues arise in caring for this patient.

As children are becoming adults with a history of childhood illnesses, need for transition programs are growing along with the child. Facilitation of a clear protocol based on already established practice principles and multidisciplinary involvement is necessary to assist the child into obtaining their full adult potential. Involvement of both adult and pediatric providers will ease this transition for the patient and their family.

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# PATIENT VOICES

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### How Much Is Enough?

Sharon Willen

In early April our family celebrated Passover. Although I'm not a very religious person, I always enjoy the Jewish rituals and find guidance in the values communicated through them. On Passover we celebrate the blessing of divine intervention that protects us from harm as individuals and as a race and has preserved us to enjoy this moment in time.

One of the traditions at Passover is to sing a song, "Dayanu," which calls out, "It would have been enough." The idea is to give thanks for each of the miracles G-d performed on behalf of the Hebrews to free them from slavery under the Pharaoh and deliver them into the land of Israel, each one in its turn being sufficient to warrant gratitude. This year the song took on special meaning for me, because it has been a year since April 2006 when a sudden change in my health triggered a decline that culminated in a liver transplant last November. Looking back on a year of challenges, I believe I have experienced more than my share of miracles.

#### *A Long, Active and Joyous Life*

When I was a pre-teen, approaching puberty, I fought off a long siege with autoimmune hepatitis that left my liver scarred. Although scarring in the liver, which the doctors call cirrhosis, is progressive, I was lucky to live virtually symptom free into my late fifties. After college, I lived the good life in New York City as a single woman with a teacher's income and vacation schedule. I traveled, studied martial arts, got an advanced degree in media studies, participated in the development of humanistic education practices and enjoyed an active social life. I met and married my soul mate, Michael, after turning thirty. My relationship with my step-sons deepened over the years and I had the pleasure of



becoming a grandparent without paying most of the dues of parenting. The craft work and sewing projects I dabbled at brought praise and surprising offers of retail representation, which I declined. I made a couple of self-directed career changes, was recognized with awards and promotions, wrote books and articles that were published, bringing me a sense of personal achievement and royalty checks to boot. So in the spring of 2006, though I didn't want to die, I honestly felt that if the worst happened, it would have been enough to have lived the life I had been granted.

#### *Courage, Optimism, Patience and Grace*

I have no rational explanation for the strength that pulled me through the months between April and November 2006. As my body became more and more debilitated and my mind more and more poisoned by toxins unable to be eliminated by a failing liver, I seemed to get more and more organized and determined to "do the right thing" to survive. It would have been enough if I had only



been shielded from realizing the extreme peril of my situation, but I was given so much more. When I couldn't get my size 8 clothes over a belly distended with abdominal fluid, friends took me shopping in Old Navy's maternity department. When I was too confused and weak to drive, they ran errands to the library and supermarket and pharmacy and drove me to the doctors and labs. They cooked low sodium meals for me and full-flavor meals for Michael. Through inspired referrals I hooked up with a highly-qualified nutritionist who had had a kidney transplant herself years before, a physical therapist with a heart as big as the sky, and an energy healer and spiritual guide who shared with me the meditation practice that helped me engage my deeper wisdom in meeting the paradoxes of this imperfect improvisation we call life. It would have been enough to stay alive, but to suffer so much without fear or despair...?

#### *Medicine and Miracles*

I took care of rewriting my will, putting details into my end-of-life medical directive, and dealing with insurance issues, but I could not face nor accomplish the huge task of determining which liver transplant center to seek help from. Transplantation is organized in this country through the United Network for Organ Sharing (UNOS). After medical evaluations determine that a patient is sick enough to be listed as a potential organ recipient and strong enough to survive the operation, candidates get prioritized by a formula based on various lab results and other criteria. This takes the subjectivity out of a system that could otherwise be manipulated, but means a person like me with an auto-immune diseased liver would receive a less competitive placement on the list due to my low MELD score that was not consistent with the severity of

## PATIENT VOICES, continued

my illness. My cousin in Boston who is a retired lawyer and active in the professional community did research for me that led us to select NY Presbyterian Hospital-Columbia University Medical College's Center for Liver Disease and Transplantation. It would have been enough to have found this eminently competent transplant program, but what proceeded to happen was more.

