

New York- Presbyterian

The University Hospitals of Columbia and Cornell

LIVER CONNECTION

Volume VI, Issue 1

THE NEWSLETTER FOR LIVER TRANSPLANT
PATIENTS AND FAMILIES

Spring 2007

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From The Editors

April is Donate Life Month!!!

As many of us are buried in snow and slush, it is hard to imagine that spring is right around the corner – but it is – and so is Donate Life month! There are many events being planned here at NYPH and within the transplant community to increase organ donor awareness, recognize donors and donor families and celebrate the miracle of transplantation.

- TRIO's 12th Annual Donor Tribute April 14, 2007 at St. Patrick's Cathedral.
- Organ Donor Awareness Week at NYPH-Cornell, April 16-20, 2007.
- New York Presbyterian Hospital's **Circle for Life: A Transplant Awareness Celebration** on May 4, 2007 from 11:30-1:30pm.

You will see pictures from our post-transplant holiday party interspersed throughout the newsletter. The party was an overwhelming success and a reminder that we have outgrown our space! Thank you to everyone who came for making the party such a huge success!

We would like to thank our social work interns, Dalia Teen and Adline Warwick-Thompson, for all of their enthusiasm and contributions this past year. This May will mark the completion of their Master's in Social Work programs

Organ Donor Awareness Week!!! April 16-20th

To raise awareness about the need for organ donation, we will be setting up an information table for one week in Cornell's Greenberg lobby.

We are looking for transplant recipients and loved ones to volunteer to give out information and share their experiences.

If you are interested in volunteering, we will be training for the event on:

Wednesday, April 11th at 4:00pm

1305 York Avenue

(on the corner of East 70th Street) – 2nd Floor

For more information or to RSVP for the training, please contact:

Dalia Teen, SWI, 212-746-3203, dat9025@nyp.org
Jennifer Keen, LMSW, 212-746-3245, Jek9028@nyp.org

at Fordham University and, therefore, the end of their internships. We thank Dalia and Adline and wish them well in their future endeavors! They have left big shoes to fill!

For those of you who have been diagnosed with liver cancer and are interested in more cancer specific support, please contact Lynette Williams, LMSW (212-305-5274) or Madeline Encarnacion, LCSW, (212-305-6320), NYPH oncology social workers, for groups being offered for patients living with cancer. Madeline also facilitates a Spanish speaking support group!

We are very interested in receiving patient stories. This includes stories from patients who are waiting for transplant. Also, if there is a transplant related organization or event that you think would be a good resource to other patients, please let us know. Email (aim9003@nyp.org) or mail to the address below.

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TRANSPARTY PICTURES

Holiday Party a Huge Success!

The glittering Faculty Club room was bursting at the seams as over 250 happy transplant recipients and families greeted old friends and new, waited patiently in lines for scrumptious food and posed for pictures with their doctors, NPs and other transplant team members. With her son, one of our patients, Anna Leanheart, even celebrated her 3 year transplant anniversary with us!



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TRANSPLANT NEWS

CIRCLE FOR LIFE: A TRANSPLANT AWARENESS CELEBRATION

The biggest problem facing the transplant community today is the extreme shortage of organs. In order to be able to remedy this shortage, organ donation awareness opportunities must increase dramatically. The New York-Presbyterian Transplant Institute, a joint effort between Columbia University and Weill Cornell Medical Centers, is one of the nation's premier centers providing comprehensive services for patients needing heart, kidney, lung, liver, and pancreas transplantation, and is currently the 3rd largest multi-organ transplant center in the country. This position gives New York-Presbyterian a unique opportunity to be able to help publicize the profound need for an increase in registered donors. To that end, New York-Presbyterian Transplant Institute will present:

Circle for Life: A Transplant Awareness Celebration

Friday, May 4, 2007, 11:30am - 1:30pm

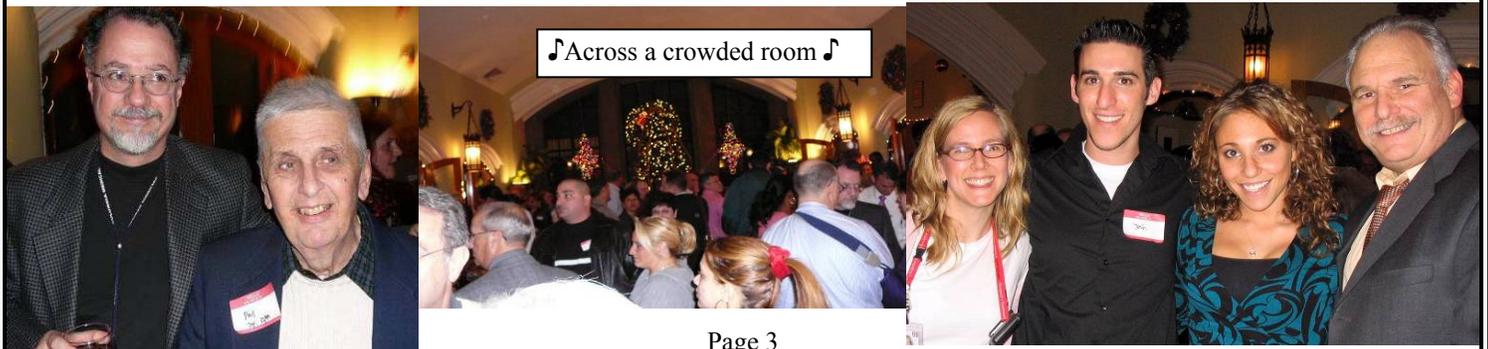
Armory Track and Field Center - 216 West 168th Street
near the New York Presbyterian Columbia Medical Center campus.

