

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

Volume V, Issue 3

THE NEWSLETTER FOR LIVER TRANSPLANT
PATIENTS AND FAMILIES

Fall 2006

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From The Editors

In addition to highlighting exciting New York State transplant legislation and new members of the CLDT team, the theme of this quarter's newsletter is caregiver support. In the transplant process, the needs of the caregiver are often lost in the care of the patient. It is the patient who becomes the priority to the caregiver and the Center. As a team, we insist that there is an adequate caregiving team in place for patients in order for them to be listed. We tell patients they need a caregiver at their medical appointments. After transplant, the caregivers need to learn how to do wound care or administer IV antibiotics if needed. With these great caregivers, we know that our patients and your loved ones are in good hands but who is taking care of the caregivers?

There are many caregiver support groups both here at the hospital and in the communities. Unfortunately, we often hear caregivers say "I'm all alone" but when given resources to assist them they do not follow through, often because they do not make time to care for themselves. In Dr. Hafliger's article, she speaks to the needs of the caregivers and the importance of self-care. Further, there are many caregivers here in the liver transplant community who are eager to speak to other caregivers going through the transplant process. Contact your social worker or nurse

practitioner to be connected to someone who is going through the same situation you are.

Please note there are changes to the post-transplant support group meeting schedule. In an attempt to make the group more accessible to those in the hospital we have scheduled additional group times on 7HS. Again, these groups are for any post-transplant patient and/or family member who has received a liver transplant and is looking for additional support.

As the Fall season approaches, please be aware of the importance of obtaining your flu shot. Please contact your primary care physician to investigate availability.

Finally, please note all of our staff additions! We are very excited about all of our new team members. Of special note, pediatric patients and families now have their own social worker, Meridith Berger. Look for new resources for pediatric patients and families in the months to come!

Transplant Recipients Only

The Post-Transplant Holiday Party this year will take place on Monday, December 18th from 4:30-7:30pm in the Faculty Club of New York Presbyterian Hospital. Hopefully, we will not have any other competing events this year – such as the NYC transit strike! As we are in the process of changing our patient address database, if you have not received an invitation by the middle of November, please contact your social worker for more information. For those of you who have not been to the party before, it is a great opportunity to celebrate the spirit of the holidays with your caregivers – both family and CLDT staff - in a more casual environment as well as an excellent opportunity to meet other people like you. Don't miss it!!

As the year ends, it is important to remember the holidays can be a difficult time for your donor families as well. If you haven't written a letter to your donor family already, this is often a good time. If you are struggling with what to write, please speak to your caregivers here who can help guide you if you are having difficulties. Remember – the letter will never capture everything you feel – sometimes it helps to just start with a "thank you."

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

12th Annual Walk the Walk for Organ and Tissue Donation Sunday, October, 22, 2006 – Central Park, NYC – Rain or Shine

On Sunday, October 22, 2006, the Kidney and Urology Foundation of America is sponsoring their 12th Annual Walk the Walk in Central Park.

The Kidney & Urology Foundation of America, Inc. is a national, not-for-profit organization dedicated to helping people avoid the debilitating effects of kidney and urologic diseases and to see that no one ever has to wait for lifesaving medical care, particularly organ transplants. Every year approximately 1 in 4 people will be affected by one of these diseases. Every year, 84,000 people die from kidney disease or conditions associated with kidney disease every year. In the United States, over 92,000 people are waiting for an organ or tissue transplant in this country. Every 13 minutes a new name will be added to the organ transplant waiting list with 17 people dying each day waiting. *Each year, 10 to 14 thousand people who die meet the criteria for organ donation, but less than half were actually donors.*

So, while most of you are waiting for a liver transplant and probably are wondering how the Kidney and Urology Foundation affects you, at some point, many of you may also be faced with kidney or urologic diseases (i.e. diabetes) whether it is before transplant, while you are hospitalized, or post-transplant. Most importantly, however, remember organ and tissue donation and awareness affects everyone – without donors, transplantation cannot exist!

So put on your walking shoes and join the 2 mile walk in Central Park. There will be food, games, prizes and fun. For more information or to make a donation, please contact (212- 629-9770 or www.kidneyurologyfoundation.org).