The evaluation testing is usually done over a period of a month or more, but because we live in Asheville, North Carolina, NY Presbyterian sequenced appointments so that I could complete all the necessary tests in two days. As sick as I was, Michael and I made the weekend trip (14 hours) to NY by car to avoid exposure to "airplane air." Picture the two intense days of testing, a Monday and Tuesday, as a marathon of physical SAT's with my life rather than college admission hanging in the balance. When my local Asheville GI doctor called on Tuesday of the following week with the results, he had good news and bad news. I remember collapsing a bit against Michael's shoulder as the doctor relayed that the last evaluation test (MRI) showed a spot of cancer on my liver. The good news was that this development gave me "25 points" and I would be on the top of the organ sharing list for transplant candidates with my blood type (B). On Wednesday I had two tests in Asheville which found the cancer had not spread to my lymph nodes or bones. We were instructed to get up to New York for an appointment the following Monday for a radiology procedure targeting the spot to prevent it from growing or moving while I awaited a donor liver. On Friday one of the liver transplant doctors called and asked Michael if we were "in town" yet because they had a matching liver for me. No, we were still in Asheville and there's no way we could have gotten to New York within the three hour window of opportunity, so the liver would go to another candidate. Obviously our surprise at their success in finding a liver so soon and our disappointment at missing the opportunity motivated us into quick action.

We made hasty decisions on what we'd need while in NY waiting for the next available liver and packed my Subaru Outback so full I couldn't lean the seat back on this repeat two day trip. Arriving Sunday night to take up temporary residence at my parents' home, we unloaded the car into their living room to sort through later as the plan was for me to stay there while Michael went home to close down our house and then find us a more permanent residence in the New York area for after the transplant, if I was fortunate enough to get one. At that point, after those three exhausting weeks of anxiety and travel, I was 85 pounds and barely alive. It would have been enough for me to ultimately receive a liver transplant, but when Mike's cell phone rang at 4 a.m. on Monday morning, the very next day, with the news that another liver was available for me, there was clearly more than medicine at work on my behalf.

Back in September, humbled by the knowledge that in order for me to live, someone else's life would have to end, I'd written in my journal asking that my "liver donor will have a quick and painless death so that I may have a successful transplant operation

without complications before Passover 2007 and begin my 'new life' in synch with the spring cycle of rebirth in nature." In addition to my own meditation, so much positive thinking was put forward on my behalf by family, friends, friends of friends, prayers in synagogues and churches, prayer groups of people I've never met in places I've never been. The love and intelligence of the universe foresaw better than I did the long period of early recuperation that would be necessary before we could return to our true home snuggled in the glory of the Pisgah Mountains. Thus, Monday morning, November 20, my life intersected expeditiously with that of a generous and courageous 70 year old woman from Staten Island who died suddenly of a brain aneurysm and her family who honored her previously stated wish to be an organ donor.

When I lay down on the operating table 8:30 a.m., I was completely calm. I don't remember injections or tubes or medical discussions or even the anticipated stark light and cold temperature of an OR. My most vivid memory is of being held in God's palm, bathed in golden light, caressed by the white feathery wings of an angel standing behind my head, with a circle of all those well-wishing people from everywhere right there holding hands around me. I went to sleep confident of a positive outcome. I awoke to begin my newly-extended life twenty-one hours later at the exact moment the soft, multi-colored dawn of a new day was sparkling on the windows of the buildings on the Jersey heights across the Hudson River from my hospital bed in ICU. A powerful omen, an extraordinary gift. My donated liver kicked in immediately and we never looked back.

I moved quickly from ICU to "the step-down unit," to a semi-private room on the transplant floor. Though there was a gift shop in the hotel lobby, my most cherished gifts came from other sources. The discovery that beauty is expressed by the soul, not projected by the skin - learned from doctors, nurses, techs and other patients and their visitors who told me how great I looked being up walking with my IV pole so soon after transplantation. When I saw myself in the bathroom mirror, I did not recognize the image of the holocaust victim reflected. The gift of peace of mind came from the pathology report on the liver removed from my body. What had appeared to be cancer was some other anomaly; so - no cancer before, no threat of cancer returning. My step-sons went out of their way to visit from western New Jersey and Tokyo, Japan, to deliver hugs and support my healing, becoming sons in my heart on yet another level. Friends of a friend of Michael gave us an open-ended, rent-free lease to the guest cottage on their estate in Greenwich, CT. In the four months we stayed there, they literally treated us as their guests, allowing us the use of their laundry, bringing us homemade soup and little gifts. From them and others, I learned the true nature of charity and the blessing you bestow on others by allowing them to give. I was joyfully reconnected with several life-long friends in the NY metro area whose lives had taken us in divergent directions in the more recent past. Particularly gratifying was hearing how many people who had pulled for me had their belief in a greater power and their

