

New York- Presbyterian The University Hospitals of Columbia and Cornell LIVER CONNECTION

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THE NEWSLETTER FOR LIVER TRANSPLANT
PATIENTS AND FAMILIES

Winter 2006

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From The Editors

Happy Holidays! Hopefully you all had a wonderful Thanksgiving and are gearing up for the New Year!

We are very excited about the new babies born to our transplant recipients! There have been four new babies (one baby is missing from the section) born within the past three months to liver transplant recipients. These recent births are a valuable reminder that it is possible to have children safely in collaboration with your transplant team and ob-gyn. Congratulations to their families!

While putting this newsletter together, it struck me that there is a lot of important work that is being done by our pre- and post-transplant patients to increase awareness about liver disease, transplantation and organ donation. Numerous transplant recipients have become active in local and national organizations, including the New York Organ Donor Network, National Kidney Foundation's Team Liberty, Polycystic Kidney Foundation, Transplant Support Organization (TSO), TRIO (Transplant Recipients International Organization), TSL (Transplant Saves Lives) and our own post-transplant and educational groups.

In the spirit of giving thanks, we would like to acknowledge some of our transplant recipients and families who have become active in the transplant community at large. Of course, this is just a small sample – we know many more of you are doing your own part to educate those around you. By looking at these examples, it struck us as to how important (and sometimes easy!) it can be to increase awareness:

- The Lupo family has been busy since their father's transplant. Breanne Lupo, Anthony Lupo's daughter, is a Ridgewood High School senior (and aspiring future nurse!) who organized a community service project highlighting and providing information about organ and tissue donation. Breanne's community project targeted 400 Ridgewood, NJ community members. Breanne's older sister, Justine, is active in her university's Donate Life organization.
- After his transplant, Man Pan Lee (M-P) submitted articles to the Chinese World Journal, the number one Chinese newspaper in the U.S., about liver disease and organ donation in hopes of increasing awareness within the Chinese community. Through his work, the

New York Organ Donor Network found him and has recruited him to volunteer to help better reach the Chinese population!

- During April, National Organ Donation Month, John McDonald spoke to two different groups at his church, St. Catherine's, to educate the mothers of the Parenting Center about the organ donor shortage and, a week later, to their school's parent/teacher monthly meeting. Lots of myths regarding transplant and organ donation were debunked! In addition, he is involved in his local TSL group and sends out regular emails to family and friends about the shortage of organs and the importance of organ donation.
- After participating in the U.S. Transplant Games with fellow liver transplant recipient Ralph Faga, John Rice has taken an active role on the executive board of Team Liberty, planning and fundraising for the U.S. transplant games in Pittsburgh, PA in 2008. John and his family have also been involved in liver disease, transplant, and organ awareness fundraising efforts.
- Jeff Isaacs has been actively involved both before and after his transplant with the Polycystic Kidney Foundation and NJ Sharing Network. He has played an active role in increasing awareness and providing support to those afflicted with the disease. Jeff also includes information on organ donation and NJ Sharing on all correspondence from his real estate practice!
- Gina Williams has played an active role in educating the NYPH transplant community by helping to facilitate production of our newsletter!
- Ralph Faga and Dennis Kubiak have been loyal participants of the educational workshops and post-transplant groups in order to provide support and education to other pre- and post-transplant patients.

For those of you who are interested in becoming more involved, John McDonald provided some suggestions based upon his own experiences which are really true for any type of presentation.

- Keep it simple and factual.
- Integrate your own personal experience with need to spread the word.
- Use reliable information from the internet. The numbers are an eye-opener and impact the audience.
- Start out by addressing small friendly groups. You can grow from there.

Don't forget, though, talking one on one is *invaluable* – putting a name and face to transplantation may change one's decision about being an organ donor. Remember, you are all great examples of how important organ donation is. Again, good work and congratulations to everyone for all their efforts!

In keeping in line with organ awareness, if you have any letters for your donor families, please forward them to your social worker. If you have any questions as to how to start the letter, your social worker can also help guide you through the process and provide you with some ideas as to how to start the letter.

Happy Holidays!

As a reminder, we are always looking for articles from liver patients, both pre- and post-transplant. Please email (aim9003@nyp.org) or mail to the address below.

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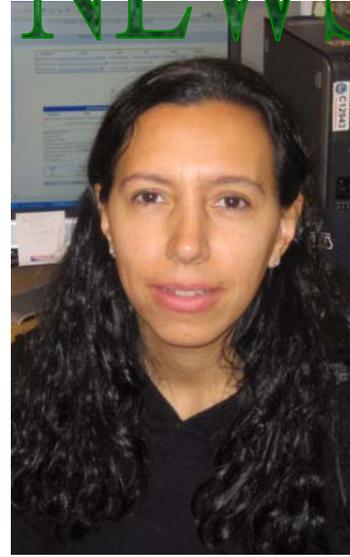
TRANSPLANT NEWS

TRIO Honors Margie Fernandez-Sloves, NP!

Transplant Recipients International Organization (TRIO) is an independent, non-profit, international organization committed to improving the quality of life of transplant candidates, recipients, their families and the families of organ and tissue donors. Every year, TRIO honors three areas of transplantation: clinician, donor family, and recipient. This year's event was held on November 3rd at Marina del Ray in the Bronx. This year's honorees included Dr. Thomas Schiano, Medical Director of Mt. Sinai Medical Center, Family of donor Paul Anthony Lopez, and recipient of the year, Linda Shatzer. Many of you may remember that Dr. Emond was awarded last year.

