From The Editors
Happy Spring!

We hope this newsletter finds you happy and well. I would like to apologize to those of you who did not receive the Winter newsletter prior to the start of the groups. For various reasons, we were unable to finalize the copy so we hope this newsletter finds you in a much more timely manner – especially since we’d love to see more of you at the groups!

April is National Donate Life Month, a nationally designated time to promote organ, tissue, blood and bone marrow donation awareness. Nearly 90,000 people are waiting for organs in the United States with more than 8,000 in New York State. Remember: one person can save the lives of eight people.

In honor of National Donate Life Month, the Manhattan chapter of the Transplant Recipients International Organization (TRIO) is holding their 11th annual donor tribute on Saturday, April 1st from 2-3:30pm at St. Patrick’s Cathedral in midtown. The nondenominational ceremony is a tribute to the heroic donors and their families who continue to give the greatest gift of all – life. This is a very special and emotional opportunity to remember organ donors and their families. For more information, we’ve included the flyer in this mailing. We hope to see you there.

With the donor awareness and remembrance in mind, we encourage you to write letters to your donor families. Sadly, despite the increasing number of transplants being done in this country, rarely do donors and recipients meet. Most recipient letters do not lead to a donor family meeting; however, the most important thing is that the gift of life is acknowledged. For those of you who have not written your donor letter yet, now is the time to put pen to paper to express your appreciation as well as your condolences to your donor family. You can give your letter to your social worker or transplant coordinator and it will be forwarded appropriately.

An important reminder: we are always looking for articles from liver patients – both pre- and post-transplant. Please email (aim9003@nyp.org) or mail to the address below. We welcome the opportunity to hear from new voices!
Liver Walk

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. If you are interested in participating, call 212-943-1059. We are in the very early stages of trying to organize a NYPH team for the NYC Liver Walk. Last year, our Team Gratitude was the largest hospital affiliated team with 28 walkers. Team Gratitude was the 2nd largest team overall and 2nd largest fundraiser! Contact Aimée by phone (212) 305-1884 or email (aim9003@nyp.org) for more information or if you are interested in organizing this year’s team.

The dates and locations are:
- Sunday, May 21, 2006
  Eisenhower Park
  LONG ISLAND

- Sunday, June 4, 2006
  Riverside Park
  NEW YORK CITY

- Sunday, June 11, 2006
  Liberty State Park
  NEW JERSEY

Transplant Games

The U.S. Transplant Games will be held June 16-21, 2006 in Louisville, Kentucky. The Games is an event that takes place to increase awareness of organ and tissue transplantation as well as to celebrate life for transplant recipients, friends and families. This four day athletic competition is open to anyone who has received a solid organ transplant – heart, liver, kidney, lung and pancreas. Bone marrow recipients are also eligible to participate.

Team Liberty has been organized by recipients in the tri-state area to compete. Those interested in being a part of this team should contact Nita Bitta at nbatta@nkfogreaterny.org. As of now, there is already one liver transplant recipient, John Rice, who will be competing in cycling events at the Games. Good luck John!

To register, you may download the registration forms to fax or mail your registration in or you may register online. The registration deadline is May 5, 2006. Go to the website for more information: http://www.kidney.org/news/tgames/index.cfm
What is Medicare Prescription Drug Coverage (Part D)?
Medicare prescription drug coverage is insurance that covers both brand-name and generic prescription drugs at participating pharmacies in your area. Like other insurance policies; if you join you will pay a monthly premium, which varies by plan, and a yearly deductible (no more than $250 in 2006). You will also pay a part of the cost of your prescriptions, either a co-payment or coinsurance. Costs will vary depending on which drug plan you choose. Some plans may offer more coverage and additional drugs for a higher monthly premium. If you have limited income and resources, and you qualify for extra help, you may not have to pay a premium or deductible. You can apply or get more information about the extra help by calling Social Security at 1-800-772-1213 (TTY 1-800-325-0778) or visiting [www.socialsecurity.gov](http://www.socialsecurity.gov).