Our Educational Workshops Are Important! (From One Who Knows)

John Rice

In November 2003, when I was told the liver cancer I had would kill me without a liver transplant, I was very confused and unsure what my future would be like. I didn't know if I even had a future. Over the next two months, I never knew what to expect. Although the team at Columbia explained everything to me, there was just so much information for me to really understand. I was very sick, and taking too many strong medications (like Avastin) for me to put it all together. Looking back I think I was missing that fact altogether.

While I was waiting to be transplanted, I was told to attend the transplant workshop meetings being held at the hospital. These meetings were organized to help patients like me understand the day to day changes that would be taking place in my life, but I was too sick to realize how important the information could be.

In July, two months after I was blessed with a new liver, I went to a meeting. I should have listened to my doctors from the beginning. The pre-transplant meetings are so full of information about this new life of mine, that I sometimes wonder if I could have recovered as well without them. The medications, the surgery, the after-care, the tests, were all easier to understand after listening to other patients who went through it all before me.

After transplant, there are still a million questions. The constant changes in the medications make it even more important to attend the post transplant meetings.

The new life we have been given is not guaranteed. We have to learn to take care of it, and that is also made easier by listening to the people who experienced all the ups and downs that we will no doubt go through. Please take it from one who went through it: These meetings will help you.

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TRANSPLANT NEWS CONTINUED

GOVERNOR SIGNS SERIES OF BILLS ENCOURAGING ORGAN DONATION

A Win for Willie Brodsky

From a press release on August 18, 2006

Governor George E. Pataki today announced that he has signed into law a series of bills that will encourage organ and tissue donation in New York State. ensuring that countless additional New Yorkers receive the “Gift of Life.”

Willie Brodsky, 14, who suffers from an auto-immune disorder, came to Albany earlier this year to lobby for these bills. She is the daughter of Assemblyman Richard Brodsky. Today, she thanked the governor, legislative leaders and lawmakers in a statement released by Pataki’s office.

She said the new laws will “help save thousands of lives” and called this “a very big day for families across New York.”

Assemblyman Brodsky, 60, quit the state attorney general’s race in May to donate a kidney to his daughter, only to discover he suffers from kidney disease himself. He is now being treated for the condition, which he says is under control.

Recent statistics show that there are more than 87,000 people on organ transplant waiting lists in the United States, including more than 8,000 New Yorkers. Additionally, there are tens of thousands in need of tissue transplants. In 2004, there were approximately 14,000 organ donors allowing for more than 27,000 organ transplants to be performed in the United States. Despite this positive development in the organ and tissue transplant arena, the number of patients who have died while waiting for a transplant has tripled during the past decade.

The signed bills:

- require driver’s licenses to prominently display the words “organ donor” for those who consent

- mandate license applications and renewal forms to include a check-off for a \$1 donation to the “Life, Pass It On” fund
- require the state Health Department to educate New Yorkers about the need for organ and tissue donation
- direct the Transplant Council to report on issues surrounding “presumed consent”*
- transform the state Organ and Tissue Donor Registry to one of intent, not consent
- re-names the state Organ and Tissue Donor Registry the “Donate Life” Registry
- and provide up to \$10,000 subtracted from federal adjusted gross income for some unreimbursed expenses incurred by living donors.

* A clinically and legally indicated candidate for deceased organ and tissue recovery is presumed to have consented to organ and tissue recovery if he or she had not registered a refusal [“opted out”]. (Definition from A Report of the Presumed Consent Subcommittee , United Network for Organ Sharing Ethics Committee.)

LOLA – LATINO ORGANIZATION FOR LIVER AWARENESS

Support Group Meeting Agenda 2006 – New York Blood Center 310 East 67th Street NY 10021

September 20 th	Open Group Discussion	Members/Public
October 18 th	Nutrition and Exercise	Monica De Feo – Montefiore Medical Center
November 15 th	Fibrosis, Cirrhosis, & ASLD (Advanced Stage Liver Disease)	TBA
December 20 th	LOLA Holiday Gathering	Members Only

All support group meetings are bilingual and held every third Wednesday of each month beginning at 6:00pm unless indicated above. Please call to attend: 718-892-8697

Por favor llame nuestra oficina al (718) 892-8697 para confirmar su asistencia. Esperamos verlos entonces.