Circle for Life will bring together transplant recipients, donor families, living donors, and medical professionals who have cared for them, in a celebration of what's already been achieved in giving the gift of life. Much more importantly, we hope this celebration will serve to raise community awareness about organ donation and the clinical innovations in organ donation and preservation that make increased donation opportunities possible. Key opinion leaders in the arena of solid organ transplantation will address the audience on such topics as extended donor criteria organs, living donor opportunities, and the latest advances in preserving and transporting organs. Representatives from organ donor networks will speak on donor criteria, and will attempt to dispel some of the myths commonly associated with organ donation. Community leaders and elected officials will be on hand as well and will serve to help us in generating broad press coverage to help spread the message further.

Many of you may have received your Save the Date announcements already for this event. Invitations will go out to all post-transplant recipients. Due to space constraints, the invitation will allow for the adult transplant recipient and one guest, or for the pediatric transplant recipient, two guests. Be on the lookout!

TRIO 12th Annual "Remember and Rejoice" Ecumenical Service

The Manhattan chapter of the Transplant Recipients International Organization (TRIO) is holding their 12th Annual Donor Tribute on Saturday, April 14th at 2pm. The donor tribute takes place annually at St. Patrick's Cathedral in midtown Manhattan. The nondenominational ceremony is a tribute to the tri-state area's heroic donors and their families who continue to give the greatest gift of all - life. For more information, their flyer is included or contact, Lorraine DePasquale, President, by email at: triom@aol.com or telephone, 718-597-5619.



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TRANSPLANT NEWS, continued

TRANSPLANT NEWS, continued



2007

It's that time of year again!

The American Liver Foundation (ALF) is a nonprofit, national voluntary health organization that is dedicated to the prevention, treatment and care of hepatitis and other liver diseases through research, education and advocacy on behalf of those affected by or at risk of liver disease. Every year the ALF organizes Liver Walks in the greater NYC area to assist in fundraising efforts to support its mission.

In the past, our NYPH team, Team Gratitude, has been the largest hospital affiliated team and one of the largest fundraisers. Patients and families of CLDT have also walked and organized independent teams with many being noted to be among the biggest fundraisers! If you're interested in participating or joining our team, Team Gratitude, contact Aimée by phone (212) 305-1884 or email (aim9003@nyp.org). The baton has been passed from Gina Williams to John Rice (JohnnyRice902@aol.com) this year for Team Captain. Updates to the Team website will occur in the near future.

If you have a more general question about the Liver Walk or are interested in company sponsorship, please contact Gina Parziale at (212) 943-1059 or via email at gparziale@liverfoundation.org. Sponsorship opportunities range in size from \$500-\$10,000 so companies of all size can participate!

Sunday, May 20th **Eisenhower Park, Long Island**

Start/Finish: Parking Field 6A

Walk Route: The 5K (3.1 miles) walk will take place inside this beautiful park.

*Directions: Take Northern State Parkway or Southern State Parkway to Meadowbrook Parkway to Stewart Ave. (Exit M-3). Turn left on Stewart Ave to the park.

Sunday, June 10th **Battery Park, New York City "New Location"**

Start/Finish: Castle Clinton in Battery Park.

Walk Route: The 5 K (3.1 miles) walk takes place along the Hudson River with beautiful views of the Statue of Liberty and on the Hudson River Park Walkway/Esplanade.

*Directions: By subway: 4/5 to Bowling Green, R/ W to Whitehall Street or #1 to South Ferry;
By bus: M1, M6, M15 to South Ferry

Sunday, June 17th **Liberty State Park, New Jersey**

Start/Finish: Historic CRRNJ Terminal South Field

The 5K (3.1 miles) walk is along scenic Liberty Walk with stunning views of the Statue of Liberty.

*Directions: *By public transportation:* Take PATH subway to Pavonia/Newport or Hoboken. Then take Light Rail to Liberty State Park. *By car:* Take Holland Tunnel to New Jersey Turnpike. Liberty State Park is at NJ Turnpike Exit 14b.

All walks rain or shine!
Check in time 8:30am
Start time 9:30am

TRANSPLANT NEWS, continued

TRANSPLANT NEWS, continued



16th World Transplant Games

Bangkok 2007

25 August - 3 September

www.16thworldtransplantgame.com

The National Kidney Foundation has organized Team USA since 1992 to participate in the World Transplant Games. One of the beliefs behind organizing and staging international sporting events for transplant athletes is that it will increase organ donation awareness and demonstrate the physical success of transplantation. Like the U.S. Transplant Games held this past June, it will also allow for an opportunity to be part of a special bond between recipients, donors and the transplant community.

The World Transplant Games is a five-day, multi-sport event held biannually in the odd-numbered years. Organized by the World Transplant Games Federation, the event attracts transplant athletes from around the world. The 16th World Transplant Games will be held August 25-September 3, 2007 at Bangkok's Hua Mark Sports Complex, the top sports venue in Thailand. Sporting events will include badminton, bowling, cycling, golf, mini-marathon, rifle/pistol shooting, squash, swimming, table tennis, tennis and volleyball. For more information, please call (866) TX-GAMES or (800) 894-2637. You can also e-mail your questions to: transplantgames@saltlake.org.

The Winter World Transplant Games are staged in the intervening years and have provided an opportunity for many not only to compete on the ski slopes but to enjoy the warmth and friendship which are at the centre of these Events. Finnish Transplant Sports Association will host the 6th Winter World Transplant Games March 26-31, 2008 in Rovaniemi, Finland. For more information, visit <http://www.rovaniemi2008.com> or <http://www.wtgf.org/winter.htm>.

Just remember, if any of you are fortunate enough to attend either of these events, it is critical that you speak with your transplant coordinator to ensure a safe trip!

If you aren't able to make Bangkok, the next U.S. Transplant Games will be held in Pittsburgh in 2008!!! I know there are transplant recipients recruiting team members already! If you're interested call or email Aimée! Read what John Rice has to say below.