In addition to the Triangle Awards, TRIO also presented "The Anita Principe Award", an award named after Anita Principe, a former transplant coordinator at Montefiore Medical Center who has been a pioneer and leader in the field of transplantation.

We are proud to announce that this year's Anita Principe Award was presented to Margie Fernandez-Sloves, NP, transplant coordinator here at New York Presbyterian Hospital. For those of you who do not know Margie, she has been working at CLDT since 2003 as a nurse practitioner and transplant coordinator. Prior to joining us, Margie worked as a transplant coordinator at Mount Sinai Medical Center in the fields of clinical research, lung transplantation, and intestinal transplant. Margie is currently working on her Doctorate in Nursing Practice at Columbia University.



Margie's dedication, expertise and hard work are greatly appreciated here at the Center for Liver Disease and Transplantation by both patients and staff. Thank you to TRIO for recognizing her importance and value in the transplant community. Congratulations Margie!

For those of you who would like to get involved with TRIO, please contact: Lorraine De-Pasquale, President PO Box 122, Throggs Neck Station, Bronx, NY 10461 718-597-5619.

New York Organ Donor Network Donor Luncheon – Sunday, October 22nd

The New York Organ Donor Network's Donor Family Recognition Luncheon is organized to say thank you and to acknowledge the unique and life affirming gifts that the families of donors have given to others. It is also a way for them to come together with other donor families and representative recipients and to remind them that their gift, given at a time of their own pain and loss, really has the power to give life and return the recipients to well being. For many of the families of donors, seeing and hearing from someone who received a second chance at life is almost as good as hearing from the recipients of their own loved one's donation.

At the luncheon, donor families also have the opportunity to memorialize their loved one with a square on the New York Organ Donor Network Memory Quilt and to receive the New York State Medal of Honor. The New York State Medal of Honor was established in 2002 by Governor George Pataki to recognize organ and tissue donors. There was not a dry eye in the house as each donor name was announced and a brief description of each donor read. The afternoon included an introduction of recipients, keynote address by Dr. Jean Emond, the Memory Quilt pinning, readings from donor son, James Mateiko, and recipient speaker Gillian Cohen.



Transplant News continued bottom, page

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TRANSPLANT NEWS, continued

TRANSPLANT NEWS, continued

POST-TRANSPLANT SUPPORT GROUP AT CORNELL MARK YOUR CALENDARS!!!

OUR FIRST MEETING:
Thursday January 25, 5:30 PM

Where:
1305 York Ave (at the Southwest corner of York Ave and 70th Street)
4th Floor Conference Room

Facilitators:
Dalia Teen, SWI, 212-746-3203, dat9025@nyp.org
Jennifer Keen, LMSW, 212-746-3245, jek9028@nyp.org

At our first meeting, we'll share experiences and decide when and how often groups will meet. Future meeting dates and times will be posted in clinic and mailed to all post-patients. We hope to see you there!!!

Please RSVP to either Dalia or Jennifer. Light refreshments will be served.

In Response to Your Letters

There were many responses to the caregiver essay in the fall newsletter. Some of you were offended by the frank expression of frustration and burnout by the caregiver, while some of you related to the ups and downs of the transplant process and the fear and difficulty of caring for a loved one. Transplant affects the whole family and care team. All too often we only focus on the patient. The reality is that the caregivers are going through the transplant process as well. They face enormous hurdles, have to make personal sacrifices, struggle with fatigue, resentment and fear. For many, the process does not end with the surgery and immediate post-recovery.

Many families are unprepared for the long road ahead. Some believe they just have to "pass the psychosocial evaluation" or get all their tests done to get the patient listed. The reality is that becoming listed or receiving a transplant is just the beginning. Each transplant recipient's journey is very different, especially depending upon the cause of their liver disease and the complications from their illness and transplant.

Caregivers need to be prepared for the journey ahead, they need to plan and delegate. They also need support for themselves. Only when we all work together as a team can transplant have the potential to be a miracle and a success.

Sincerely, Silvia Hafliger

So you've had a liver transplant !

Jessica Chipkin

Chances are you battled and conquered one hell of a disease. You're alive; you are living your life just how it was and just how it should be. Only now you have a story to tell. Or maybe you don't want to tell it. Maybe you would just rather talk about life, and how good it is now. Maybe it would be nice to hear what others in a similar state of mind have to say.

There are a lot of us out there. We all have amazing stories that we may not get to tell too often. Sometimes being a post-transplant patient is lonely. We are by no means alone, but sometimes the separation from the hospital makes us yearn to talk to someone who can relate. Someone to whom you don't have to explain how you're feeling from a certain medication, a slight ache, or an emotional upper/downer. They just *know* what you mean.

I know because I've been there, and I'm still there. I had my liver transplant on June 24th, 2005, right before my 22nd birthday. It's been quite an amazing roller coaster ride since then, and for some reason I think it will always be like this. I find myself going about my days lately, feeling a bit incomplete. I have a great family, fantastic friends, amazing boyfriend, and an excellent job. But something is missing. I want to interact with people who have the one thing in common with me that none of my family members or friends have; a transplant.