NEW FACES

As you probably already know, we have had many new additions to the clinical and administrative staff this year with many new faces starting this past July. In the case of Mary Donovan, this also means we've lost members of our team. For those of you who had Mary as your transplant coordinator, please read below the personal introduction from your new transplant coordinator, Ed Eggleton, NP.

We are very excited about the growth in our team. We hope you all have the opportunity to meet and come into contact with all of our new staff.



Sarah Bellemare, MD, Assistant Professor of Surgery, joined the CLDT in February 2006. Some of you may know her from when she completed her transplant fellowship here several years ago. Her clinical research focus is in living donation and minimally invasive liver surgery. Dr. Bellemare comes to us from the University of Montreal School of Medicine, where she established the living liver donor program at the Hôpital Saint-Luc at CHUM (Centre Hospitalier de l'Université de Montreal). She received her MD from the Université Laval in Quebec and completed a fellowship in liver transplantation and advanced hepatobiliary surgery at New York-Presbyterian Hospital/Columbia (NYPH/CUMC). Dr. Bellemare conducted Quebec's first living donor liver transplant in December 2004 and was celebrated in Montreal. *La Presse*, the largest newspaper in Quebec, named her Person of the Year for 2005.



Meridith Berger, LMSW – Hello! Let me introduce myself- I am Meridith Berger, the new Pediatric Liver/Small Bowel Transplant Social Worker. I have met many of you during your inpatient stays at CHONY, as I was previously working as the Social Worker on 4T. I am thrilled to now be working exclusively with the Liver/Small Bowel patients and team on both an inpatient and outpatient basis. Working with children has always been my passion. After graduating from the University of Maryland, I went on to pursue a Masters in Social Work from Columbia University. I have been working in various social work settings in New York City for the last ten years, including the mental health department of a city foster care agency, Big Brothers Big Sisters Corporate Mentoring Program and a youth empowerment organization (SHiNE). I chose to make this switch because I am amazed and inspired by the many children and families I have met on this service. I look forward to working with you!



Ed Eggleton, NP - As many of you know, Mary Donovan, NP has moved on to the School of Nursing. From what I can tell, her patients will miss her a lot. This can often be a nerve-racking time for some patients as many uncertainties arise. In an effort for you to get to know me better and get an idea of my experience, I wanted to share that info with you in this month's newsletter. For starters, I have been a registered nurse for over 10 years and a Nurse Practitioner for just about 4 years. I grew up in the rolling hills of Connecticut, went to UCONN for my undergraduate degree and after many years of travel nursing, came to Columbia for my NP degree. For the last 3 years, I have worked and trained at Mt. Sinai in the Department of Liver Diseases and the Transplant Institute. I was one of 20 or so NP/PA fellows trained nationally by the AASLD (American Association for the Study of Liver Diseases) last year and gained very valuable training. My experience with liver disease patients, pre and post transplant care, and UNOS is up-to-date. Patients should rest assured that they are in good hands. Change can always be difficult but I strive to make sure your needs are met and that good care is given to all patients. Feel free to contact me via relay-health.com or via the main office number.



Scott Fink, MD, MPH, also joined CLDT in July 2006. Dr. Fink, an Assistant Professor with a joint appointment in the Departments of Medicine and Surgery, will focus on end-stage liver disease, inclusive of pre- and post- transplant patients. Dr. Fink is a hepatologist with research interests in liver transplant and liver disease treatment outcomes, whose current research focuses on predicting the severity of fibrosis and progression rates in recurrent hepatitis C after living and deceased donor liver transplantation and in non-alcoholic fatty liver disease. Dr. Fink completed an advanced hepatology fellowship in Columbia's Department of Medicine following his gastroenterology fellowship at the Brigham and Women's Hospital in Boston. He graduated from New York University School of Medicine and completed his MPH at the Harvard School of Public Health.

