

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

Volume V, Issue 2

THE NEWSLETTER FOR LIVER TRANSPLANT  
PATIENTS AND FAMILIES

Summer 2006

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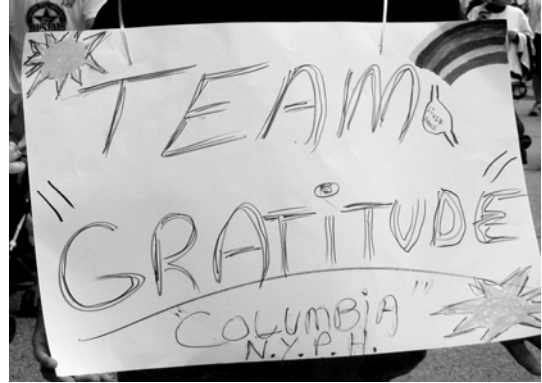
Happy Summer!

We hope you are all enjoying the beginning of the warm weather. There are lots of exciting things happening already and more to come over the summer.

As you can see inside we have included pictures from the June 4<sup>th</sup> American Liver Foundation NYC Liver Walk in Riverside Park. For those of you who walked, thank you for your support and enthusiasm. To our Team Captain, Regina Williams, thank you for all your work and help in organizing a successful event. And, to those of you who walked at other locations, your efforts are also greatly appreciated. I know there was a particularly big fundraiser for the Liberty State Park walk on June 11th. Walker Robert Osekavage individually raised over \$2000!

A reminder to our patients, if you do not have an answering machine, please get one and if you still have call intercept on your home phones, please have it removed. It is crucial that your medical team can reach you as quickly as possible. You do not want any delays in having the surgeon reach you if you are being called in for a transplant or if your transplant coordinator or hepatologist are calling you because your labwork is abnormal. So, again, please help us in reaching you as quickly as possible!

If English is not your primary language, please contact our



office ahead of time so we can plan ahead for your interpretation needs. While we try to meet the needs of our non-English speaking population, if you have not been identified appropriately in our system as having interpretation needs there may be a delay in being able to service you when you come to your appointments. With that said, we do have 24 hour access to a telephonic interpretation system when a interpreter is not available in person.

Please read carefully through the newsletter – there are a lot of interesting articles from our nurse practitioners, an inspiring patient story and an interview with our Chief, Dr. Brown. As you can see, we're trying to include more pediatric focused articles – please keep the interest and feedback coming! We look forward to hearing what you like about the newsletter and what you'd like to see in it. After all, the newsletter is for you.

Lastly, good luck to those transplant recipients – liver, heart, lung and kidney – who are participating in the U.S. Transplant Games this month. Liver transplant recipients, Ralph Faga and John Rice, are both competing in multiple events under Team Liberty, the area's local team organized by the National Kidney Foundation. This four day event will take place June 16-21 in Louisville, KY. This is a great opportunity to see how well transplantation can work to save lives and restore recipients to their previous level of functioning. We're proud of you!

Thank you to everyone who contributed!

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

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CENTER FOR LIVER DISEASE AND TRANSPLANTATION

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NEW YORK WEILL CORNELL MEDICAL CENTER ♦ 525 EAST 70<sup>TH</sup> STREET ♦ ROOM K-305 ♦ NEW YORK, NY ♦ 10021 ♦ 212-746-4129

# TRANSPLANT NEWS

## Relay Health

Some of you may have noticed during your clinic visits that there have been signs for Relay Health. You may have wondered – what is Relay Health and how can it help me? The Center for Liver Disease and Transplantation/Columbia has purchased Relay Health to help organize and streamline communication between patients and providers in a safe, secure, and confidential manner. Relay Health is a secure forum, unlike regular email, for you to speak with your providers, get lab results or make appointments. This service also allows you to have a “webVisit” which allows you to seek care from your hepatologist, surgeon, nurse practitioner, or psychiatrist without coming in for an appointment. Of course, these are for non-emergency needs.

If you have internet access and want to become a Relay Health member, follow these instructions:

1. Go to [www.relayhealth.com](http://www.relayhealth.com) to register.
2. Click *Register as a New User*.
3. Use a Relay message to:
4. Request your next appointment
5. Get your lab/test results
6. Refill your medication
7. Request a webVisit to speak with your provider about non-urgent medical needs.