I know there are many people reading this article who know what I mean. You are who I want to meet and talk to! Being both a patient as well as an advocate for the new Cornell support group, I'd like to extend this opportunity for you to come out to the first meeting. Let's meet, chat, anything.

Let's take advantage of the greatest gift we were ever given... a second chance.

I look forward to meeting you all.

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NEW FACES



Kimberly Morse, LMSW – Hi, I would like to introduce myself as the third social worker for the liver transplant team, following patients with last names beginning G-O. I am a native Californian, and am proud to call myself a New Yorker, after recently moving to Manhattan! After completing my Bachelor of Social Work program at Azusa Pacific University, in sunny southern California, I ventured to rainy Seattle to receive my Master of Social Work from the University of Washington. I have several years experience working with adults in the hospital setting and I am excited to join the liver transplant team. I look forward to meeting my new patients and their families!

Mercedes Martinez, MD - Dr. Martinez joined the pediatric liver and small bowel transplant program in July 2006. Originally from Cuba, Dr. Martinez received her medical degree and completed her general surgery residency in Cuba prior to moving to NYC where she has specialized in pediatric medicine. Many of you may recognize Dr. Martinez from the three years she worked as a Pediatric Gastroenterology and Nutrition Fellow at the Morgan Stanley Children's Hospital at New York Presbyterian Hospital. We are very lucky to benefit from Dr. Martinez's significant experience in both clinical and research settings.



Anastasia Balducci, PharmD, Transplant Pharmacist

My name is Anastasia Balducci (Stacey), and I recently joined the liver transplant team at the Columbia University campus of New York Presbyterian Hospital as the new clinical pharmacist in September of 2006. I received my pharmacy degree from the Medical University of South Carolina in 2001 and afterwards worked as a staff pharmacist at a local hospital for 3 years. In 2004, I began a 2-year pharmacy residency program, of which 1 year was devoted to learning about transplant medicine in kidney and liver transplant patients. At Columbia, I work closely with the liver transplant team to ensure the safe and appropriate use of medications in our liver transplant patients; I also assist in teaching new transplant patients about their medications prior to their discharge from the hospital. I basically act as a drug information resource for the liver team, the patients, and other Columbia staff. I am very excited to have the opportunity to work here at Columbia with such an excellent group of clinicians and patients.

Adline Warwick-Thompson, Social Work Intern

I am delighted to be joining the CLDT, as part of my internship from Fordham University, where I am in the final year of my Masters in Social Work. Since many of you are prompted to ask where I come from when you hear my accent, perhaps I should take this opportunity to introduce myself. In August 2001, I left my hometown of London, in order to move to New York. I came to the United States with a training and work background in Psychological and Organizational Counseling from the UK where I had been working as an organizational counselor within a Staff Stress Management and Counseling Service for Hammersmith Hospitals NHS Trust, a large group of London teaching hospitals, with much the same atmosphere as Columbia-Presbyterian. Here in the US, whilst working towards my MSW, I have been involved in planning and implementing a Psychosocial Support Program for Patients and Families at Dickstein Cancer Treatment Center, White Plains Hospital. Together with a nurse practitioner at the cancer center, we also launched the Men's Health Forum, in order to focus on the largely unaddressed needs of men with prostate cancer. I am pleased to say that this forum is now a thriving part of the Cancer Center. In keeping with my interest in seeking to create new services for patients and their families, I am now very excited to be setting up the Caregivers Forum here at New-York Presbyterian, which you can read about in this newsletter. I hope to see many of you there!



Dalia Teen, Social Work Intern

Dalia is a second year Advanced Standing student from Fordham's Graduate School of Social Work. Her concentration is Client-Centered Management, so in addition to her work with patients, she will be working on administrative projects including an organ donor awareness event and the post-transplant patient support group at Cornell (see page 3). Prior to attending graduate school, Dalia completed her Bachelor's in Social Work at Fordham, and went on to spend 5 years working at an Early Head Start program at The University Settlement House. She is at Cornell Mondays, Wednesdays, and Fridays and can be reached at 212-746-3203.

BABY, BABY, BABY!

BABY, BABY, BABY!



First baby of the CLDT!

Shannon Boyle's new baby girl! Piper was born on Oct. 13th and weighed 3.13 lbs and was 16 inches. She was 4 weeks early but she is doing so great now. Piper is almost 7lbs and about 20 inches. She was born at St. Barnabas Hospital in Livingston NJ. Her full name is Piper Mary Mogila. Piper's middle name is after Shannon's mother Mary, who gave Shannon part of her liver 4 years ago at NYPH.



Melissa Rodriguez is followed at NYPH Cornell--she had a liver transplant in 1985 at Yale for autoimmune hepatitis. She is photographed with her two children: Reece Hayden Rodriguez, born October 4, 2006 and Jesse Dalton Rodriguez born May 11, 2004. Everyone is healthy and doing well!



Gina DiBella and her husband, Thomas, welcomed son, Carmen Mario DiBella on November 25, 2006 at 3:22 in the afternoon. Carmen is 7 pounds 2 ounces and 19 $\frac{3}{4}$ inches. Gina, who had her liver transplant May 29, 2004, says Carmen is happy and healthy - keeping his parents up all night crying!