Since 1992, the National Kidney Foundation has hosted the U.S. Transplant Games. Last June, Ralph Faga and I took part in the Louisville, Kentucky 2006 Games and it was an experience that I will always remember. Organ donor families, donors and almost 7,000 transplant recipient participants of liver, kidney, heart, lung, pancreas or heterologous bone marrow were all there for one reason. Ten thousand people from all over the country wanted everyone to know that "transplantation works." Competing in events such as track and field, swimming, golf, bowling, basketball, table tennis and cycling gave us the opportunity not only to meet and encourage each other but also to show appreciation to the donors and donor families who gave us the "Gift of Life."

These events are not about winning or losing but are more about getting the word out. It was well covered by the media, both national and local. This demonstrates not only the need but the great successes of organ donation. Just being there, means you're already a winner. Athletes of all shapes, sizes, age and of varying abilities become part of one family, and it is an experience that reaffirms the commitment of all involved—doctors, nurses and patients.

As inspiring as the games in 2006 were, the 2008 games in Pittsburgh promise to be even better. As the success of transplantation grows, so does the number of patients able to participate or just watch the games. Our team had 23 members last year, and we hope to field 50 next year. As a member of the steering committee for the team, I am hoping to reach as many new members as I can as I saw first hand what the experience did for everyone involved. If you think you might be interested in competing, or just being a spectator, please contact your social worker, or you can contact me directly at JohnnyRice902@aol.com for more information. Live Strong.

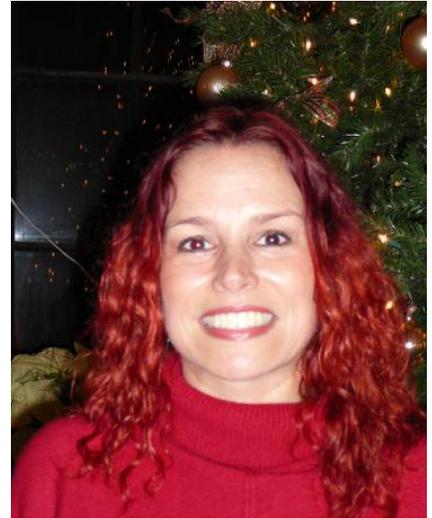
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LC TALKS WITH

Dianne LaPointe-Rudow, DrNP



Liver Connection (LC): How did you come to be in liver transplantation?

Dianne LaPointe-Rudow (DL): Actually it was by accident. I used to work at NYU medical center. I worked as an ICU nurse in their open heart unit. Then I was an instructor for the ICU. I really missed taking care of patients when I worked as a teacher. My friend, Patricia Harren, who works here as well said, “Oh, there’s a job in the liver transplant program.” So I took it thinking “I’ll do that for a little bit,” because I always thought I’d like open heart surgery again. But when I worked in transplantation I became really passionate about it and I just realized it was the thing I wanted to do. I worked at NYU for about seven years, as a transplant coordinator. I had my daughter during that time. I worked in the outpatient area, saw the patients with the doctors, helped get them listed and educated, a lot of what I do now. But at the time that I became a nurse practitioner, they were reluctant to allow us to practice as nurse practitioners. They didn’t give us a lot of independence and I had already been doing it for a long time. When Dr. Emond came here to start this program, he asked Patricia and me to interview. They hired us and Patricia and I got to design this program from scratch. Columbia’s liver program is a lot different than other liver transplant programs, in that all our transplant coordinators are nurse practitioners. We have a lot of autonomy. We get to see patients alone and manage them. That’s not true in a lot of transplant centers. I’ve been able to grow and develop here a lot more than I was able to do at NYU.

LC: I’ve always wondered about the differences between a Nurse Practitioner (NP) and a Physician Assistant (PA), and also what a transplant coordinator does?

DL: A transplant coordinator (TC) is a nurse who is involved in some part of the transplant process. Around the country, they may be pre- or post-transplant coordinators or organ procurement coordinators. They help get the patients listed. They are on call at night to get the donors coordinated and the donor organs to the hospital. Post-transplant they help patients, educate them, manage their recovery and their immuno-suppressants.

In our program, since the NPs are TCs, we do a lot of the same things the traditional TC will do but, because we have an advanced degree (the NP), we are able to do more. We’re able to see patients independently, we’re able to prescribe, to bill. We’ve been able to design our whole transplant program around allowing people to do what they do best. The surgeons operate. That’s

what they do best. We are in the outpatient clinic managing high blood pressure, or trying to figure out the best way to handle side-effects so the surgeons can perform the miracle of the transplant surgery. Our hepatologists can manage very complicated patients; they bring new patients into the practice; perform procedures. The NPs manage the day-to-day operations of the clinic. I spend a lot of time on health maintenance, on educating patients, making sure they’re getting back to their normal life. That’s the benefit of having the NPs see the patients as opposed to just the physicians. It really complements the work of the physicians.

The PA is a different model. PAs have different training. They learn a lot of the same things a NP does. They have different abilities in terms of prescriptive authority within New York State; and their ability to see patients independently is a little different. They are not nurses. I think they’re valuable. It’s a different philosophy than nursing. That’s why we’ve chosen to hire PAs for our inpatient unit. They help the resident physicians; they manage the patients. They also go to the OR. It’s a little fuzzy.

LC: What do pre- or post-transplant patients ask or complain about the most when you see them?

DL: I think it’s their weight [laughing, because the

LC TALKS WITH, continued

LC TALKS WITH, continued

interviewer had just done that during her own exam]. After their transplant, patients feel so much better. It's a remarkable improvement and they can see the difference right away. Sometimes they'll complain about the side effects of the medicines. That's early on; once they get used to the medicines I don't really see people complaining about the medications. They do complain about their weight. That's because when you're feeling well it's very hard to push away the food. You get the appetite back that you lost for awhile. Your body's healthy, so it can gain muscle and can recover. But then patients can also gain fat. It's hard to exercise and do all the things you need to do. Especially because you've been sick for so long, it's hard to get back in shape again. But it's important that people do that.

LC: With all the patients you see, is there a pattern among transplant (or liver disease) patients that is distinct from those with other health problems? You were a nurse at NYU with a different set of patients. Is there a difference?