There is no charge for using the service for routine communications such as appointment requests, lab results, or medication refill requests. There may be an insurance co-payment or out-of-pocket fee for webVisits. Hopefully, you will be able to save yourself a trip to the office! Remember, though, this does not mean you will be answered right away. Pay attention to the pop-up message which will tell you the time-frame in which you will receive an answer!

Please note that this service is not available to patients at the Cornell Campus.



Marching along together



Smiles of a spring day

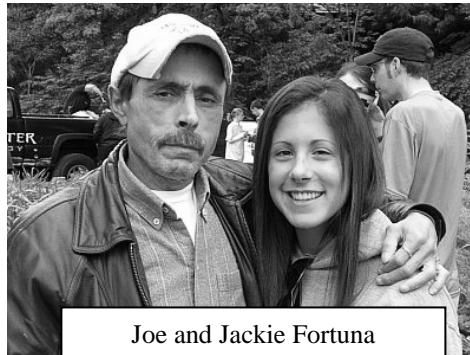
# Liver Walk 2006



On Sunday, June 4<sup>th</sup>, those affected with liver disease, liver transplant recipients and their families joined the Center for Liver Disease and Transplantation (CLDT) staff for the American Liver Foundation (ALF), Greater New York Chapter, Liver Walk. The annual liver walk stresses the importance of liver wellness and disease prevention and was a culmination of months of fundraising. New York Presbyterian CLDT was represented by the fundraising team: Team Gratitude. Monies are still coming in, however, as of now, Team Gratitude raised more than \$4,000.

The 2006 liver walk began at 83<sup>rd</sup> Street and Riverside Drive in New York City's Upper West Side. The 3 mile walk ran north along the Hudson River. The cool, overcast day served as a perfect backdrop for the annual event. Along the walk, transplant recipients and families shared their experiences with fellow participants and those waiting for transplant. A strong sense of community was present throughout the day.

Not just a fundraiser, the liver walk continues to promote ALF's presence and



Joe and Jackie Fortuna



The Lupo family

identity on the cutting edge of liver disease research. ALF is the nation's leading nonprofit organization promoting liver health and disease prevention. ALF provides research, education and advocacy for those affected by liver-related diseases. There are 25 chapters and more than 200 support groups, serving over 75% of the United States.

The ALF Greater New York Chapter represents the five boroughs of New York City, Long Island, Westchester, Orange and Rockland Counties and Northeastern New Jersey. The Greater New York Chapter also promoted the May 21<sup>st</sup> walk in Eisenhower Park, in Long Island and the June 11<sup>th</sup> walk in Jersey City's Liberty State Park.

Tax deductible donations can be made The American Liver Foundation via phone [(800) GO-LIVER], mail: American Liver Foundation, 75 Maiden Lane, Suite 603, New York, NY 10038; or online at: <http://www.liverfoundation.org/donations.shtml>.

Hope to see you all there next year!

## LC Talks With

### Robert S. Brown, Jr., MD, MPH

**Dr. Brown is the Chief of the Center for Liver Disease and Transplantation. Some of you see him for check-ups as your team hepatologist. All of you have seen him in the hallways of PH 14 or behind the check-in desk, his wide grin lighting up his face and your day. He took a few minutes out of a busy day, which included an emergency endoscopy, to answer some questions about his work here in CLDT. We talked as we walked to the Milstein Hospital where the emergency endoscopy would occur.**

**Liver Connection (LC):** You and Dr. Jean Emond [interviewed in this newsletter last summer] started this center, recruiting the best surgeons, hepatologists, nurse practitioners and so on. There were others (liver transplant centers) in the city before. How did you come to start this center and why?

**Robert Brown (RB):** We were both excited by the merger of New York Hospital and Columbia Presbyterian to form New York–Presbyterian. We felt that the rich academic and clinical environment that the Cornell and Columbia Medical Schools provided would offer us an opportunity to build something in liver disease and transplantation that could be unparalleled. The two best medical schools in the biggest city in the world offered a foundation to excel in both science and clinical care and to build a comprehensive liver center that could offer care to all. We also felt the other transplant centers in the city were focused only on transplantation. We wanted to take a broader focus: to care for all types of liver disease with both medical and surgical treatment, and to build something more all encompassing.