NEW FACES, CONTINUED

NEW FACES, CONTINUED



Coraleen I. Fosella, NP, MA – Coraleen joined the CLDT Cornell campus in March 2006. She worked as a Nurse Practitioner in the Gaucher’s program in Human Genetics at Mount Sinai School of Medicine for 6 years. Prior to that, Coraleen was an in-patient NP at the Rockefeller University Hospital where she was involved with clinical research. Her personal preference will always be critical care nursing as she worked for many years at the surgical intensive care unit (SICU) in Milstein Hospital at the Columbia campus where she was involved in providing direct care for initial liver transplant patients, among these complicated acutely ill surgical patients.

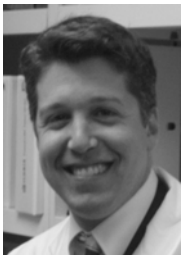
She hopes to greatly contribute in the care of patients and further success of the CLDT program and is looking forward to getting to know all of you well so she can address your needs proactively.



Nicholas Ginzburg, MHA. Mr. Ginzburg joined CLDT in May 2006 as our service administrator. He has a Masters degree from Hofstra University in Health Administration. He has more than ten years of health-care management experience with most recent position of Assistant Director of the Cardiovascular Institute at Mount Sinai Hospital. Mr. Ginzburg is also an Adjunct Professor at SUNY Old Westbury, where he teaches undergraduate courses such as Healthcare Administration and Health & Society.



James Guarrera, MD joined CLDT in July as an attending transplant surgeon. Dr. Guarrera, Assistant Professor of Surgery, will direct a pioneering clinical trial in machine perfusion of donor livers, which may transform the management of deceased donor organs and increase the number of usable livers for transplantation. Dr. Guarrera, who graduated from Mt. Sinai School of Medicine, completed his general surgery residency and transplant fellowship at Columbia, focusing on liver, renal and pancreas transplant and hepatobiliary surgery. He is an international expert in organ preservation, which has been a research interest since early in his residency. He began training in multi-organ procurement in medical school and has performed and supervised NYPH/CUMC procurements since he was a surgical resident.



Benjamin Samstein, MD joins the surgical staff after training in abdominal organ transplantation and liver surgery at Columbia University Medical Center. Dr. Samstein, Assistant Professor of Surgery, is a superb technical surgeon who is keenly interested in developing novel therapies to control the B-cell component of the immune response. In parallel with his clinical work, he will conduct translational research to understand the B-cell response in transplantation in collaboration with Drs. Betty Diamond and Anne Davidson. Dr. Samstein is a graduate of the School of Medicine at Stony Brook State University of New York. He completed his residency in general surgery at Columbia University in July 2004 and a transplant fellowship (kidney, liver and pancreas) at NYPH/CUMC. His clinical expertise also includes laparoscopic liver surgery. In 2000-2001 he spent two years performing basic research in transplant immunology under the mentorship of Dr. Jeffrey Platt at the Mayo Clinic. Dr. Samstein lives in New York City with his wife and daughter.



Abby Siegel, MD, Assistant Professor of Medicine, is an oncologist who focuses on the treatment of hepatocellular cancers (HCC) and other hepatobiliary malignancies. Many of you may have already met Dr. Siegel if you have been diagnosed with liver cancer. Dr. Siegel completed her internship and residency at NYPH/CUMC, and then obtained her hematology and oncology fellowship training at the Dana Farber Cancer Institute/Massachusetts General Hospital in Boston and at NYPH/CUMC. Her research interests focus on ethnic disparities in HCC treatment and clinical trials in hepatobiliary cancer with novel, targeted agents. She has received numerous awards including a Pades Grant for 2005-2008, and a teaching award from the medicine residency program as the best junior faculty member in 2006.

NEW FACES, CONTINUED

NEW FACES, CONTINUED



Kimberly Fredericks, Camille Grizzle, Rochelle Donaldson, Dr. Ilan Weisberg (hepatology fellow), and Coraleen Fosella, NP

Other recent additions to the Columbia support staff are:

- Celeste Santiago, Office Assistant – Celeste’s primary role is to schedule pre-transplant evaluation tests for patients.
- Heather Hamilton, Administrative Assistant – Heather provides primary administrative and clerical support for Lori Rosenthal, NP and Ed Eggleton, NP.
- Lisa LeBrecht, Administrative Assistant – Lisa provides primary administrative and clerical support for Dianne LaPointe-Rudow, NP and Margie Fernandez-Sloves, NP.
- Glorysel Perez, Office Assistant – Glorysel’s responsibilities include appointment scheduling, coverage for the PH14 and Garden (oncology) practices and back-up coverage for the PH14 liver transplant clinic.
- Sharifa Bailey, Financial Coordinator – Sharifa is our new financial coordinator at the Columbia campus. She will obtain insurance authorization for transplantation as well as counsel patients regarding their insurance benefits for transplant. Please contact Sharifa with any changes to your insurance! Sharifa also provides back-up support to Camille Grizzle, the Cornell campus financial coordinator.
- Annette Chevalier, Administrative Assistant – Annette will provide administrative support for Dr. Benjamin Samstein and Dr. James Guarrera.

New Cornell support staff are:

- Rochelle Donaldson, Office Assistant – Rochelle will provide scheduling, administrative and front desk support at the Cornell campus.
- Kimberly Fredericks, Billing Specialist – Kimberly joins the Cornell Campus as a billing specialist.

Noteworthy: Camille Grizzle was promoted to Financial Coordinator at the Cornell campus. Congratulations Camille!



Sharifa Bailey



Lisa LeBrecht



Glorysel Perez



Celeste Santiago

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Transplant Games

Transplant Games

2006 Olympic Transplant Games – Louisville, KY

Ralph Faga

I was blessed to be able to participate in the 2006 Transplant Games presented by the National Kidney Foundation. I was healthy enough nine months after a liver transplant to enter the Golf Event at the Games. Prior to my transplant on September 7, 2005, I was not able to play golf for two years.

I practiced and played a couple of times before I left and when I got to the event. I watched the children as young as nine years old with heart transplants and teenagers who ran races that were given transplants at eight months old and another at three years old. One sixteen year old girl, who had two liver transplants at different ages in her life, won a gold medal!

Life gets better – we grow stronger everyday after our gift of life – a donor’s heart, liver, lung or kidney. We also suffer some setbacks or complications but compared to pre-transplant, we are given the chance to live.

I listened to athletes who ranged in age from nine to eighty talk about their desire to run, jump, play a team sport or just engage in the spirit of the games – such a natural high! A few thousand athletes from every one of the United States came together to experience a sense of normality by being in an environment of others who know what it is to be sick, wait in doctors’ offices, and take medications. They all got a chance to be free mentally and fly like birds – no worry about their medical issues. Their only problems were “when is my next event?” or “Where is the shuttle to get to the track and field events?” or “When’s dinner?” It was an important motivator for each recipient to be in a group of thousands of athletes. More importantly, we met and saw thousands of donor families who came out to these games to feel part of what the athletes competing in the events already felt knowing they are a big part of why we were there.

If it wasn’t for the strong and tough decisions to allow their



loved ones that passed away to donate their organs, there would be no games. While the majority of the donor families who came did not know who their recipients were, they were unified with the rest of us. It created a spiritual environment that I have never experienced before. The opening and closing ceremonies were like the real Olympics. The love that was felt as we all were together, all the teams and donor families from every state, was literally overwhelming.

At the ceremonies, a few donor families met their recipients after many years. This was a very spiritual, warm, heartfelt and emotional sight for more than those meeting; there wasn’t a dry eye among the five or six thousand donors and athletes watching this exchange. The standing ovations were long and well-deserved.

I would like to finish by saying these Olympics are an event that, if possible, every transplant patient and donor family should experience once if not more times in your life – even if you don’t compete. Your outlook on the future and your gratitude for your gift of life will only increase your awareness and your compassion to give back to all people with medical problems. It will act as a daily reminder to pray for your donor, live each day as a new day for the rest of your life, take one day at a time, and, finally, to keep a positive outlook on life and an open heart and ear for other people in this world.

Thank you Columbia Liver Transplant Team.



Ralph Faga and John Rice, proud team members representing National Kidney Foundation of Greater New York.

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SILVIA'S CORNER

SILVIA'S CORNER

Preventing Emotional Bankruptcy

Silvia Hafliger, MD

Caring for a loved one with a chronic liver failure is emotionally and physically demanding. After the initial crisis, shock and disbelief of being diagnosed with cirrhosis passes, the long journey of undergoing a battery of tests and evaluations in order to become listed begins, followed by the equally demanding grueling wait on “the list.”