SILVIA'S CORNER

SILVIA'S CORNER

Lessons on Pain Management: "Severe pain is world destroying" (Elaine Scarry from the *Body in Pain*)

Silvia Hafliger, MD

Pain is an unpleasant *sensory and emotional* experience associated with actual or potential tissue damage. It is always real. Social and emotional issues can intensify or ameliorate pain. All patients undergoing a liver transplant experience some pain. Some have chronic pain syndromes unrelated to liver disease such as chronic back pain or arthritis; others will only have pain immediately after the operation.

Acute pain is usually as a result of tissue damage and/or inflammation that lasts less than six months. Post-surgical pain is considered acute pain. *Chronic pain* involves changes in the peripheral and central nervous pathways, lasts longer than six months and includes nerve damage due to diabetes, HIV, Hepatitis C, osteoporosis or immunosuppression.

Acute post-operative pain is managed with patient controlled anesthesia (PCA). You can administer pain medication, usually Morphine or Dilaudid, directly into your blood by pressing a button connected to an intravenous pump. Don't worry - you will not overdose on pain medication. The duration of the administered medication is generally short, but you can expect relief immediately. Some people experience drowsiness, vivid dreams or even hallucinations from opioids. Nausea, constipation and itching are common side effects. If you experience these side effects, please let your doctor know.

Once you have left the intensive care unit (ICU) and are on 7HS, the transplant unit, you will be switched from the intravenous pump to oral medication such as Oxycodone. Most patients will receive 10 mg of Oxycodone every 4-6 hrs if in pain. Most patients go home with Oxycodone pills and slowly taper off the pain medication over the next 2-3 weeks.

If your pain is chronic and you are *waiting* for a liver transplant, caution applies. All Opioids (Fentanyl, Methadone, Dilaudid, Oxycodone/ Percocet, Vicodin) can worsen your memory and make you slow and disoriented. If you suffer from hepatic encephalopathy, we strongly encourage lowering opioids to the lowest possible dose.

Due to low platelets and risk of bleeding, **all non-steroidal analgesics**, such as *Motrin, Aspirin, and Aleve* are **forbidden**. You may use Tylenol in moderation. The maximum dose a day is 2000mg or four extra strength Tylenol a day. Remember Percocet and Vicodin are compound medications and include usually 500 mg of Tylenol in addition to opioids.



If Tylenol does not alleviate your discomfort Ultram may be an alternative choice. If the pain is severe, low dose Methadone 2.5 mg every 6 hours may be an option.

If you have chronic pain *after* the transplant, and you require an opioid, we usually recommend Methadone. It is long acting, minimizes withdrawal symptoms and has minimal effects on the thyroid and pituitary gland. All opioids need to be tapered off slowly, as patients develop physiologic dependency. This *does not* imply that you are addicted. It simply means your brain and body have developed a tolerance.

If you are taking opioids, we recommend that one physician prescribes the medication. You should also use the same pharmacy and always communicate any change in your dose to your doctor or nurse practitioner. These medications are regulated, cannot be called in to the pharmacy and require close monitoring. Usually you can only get a 30-day supply at a time.

Neuropathy can also be a significant source of pain for patients pre and post-transplant. Neuropathy is damage to small nerve endings in the feet and/or hands, often associated with diabetes. Medications such as Neurontin, Lyrica or Keppra can decrease firing of nerve endings, thereby reducing pain.

Remember anxiety and depression worsens pain. Addressing emotional or social stress will decrease pain perception and suffering. Exercise and stress reduction activities, including yoga and meditation, are important activities as they can alleviate pain and increase mobility and functional status.

The most important thing to remember when suffering with pain is to discuss your pain with your clinicians. Do not try to control pain on your own! Inappropriate use of pain medication can jeopardize your overall health as well as your status as a transplant candidate.

"Happiness is not being pained in body or troubled in mind" (Thomas Jefferson 1743-1862)

Have a healthy and happy holiday season!

PEDIATRICS

PEDIATRICS

Nutritional Guidelines for Children Awaiting Liver Transplants

Susan Brodlie, Pediatric GI Nutritionist

Proper nutrition before, during and after the transplant process ensures that the liver is able to carry out its many important functions. For children awaiting liver transplants, nutrition plays a vital role in treatment.

The liver helps us to absorb fat soluble vitamins - vitamins A, D, E and K. It also helps produce serum proteins which are necessary for the normal growth and function of our bodies. Furthermore, it helps maintain normal blood glucose levels and removes toxic elements from our systems.

A malfunctioning liver presents major obstacles to healthy growth – imperative for child development. Ideally a baby, child or adolescent should eat a balanced diet that provides all the necessary calories, proteins, fats and vitamins and minerals. For babies, we recommend an infant formula that they can absorb and utilize to grow and the proper introduction of solids. For children, we continue to introduce new foods and textures as well as incorporating variety. For adolescents, we encourage healthy balanced diets with adequate nutrients to support their needs as they go through puberty.

However, it is often difficult to provide a calorically adequate diet for babies, children and adolescents with chronic liver failure. Liver failure can lead to decreased appetite, anorexia, nausea and vomiting, fat malabsorption, alterations in energy and protein metabolism and medication-induced losses. Our initial goal is to offer food/formula by mouth. Therefore, we often concentrate baby formulas to give more calories in a smaller volume and sometimes recommend giving smaller volumes of formula more frequently. Both of these strategies help counteract the effects of decreasing intakes. We also provide supplemental fat soluble vitamins to all our patients in addition to their regular diets.