**LC:** How often do you get a call from the Organ Procurement and Transplantation Network (OPTN) with a liver?

**RB:** We get calls from OPTN, either locally or from far away. The calls come in bunches. It would be nice to say it was one every other day. But often times it's five times in one day and then none for a long stretch. It depends on how many patients we have listed who are at high priority, the blood type and the organ availability. I would say we get about ten calls on average per week of which about one third of them lead to a transplant. It's always exciting when you get a call with a liver because this is the opportunity to do what we do, which is to save lives. It's always tempered by the fact that we know for every liver donor there is tragedy associated with it. Since you can't fix the



tragedy, it's nice that the person decided to proceed with donation to save lives.

**LC:** Along those lines do you think there is a better way to distribute donated organs, livers in particular?

**RB:** The current system is the best system that we have ever had. Unfortunately, when you're distributing a scarce resource you can never make everybody happy or help all that need help. The problem isn't how we're giving out pieces of pie. It's that the pie isn't big enough. This system was arrived at by clear evidence-based analysis to derive the maximum survival benefit. And it does. It doesn't fix the problem that there aren't enough organs for people who are still at risk of dying, which is what pushes us, one, to try to increase deceased organ donor supply and, two, to pursue things like living donation and extended criteria donors and other ways to push the envelope to make more livers available. I don't have a problem with the current system of *prioritization*. I do have a problem with *distribution*, i.e., the fact that organ distribution is inequitable across the country. The MELD score at the time of transplant should be the same no matter where you live, not different in Florida and in New York as it is currently.

**LC:** I thought the MELD score was supposed to have fixed that.

**RB:** No, it hasn't because the distribution of organs is still local. If you live in FL and you have a MELD score of 15 you have a higher likelihood of receiving a liver than someone with a MELD score of 20 who lives in California, because Florida livers stay in Florida and

California livers stay in California. So though the MELD score prioritization scheme equalizes the access to transplant within a single distribution unit, local allocation has prevented a solution on the national level.

LC: You did research in autoimmune liver disease. Why is there so little research given there are so many autoimmune diseases?

RB: I still try to do some research in autoimmune liver disease. There isn't a lot of research because, in liver, it's so unusual, rare. And we're pretty good at treating it with existing medications, if we find patients early enough. The problem is it's hard to diagnose and most of the patients we find already have advanced liver disease. We tend to use the same research we used in transplantation on immunosuppressive drugs to find the right immunosuppressive cocktail for autoimmune patients. But we do need to do a lot more research on why people get it, what are the determinants. That's something we really need to do.

LC: Of course the big one is Hepatitis C, another area in which you do research.. We know it's epidemic. Can you tell us anything new?

RB: There are a lot of new drugs coming out. I think the future's very bright for Hepatitis C patients. Unfortunately most of these medications will still require the use of pegylated interferon [antivirus], which is difficult [because of side-effects]; **but compared to when I started in this business, we cure more people than we don't cure.** Once again, the problem is that many of the patients are not screened and detected early and their disease is too advanced to be able to fix it without transplantation. And we still have no options for people who can't tolerate interferon or for whom it doesn't work.

LC: Is the growth rate increasing for Hepatitis C?

RB: No, new infections are falling. But significant liver disease from Hepatitis C is rising due to the epidemic of transmission that occurred 20 to 30 years ago that are now developing advanced liver cirrhosis and cancer, because it's a very slow disease.

LC: The epidemic, when it was hidden actually, before people even knew what it was?

RB: Exactly. Now we're seeing a big problem.

LC: Do you see improvement in the way liver disease is perceived in the community? Is the stigma still as strong? Is there a connection between that stigma and lack of deceased liver donations?

RB: There is still a strong stigma to liver disease in the community mostly because it's associated with alcohol

and drugs. I don't think it affects organ donation in general. I think what affects organ donation is that Americans like to ignore the thought of death. So we don't deal with decisions on death and dying in advance. And we don't have as much of a community spirit as we used to or they have in Europe where they would presume that their organs would go to the public.