The family/caregiver needs to learn to live with uncertainty. There is the uncertainty about the timing of transplant, worries about cancer recurrence or spread, and fears about recurrent esophageal bleeding. There will be bouts of confusion and disorientation in the recipient requiring close supervision and adjustment of medications. Periods of seeming stability are followed by medical emergencies and admissions to the hospital.

The person with chronic illness may become irritable, demanding or reject help offered. It is often hard for families to find a balance between not becoming overprotective and “smothering” versus allowing the patient to be as independent as his or her illness allows.

Under these trying circumstances burn-out in families and caregivers is not uncommon. A caregiver may gradually become distant, irritable, callous, resentful and depressed. Other signs of emotional burnout are poor sleep, loss of appetite, increased crying, difficulty with concentration, increased pains, headaches or back pain. A balance needs to be achieved between being over-involved versus becoming distant, angry and ambivalent.

To care for a transplant patient requires endurance. In order to be available for the long haul caregivers can't neglect their own physical and emotional needs. If you start to recognize signs of burn-out you need to get



help. Although time is limited, you need to schedule time for yourself. Even 30-60 minutes a day can be a great investment. I recommend finding time to exercise or walk at least 5 times a week. Getting enough sleep, eating regular meals and maintaining contact with your friends are essential.

Illness can be isolating but caregivers must make an effort to maintain communication with friends and family. It is normal to be angry and resentful and it helps to let those emotions out. Caregivers may want to find a therapist to help sort out difficult emotions or find peace in church activities or a caregiver support group. I recommend one evening out to have dinner or see a movie. Leisure activities are not frivolous but keep you emotionally balanced. These activities need to be planned otherwise you will not find time to do them.

After reading this, you may feel more pressure on you, but it is important to remind yourself that you can delegate some care responsibilities. You do not have to be super wife/husband or super daughter/brother. Given the opportunity to help, many neighbors or friends are willing to pitch in. Frequently caregivers are too proud to ask for assistance—they don't want to be a burden. However, you have to remember that transplant is a team effort, from the liver team at the hospital, to the organ donor team in the community, to the care team at home.

Take care of yourself!

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PEDIATRICS

Safety and efficacy of live viral vaccines in pediatric post liver transplant recipients on monotherapy immunosuppression.

Patricia Harren, DrNP and Kara Ventura, CPNP

Now that it is the beginning of a new school year, we frequently get questions from our patient's parents, their physicians and schools asking if the patient can have live viral vaccinations. Using specific criteria here at Columbia we have routinely allowed patients to receive live virus vaccinations in liver transplant recipients when they are on immunosuppressive medication (cyclosporine or Prograf) alone for at least 3 months. This is not the case with all transplant centers* and we decided to look at the patients we had transplanted here at Columbia to see if the vaccinations were effective and to see if the patients had any reactions to the immunization.

Historically, solid organ transplant recipients have not been permitted to receive attenuated (weakened) live vaccines such as measles, mumps, rubella (MMR) and varicella (Varivax – chicken pox) post-transplantation. It is generally accepted that the immune system of a patient who has received a solid-organ transplant, receiving immunosuppression will not mount a response as effective as in the normal subjects. The concerns are that patients on immunosuppression will contract the disease they are being immunized for and that they would become very sick as a result. This common practice of not immunizing patients with live vaccines specifically Varivax and MMR puts the patient at risk of contracting the community acquired virus throughout their lives.

Recently we reviewed the charts of the children who received their liver transplant here at Columbia, specifically looking to see if any patients had a bad reaction to the vaccination. In addition, we looked at their blood work to see if the immunization actually worked and if they were now immune to the virus. At the time of live vaccine administration, patients were taking either Prograf or Neoral alone. Ten percent of patient's who received MMR reported fever of greater than 102 F and a rash 3 to 14 days after immunization. Five per-



cent of patients that received Varivax (chicken pox vaccine) reported fever greater than 102 F and localized rash around the injection site 1-7 days post immunization. These reactions were similar to that of patients who are not taking immunosuppressive medications. Most patients became immune to chicken pox and measles, mumps and rubella after vaccination, only a few needed to receive a second immunization to become immune.