If a child is still not able to take enough calories by mouth, we often initiate nasogastric tube feedings. This type of feeding maximizes the nutrition we are able to provide, while still encouraging the child to take formula by mouth. It is important to emphasize that feeding does not have to become a struggle, when an NG tube is in place. An NG tube can be used to provide formula overnight and/or to provide feedings every 3-4 hours. This mimics a normal eating schedule.

Finally, if a child is not able to be fed into the stomach or the intestine (enteral feedings), we can still meet nutritional needs using Total Parenteral Nutrition (TPN). TPN is a solution that is run into a central venous catheter (Broviac/PICC/ Portocath) and consists of carbohydrates, protein, fats (often provided 3 times/week), vitamins and minerals. It can be run over 12 – 24 hours, in a way that is safe for your child.

While TPN is a ‘last resort,’ it is commonly used to provide nutrition when enteral feedings are not possible. When a patient is receiving TPN, oral feedings or oral stimulation is recommended to maintain feeding skills.

These nutritional guidelines are instrumental in helping to treat or prevent malnutrition, to optimize nutritional status, to monitor and supplement vitamins to prevent deficiency, to limit the risk of complications such as hypoglycemia and infection, to promote growth and development and finally, to improve the patient’s quality of life.

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PATIENT VOICES

PATIENT VOICES

Wow! I Can't Believe It!

Jeffrey Isaacs

November brings Thanksgiving and **the first anniversary of my liver transplant!** Looking back who knew that I would make it this far? Because someone decided to give me the Gift of Life, I now have a second chance at life. I am thankful to my donor and his family for donating his organs.



My transplant would not have happened if it wasn't for the great transplant team at Columbia-Presbyterian Medical Center. From the doctors, to the surgeons, the psychiatrist, the social workers and last but not least all the wonderful nurses.

When I started coming to the transplant center (CLDT) I never knew I would meet such wonderful people who cared about my quality of life. Every step of the way, there were people I met that would help me through the steps to receive a transplant.

The first step was meeting the doctors on the 14 floor CLDT. Then it was the testing for my MELD score. Next it was onto the series of seminars given by the transplant team. Everyone should make it a point to attend these seminars (the workshops, see p.11). There is a lot to learn from these experts and your fellow transplant recipients.

I made it onto the transplant list and the wait began. My doctor told me to go home and prepare for a transplant, within 4 to 6 weeks. I had a rare hereditary disease call Polycystic Liver Disease, which was now destroying my liver at a fast pace.

I received my first call to come in for a transplant 9 days later. After an 11 hour stay I was told the operation wasn't going to happen that day. The surgeon was more disappointed then I was.

I went home a bit disappointed but I knew my time was near. Finally realizing this was going to take place I needed to get my life in order. There certainly is a lot to get ready. From setting up my support group, getting my bills paid, to taking care of my dog, my house, my job, etc.

But, I didn't get a chance to finalize all the details. The next day I got my second call to come in for my transplant. I

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After the Transplant

Henny Brener

After having been sick with liver disease, evaluated by the doctors on the transplant team and hence listed for a transplant, the seemingly endless waiting came to an end on a sunny Sunday afternoon in July. I received the new organ and was closely monitored in the hospital for two weeks by very competent nurses. The staff of surgeons and residents who made the daily rounds was kind and reassuring that I would be well again.

The day arrived for my discharge. The transition from the security of the hospital to home was a cause of anxiety and apprehension. In the hospital we are assisted in the process of recuperation, the medications are brought to us; the scans done as scheduled, the therapist helps us to get moving around, etc. We leave the womb of security and now are on our own.

The first two and a half months are the most difficult. I had intense pain, felt tired, lethargic, sapped of all energy. Everything hurt me while I was healing internally. You can be short-tempered with those dear to you, and they should be forewarned that it can happen.

The most important person for me during this period of recuperation was my spouse, making sure that my medications were taken on time and resolving pertinent issues of the moment. When home cooking was not possible and good nutrition is essential, ordering take out, while making healthy food choices, was an option. Chores which were so elementary for me before transplantation seemed challenging; I had difficulty bending, reaching, and general range of movements.

Pain can be quite a downer, and sometimes I felt like crying and was utterly unhappy, I chose to compensate by trying to look my best under the circumstances. I would recommend that men shave daily and both men and women should get dressed in the morning even if much time is spent just resting. Listen to your favorite music and watch comedy DVDs to lift your spirits!

Soon one begins to feel the effects of all the medications. There are changes in the body which did not exist before. The doctor's office can always be called if you do not feel well. Your nurse practitioner is available with kind reassuring words of advice, and is a vital liaison between you

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PATIENT VOICES continued

PATIENT VOICES continued

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know people wait along time for a transplant but I was going downhill very fast. After my transplant, the doctors told me I was a very lucky person. After my surgery, seeing my actual liver, the doctors told me I had only a few weeks left to live. I even have a picture of my old and new liver.

How do you make it through the first year? With a lot of help! Your caregivers will have their hands full. From putting up with you, getting you to all your doctors appointments, having blood drawn, and making sure you take all your pills.

My children and friends really stepped up to the plate. It was going to be my turn to be waited on by my children. They gave up vacation time from their jobs to return home and take care of me. It was fun at first, but I needed my space. Fortunately for me, I didn't have any side effects from all the new medications I was taking. After two weeks of the wonderful care I was receiving, I gave my kids their walking papers. My daughter who lived nearby called me during the day, and if I didn't answer on the second ring, boy was I in trouble.