LC: Why is that, though? You think it's a community spirit. I don't think of Europeans as having more of a community spirit.

RB: Oh, I think the Spanish feel Spanish and they feel a connection and desire, or perhaps obligation to help other Spaniards, which is why they accepted presumed consent.\* Americans are at our hearts isolationist and value individual liberties which has its pluses. On the other hand the attitude of "If it helps me, or if it helps my family, okay. But who cares about the guy down the street, who may be different from me..." is not productive. The biggest problem is that we only deal with death when people are *in extremis* and then we ask their families to make difficult decisions. Individuals should make those decisions for themselves well in advance and those decisions should be binding on their doctors and families. We should declare our decision to be a donor on our income tax each year or move toward an "opt out" system.\*

LC: As medical director of CLDT you are a busy man, yet still see patients. How do you think you best serve the patients here? And in the future? Put another way, what gives you the most satisfaction about your job?

RB: Seeing patients is the greatest satisfaction that I have in this job. I'm a doctor first and run the center second. As I get busier it gets more difficult to balance but I certainly try. The thing that gives me the greatest joy is making people healthy. The best visits are the ones where they see the nurse practitioners; they're doing great, look fantastic, and I get to just wave and shake their hands. But I hope that what I do most and best is to take care of people with complex liver problems. And that's what I see myself doing in the future, that and trying to continue to build a better structure to take better care of patients with liver problems and to create a scientific enterprise to learn more about these problems and design possible solutions.

\* *A clinically and legally indicated candidate for cadaveric 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)

# SILVIA'S CORNER

## SILVIA'S CORNER

### How To Manage Your Health After Liver Transplant: Tips To Keep Your Liver For A Long Time

*Silvia Hafliger, MD*

Getting a new liver is a joyous moment, you feel reborn and your body and mind start to heal. You have started a new journey, but you need to learn how to live as an organ recipient. It is hard work, especially at the beginning. It is a lifelong commitment of taking medication, eating healthy and exercising.

Unfortunately, some of you will not be able to have the discipline that it takes to keep that liver healthy. We are all creatures of habit and many of you will become a bit careless and lazy when it comes to taking medication, coming for blood tests or keeping your nurse practitioner up to date. The results are usually disastrous. Every month we see patients in the hospital with severe liver rejection due to medical non-compliance. Sometimes we can stop the immunological attack on the liver sometimes we can't. Transplant allows for no mistakes, and the line between health and death is very narrow.

In order to keep your white cells (lymphocytes) from recognizing the liver as a foreign object you need to take anti-rejection medication every 12 hours. The level of Prograf or Neoral needs to be just right. This level will be different for every person. If your Neoral or Prograf level is too high you damage your kidneys, you get a severe headache and trembling hands. If you frequently miss one or two doses of your immunosuppression, your liver becomes inflamed, liver enzymes (AST/ALT) will creep up, and your Bilirubin will increase. The result of chronic inflammation is scarring or cirrhosis. You end up where you started from.

#### *Some of the barriers that keep you from staying healthy:*

##### 1. Lack of knowledge

➤ There is a lot to learn about liver transplantation. We do not expect you to be experts regarding your illness and your medical needs, but we do expect you to attend the educational workshops and learn as much as you can to take care of your new organ. We want you to be able to ask questions and know when something isn't right. You also need to learn your medications and know what you are taking them for.

##### 2. Lack of resources (financial and social support)

➤ Medication costs are huge. Please make sure you keep your insurance up to date. Call your social worker or financial coordinator when you run into trouble with paying for your medication or insurance premiums. But please call before taking your last pill! **We don't have extra medication at hand.**

➤ Your caregiving team is your greatest asset. You can't go



through the transplant process alone. It's important that when you are organizing this team that you find caregivers who will be able to go with you to your medical appointments in the beginning, learn your medications and learn who your medical providers are. They need to know who to call when there is an emergency or when something is just not quite right.

##### 3. Lack of organizational skill

➤ The best way to not forget your medication is to be organized. Pill boxes, alarm watches, telephone reminders are some methods patients have found helpful. Team up with your care partner, two minds are better than one. Plan ahead and check your medication in advance. Do you have enough to go on a trip/weekend? Keep your pills on your person when you travel.