# PATIENT VOICES, continued

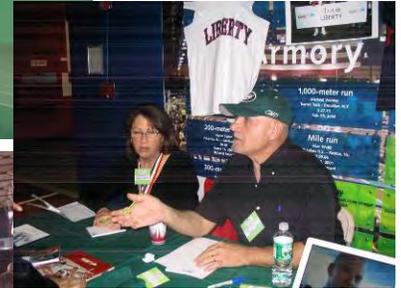
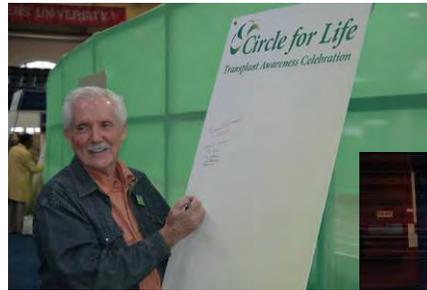
## PATIENT VOICES, continued

joy in life reinforced by my success. To have survived the operation would have been enough, but to be blessed with so much love and to discover the value of my simply being in this world was almost overwhelming.

### *Unto the Promised Land*

Of all the miracles and support that helped me survive and grow through this ordeal, one stands out above the rest. When the Hebrews were seeking escape from their travails and the danger in Egypt, the prophet Moses guided them, and ultimately parted the Red Sea to make their departure possible. My prophet and miracle worker was and remains my husband, Michael. It was Michael whose steady confidence, can-do approach, complete acceptance, and never-tiring practical assistance protected me from all plagues, took all responsibilities off my shoulders, pulled me through drug-induced post-surgery depression, and revealed to me an intimacy that bears no resemblance whatsoever to Hollywood or network TV. Michael has brought me home to a life filled with promise yet to be defined. To be home again would have been enough, but to be watching Michael fill the hummingbird feeders on our deck in anticipation of their imminent return, transformed in body, mind and spirit - this is surely more, much, much more, than enough.

NOTE: Liver disease strikes 1 in 10 Americans. Approximately 6,500 liver transplants were performed in 2005. Currently over 17,000 people are waiting for a liver transplantation. Up to a third of the people on the list each year die because of the shortage of organ donors. I feel that every contribution I will ever make to family, community, or the betterment of all creation will honor my parents for giving me life and my organ donor and her family for extending my life. Your positive influence in the world can live on also if you choose to become an organ or tissue donor and communicate this wish to your family. Find out more about organ donation and how to register in your state at [United Network for Organ Sharing](http://www.donatelife.net) (<http://www.donatelife.net>).



# EDUCATIONAL WORKSHOPS

**Sessions will be held on Thursdays, 2:30-4pm**

Milstein Hospital Building  
Reemtsma Conference Room  
7 Hudson South, Room 7-213  
177 Fort Washington Avenue (between 165<sup>th</sup>/168<sup>th</sup> Streets)  
New York, NY 10032

- July 12<sup>th</sup>: PATIENTS' STORIES OF TRANSPLANT**  
*Meet transplant recipients, donors and caregivers.*
- July 19<sup>th</sup>: AN OVERVIEW OF LIVER DISEASE & LISTING CRITERIA**  
**How does the liver function? What is cirrhosis? How does listing work?**  
*Speaker: Paul Gaglio, MD, Transplant Hepatologist*
- July 26<sup>th</sup>: LIVER TRANSPLANTATION SURGERY: DECEASED VS. LIVING RELATED DONATION**  
*Speaker: Benjamin Samstein, MD, Transplant Surgeon*
- August 2<sup>nd</sup>: POST-TRANSPLANT DIABETES AND NUTRITION**  
*Speaker: Marisa Wallace, NP, Diabetic Educator  
Brenda Klein, Nutritionist*
- August 9<sup>th</sup>: TOUR OF THE OPERATING ROOM – 3:00 PM – NOTE CHANGE**  
*Tour of the 7HS Transplant Unit will occur prior to the OR tour so don't be late!*
- August 16<sup>th</sup>: IMMUNOSUPPRESSANT MEDICATIONS AND THEIR SIDE EFFECTS**  
*Speaker: Stacey Balducci, PharmD, Transplant Pharmacist*
- August 23<sup>rd</sup>: LIVER DISEASE AND TRANSPLANTATION: THE BURDEN ON THE BRAIN**  
*Speaker: Silvia Hafliger, MD, Transplant Psychiatrist*
- August 30<sup>th</sup>: OPEN FORUM**  
*Facilitated by Psychosocial Team.*