The rest of my support group was made up by my close circle of friends. I had meals cooked to my dietary restrictions, a car and driver at my call, a cleaning lady to take care of all my chores around the house and a lot of visits to see how well I was doing.

During my 14 day stay in the hospital, my friends were busy making over my house. I came home to a clean and newly decorated home. That really gave me a lift upon leaving the hospital. I helped a lot of people out in the past and now it was time for me to be on the receiving end.

I went home from the hospital with a lot of pills. Echo Pharmacy sent me home with a complete transplant care package. Their weekly pill containers have been great to use. It made it so easy to sort out the pills I needed to take each day. Also, their phone calls remind me to reorder my medications, before I run out.

My daughter found online a special watch for me to use. The watch is made by Cadex. It is a programmable watch to remind you to take your pills. The Cadex Watch has the following functions – real-time calendar clock, daily medication alarms, medical alert databank and an Alert Button to display medical information. Their website is www.cadexproducts.com. I just use the alarm setting.

I also joined Medic Alert. This is one of the nation's leading emergency medical information services. I wear a Medic Alert bracelet with my liver transplant info. There is also an emergency number to call for all my medical history, medications I'm taking, doctor contacts and my emergency contacts.

This is one site where you can keep your medical history up to date. Once you enter your medical history, doctors contact numbers, medications you are taking, it's at your fingertips. Medic Alert even sells a special USB-enabled device to store all your medical information. It makes it easy if you plan on being out of the area and need your medical history in an emergency. You can download x-rays and your latest blood tests. Their website is www.medicalert.org.

Last, remember to visit the Post-Transplant Support Group, which is run by Aimee Muth (see p. 12). It is great to meet with other transplant recipients and trade stories, to see new transplant recipients and the ones who have been coming back for years. It's GREAT TO HAVE A SECOND CHANCE AT LIFE and make new friends. Thanks to the Columbia-Presbyterian Medical Center Transplant Team!



Brener continued from page 8

and your doctor. The bottom line is, that the side effects are to be expected, it is just that we never had to confront these issues in the past.

Avail yourself of the information provided to you by the social work services of the hospital, the Patient's Guides and find additional information on the internet about transplant recovery. Of course, nothing replaces your dedicated doctor.

To get well again, have realistic expectations, don't push yourself and listen to your body which is the best indicator to you to guide you back to wellness.

I suggest keeping a daily journal of your blood sugar, weight, intensity of pain and the frequency of taking your pain reliever both day and night. This became a valuable tool for me in the months after transplant, and enabled me to monitor the progress I made, which at times felt stagnant.

The road ahead is a bit rocky, but it does even out. I looked back at my diary after only three months and while I was still not well, I was so much better. I no longer took pain relievers, and was more active at home. At three months I felt that I was really going forward and once again was becoming independent.

Certainly there are still some subtle side effects of the medications. In my case I experienced vision change, occasionally not being able to verbalize a word or a thought I wanted to express, a lower level of energy, hair loss, increased appetite, and skin blotches which come and go.

Patience, a positive attitude and a sense of humor are essential for recovery.

The reality is that no matter how upsetting these side effects are, it is great to be alive and I look forward to years of a productive future.

I always remember that I have the privilege to live from the generosity of a selfless family who through their heartache gave me the gift of life. I will be eternally grateful to them.

Wishing you all good health and a wonderful life ahead. Take joy in each day.



Gina's Butternut Squash Soup

- 1 butternut squash (peeled and cut into medium pieces)
- 1 small onion, chopped
- 2 stalks celery, chopped
- 3 medium carrots, peeled and chopped
- 4-5 cups chicken broth (depending on how thick you want it). I use packets of powdered boullion, 2 regular and 2 -3 very low sodium.
- small amount of oil
- a pinch of this or that (cumin, turmeric, thyme)

Fry the onions until transparent. Combine all ingredients in a large pot, cover, bring to boil, then simmer for a half-hour to forty-five minutes. Finally, puree in blender.

It's yummy. You can vary it by not pureeing all the veggies, adding more veggies, more liquid and/or more seasoning. I like it thick and sometimes toss in left-over chicken pieces for a balanced meal.

***Please use low-sodium broth or boullion if you are on salt restrictions!**

Any tasty, nutritious recipes out there? We'd love to print them here for everyone to use. Our nutritionist, Brenda Klein, will check the recipes for suitability.

CAREGIVING

A Caregiver's Perspective

Marilyn Prochilo

In December 2004, my husband Salvatore was diagnosed with hepatocellular carcinoma, or simply put cancer of the liver. One month later, he began the grueling transplant evaluation process, an extensive medical and psychosocial assessment to determine if he was a suitable candidate for liver transplant surgery. In March he was placed on "the list." As his health continued to decline, we lived each day uncertain of our future, anxiously waiting for a liver that would save his life.

Caring for a liver transplant patient takes strength and endurance. Together, you enter into a process that will last a lifetime, frequently shadowed by uncertainty, stress, anxiety, and depression. For almost 2 years following my husband's initial diagnosis, we felt as if we were living life on hold.