##### 4. Psychological (the meaning of having to take pills and manage a chronic illness).

- The personal meaning of having to take medication may be a reason for "forgetting". It is frustrating to have to take so many pills, not to be like other people, to have a daily reminder of your illness.
- Maybe you are becoming depressed and starting to lose hope?
- Maybe you start to feel fatigue and burn out.
- Maybe you hate the taste of the medication.
- If you start to feel any of these things, inform your medical team pre- or post-transplant. Talking about your thoughts and feelings with somebody you trust can help. If possible, your nurse practitioner may be able to simplify your medication schedule or regimen. Sometimes, changing to a different immunosuppression may be a solution.

An ounce of prevention is worth a pound of cure. Please keep communicating with your nurse practitioner, come for regular blood tests, and give us a phone number where we can reach you. Again, your caregiving team is your greatest asset – they can help you overcome some of the barriers listed above. Always ask questions, and tell us when you are having difficulties. Tell us if you become ill, take new medications, or plan to travel.

Enjoy your summer. See you at the seminars!

# Coordinator Counsel

## TRANSPLANT EVALUATION: WHAT IT MEANS AND WHAT IS A PATIENT TO DO?

*James Spellman, NP, MSSW, MDiv*

Transplant evaluation can be unfamiliar territory for some patients. The transplant evaluation is often unlike past medical encounters that a patient has had. Patient uncertainty can arise when some patients do not completely understand what the transplant evaluation is, and what it is not about.

A transplant evaluation is very involved and patients can lose their way. Once a patient starts a liver transplant evaluation, minimally, their medical life will flow down two tracks:

- 1) Day-to-day life with liver disease.
- 2) Liver transplant evaluation.

These tracks are separate though related. It is in a patient's best interest to know what track they are dealing with.

### *Track 1: Day-to-day life with liver disease*

Daily life with chronic liver disease is real, it is here, and it is now. Patients with chronic liver disease usually have to live with one or all of the following signs and symptoms: hepatic encephalopathy, esophageal varices, ascites, edema, itching, osteoporosis, and surveillance imaging for liver tumors. Comorbid conditions, like diabetes and hypertension, also exist and are important to manage successfully to promote long term health. In order to have the best quality of life and keep oneself as healthy as possible it is important to manage the symptoms of end stage liver disease. The daily-lived reality of chronic liver disease is immediate to the individual and his or her well-being should be maximized.

### *Track 2: Transplant evaluation*

Importantly, liver transplantation permits the opportunity for many to regain their life and health and prevents premature death due to liver disease. As a result, most patients involved in liver transplant evaluation are involved in a



futuristic endeavor. As important as a liver transplant will be, for most in the evaluation stage it is an abstract idea of what may happen in the future.

At a minimum, transplant evaluation means that a patient will undergo an extensive medical and psychosocial assessment to determine one's readiness and appropriateness for liver transplant surgery. In order for a patient to receive an organ they must be placed on the transplant waiting list that is managed by the United Network of Organ Sharing (UNOS) that is contracted for this purpose by the federal government.

Transplant evaluation involves a team approach. Some of the team members include: transplant surgeons, hepatologists, nurse practitioners, physician assistants, social workers, psychiatrists, and financial coordinators. Having to interact with so many team members can also add to patient confusion in the evaluation process.

When discussing your medical care in the transplant center you will usually be discussing issues that relate to your general liver care or about your liver transplant evaluation.

It will help you and your providers if you fully understand what track you are speaking about: management of the symptoms of end stage liver disease (day-to-day life with liver disease) or issues related to your liver transplant evaluation. If you have any questions, please speak to your transplant coordinator.

# PEDIATRICS

## PEDIATRICS

### Intestinal Transplantation

*Patricia Harren, DrNP and Kara Ventura, CPNP*

The pediatric liver transplant division is now doing intestinal transplants. There are numerous reasons why a child would need a small bowel transplant. Having this option available can improve the quality of life of children who are dependent on nourishment through tubes and intravenous lines.