DL: No, I don't think there's a difference. There's a lot of information out there for liver diseases, a lot of support groups, American Liver Foundation (ALF), TRIO, and LOLA. I think patients with Hepatitis C are more likely to be on the internet with chat groups trying to learn from other patients what to do.

LC: That's a recent phenomenon, isn't it?

DL: Yes, it is, and I think Hepatitis C patients do that a lot more than those with other liver diseases.

LC: What other advice besides the weight gain warning do you find yourself giving the most to your patients?

DL: The other thing that's key is that you have to treat your whole body not just your liver. People become so focused on their liver that they think that every thing that happens to them is because of the liver. Pre-transplant: The pain in their big toe is from their liver; their sinus infection is from the liver. They neglect the other parts of the body. I see this even more post-transplant. They check their blood every month like we tell them to, but it's harder to get them remember to get their mammographies; or to have their physical exam; to get their prostate checked. People think that just because their liver enzymes are normal, everything else is okay. After the transplant, our patients are living longer and longer. They're getting diabetes; they're getting heart disease and high cholesterol. I think they don't take those ail

ments as seriously as they take their liver disease. I think those diseases are even more dangerous than liver disease and they need to take those seriously as well.

LC: Are there many post-transplants who eventually stop the regime for protecting their new organs? What happens to them?

DL: There are a small group of patients that actually stop the medications and those patients typically will reject and lose their organs. But more commonly there are people who feel well again and every now and then they'll take their meds late or they'll forget a nighttime dose—they'll get sloppy. Those patients are also at risk for rejection. So it's important to make sure that you take your medicines on time every day and you don't miss a dose, even if you're five, six, seven years out. At five, six, seven years out you're on such a low doses of immuno-suppression that even missing one dose can be dangerous.

LC: Yes, some of us need to hear that loud and clear.

You've done research in nursing and transplantation. What do you find interesting about this part of your job? What are some important results from this research?

DL: I do a lot of research in living donation. I'm really fascinated by the live donor experience. I've had a couple of publications about that. I also like to write articles that are more practical, about how things are done in the field. For example, NY State regulates living donation very carefully and we're held to a very high standard and I'm not convinced the rest of the country is held to the same standard. We've learned a lot over the years on the best way to set up a live donor program, how to handle some of the ethical dilemmas that we face and how to care for the donor. I like to publish about that so that the rest of the transplant community can learn from our experience.

LC: You're doing a study now of living donation.

DL: Yes, the A2ALL (Adult to Adult Living Liver donor) study that is measuring the overall outcomes for live donors and recipients. There are only a couple of centers around the country involved in this study. Dr. Emond is the principal investigator for that and I'm a sub-investigator. It's exciting to be a part of that.

LC: What should patients do, especially post-transplant, when they have an illness or minor surgery or they're hospitalized? When should they call you and when the

LC TALKS WITH, continued

LC TALKS WITH, continued

emergency liver center number?

DL: If you're hospitalized over the weekend for something, you break a hip or whatever, you let your doctor who's taking care of you know that you're a transplant patient, and give them our number. They'll call us if they have any questions. But if it's during the week, you call and speak to your NP. They might say thank you very much, I hope you'll be fine or they might say oh we must make sure x, y and z happens. It's better to be cautious and just to inform them.

LC: But you can't assume that any hospital will make the call you request. You have to be pro-active.

DL: Right. Some doctors just won't call. They'll think they know what to do. Sometimes mistakes can be made. They may be giving you antibiotics you shouldn't be taking. It's always better to call to make sure everything's okay.

LC: Relay Health. I forgot totally about it after I registered. That's another way to communicate with the liver center. How does that work?

DL: Any patient who is part of our practice can go online and register. They would indicate their doctor and their NP. The patient would get a welcome to the system. Then they can go online and ask questions; if they had labs drawn, they can email us: "I had labs drawn at Quest on 34th Street on Tuesday; can you let me know the results? Then that would signal the labs secretary to check and get the labs which would signal me to look at the labs and to bounce you an email to say everything's fine. Then you wouldn't have to play telephone tag with your NP. You can say, "My local doctor started me on a new blood pressure medicine, is this one okay?" If you need a lab slip mailed, you can do that. It's harder to make appointments, because it's helpful to speak to a person so you can have your choice of days. But simple questions you can do that way. There's also the ability to do an online consultation for a small fee. If you have a medical problem and you want to discuss it or a rash, say, you can take a picture and send it to show it to someone. Most of our patients choose not to do that but I know Dr. Brown has a lot of patients who do. They ask him very complicated questions and he'll type up a big long answer. The majority of patients use it for quick interactions. But the important thing is you wouldn't use it for an emergency situation. If you have a fever and you're yellow, you don't use the internet, be

cause you don't know when someone's checking that or if they're away.

LC: You've done some interesting work outside the liver center. Can you tell us about that?

DL: I was president of the North American Transplant Coordinators Organization (NATCO), two years ago and that was very exciting. Last year and this year I've been on its public policy committee, so I lobby in Washington. I've done Congressional hearings to educate Congress about Medicare and the need to extend Medicare coverage for kidney recipients. We've lobbied to get money appropriated for HRSA¹ grants because HRSA had some pilot projects to allow live donors to get travel reimbursement and the government passed laws to allow the bills to go forward but never appropriated money so for the last year we've been working to get money for that.

LC: You mentioned Medicare hearings for kidney recipients; is this for liver as well?

DL: Medicare coverage for liver recipients is indefinite, but for kidney recipients who have Medicare because they have kidney disease, they have only 36 months of coverage. After 36 months, they may not have ways to pay for their medications unless they've gone back to work and gotten a job that provides insurance coverage. It's been very hard to convince Congress to extend Medicare coverage for kidney recipients.

I've also been working with NATCO on trying to help live donors without insurance for their follow-up care. There's no protection for live donors to avoid discrimination when they apply for health insurance or life insurance after they've donated. We're trying to get laws passed to protect them.