In October 2005, my husband gratefully received a liver transplant. When he was ill he needed a lot of assistance, not because he didn't want to take care of himself, but because he was unable to. Caregivers play a crucial role throughout the transplant process. At the CLDT a caregiver must be in place in order for a patient to be listed. Caregivers are relied upon to help ensure positive patient outcomes.

My role, as my husband's caregiver, has been complex and multifaceted. I arranged and accompanied him to all of his appointments, monitored his health, managed his medications, filled his prescriptions and medication boxes, administered or reminded him to take his medications, changed his dressings after his surgery, quit my job to run his business when he was unable to work, spent hours on the phone negotiating with insurance companies, and disputed denied claims and won. I managed our household, handled our dwindling finances, paid the bills, cared for other family members, kept an eye on my husband's day-to-day condition, drove him to the emergency room at 3:30 in the morning when his temperature reached 101, stayed in touch with the members of his healthcare team, became his advocate, and worried constantly until he was feeling well and on his feet again.

Caring for another person can be lonely, isolating, and often stressful. But you are not alone. The CLDT offers edu-

cational workshops, literature, support groups, and individual counseling. Take advantage of these resources. As a caregiver, it is important to learn as much as you can about liver disease and transplantation. Knowledge and support are empowering.

Don't hesitate to ask questions. Finding answers and receiving support will help you and the person you are caring for successfully navigate the transplant process. Your efforts will pay off. You are an important member of the transplant team. Ask others for assistance, delegate responsibilities, and most importantly, make time for you, even if it seems like another thing to add to your to-do list.

Attending support groups and educational workshops at the CLDT or within your own community can help you find answers, and reduce stress, anxiety, and depression. You'll have an opportunity to meet others with similar thoughts and concerns, exchange important information, learn ways to overcome barriers, and remain strong.

Three months after his surgery, my husband returned to work, 6 days a week. He feels better now than he has in years. Receiving a liver transplant is an extraordinary gift. It is the gift of life. We will be eternally grateful to the donor and their family along with the outstanding team of professionals at the CLDT. Today, we are able to live life enthusiastically, with optimism.



CAREGIVING, CONTINUED

CAREGIVING, CONTINUED

CALLING ALL CAREGIVERS

COME TO OUR NEW CAREGIVERS FORUM STARTING JANUARY 11TH @ 4PM

- Join us in a relaxed environment, which will promote an honest and open exchange about caregiving for patients with liver disease, both pre and post transplant.
- Find support and encouragement from others going through the transplant experience.
- Develop more effective coping strategies along the way.
- Hear from speakers on different topics related to caregiving.

Learning about every aspect of the transplant experience enables our patients and their families to be better equipped to cope with what can, at times, be an overwhelming and stressful process. While our Educational Workshops and post-transplant support group provide invaluable access to the knowledge necessary to feel equipped for the journey ahead, we urge caregivers to participate in this special forum designed specifically for you.

We know, both from the research literature, and from our experience here at the CLDT that the caregiver is the key source of support for the patient and plays an instrumental role both practically and emotionally in relation to the patient. We also know that the caregiver actually influences how patients both adapt and cope with their illness, treatment and recovery. For these reasons, it seems clear that the better you equip yourself for the road ahead, the more your loved one will benefit.

So, if any of the following subjects resonate with you, do come and join us.

- How have roles and responsibilities changed within your family?
- Have some relationships in your family become closer, whilst others have become more distant?
- Has the patient's condition affected family members' ability to talk directly and openly with one another?
- Who does the worrying in your household?
- Do you feel like you are living your life on hold?
- How can you manage stress more effectively?
- Do you have any concerns about sexuality or intimacy?

Caregivers bear a huge responsibility. Our aim is to help share that load. Remember – STRESS is a six letter word which is far worse than any four letter word!

For more information, contact Adline Warwick-Thompson, Social Work Intern, at (212) 305-1884.

Forum starts:

January 11th, 4pm to 5:30pm

Reemtsma Conference Room

Milstein Hospital Building, 177 Fort Washington, 7 Hudson South, Room 7-213.

It will be held the second and fourth Thursday of every month through March 2007.

EDUCATIONAL WORKSHOPS

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 165th/168th Streets)
New York, NY 10032

- Jan. 18th:** **PATIENTS' STORIES OF TRANSPLANT**
Meet transplant recipients, donors and caregivers.
- Jan. 25th:** **AN OVERVIEW OF LIVER DISEASE & LISTING CRITERIA**
How does the liver function? What is cirrhosis? How does listing work?
Speaker: Dr. Paul Gaglio, Transplant Hepatologist
- Feb. 1st:** **LIVER TRANSPLANTATION SURGERY: DECEASED VS.**
LIVING RELATED DONATION
Speaker: Dr. Sarah Bellemare, Transplant Surgeon
- Feb. 8th:** **THE DEADLY COMBINATION OF SMOKING AND IMMUNOSUPPRESSION**
Speaker: Dr. Silvia Hafliger, Transplant Psychiatrist
- Feb. 15th:** **IMMUNOSUPPRESSIVE MEDICATIONS AND THEIR SIDE EFFECTS**
Speaker: Edward Eggleton, NP, Transplant Coordinator
- Feb. 22nd:** **TRANSPLANT COMPLICATIONS: DIABETES AND OSTEOPOROSIS**
Speaker: Marissa Wallace, NP and Dr. Elizabeth Shane
- March 1st:** **TOUR OF THE OPERATING ROOM**
Facilitated by Psychosocial Team.
- March 8th:** **OPEN FORUM**
Facilitated by Psychosocial Team.