Enroll Now to Avoid Penalties
To avoid penalties, **YOU MUST SIGN UP FOR A PLAN BY MAY 15, 2006**. After May 15, you will be charged an additional 1% for every month you delayed enrollment. This 1% penalty will be added to your monthly premium. Members have the option of switching Part D plans during open enrollment. Open enrollment runs from November 15 to December 31 each year. Dual Eligible (people with Medicare and Medicaid) can switch plans at any time.

Dual Eligible Patients (people with Medicare and Medicaid)
All dual eligible patients have been automatically enrolled in a Medicare Part D Prescription Drug Plan. From now on, Medicare Part D will cover your medications (Medicaid will continue to cover over-the-counter (OTC) medications such as aspirin and vitamins). Please note that dual eligible patients are responsible for monthly co-pays. Depending on income, co-pays vary form $1 to $5 per medications.

Will Medicare Part D cover Immunosuppressants?
- If Medicare authorized and paid for your transplant, then immunosuppressants are covered at 80% through Medicare Part B. Supplemental insurance coverage (private insurance/Medigap/HMO) will pay the remaining 20%. Medicare Part D will not cover immunosuppressants. Medicare Part D will cover the remaining medications.
- If you received your transplant BEFORE becoming Medicare eligible, Medicare Part D will cover immunosuppressants when you become eligible (turn 65 or after 2 years on Social Security Disability (SSD) – which ever comes first).

Pick a Plan
There are several ways to begin researching Medicare Prescription Drug Plans. Each of following three options use the Medicare Prescription Drug Plan Finder search engine found at [www.medicare.gov](http://www.medicare.gov). If you are not computer savvy, enlist family (children and grandchildren are great resources!) and/or friends to assist.
First things first, obtain a list of medications with dosages and quantity from your pharmacy, then:

1. Call Medicare: 1-800-MEDICARE
   - The Medicare hotline will assist you in picking a plan based on your geographic location and medications needed. The hotline utilizes the Medicare internet search engine.

2. LINCS (Linking Individuals in Need with Care and Services) 1-888-795-4627
   - Offers free counseling/assistance for persons searching for a prescription drug plan
   - LINCS is a service provided by the Medicare Rights Center in collaboration with AARP

3. Use the Medicare website to research various plan options:
   - Go to www.medicare.gov
   - Follow the link to “Compare Medicare Prescription Drug Plans”
   - Follow the link to “Find a Prescription Drug Plan”
   - Follow the link to “Personalized Plan Search” or “General Plan Search” (both will give you specific plan options)
   - Provide information requested (Medicare information, zip code, current coverage…)
   - Follow link for “Search for Prescription Drug Plans”
   - Follow link for “Enter My Medications”
   - Enter your list of medications, then follow link for “Continue with Selected Medications”
   - Follow link for “Change/Update My Drug Dose and Quantity”
   - Once dosages and quantities have been updated, you can choose to look at plans that are accepted at your local pharmacy. Or you can simply continue to plan list.
   - The plan summary list provides extensive information including estimated yearly out-of-pocket costs, in-network pharmacies, mail order options, annual deductibles, monthly drug premiums, and monthly cost-sharing.
   - **DO NOT ENROLL IN PART D PLANS ONLINE.** Call the individual plans to confirm medication coverage. **ENROLL OVER THE PHONE.**

**Things to Keep in Mind**

- **Coverage:** If you have drug coverage now, does it cover at least as much as the plan covers? Your current plan can tell you if it does. How complete is the plan’s formulary? (The “formulary” is the list of certain kinds of drugs that the plan will cover subject to limits and conditions.) Are the drugs that you take in the plan’s formulary?
- **Cost:** What is the monthly premium? What is the yearly deductible? Do you pay a co-payment (a set amount like $10 for a generic drug) or a coinsurance (a percentage of the drug's cost like 10% of the cost of a generic drug)? Which do you prefer? Does the plan uses tiered cost sharing (Different co-pays for generics, brands, or for specific drugs). How many tiers are there? What is the difference in price between tiers?