As the Pres. of NATCO, I also developed educational symposiums for nurses. I'm one of three editors of a nursing textbook that will come out this month. It's the first transplant textbook that encompasses the clinical aspects, the patient care aspects and the organ procurement aspects. It was started when I was president of NATCO. It's nice to finally see it in print.

I'm on the UNOS² board; UNOS is the allocation system. This is my third year on their executive committee. With UNOS we've been working on policy to improve the care of the live donor. We've been improving the surveillance of transplantation programs and holding them accountable for good results. I think nowadays that

LC TALKS WITH, continued

LC TALKS WITH, continued

there's a lot of oversight of transplant programs. The Senate finance committee is looking at how the allocation system has been set up in this country so they are making sure that patients are being taken care of appropriately and that their dollars are going to the right places. Medicare has new policies coming into place to regulate transplant programs. JCAHO³ is now starting to look at transplant programs and to regulate them. New York State Department of Transplantation regulates it as well; so there are a lot of overseers, telling transplant programs how to practice. With that, UNOS has had to make sure that they have all their ducks in a row, in terms of making sure that programs are set up appropriately, that patients' safety is of utmost importance and that our allocation system is fair. They're constantly making improvements to that and the board votes on all those things. It is exciting to be a part of all that.

LC: Dr. Brown, in his recent "Talk with LC" spoke about the European approach to donation, where it's assumed a person will donate organs at death unless they've previously chosen not to donate.

DL: That's called presumed consent⁴ and it is very successful in Spain. NY State has just passed legislation and will hold public hearings on investigating whether or not they should put together a pilot project on that.

LC: So that state by state they could implement presumed consent?

DL: Yes, but we're a long way away from that, unfortunately. What has happened the past two years is the Organ Breakthrough Collaborative. That's been run by HRSA and they have put together a group of experts in transplant and brought the whole community together to use their best practices in terms of getting consent for donors and to share organs better. In the last two years there's been a significant increase in the number of consented organ donors, more than ever before in history.

LC: What do you like best about your job?

DL: I think that transplant is an amazing field because you're meeting patients who have end stage disease. It's such a miracle that you can actually remove their liver and put a new one in and they're healthy again. Seeing patients' health restored is so amazing. This month one of my young patients had a baby and I felt like I delivered that child too. Without transplant she would not have contin-

ued to live, never mind have a child. What an exciting experience. It never gets boring or old.

LC: What do you like best about this particular transplant center?

DL: I think this program is different than others. We really have a team; a team that works together to take care of the whole patient. We have phenomenal surgeons and hepatologists. We have excellent nurses. We have very smart social workers and we have a psychiatrist and a pharmacist and wonderful support groups. We really pay attention to the patient and the details as opposed to it just being a factory.

LC: I was treated so well here and my expectations are so high that I'm constantly disappointed everywhere else. I expect everyone to be the same dedicated kind of very spirited group. Was it my imagination, or was it the prednisone, that there is something special here? What is it? Maybe it's the teamwork?

DL: Every member of our team has been hired or has been handpicked. The founders of this program, Dr. Emond, Dr. Brown, Patricia and I, have been in transplant for years. We passionately believe in what we do. We also like to think outside the box and make a difference. We've paid attention to everyone we've hired and expect the same from them. We all have drive and are excited about what we do.

1. Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services.
2. United Network for Organ Sharing
3. Joint Commission on Accreditation of Healthcare Organization
4. See Newsletter, Summer 2006 Issue



SILVIA'S CORNER

SILVIA'S CORNER



Sex and Intimacy for the Transplant Patient

Silvia Hafliger, MD

Inspired by the recent announcement of four babies born to mothers who had a liver transplant and with Valentine's Day coming up, I have decided to write about an often neglected topic in transplant patients, sex and intimacy.

Sexual difficulties are very common in medically ill patients and are seen in men and women. They can pose a great strain on a relationship. With all the medical problems a liver transplant patient has to cope with, sex may not be a top priority. But sexual function is part of our life; it is a body function like breathing or eating. Sex is the spice of life; it can provide great comfort and relaxation. Sex is more than having an erection or orgasm; it is about communication both with oneself or a partner. It is about connecting with another person and sharing intimate moments. Remember the most important sexual organ is the brain.

How can you enhance your sexuality?

You need to feel entitled to be a sexual person. Despite all the medical problems you deserve to have pleasure. You need to liberate your sensuality. Feel your body and skin. Often senses are numbed due to illness and trauma but they can be reawakened. *Good sex is planned.* If you expect to have spontaneous sex you will be disappointed. You need to set aside time. You may have sex once the children are not around, before you take your medication, in the morning when you are less tired. You need to have positive communication with yourself or partner. *Positive feedback acts as reinforcement.* The more excitement you show the more excited your partner gets. Get to know your sexual scripts. How do you like sex, how often? Often your partner will have a different script and you need to negotiate and find a middle ground. *You have to give in order to get.* Take an active role, don't be passive.

What can get in the way of good sex?

Remember the most important sexual organ is your brain. Depression, anxiety, fears all cause sexual dysfunction. Fear of failure, fear of pain, fear of not being attractive or fear of infecting your partner with Hep C/B/HIV all contribute to sexual dysfunction. More than fifty percent of patients with cirrhosis experience sexual dysfunction. Men may notice loss of interest, testicular shrinking, breast enlargement, and female hair pattern. The liver plays an important role in the breakdown of sex hormones, such as estrogen or testosterone.

With increased scarring of the liver, more estrogen remains in the body leading to above problems.

Smoking, alcohol consumption, diabetes, many medications such as spironolactone (aldactone), propranolol (innderal), steroids (prednisone), anti-hypertensives, and anti-depressants can interfere with sexual function. Fatigue and lack of lubrication (anything that dries the mouth will dry the vagina) can decrease sexual pleasure or interest.