Before 1970, patients unable to maintain nutrition through their own gastrointestinal tract died of severe malnutrition, weight loss and dehydration. The introduction of total parenteral nutrition (TPN) saved many lives and was the recommended treatment for patients with intestinal failure. Although life-saving for many, for others TPN had complications including frequent infections in the blood and the development of cholestatic liver disease. These complications resulted in death for many patients suffering from intestinal failure. Thus the need to develop a life saving procedure such as intestinal transplantation remained urgent.

However, despite the need for intestinal transplantation, intestinal transplant researchers concluded over twenty years ago that the challenges to successful small bowel transplantation were quite daunting due to the complexity of the small intestine.

Throughout the last 15 years, numerous advancements in the field of intestinal transplantation have been made. These advancements are in the areas of patient and donor selection, surgical techniques, immunosuppressive regimens, and management of post-operative complications. More than 80% of all the current survivors are able to stop TPN and resume normal daily activities. The longest survivor from intestinal transplant remains well 17 years after transplantation. Dr. Dominique Jan, professor of clinical surgery, transplanted this patient in Paris. Dr. Jan is now full time faculty here at Columbia University developing the pediatric intestinal rehabilitation center.

#### **Indications for Intestinal Transplantation**

Currently, intestinal transplantation has become the accepted treatment for patients with permanent intestinal failure and life threatening complications of TPN.

One type of intestinal failure is known as short bowel syndrome (SBS). This is the direct result of loss of a significant portion of the small intestine caused by surgical resection. Having a decreased length of small bowel impedes the ability of the small intestine to absorb adequate nutrition, fluid and electrolytes. In infants, short bowel syndrome is most often caused by surgical repair of congenital defects such as gastroschisis (when infants are



born with their intestine outside of their abdomen), intestinal atresia or mid-gut volvulus (abnormal blockages and twists of the intestine). SBS may also be the result of massive resection for removal of necrotic bowel in infants who have necrotizing enterocolitis (an infection of the small intestine). In adults, trauma to the abdomen causing damage to the intestine or disruption of blood flow to the intestine may require substantial resection of the small intestine. Diseases such as Crohn's disease may necessitate removal of all or significant amounts of small intestine.

Another type of intestinal failure is caused by disorders of the small intestine that impair the motility or absorptive ability of the small intestine. With this type of intestinal failure, the entire bowel is present but unable to digest and absorb nourishment, nutrition or fluid.

Currently, to be considered for intestinal transplantation, patients must have irreversible intestinal failure and a life threatening complication of TPN. These complications include liver disease, loss of venous access, repeated episodes of life threatening line sepsis and severe dehydration despite intravenous fluid replacement. As survival rates continue to improve other indications for intestinal transplantation may be related to the quality of life of patients receiving daily TPN, as well as the costs that are associated with TPN and central line maintenance.

The inability of the intestine to absorb nourishment and hydration should be considered an indication for referral to an intestinal rehabilitation center. The ultimate goal in intestinal failure is to improve the utility of the small bowel. With time, specific medications, and various feeding methods, the intestine sometimes can improve its function so the patient no longer needs TPN. In cases of severe intestinal failure especially those with complications of liver disease, intestinal transplantation is a life saving option.



# PATIENT VOICES

## PATIENT VOICES

### Alyssa And Me

*Teresa Palazzo-Barrezueta*

I have been reading the newsletters for three years now and have truly appreciated the time and effort put into them to give me so much knowledge on liver disease and transplantation. I have enjoyed reading the patient stories as they have been a good and important reminder we aren't alone. From learning about my daughter's need for a liver transplant until the actual surgery, I was on a mission to learn and I was a sponge absorbing any bit of information available. I attended all the workshops and took notes. I kept a three ring binder with all the obtained information, lab results, discharge papers, newsletters and any information pertaining to medicines. I also kept an event log. After all the reading and researching there was still another side about transplant patients that I felt was lacking attention. With that in mind I decided to tell you a story about a child who suffered liver disease, my daughter Alyssa. She is truly an inspiration to everyone, young or old, healthy or sick.