**Alert your Pharmacist**

- Alert your local and/or mail order pharmacy of any changes to your prescription drug coverage. The pharmacist will verify your new plan and confirm that your medications are covered.

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HEALTH CARE PROXIES

Jennifer Keen, LMSW

As part of the NYPH CLDT listing process, we ask that patients complete a New York State Health Care Proxy. A health care proxy is someone you appoint to make healthcare related decisions for you in the event that you are not conscious or, for some other reason, unable to make health care decisions for yourself.

Thoughts about health care proxy or other advance directives inevitably lead people to contemplate a decline in health or death, topics that most people try to avoid thinking about. For this, and other reasons as well, people often will delay completing the health care proxy or avoid the process altogether. This is the wrong approach.

Think about a health care proxy as your opportunity to really control your medical care if you are not able to make those decisions. Without this document and the discussions that accompany it, others are left to guess what you would want done. Having a health care proxy can relieve the stress of your family and friends should you ever experience a critical health event. Also, if you later improve, you automatically go back to being responsible for all decisions.

For many people, a spouse, parent, child, or sibling is the first choice for a health care proxy. However, you are strongly encouraged to select someone you feel will be able to carry out your wishes, and that person may not be a family member. This should be someone who will be accessible to the medical team and nearby if you are hospitalized. The New York State health care proxy form also offers the option of appointing a back-up proxy, which is a good idea in case your primary proxy is unavailable.

Once you’ve considered whom you would like to appoint as your primary and secondary health care proxies, the next step is to have a conversation with them so that they know that they know that you are doing so. During this conversation, you also want to take the time to tell them what you want and make sure that they feel comfortable carrying out your wishes. You may need to consider someone else if one or both do not believe that they are able to do so.

When you have two people who are willing to be your proxies, you are ready to complete the health care proxy form. Your social worker can provide you with an official health care proxy form to complete, if she has not already. Some important things to keep in mind while completing the form:

1. You DO NOT need an attorney or a notary to sign the form. You DO need to have two witnesses, both over the age of 18, sign the form. Whoever you are appointing as a health care proxy CANNOT be a witness and SHOULD NOT sign the form.
2. There are specific instructions included on the form, and in addition to these, we often encourage our patients to include the following two statements under the section of the form that states, “I direct my agent to make health care decisions in accord with my wishes and limitations as stated below:”
   - “My proxy knows my wishes regarding artificial nutrition and hydration.”
   - “My proxy knows my wishes about participating in research studies.”
Side Effects of Anti-Rejection Medication

Silvia Hafliger, MD

All patients after transplant will be taking anti-rejection or immunosuppression medication. The immune system consists of white blood cells, B and T lymphocytes. These cells are always on the lookout for foreign objects, whether these are viruses, bacteria, a splinter or a new liver. When something is recognized as “not self” a process is initiated to eliminate and/or attack the intruder. We have a whole army of cells in reserve that can be called up to fight an enemy.

We are able to interfere with the process of mobilizing this army of dormant cells, by giving you Prednisone, Cellcept, Neoral or Prograf. As long as you have a steady level of medication in the blood, the army of T/B cells stays asleep. One reason for taking Neoral or Prograf every 12 hrs is to keep an adequate level of medication in your blood. These medications keep your liver from becoming inflamed or scarred.