**These sessions are MANDATORY!**

*Spanish Interpreter Available. (Hay un interpreter espanol disponible.)*

**For more information contact:**

**Silvia Hafliger, MD, at (212) 342-2787 or Aimée Muth, LCSW at (212) 305-1884**

**Who:** POST-TRANSPLANT RECIPIENTS

**Where:** NYPH-Columbia University Medical Center  
Milstein Hospital Building  
177 Fort Washington  
Reemtsma Conference Room,  
7 Hudson South, Room 7-213

**When:** 10:00 – 11:30am,  
First and Third Thursday of every month:  
Thursday, July 19<sup>th</sup>  
Thursday, August 2<sup>nd</sup>  
Thursday, August 16<sup>th</sup>  
Thursday, September 6<sup>th</sup>  
Thursday, September 20<sup>th</sup>

**Facilitators:** Aimée Muth, LCSW  
212-305-1884, aim9003@nyp.org

**CAREGIVERS**

New York-Presbyterian Hospital-Columbia  
Please note the groups on *June 28<sup>th</sup>* and *July 12<sup>th</sup>* will be held:  
Presbyterian Hospital building,  
622 West 168<sup>th</sup> Street across the hall from the  
PH14 Transplant Clinic.

*From July 26<sup>th</sup> on*, the groups will be held at:  
Milstein Hospital Building  
177 Fort Washington  
Reemtsma Conference Room,  
7 Hudson South, Room 7-213

4:00-5:30pm, Second and Fourth Thursday of every month:

Thursday, June 28 <sup>th</sup>	PH-14, Room 101
Thursday, July 12 <sup>th</sup>	PH-14, Room 101
Thursday, July 26 <sup>th</sup>	Reemtsma Conf. Room
Thursday, August 9 <sup>th</sup>	Reemtsma Conf. Room
Thursday, August 23 <sup>rd</sup>	Reemtsma Conf. Room
Thursday, Sept. 13 <sup>th</sup>	Reemtsma Conf. Room
Thursday, Sept. 27 <sup>th</sup>	Reemtsma Conf. Room

Kimberly Morse, LMSW  
(212) 305-3081 krm9020@nyp.org

## CAREGIVERS FORUM

Kimberly Morse, LMSW

The newly developed Caregivers' Forum not only provides an opportunity to interact with other caregivers and support one another, but offers relevant information that can be helpful in coping with the caregiving experience. Please note the topic-based discussions below. Adline Warwick-Thompson, Social Work Intern who began the group, has completed her internship, so I am now facilitating this group for the transplant caregivers from Liver, Heart, Kidney, and Lung. Please feel free to contact me as needed. Hope to see you there! (See above for contact information.)



*Cycles of 6 sessions are repeated four times a year. July 12<sup>th</sup> will begin a new cycle ending September 27<sup>th</sup>.*

**SESSION 1: INTRODUCTION TO CAREGIVING**

**SESSION 2: BALANCING DEMANDS AND RESOURCES**

**SESSION 3: SHIFTING FAMILY ROLES AND RESPONSIBILITIES DURING THE TRANSPLANT PROCESS**

**SESSION 4: DETERMINING THE EFFECTS OF ILLNESS ON FAMILY COMMUNICATION PATTERNS**

**SESSION 5: RECOGNIZING THE SIGNS AND SYMPTOMS OF STRESS**

**SESSION 6: MANAGING STRESS DIFFERENTLY, DRAWING TOGETHER THE GROUP EXPERIENCE**

As many of you are not able to participate in the Caregivers' Forum or would like additional resources, please note the new caregiver resource section toward the end of the newsletter; this will now be featured every quarter. There are many existing resources that offer vital information and support to assist in coping with the caregiver journey. If you have discovered a resource that might be helpful for others, please feel free to share and we can make it an addition to the newsletter.