To date we have found that routine administration of attenuated (weakened) live viral vaccinations after pediatric liver transplantation for patients taking Neoral (cyclosporine) or Prograf alone is safe and effective and should be considered for all patients meeting that criteria to prevent missed days from school, emergency department visits and illness related to the community acquired viral illness the immunization prevent. We need to continue to monitor patient's blood work to make sure that they stay immune overtime or if they need a booster vaccination.

* Not all transplant centers recommend live viral vaccinations for their patients and it is not appropriate for all patients. No patient on immunosuppression should receive live viral vaccination unless specifically instructed to by their transplant center.

PATIENT VOICES

PATIENT VOICES

The Truth About Being the Liver Transplant Caretaker

Suzanne Bonk

The worry never ends. The love never stops. The responsibility of making sure that all medicines (and there are a lot) are ordered in a 90 day supply and kept stored. The appointments for your loved one never end as my husband had to have TWO transplants within a 3 month time period and has had many health issues such as diabetes, high blood pressure and hepatitis C. This added more worry and work to my life. I had to give up my part-time job and put my life on hold to be able to care for him and get him to all his appointments, etc. Making all the appropriate calls, the constant worry about the possible death of your loved one and the financial concerns are very stressful. Our round trips to the hospital are about 142 miles and approximately 2.5 hours long each way due to traffic. I was always in fear that we were so far from the hospital if something would happen to him. From the time he had his first transplant to the present, I have made 67 trips!!!! This was a heavy burden and I did it by myself.

Most of the time, John had a mind of his own and went against the grain with me. It was difficult. Because of his two surgeries and all the chemicals (the prednisone!) in his body, he was initially childlike and it was like dealing with an eight year old. My God, it was hard and I felt so alone. I thought it would never end, but it did after four months.

It has been seven months since his second transplant and life is getting a lot better. He has returned to work full-time and I am back to work. His short term memory is stale but he sure can do his job tremendously; he works with computers. It has not been easy and if someone were to ask me if I would do it again, at this time I cannot answer that question. It has aged me physically and mentally, I am still afraid.



I want you all to know that John and I have been married for 24 years, no children by choice and we are joined at the hip. We have great respect for each other and love each other unconditionally. Even the happiest couples can be put to the test, but we have survived. Just recently, I have started to leave him home and do fun things with my family and friends.

I know that this piece is on the dark side but I do want to bring up your spirits. Throughout all of this, as I said, John was extremely difficult and moody. When I went to my psychiatrist I would talk about John's health constantly and how it affected me and this one day he said to me, "Susan, do you want to kill yourself?" I said "NO, I want to kill him." Needless to say, we both laughed and he told me that things were going good and I was doing well. Thank God.

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CENTER FOR LIVER DISEASE AND TRANSPLANTATION

COLUMBIA UNIVERSITY MEDICAL CENTER ♦ 622 WEST 168TH STREET ♦ PH14 ♦ NEW YORK, NY ♦ 10032 ♦ 212-302-0914
NEW YORK WEILL CORNELL MEDICAL CENTER ♦ 525 EAST 70TH STREET ♦ ROOM K-305 ♦ NEW YORK, NY ♦ 10021 ♦ 212-746-4129

EDUCATIONAL WORKSHOPS

EDUCATIONAL WORKSHOPS

**Sessions will be held on
Fridays, 2:00 to 3:30 PM**

Milstein Hospital Building
First Floor - Clark Conference Room 3
177 Fort Washington Avenue (between 165th/168th Streets)
New York, NY 10032