Despite the benefits of these medications, some of you will have side effects from these medications that can affect your mood and behavior. The medication most commonly associated with neuropsychiatric side effects is Prednisone. The brain effects from Prednisone can be mild. You may feel a bit jittery, have trouble sleeping or feel a bit more emotional. Five to ten percent of patients will have serious mood changes that can include a severe depression or mania. Mania is the brain’s inability to slow down. You may notice a tremendous amount of energy to the point of needing very little sleep. You may experience unusual ideas, paranoia or engage in risky financial endeavors. Your thoughts may be very fast; you may have a hard time concentrating or paying attention. You are easily upset or irritable. You may get very annoyed at your care team. Some patients become very frightened and feel as if they are living a bad nightmare. Sometimes your mind will create visual hallucinations (i.e. seeing objects, colors etc.).

If you or your care partner notices these symptoms you need to let us know immediately. There are medications that can counteract these unpleasant effects. Some of these medications include Zyprexa, Seroquel or Klonopin. If the side effects are recognized early, they can usually be controlled within a few days. The effect of Prednisone is not permanent and does not cause brain damage.

Prograf and Neoral can also affect your mood or behavior. Mild side effects include insomnia, colorful vivid dreams, shaking of your hands (tremors) and headaches. Very few patients may notice difficulty with speaking. In some cases, we have seen seizures. Some patients have pains in their feet called peripheral neuropathy. Lowering the medication or switching to a medication that is better tolerated by the brain, such as Rapamune, can control these side effects. Cellcept has little effect on the brain but may cause stomach upset or diarrhea. It can also lower your white cells and platelets.

Remember not everybody has problems. The majority of patients will tolerate these life saving pills just fine. However, if you don’t feel like yourself or your care partner notices a change from your normal behavior, speak up and let us know.
On December 31, 2004, at 7:20 p.m., I received a very surprising phone call from Dr. John Renz. Dr Renz informed me that there was a liver for me and that I should come to the hospital as soon as possible. Never expecting to receive this type of call on the eve of a new year, I proceeded to get ready for a big change in my life.

I went into surgery at 1:00 a.m. on January 1, 2005 and for the next 9 hours was transplanted with a new liver by a superb team of hospital professionals. When I came out of surgery I was transported to Surgical Intensive Care Unit (SICU) for the next two days.

While in the SICU, I was under constant care from the nurses, doctors and surgeons. I was then transferred to the step down unit on day 3, where I continued to receive constant care prior to my release on January 11, 2005.

At first I was not so keen on leaving the hospital only because I was in pain from the surgery, and felt that my best treatment would be to stay in the hospital. However, when this was discussed with the doctors, they assured me that the best place for me to be was at home. Once again the doctors were correct.

When I arrived home on January 11, 2005, I just took it easy. I made certain that I followed my medication schedule very carefully and on a timely manner. I also made certain that I was up and about by walking around the house as well as outside in the fresh air.

As the days went by I could feel that things were getting better with my body from the liver transplant operation. After the staples were removed from my incision, I was approaching my thirtieth day of recovery and was feeling much better.

I am now in my fourteenth month as a liver transplant recipient. I watch my diet and health very carefully. I am fortunate not to have had any setbacks whatsoever. I visit my nurse practitioner and doctors every 6 to 8 weeks. My medications and laboratory results are carefully monitored.

My second chance at life would not be possible without God, my wonderful wife Christine, our families, our friends, as well as my donor and family.

Thank you all very much!
These two statements are important to include so that your proxy is able to make decisions about a feeding tube AND so that your proxy would be able to make you eligible for research protocols that may be beneficial.

The health care system is complicated and it is difficult to anticipate all possible medical situations. The health care proxy allows the proxy to make decisions based on the unique medical situations you could encounter. Rather than attempting to document all of possible scenarios and wishes, we strongly suggest that you share this information with your proxy.

3. Once the form is finished, make sure that your proxy has a copy AND bring a copy to be put in your file at the clinic. Keep a copy of the proxy in your wallet. NEVER GIVE AWAY YOUR ORIGINAL COPY.

4. You may decide to make changes to your proxy over time, and if you do, please be sure to get a copy of your updated document to us.