Alyssa was born a healthy beautiful girl, but soon got sick at two months of age and was hospitalized. From that moment on, Alyssa would battle for her life. During the hospitalization, Alyssa had to get a tracheotomy and she lived with a trach tube for two years. During those two years she underwent an airway reconstruction and countless airway laser surgeries. During that time, at a pre-op appointment, for yet another surgery which was airway related, Alyssa's spleen was found to be enlarged and platelet count was low. She then began months of testing and later diagnosed with an unknown cause of liver cirrhosis, confirmed by a biopsy. Then at age 2 ½, Alyssa received good news that her trach tube was ready to be removed. Unfortunately Alyssa's break was short lived. At age 3 she began running into trouble with bleeding in the esophagus (due to the scarred liver), and she then endured months of endoscopies. On September 19, 2003, Alyssa received her gift of life. She had her liver transplant done at just age 3 ½.

Alyssa has truly been blessed. She had an amazing speedy recovery and was sent home within 7 days. Since her transplant, Alyssa has not had any liver complications or rejections. Although she still has airway related medical issues, she is a trooper and her strength continues to amaze everyone around her. Her life experiences have molded her into a very understanding and compassionate person. She is always



full of life and joy and appreciates all the small things in life. She is truly a special person. Her life is very different from the lives of most kids her age but if you met her you would never guess it.

Alyssa's journey was a physical battle but as a parent I too lived in a struggle, but an emotional one. Being a new mother of an infant, life was quite different than I had expected. Instead of frequent park trips or mommy and me classes, life consisted of constant phone calls with doctors, blood work, procedures, surgeries, doctor appointments and hospitalizations. I began to feel helpless. There wasn't time to think, just do and be strong. I knew I had to keep myself together for her, and I did a great job on the outside but inside it was a constant struggle. I became fixated on Alyssa getting better and in doing so forgot how to fully enjoy life. There was no longer a difference between a weekday and weekend; everyday was the same: just getting by in a state of survival mode. Aside from our team of support, I felt no one on the outside understood, yet I expected them to and was bitter if they didn't. It became too hard to listen to a mother's panic story when their baby had a common cold or even a friend's bad day at work. I had a hard time relating to the world around me and I had buried myself in a hole.

It took me a while to let go and relive life again. It took even longer for me to be at ease, for example, if I forgot to use the hand sanitizer! I still continue to better my life and Alyssa's life using the past as a motivation and Alyssa as an inspiration. I have learned there is no way around these unfortunate things but to just get through it by staying positive. It changes you forever but makes you appreciate things better. Good luck and thank you.

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CENTER FOR LIVER DISEASE AND TRANSPLANTATION

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# MORE PICTURES

## MORE PICTURES



Social Workers Jen and Liz



NP's Rule!



Munchkins



Ray and son

# EDUCATIONAL WORKSHOPS

## EDUCATIONAL WORKSHOPS

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

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

- July 7<sup>th</sup>:** **PATIENTS' STORIES OF TRANSPLANT**  
*Meet transplant recipients, donors and caregivers.*
- July 14<sup>th</sup>:** **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*
- July 21<sup>st</sup>:** **LIVER TRANSPLANTATION SURGERY: DECEASED VS. LIVING RELATED DONATION**  
*Speaker: Dr. Milan Kinkhabwala, Transplant Surgeon*
- July 28<sup>th</sup>:** **IMPORTANCE OF FINANCIAL COORDINATION AND TRANSPLANT**  
*Speaker: Carolyn Jones, Billing Director*
- August 4<sup>th</sup>:** **HEPATIC ENCEPHALOPATHY: HOW TO RECOGNIZE IT AND TREAT IT?**  
*Speaker: Dr. Silvia Hafliker, Transplant Psychiatrist*
- August 11<sup>th</sup>:** **IMMUNOSUPPRESSANT MEDICATIONS AND THEIR SIDE EFFECTS**  
*Speaker: Lori Rosenthal, DrNP, NP-C, CCTC, Transplant Coordinator*
- August 18<sup>th</sup>:** **CAREGIVER'S SUPPORT GROUP – CAREGIVERS ONLY- NO PATIENTS**  
*Facilitated by Psychosocial Team*
- August 25<sup>th</sup>:** **OPEN FORUM**  
*Facilitated by Psychosocial Team*