# LOCAL AND NATIONAL RESOURCES

## NATIONAL

- *United Network for Organ Sharing*  
<http://www.unos.org>, (888) 894-6361
- *American Liver Foundation*  
800.GO.Liver or <http://www.liverfoundation.org>
- **FRIENDS' HEALTH CONNECTION**  
(800) 48-FRIEND, [WWW.48FRIEND.ORG](http://WWW.48FRIEND.ORG)
- **COTA (Children's Organ Transplant Association)**, (800) 366-2682, [www.cota.org](http://www.cota.org)
- **Well Spouse Association**, (800) 838-0879,  
[www.wellspouse.org](http://www.wellspouse.org)
- **Liver Cancer Care**, <http://www.hopeforlivercancer.com>
- **Liver Cancer Network**, <http://www.livercancer.com>
- **Hemochromatosis Foundation**,  
<http://www.hemochromatosis.org>
- **PBCers Organization**, <http://www.pbcers.org>
- **Biliary Atresia and Liver Transplant Network**,  
<http://www.transweb.org/people/recips/resources/support/oldbilitree.html>
- **The FAIR Foundation**, 760-200-2766,  
[www.fairfoundation.org](http://www.fairfoundation.org)
- **National Hepatitis C Advocacy Council (NHCAC)**, 877-737-HEPC, [www.hepcnetwork.org](http://www.hepcnetwork.org)
- **National Minority Organ Tissue Transplant Education Program (MOTTP)** - 2041 Georgia Avenue, NW Ambulatory Care Center, Suite 3100 Washington, D.C. 20060  
(202) 865-4888, (800) 393-2839, (202) 865-4880 (Fax)
- <http://www.transweb.org> - nonprofit educational resource for the world transplant community, dedicated to promoting donation and providing transplant education for patients, families, students, and professionals in the field.

## Connecticut

- *Transplant Recipients International Organization (TRIO) – New England Chapter*- 617-266-9559
- *Connecticut Coalition for Organ and Tissue Donation (CCOTD)*, (203)-387-9332 or  
<http://www.ctorganandtissuedonation.org>

## New Jersey

- *The Central NJ Transplant Support Group* - 732-450-1271 or <http://www.njtransplantsupport.com>
- **NJ Sharing Network** - 841 Mountain Avenue, Springfield, NJ 07081, 973-379-4535, 800-SHARE-NJ

## New York

- *Transplant Support Group of Western New York*, 716-685-4799, [mmar1@juno.com](mailto:mmar1@juno.com)
- *Children's Liver Alliance (Biliary Atresia and Liver Transplant Network)*, 718-987-6200 or  
[Livers4kids@earthlink.net](mailto:Livers4kids@earthlink.net)
- *Transplants Save Lives, Inc. Support Group (Rockland and Orange Counties)*  
[newheart93@aol.com](mailto:newheart93@aol.com)
- *Transplant Recipients International Org.*  
LI: 516-798-8411, [www.litrio.com](http://www.litrio.com),  
NYC: 718-597-5619
- *TSO Transplant Support Organization*  
[www.transplantsupport.org](http://www.transplantsupport.org)
- *TSO of Staten Island*, 718-317-8073 or  
[www.transplantssupport.org/staten.html](http://www.transplantssupport.org/staten.html)
- *LOLA (Latino Organization for Liver Awareness)*, 888-367-LOLA, 718-892-8697 or <http://www.lola-national.org>

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## CAREGIVER RESOURCES

- *Caring Today*  
Phone: 203-254-0783  
E-Mail: [editor@caringtoday.com](mailto:editor@caringtoday.com)  
Website: <http://www.caringtoday.com/>
- *Family Caregiver Alliance*  
Phone: (800) 445-8106  
Website: [www.caregiver.org](http://www.caregiver.org)
- *National Alliance For Caregiving*  
Email: [info@caregiving.org](mailto:info@caregiving.org).  
Website: <http://www.caregiving.org>
- *National Family Caregivers Association*  
Phone: 1-800-896-3650  
E-mail: [info@thefamilycaregiver.org](mailto:info@thefamilycaregiver.org)  
Website: <http://www.thefamilycaregiver.org>
- *Strength For Caring*  
Website: <http://www.strengthforcaring.com/>
- *Today's Caregiver*  
Web site: <http://www.caregiver.com>

# AREA SUPPORT GROUPS

## **Englewood, NJ (Hepatitis)\***

Meets Second Tuesday of every month; 6:30 PM  
Englewood Hospital and Medical Center; group meets in the library. **Phone:** 201-894-3496  
Contact Jeffrey Aber for more information.