REMEMBER, a health care proxy can only make HEALTH CARE decisions. A health care proxy cannot exercise any control over your financial or other matters. In order to give someone control over these areas, you would also need to explore appointing a power of attorney. This person would not need to be the same person you appoint as your health care proxy.

Some good internet resources to review:
- http://www.health.state.ny.us/nysdoh/hospital/healthcareproxy/intro.htm
- www.caringinfo.org

Always call your social worker with any questions.
EDUCATIONAL WORKSHOPS

Sessions will be held on
Fridays, 2:00 to 3:30 PM
Milstein Hospital Building
177 Fort Washington Avenue (between 165/168th Streets)
New York, NY 10032

PLEASE NOTE THE DATES AND CHANGE IN LOCATION!

April 7th: PATIENTS’ STORIES OF TRANSPLANT
Meet transplant recipients, donors and caregivers.
Location: Clark Conference Room 3 – 1st Floor of Milstein Hospital

April 21st: 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
Location: Clark Conference Room 3 - 1st Floor of Milstein Hospital

April 28th: LIVER TRANSPLANTATION SURGERY: DECEASED VS. LIVING RELATED DONATION
Speaker: Dr. John Renz, Transplant Surgeon
Location: Clark Conference Room 3 - 1st Floor of Milstein Hospital

May 5th: KEEPING YOUR HOUSE IN ORDER
Speaker: Laurie Sternberg, Social Work Intern
Location: Reemtsma Conference Room - Milstein Hospital – 7 Hudson South

May 19th: IMMUNOSUPPRESSIVE MEDICATIONS AND THEIR SIDE EFFECTS
Speaker: Sonia Alford, PA, Physician Assistant
Location: Clark Conference Room 3 - 1st Floor of Milstein Hospital

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

These sessions are MANDATORY!

For more information contact:
Silvia Hafliger, MD, at (212) 342-2787 or Aimée Muth, LCSW at (212) 305-1884
The Post-Transplant Support Group meets the 1\textsuperscript{st} and 3\textsuperscript{rd} 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!

\textbf{Who:} Post-transplant adult or pediatric patients and family members.

\textbf{When:} First and third Tuesday of every month, 10:00-11:30.
\textit{Future dates are:}
- April 4, 18
- May 2, 16
- June 6, 20
- July 18

\textbf{Where:} New York Presbyterian Hospital
622 West 168\textsuperscript{th} Street, PH14
14\textsuperscript{th} Floor Conference Room - #101 East

\textbf{Facilitator:} Aimée Muth, LCSW
RSVP to 212-305-1884
LOCAL AND NATIONAL RESOURCES

NATIONAL

- United Network for Organ Sharing
  [http://www.unos.org](http://www.unos.org), (888) 894-6361
- American Liver Foundation
  800.GO.Liver or [http://www.liverfoundation.org](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](http://www.hopeforlivercancer.com)
- Liver Cancer Network,
  [http://www.livercancer.com](http://www.livercancer.com)
- Hemochromatosis Foundation,
  [http://www.hemochromatosis.org](http://www.hemochromatosis.org)
- PBCers Organization, [http://www.pbcers.org](http://www.pbcers.org)
- Biliary Atresia and Liver Transplant Network,
  [http://www.transweb.org/people/recips/resources/support/oldbiltrree.html](http://www.transweb.org/people/recips/resources/support/oldbiltrree.html)

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](http://www.ctorganandtissuedonation.org)

New Jersey

- New Jersey Transplant Association Inc. – Donor families and recipients
  [www.njtransplant.org](http://www.njtransplant.org)
- 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.transplantssupport.org/staten.html](http://www.transplantssupport.org/staten.html)
- LOLA (Latino Organization for Liver Awareness), 888-367-LOLA, 718-892-8697 or [http://www.lola-national.org](http://www.lola-national.org)
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 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.
*Not sponsored by the American Liver Foundation.

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.

Wilsons Disease Support Group*
Phone: 203-961-9993, Contact Lenore Sillery