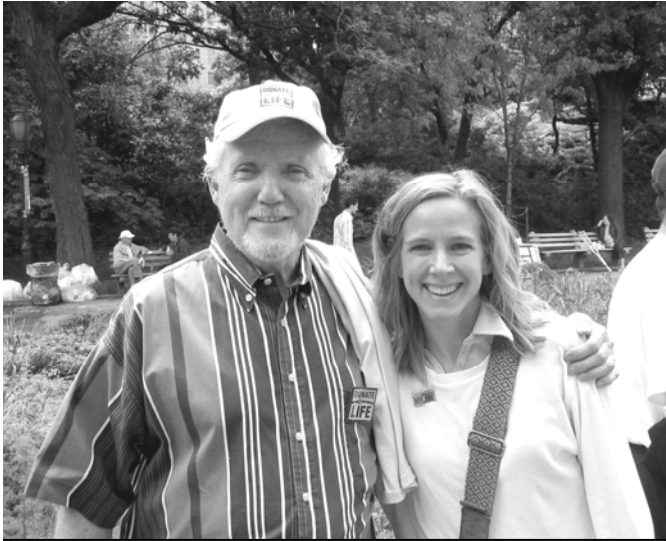
*Spanish Interpreter Available. (Hay un interpreter espanol disponible.)*

**These sessions are MANDATORY!**

**For more information contact:**

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

# POST-TRANSPLANT SUPPORT GROUP



John and Jen, Liver Walk 2006



Ralph, Gina, John and Jessica, Liver Walk 2006

The Post-Transplant Support Group meets the 1<sup>st</sup> and 3<sup>rd</sup> Tuesdays of every month to share experiences, ideas and mutual support. This is an informal group where you can really discuss anything on your mind. The dedicated group members now come for support, to discuss issues related to returning to work, disability, navigating the medical system, and frustration with not being “back to normal” as early as hoped, those “unspoken side effects” as well as numerous other issues. The group has also become critical in helping us get the newsletter out the door and organizing the liver walk.

You don't have to commit to coming every session. Join us while you wait in the clinic to see your NP or MD!

**Who:** *Post-transplant adult or pediatric patients and family members.*

**When:** *First and third Tuesday of every month, 10:00-11:30.  
Future dates are:*

July 18  
August 1, 15  
September 5, 19  
October 3, 17

**Where:** *New York Presbyterian Hospital  
622 West 168<sup>th</sup> Street, PH14  
14<sup>th</sup> Floor Conference Room - #101 East*

**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](http://WWW.48FRIEND.ORG)
- *COTA (Children's Organ Transplant Association)*, (800) 366-2682, [www.cota.org](http://www.cota.org)
- *Well Spouse Association*, (800) 838-0879,  
[www.wellspouse.org](http://www.wellspouse.org)
- *Liver Cancer Care*,  
<http://www.hopeforlivercancer.com>
- *Liver Cancer Network*,  
<http://www.livercancer.com>
- *Hemochromatosis Foundation*,  
<http://www.hemochromatosis.org>
- *PBCers Organization*, <http://www.pbcers.org>
- *Biliary Atresia and Liver Transplant Network*,  
<http://www.transweb.org/people/recips/resource/s/support/oldbilitree.html>
- *The FAIR Foundation*, 760-200-2766,  
[www.fairfoundation.org](http://www.fairfoundation.org)
- *National Hepatitis C Advocacy Council (NHCAC)*, 877-737-HEPC,  
[www.hepcnetwork.org](http://www.hepcnetwork.org)



Ray and Ralph, separated at birth?

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

**Next Meeting:** Tuesday, November 16

Speaker: Dr. Lau

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

Meets first Wednesday monthly; 6:00pm-7:00pm  
at Weill Medical College of Cornell University/New  
York Presbyterian Hospital **Phone:** 212-746-2115

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 en-  
deavor of Cornell University, Rockefeller University  
and New York Presbyterian Hospital.*

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

Meets Every third Wednesday monthly; 6pm;

New York Blood Center, 310 East 67th Street

**Phone:** 718-892-8697

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

Meets Every 2-3 months; 6:30-8:30 pm

Mount Sinai Hospital, Guggenheim Pavillion, Room  
2B

**Phone:** 212-241-5735

Contact John Leonard for more information.

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

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 chroni-  
cally 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.*