## **New Jersey - Hackensack (Hepatitis C)\***

Meets every second and fourth Monday monthly;  
Hackensack University Medical Center  
**Phone:** 201-996-3196  
Contact Mary Ann Collins for more information.

## **Long Island (Hepatitis C Courage Group)**

Meets Last Thursday Monthly; 7:00pm  
Manhasset, NY  
**Phone:** 631-754-4795  
Contact Gina Pollichino, RN for more information.

## **Long Island (Hepatitis C)**

Huntington Hospital Contact Gina Pollichino, RN  
at 631-754-4795 for more information.

## **Long Island (Hepatitis C)**

Meets first Monday monthly; 7pm - 9pm  
North Shore University Hospital at Plainview  
**Phone:** 631-754-4795  
Contact Gina Pollichino, RN for more information.  
Certain scheduling changes may occur to accommodate holidays.

## **Long Island (PBC)\***

**Phone:** 516-877-4568  
Contact Marilyn Klainberg for more information.

## **NYC – (Liver Cancer)\***

Several support groups. Contact Lynette Williams, LMSW at (212) 305-5274 for further information. A Spanish support group is also facilitated by Madeline Encarnacion at (212) 305-6320.

## **NYC - Manhattan (Hepatitis C)\***

Meets Third Tuesday Monthly; 6pm - 8pm  
St. Vincent's Hospital Link Conference Room, 170 West 12th Street **Phone:** 212-649-4007  
Contact: Andy Bartlett ([andybny@yahoo.com](mailto:andybny@yahoo.com))

## **NYC - Manhattan (Hepatitis C)\***

Meets first Wednesday monthly; 6:00pm-7:00pm at Weill Medical College of Cornell University/New York Presbyterian Hospital.  
**Phone:** 212-746-4338  
Contact Mary Ahern, NP for more information.  
*450 E. 69<sup>th</sup> Street between 69<sup>th</sup> St/ York Avenue, This support group is offered by the Center for the Study of Hepatitis C, a cooperative endeavor of Cornell University, Rockefeller University and New York Presbyterian Hospital.*

## **NYC - Manhattan (L.O.L.A. Support Group)\***

Meets Every third Wednesday monthly; 6pm;  
New York Blood Center, 310 East 67th Street  
**Phone:** 718-892-8697

## **NYC - Manhattan (PBC)\***

Meets Every 2-3 months; 6:30-8:30 pm  
Mount Sinai Hospital, Guggenheim Pavillion, Room 2B  
**Phone:** 212-241-5735  
Contact John Leonard for more information.

## **NYC - Queens (H.E.L.P.P.)\***

H.E.L.P.P. (Hepatitis Education Liver Disease Awareness Patient Support Program)  
Meets Sunday afternoon monthly;  
NY Hospital of Queens, Flushing  
**Phone:** 718-352-7772  
Contact Teresa Abreu for more information.

## **Transplant Recipients International Organization (TRIO) – Manhattan\***

Meets the second Wednesday of each month from September to June, 7:30 pm, 145 Community Dr., Manhasset, NY. The December meeting is a holiday party.  
Contact Lorraine DePasquale, Pres. at 718-597-5619 or [mailto:triom@aol.com](mailto:mailto:triom@aol.com)

## **TRIO – Long Island\***

Meets the second Wednesday of each month from September to June, 7:30 pm, 145 Community Dr., Manhasset, NY, directly across from North Shore Univ Hosp. The December meeting is a holiday party.

## **Transplant Support Organization (TSO) –Westchester County**

Third Wednesday of every month, 7pm at:  
Mt. Pleasant Community Center  
125 Lozza Drive Valhalla, NY  
2007 Meetings June 20, Sept. 19, Oct. 17, and Nov., 14 20  
**Phone:** 914-576-6617 or [tso97@optonline.com](mailto:tso97@optonline.com).

## **CT – Spousal Caregiver Support Group\***

Caregiver support group geared toward men and women who are caring for the needs of a chronically ill family member. The group meets twice a month.  
**Phone:** 203-863-4375

## **Wilson's Disease Support Group\***

**Phone:** 203-961-9993, Contact Lenore Sillery

*\*Not sponsored by the American Liver Foundation.*