Prior to transplant, many patients are infertile, women will not menstruate, sperm count in men is low. After transplantation, infertility often resolves. There have been several reports of women having successful pregnancies if they are under the care of an obstetrician specializing in high-risk pregnancies. Children whose mothers took Neoral during pregnancy do not seem to have developmental or learning disabilities. Safe sexual practices are encouraged both pre- and post-transplant to avoid sexually transmitted disease or pregnancies.

There is a great stigma and shame in patients with Hepatitis C. There is undue concern about transmitting the Hepatitis C virus and patients often feel isolated and alone. Reality is, patients with Hepatitis C have a low risk of transmitting Hepatitis C virus sexually. Kissing, hugging, and touching do not transmit the virus. Hepatitis C virus is transmitted in blood. Only patients who have many sexual partners and engage in sexual activities causing trauma to genital areas are at higher risk of transmitting the virus.

This is in contrast to the Hepatitis B virus that has a high sexual transmission rate; therefore, all sexual partners and children of a chronic hepatitis B patient need to be tested for the presence of Hepatitis B.

Remember sex is about *communication* both with your partner and doctor. Don't suffer in silence. Get help. Viagra can safely be used post-transplant. After transplant, a recipient may feel ready to have sex but a partner still suffers caregiver burn-out and may need time to recover. Be patient!

Have fun!

PEDIATRICS

PEDIATRICS

Chronic Illness and the Impact on Siblings

Kara Ventura

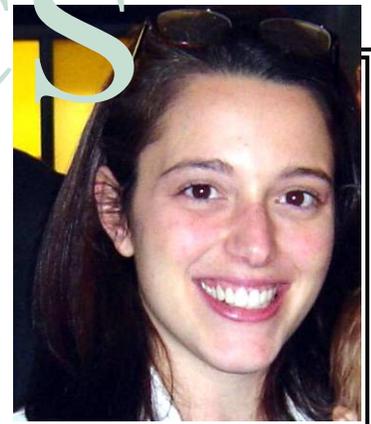
When a child is sick, parents find themselves angry, confused, and vulnerable. Inevitably the family's dynamics are altered and strained. While the mental and psychological health of every family member can impact the level of wellness of the patient, it was only in the last few years that research has been published analyzing and describing the impact of chronic illness on siblings of a chronically ill child.

While research illustrates that there is an obvious impact on siblings of children with chronic illness, their problems are not often noted. The feelings of siblings must be respected and their needs addressed. Some common and normal feelings siblings may have are:

- Jealousy
- Anger
- Frustration
- Resentment
- Fear
- Embarrassment
- Sadness
- Helplessness
- Guilt

Siblings of chronically ill children are at a high risk for developing numerous issues which can become complicated and lasting due to their conflicted feelings about their sibling's illness. They exhibit behavioral problems such as lower social competence and self-esteem, shyness, somatic complaints, poor peer relations, delinquency, loneliness, isolation, anxiety, depression, anger, excessive worry, and poor or failing grades. Siblings need to adjust to changes in the family with a sick brother or sister, assume additional responsibility, and accept that their parents are not as available to them physically or emotionally. They also will have feelings such as jealousy, shame and guilt. Children under eight years old have a greater misunderstanding of their brother's or sister's condition. Parents must watch for siblings having behavioral issues, psychological issues and physical issues.

Behavioral issues are exhibited often with behavior outbursts or tantrums. These outbursts are seen in many places including home, school, in public and even at times in medical settings. These behavioral outbursts are often a sibling's attempt to seek attention. Parents commonly find these situations difficult to manage and the sibling feels further isolated and frustrated resulting in more behavioral problems, most commonly, aggression and acting out.



An elevated amount of physical complaints are seen in siblings of ill patients. While medical complaints are often displays of psychological instability, some siblings have experienced measurable medical problems. These siblings have been found to have increased motor and physical problems and unfortunately, these physical and motor-related worries are less recognized by parents.

While physical complaints are sometimes related to psychological problems, the sibling may also be scared that they too may become sick. Fear, sadness and anger may be expressed with physical complaints. Sometimes, however, a sibling may complain of a physical problem to get attention from their parents.

It is important for parents to know that siblings often understand more of what is going on than they think. These children sense the vulnerability and unrest in the family so sometimes the sibling may hide how they are feeling so as to not overburden their parents. This can add to psychological strain for the sibling and a high amount of stress. Resentment of the extra demands put on them because of their disabled sibling may occur along with feeling neglected by their parents.

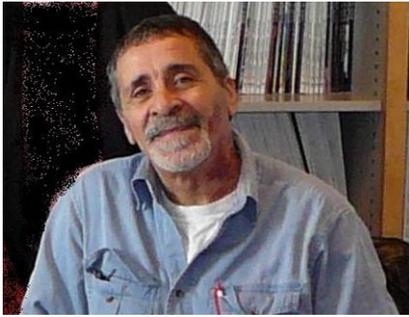
This stress and psychological unrest is seen throughout the age span of the siblings. Teenagers' adjustment problems are exhibited not only at times of crisis but even when the ill child is in remission. Embarrassment which is often felt by siblings effects teenagers and young children. While emotional problems have been noted to decrease over time, siblings still experience social limitations such as inability to have regular play dates, often missing school themselves. Lack of social activity at their own home can develop into long-term socialization problems.

Psychological adjustment problems are difficult to recognize by parents, the nature of problems siblings can encounter need to be given specific recognition as they differ from psychological problems their peers may encounter. Even during times of "normal" socialization with peers, siblings may feel guilty about enjoying themselves and may find themselves defending their ill sibling. Children who are not

PATIENT VOICES

A Memorable Evening

John Rice



There are always two sides to every story. Last night I got to experience that reality of transplant, and I feel very lucky. As a liver transplant patient of almost three years, I come in contact with many other patients and, as an active member of the post- and pre-transplant meetings, get to share the ups and downs of the many illnesses that affect all involved. With lots of work from lots of people, many of us will get that much needed "Gift of Life" and return to a life we only hoped for while waiting on a list that never seemed to move.