- Sept. 29th:** **PATIENTS' STORIES OF TRANSPLANT**
Meet transplant recipients, donors and caregivers.
- Oct. 6th:** **AN OVERVIEW OF LIVER DISEASE & LISTING CRITERIA**
How does the liver function? What is cirrhosis? How does listing work?
Speaker: Dr. Lorna Dove, Transplant Hepatologist
- Oct. 13th:** **LIVER TRANSPLANTATION SURGERY: DECEASED VS. LIVING RELATED DONATION**
Speaker: Dr. Benjamin Samstein and Dr. James Guarrera, Transplant Surgeons
- Oct. 20th:** **LIVER CANCER: WHAT IS HCC? WHAT TYPE OF TREATMENTS ARE THERE AND WHAT TO WATCH FOR?**
Speaker: Dr. Abby Siegel, Assistant Professor of Medicine –Specializing in Hepatobiliary Oncology and Hematology
- Oct. 27th:** **MANAGING ACUTE AND CHRONIC PAIN AND NEUROPATHY**
Speaker: Dr. Silvia Hafliger, Transplant Psychiatrist
- Nov. 3rd:** **TOUR OF OPERATING ROOM**
Facilitated by psychosocial team.
- Nov. 10th:** **IMMUNOSUPPRESSIVE MEDICATIONS AND THEIR SIDE EFFECTS**
Speaker: Margie Fernandez-Sloves, NP, Transplant Coordinator
- Nov. 17th:** **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



Mama Rice's Leban Salad

1qt plain low-fat yogurt
2 small cucumbers (wash, peel,
remove seeds, dice)
2 cloves garlic (mince or chop)
half cup dried mint
pinch of salt

Mix all ingredients, serve cold,
enjoy.



Note from the post-transplant group: Notice some missing faces above? WE'RE MISSING YOUR FACE AND HEALING BODY AROUND OUR TABLE! Who's going to tell you: "It's okay, you're allowed to be depressed sometimes. It's natural to be frustrated with your limitations." "Yes, you can change your diet so you can control your diabetes" or "don't increase faster than you can buy a new wardrobe." WE ARE! We've been there or are going through the same things you are. AND WE MISS YOU WHEN YOU'RE NOT HERE! BESIDES WE GIVE THE BEST "FOLD AND STUFF" NEWSLETTER PARTIES ON THE BLOCK.

Join us either in the Reemtsma Conference Room, Milstein Hospital Building, 7 Hudson South (you know where that is) or near the PH14 Clinic in Room 101. Note the change in times at the new location.

Who: *Post-transplant recipients and family members.*

When: *Future dates are:*

Thursday, September 21st - 10:00-11:30am, 7HS, Reemtsma Conf. Room

Tuesday, October 3rd - 10:00 - 11:30am - PH14, Room 101

Thursday, October 19th - 10:00-11:30am, 7HS, Reemtsma Conf. Room

Tuesday, November 7th - 10:00-11:30am, PH14, Room 101

Thursday, November 30th - 10:00-11:30am, 7HS, Reemtsma Conf. Room

Tuesday, December 5th - 10:00-11:30am, PH14, Room 101

Where: New York Presbyterian Hospital
622 West 168th Street, PH14
14th Floor Conference Room - #101 East
OR
Milstein Hospital Building
177 Fort Washington
Reemtsma Conference Room, 7 Hudson South

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

Any tasty, nutritious recipes out there? We'd love to print them here for everyone to use. All submissions will go through a thorough testing (tasting?) process. Just kidding, but our nutritionist, Brenda Klein will check the recipes for suitability.



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/resource/s/support/oldbilitree.html>
- *The FAIR Foundation*, 760-200-2766,
www.fairfoundation.org
- *National Hepatitis C Advocacy Council (NHCAC)*, 877-737-HEPC,
www.hepcnetwork.org

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

- *New Jersey Transplant Association Inc. – Donor families and recipients*
www.njtransplant.org
- *The Central NJ Transplant Support Group* -
732-530-6789 or
<http://www.njtransplantsupport.com>
- *Transplant Recipients International Org.*
NJ: 609-881-2726, 201-836-2417

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 the second Friday monthly; 10am - 11am
Harlem Hospital Center, The Ron Brown Clinic, 3rd Floor,
Conference Room 3071, 137th Street

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 Presby-
terian Hospital **Phone:** 212-746-2115

Contact Mary Ahern, NP for more information.

*525 East 68th Street at York Avenue, Room A-950. Take
the "k" elevator to the 9th floor and follow the signs. 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 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)

Westchester County (Hepatitis C)*

Meets every other Wednesday; 6pm - 8pm

Westchester Medical Center

Phone: 914-493-7641

Contact Mimi Greenman for more information.

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

Wilsons Disease Support Group*

Phone: 203-961-9993, Contact Lenore Sillery

**Not sponsored by the American Liver Foundation.*