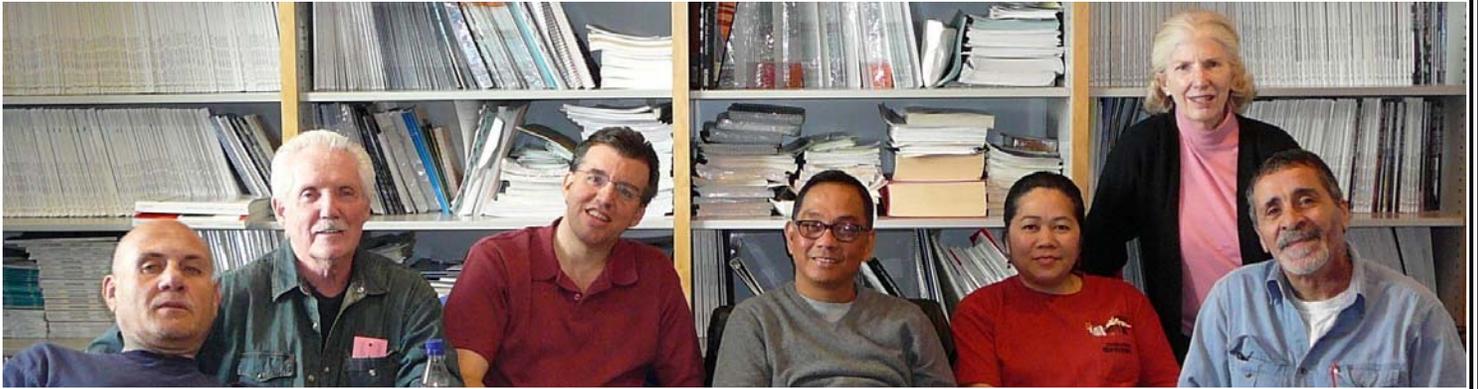
These sessions are MANDATORY!

Spanish Interpreter Available. (Hay un interprete espanol disponible.)

For more information contact:

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

POST-TRANSPLANT SUPPORT GROUP



Just look at those studious faces—happy, but a little sad too that you weren't there. We discuss the very things that you wonder about a lot but don't ask anyone about because you think you're alone. Believe you me, YOU ARE NOT ALONE in feeling cranky, spaced out, and, sometimes, depressed. But the BEST part of the time we spend together is being able to express our deep gratitude for being alive, without boring or embarrassing the people around us.

Join us in the Reemtsma Conference Room, 7 Hudson South (the transplant unit) Room 7-213.

Who: Post-transplant recipients and family members.

When: Future dates are:

Thursday, January 4th - 10:00-11:30am

Thursday, January 18th - 10:00-11:30am

Thursday, February 1st - 10:00-11:30am

Thursday, February 15th - 10:00-11:30am

Thursday, March 1st - 10:00-11:30am

Thursday, March 22nd - 10:00-11:30am

Thursday, April 5th - 10:00-11:30am

Thursday, April 19th - 10:00-11:30am

Where: New York Presbyterian Hospital
Milstein Hospital Building
177 Fort Washington
Reemtsma Conference Room, 7 Hudson South
Room 7-213

Facilitator: Aimée Muth, LCSW
RSVP to 212-305-1884

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
- COTA (Children's Organ Transplant Association), (800) 366-2682, www.cota.org
- Well Spouse Association, (800) 838-0879,
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
- National Hepatitis C Advocacy Council (NHCAC), 877-737-HEPC,
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
- *Children's Liver Alliance (Biliary Atresia and Liver Transplant Network)*
718-987-6200 or Livers4kids@earthlink.net
- *Transplants Save Lives, Inc. Support Group (Rockland and Orange Counties)*
newheart93@aol.com
- *Transplant Recipients International Org.*
LI: 516-798-8411, www.litrio.com,
NYC: 718-597-5619
- *TSO Transplant Support Organization*
www.transplantsupport.org
- *TSO of Staten Island*
718-317-8073 or
www.transplantssupport.org/staten.html
- *LOLA (Latino Organization for Liver Awareness)*, 888-367-LOLA, 718-892-8697
or <http://www.lola-national.org>

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 - 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)

NYC - Manhattan (Hepatitis C)*

Meets first Wednesday monthly; 6:00pm-7:00pm at Weill
Medical College of Cornell University/New York Presbyte-
rian Hospital. **Phone:** 212-746-4338

Contact Mary Ahern, NP for more information.

450 E. 69th Street between 69th St/ York Avenue, This sup-
port group is offered by the Center for the Study of Hepati-
tis C, a cooperative endeavor of Cornell University,
Rockefeller University and New York Presbyterian Hospi-
tal.

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.)*

Meets Sunday afternoon monthly;

NY Hospital of Queens, Flushing

Phone: 718-352-7772

Contact Teresa Abreu for more information.

H.E.L.P.P. (Hepatitis Education Liver Disease Awareness
Patient Support Program)

Transplant Support Organization (TSO) - Westchester Cty

Third Wednesday of every month, 7pm at:

Mt. Pleasant Community Center

125 Lozza Drive Valhalla, NY

2007 Meetings: Jan. 17, Feb. 21, March 21, April 18

Phone: 914-576-6617

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.*