Last night I was invited to sit in on a meeting at the New York Organ Donor Network (NYODN) by a good friend, and recent heart transplant recipient. The meeting was held to address a survey done by the NYODN's Donor Family Services. It was attended by five donor family members, three by conference call, and the rest of us at their offices on 31st Street in Manhattan.

Last night I was able to see the other side of transplant. As organ recipients we only get to see the positive side, as hard as it might seem. Except in live donor transplant, a family has to go through the loss of a loved one in order for us, and our families to enjoy this new lease on life. The sister I met last night, who lost two of her brothers, twelve years apart, and still had the courage to think of others at a time like that will inspire me forever. Organ donation affects not only the one receiving the organ, but the family members too. How many lives were touched by her decision to turn her loss into a blessing so many others will live will never be known. The mother I spoke to, who gave the gift of life after her eight year old son was killed in a car accident, spoke with such conviction about transplant that I now see it in a different light. I can now see the other side more clearly. The organs of mothers, fathers, sons and daughters that were given to us, were once part of a loved one that a family has lost. This generous gift must never be taken for granted, and after meeting the people I met last night, I know I will never forget where it came from. Please write your donor family today to say thanks.

Stickball Hall of Famer



This past July, **Antonio Herrera** was inducted into the Stickball Hall of Fame. Tony has been playing stickball since the age of eleven. In a recent newspaper article, Tony described how tough competition was in New York City and how he competed hard to be one of the "regular homeboys." Tony currently plays or coaches the *New York Emperors* team where he is an inspiration for many younger men and women.

Tony retired last year as a drug treatment counselor after 35 years of working in the human services arena. He also volunteers at Metropolitan Hospital where he gives Hepatitis C presentations. Tony is intimately aware of how Hepatitis C can affect one's life as Tony received a living related liver transplant January 8, 2001 from his son, Anthony, who is in the picture above with him. Tony's son donated approximately 60% of his liver. Today, both Tony and his son are at 100% and often share their experiences and lives with others who are sick with liver disease, undergoing interferon treatment, and/or considering living donation. Congratulations Tony!



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CAREGIVING

HELPING TRANSPLANT CAREGIVERS FIND THE BALANCE BETWEEN THEIR DEMANDS AND RESOURCES

Adline Warwick-Thompson

"There are only four kinds of people in this world - those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers." Former First Lady Rosalynn Carter, author of *Helping Yourself Help Others: A Book for Caregivers*.

An estimated 25 million Americans are family caregivers, providing for the physical and psychological needs of older parents, chronically ill spouses, or children with disabilities. Caregiving can be a demanding yet fulfilling occupation, and may leave caregivers feeling isolated and unprepared for their role. For transplant patients, the caregiver is a key source of support and can influence how the patient both adapts and copes with their illness, treatment and recovery.

We hope that our **newly formed Transplant Caregivers Group** will help those of you who are caregivers to find support and information about how to build coping skills and access resources which you didn't know you had.

Our last group focused on the subject of **How to find a balance between the Demands and Resources** involved in being a Transplant Caretaker. All the participants agreed that being better prepared for this role can be immensely helpful. Together we came up with the following suggestions which we would like to share.

ACCEPT YOUR LIMITS

As a caregiver, try and accept the fact that you don't have to do it all, and you shouldn't try. Give yourself credit rather than guilt!

At times you may lose patience, but remember that you are doing the best you can. Acknowledge what you are achieving, and accept that there are limits and ask for help.

DELEGATE RESPONSIBILITY

Doing everything yourself will leave you exhausted. Seek the support of family, friends and the community and create a **caregiver support team**. Often people want to help but they are not sure what they can do. Try to determine which individuals are suited to particular tasks. Some people are willing to help with grocery shopping or cooking, others are willing to drive, and those living further away might be able to help with filing insurance claims. Be creative and specific about how people can help.

REACH OUT FOR SUPPORT

There are a number of resources available apart from our own

Caregiver Group. For example, the **National Family Caregivers Association**, (www.nfcares.org), the U.S. Administration on Aging's excellent Resource Room and **National Family Caregiver Support Program** (www.aoa.gov - choose caregivers from scroll down menu), **Caregivers USA** directory of community-based caregiver services (www.caregivers-usa.org) and the **Well Spouse Association** (www.wellspouse.org), the only national organization focusing exclusively on the needs of spouses.

BE ASSERTIVE

Be realistic about what you can and cannot be responsible for. Set priorities and learn to say no and put limits on your time. Ask people for exactly what help would be useful. Ask friends to visit during hours that are convenient to you and your loved one. You will find that people are surprisingly helpful to respond if they are given specific tasks.

TAKE TIME FOR YOURSELF

Schedule time for yourself. Remember that you need to stay healthy in mind and body. Taking time for yourself is far from selfish. It is critical in order for you to recharge and continue caring for your loved one. If you take a break once in a while, you will find yourself better able to fulfill your role as caregiver. Above all, don't put off your own medical checkups.

DISCUSS YOUR FEELINGS

You may think that no one understands what you are going through as a caregiver. Find someone whom you know can be a supportive listener, such as a friend, clergy member, and support group member. Sometimes it can help to let that person know that you don't necessarily expect answers or solutions, just a sympathetic ear.

Being a caregiver for someone you love is one of the toughest jobs imaginable. It can be frustrating and terrifying, exhausting and overwhelming, but it can also be one of the most rewarding things you'll ever do.

But don't forget caregiver support: in order to provide the best care for your loved one, you have to take care of yourself.

CAREGIVING, CONTINUED

CAREGIVING, CONTINUED

Caregivers' Forum

The Caregivers' Forum is both a support group and an educational experience!

- Find support and encouragement from other caregivers going through the transplant experience, both pre- and post-transplant.
- Develop more effective coping strategies to deal with the multiple stressors of taking care of a loved one.
- Talk about how roles and responsibilities have changed and how you are dealing with them.

Caregivers' Forum is open to all transplant patients, regardless of the type of organ transplant. Forum takes place:

Milstein Hospital Building
177 Fort Washington
Reemtsma Conference Room - 7 Hudson South, Room 7-213
4-5:30pm
April 12, April 26, May 10, May 24, June 14, June 18



For more information, contact Adline Warwick-Thompson, Social Work Intern, at (212) 305-1884 adw7001@nyp.org. After May, groups will be facilitated by Kimberly Morse, LMSW, who can be reached at 212-305-3081.

PEDIATRICS, continued

Continued from page 12

exposed to illness may not fully understand what is going on in their peer's family and treat the sibling as different.

There are some helpful interventions that can be given to parents to ease the impact that chronic illness has on a sibling. First, it is important for parents to assess the sibling's knowledge about the illness. This can combat fears, anxiety, feelings of isolation from lack of knowing and provide an overall greater understanding of the illness to the sibling. Even when parents want to share information with siblings, they may be confused as to how and when. They need to provide consistent, age-appropriate education and spend alone time with the sibling. Parents may also want to consider private psychotherapy for the sibling so siblings have a safe place to speak about their concerns. Parents can encourage participation in psychosocial group sessions with other siblings of chronically ill children who share similar experiences. These groups have shown improvement in the mood of the sibling and decreased behavioral problems.

Siblings of chronically ill children don't always express negative feelings or actions. Some children have reported being more empathetic, patient, tolerant and loving towards others. Living with a sibling that is ill or disabled signifies the disadvantages others have. Some children also may wel-

come early responsibility that comes with having a disabled child; they are articulate in explaining their sibling's diagnosis and needs and feel it easier to relate to adults than their peers.

What parents can do?

1. Educate the siblings about the illness of the sick child using age appropriate terms.
2. Talk to the sibling about their feelings and concerns.
3. Provide opportunities for the sibling to participate in caring for his or her ill brother or sister.
4. Normalize life as much as possible; keep the sibling's routine the same.
5. Involve the sibling in other support systems outside of the family allowing for them to receive special attention.

Remember, the school can be a great resource for both the sibling and the chronically ill child. Speak to the teachers and school guidance counselors of both the ill child and the sibling about the illness so they can provide further support to your children. Let them act as another set of eyes and ears. Communication is key for both success at home and in school.

Further, remember, you are not alone. Seek support for yourselves as well! There are many support groups for parents of chronically ill children both on-line and locally. Speak to your social worker about further resources.

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EDUCATIONAL WORKSHOPS

EDUCATIONAL WORKSHOPS

Sessions will be held on Fridays, 2-4pm

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



- April 13th: PATIENTS' STORIES OF TRANSPLANT**
Meet transplant recipients, donors and caregivers.
- April 20th: AN OVERVIEW OF LIVER DISEASE & LISTING CRITERIA**
How does the liver function? What is cirrhosis? How does listing work?
Speaker: Lorna Dove, MD, transplant hepatologist
- April 27th: SLEEP AND DEPRESSION**
Speaker: Silvia Hafliger, MD, Transplant Psychiatrist
- May 4th: LIVER TRANSPLANTATION SURGERY: DECEASED VS. LIVING RELATED DONATION**
Speaker: Sarah Bellemare, MD, Transplant Surgeon
- May 11th: KEEPING YOUR HOUSE IN ORDER, INSURANCE AND FINANCIAL COORDINATION**
*Speaker: Adline Warwick-Thompson, Social Work Intern
Carolyn Jones, Billing Director, and
Sharifa Bailey, Financial Coordinator*
- May 18th: IMMUNOSUPPRESSANT MEDICATIONS AND THEIR SIDE EFFECTS**
Speaker: James Spellman, NP, Transplant Coordinator
- June 1st: THE ROLE OF THE NEW YORK ORGAN DONOR NETWORK (NYODN)?**
Speakers: Various members of the NYODN will speak about their role and services in the transplant community.
- June 8th: OPEN FORUM**
Facilitated by Psychosocial Team.

These sessions are MANDATORY!

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

For more information contact:

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

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POST-TRANSPLANT SUPPORT GROUPS

Who: POST-TRANSPLANT RECIPIENTS AND FAMILY MEMBERS

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

NYPH-New York-Weill Cornell Medical Center
 1305 York Avenue
 (Southwest corner of York Ave and 70th Street)
 2nd Floor, Rm Y.2.14.2

When: Thursday, March 22nd 10:00 -11:30am
 Thursday, April 5th 10:00 -11:30am
 Thursday, April 19th 10:00 -11:30am
 Thursday, May 3rd 10:00 -11:30am
 Thursday, May 17th 10:00 -11:30am
 Thursday, June 7th 10:00 -11:30am
 Thursday, June 21st 10:00 -11:30am

Wednesday, March 21st 5:30pm -7:00 pm
 Wednesday, April 18th 5:30pm -7:00 pm
 Wednesday, May 16th 5:30pm -7:00 pm
 Wednesday, June 20th 5:30pm -7:00 pm

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

Dalia Teen, SWI
 212-746-3203, dat9025@nyp.org

Jennifer Keen, LMSW
 212-746-3245, jek9028@nyp.org

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. And maybe it would be nice to hear what others in a similar state of mind have to say. 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 meet and chat. Let's take advantage of the greatest gift we were ever given... a second chance.



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.



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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
- 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>



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AREA SUPPORT GROUPS

Englewood, NJ (Hepatitis)*

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

New Jersey - Hackensack (Hepatitis C)*

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

Long Island (Hepatitis C Courage Group)

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

Long Island (Hepatitis C)

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

Long Island (Hepatitis C)

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

Long Island (PBC)*

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

NYC – (Liver Cancer)*

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

NYC - Manhattan (Hepatitis C)*

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

NYC - Manhattan (Hepatitis C)*

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

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

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

NYC - Manhattan (PBC)*

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

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

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 Recipients International Organization (TRIO) – Manhattan*

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

TRIO – Long Island*

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

Transplant Support Organization (TSO) - Westchester 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.*

