





TRANSPLANT NEWS

Volume 1, Issue 1

THE TRANSPLANT INSTITUTE

January 2009



Chiefs' Corner Douglas W. Hanto, M.D., Ph.D. Clinical Director





We would like to welcome you to our first issue of "Transplant News" from the Transplant Institute at Beth Israel Deaconess Medical Center.

The Transplant Institute is many things to many people. First and foremost, it is where patients seek expert opinion and care. It is also where students, residents, and fellows learn how to care for patients and for many, to prepare for a career in transplant medicine or surgery. It is also where research programs in transplantation biology, clinical trials, and outcomes seek to answer fundamental questions that will improve the longevity of transplanted organs and patients and the quality of life of all transplant recipients. Finally, it is a place where dietitians, nurses, physicians, social workers, surgeons, and a wide array of support staff work together as a team every single day to provide the best possible multidisciplinary care both inside and outside of the hospital for all our patients.

This newsletter is designed to provide patients and health providers with newsworthy and important information from the Transplant Institute and from the field of transplantation in general. For example, this issue includes interviews with a patient and a living kidney donor about their experiences, an update on probiotics from Asha Kasaraneni MS RD

our transplant nutritionist, information on the 2010 U.S. Transplant Games, a staff profile of Dr. Martha Pavlakis, information on new clinical trials designed to kidney function after transplantation, information on our new Advanced Vascular Care Center, and much more. We would like to thank everyone who has contributed to this inaugural issue.

We hope that you enjoy each issue that will come to you either by email or as a print copy every 3 months. We are always interested in your feedback and any ideas you might have for the content of our upcoming newsletters. Our best to everyone in 2009.

New Transplant Institute Website Launched

Everything you need to know about transplantation and organ donation

We recently launched one of the most comprehensive websites on transplantation. Transplantation is a complex maze of highly technical and sometimes confusing information, rules, and regulations. Our website makes navigating this maze a little easier for patients, family members, and referring providers.

When visiting the website, you will find useful and helpful information about our kidney, liver, and pancreas transplant programs, our comprehensive dialysis access service, and our hepatobiliary surgical care. Also, look for videos of patients who share their personal stories, podcasts on coping with stress, as well as other how-to topics, and illustrations of transplant and living donor surgery.

To visit our new website, go to www.bidmc.org/transplant.

The Art of Life

An interview with Gerry Fellows, a liver transplant recipient

An artist depends upon creativity, energy, and a clear mind to make one's vision come alive on the canvas. Gerry was a very successful artist, but the symptoms of his liver disease made it difficult to create and finish the paintings for which he was recognized and admired. A liver transplant in July 2004 gave him the opportunity to resume his career as an artist. His personal story is highlighted in a video on our new transplant website. Recently, we interviewed Gerry about his transplant experience.

Describe your quality of life in the weeks and months leading up to transplantation.

I tried to stay busy. I was able to do most of my daily activities, but I was tired and nauseous a lot of the time. I was also anxious about my health and my future.

What helped you to cope with waiting for a transplant?

I got as much information as I could from the transplant center staff. They taught me what to expect and how to deal with it.

What do you remember about the day you were called in for your transplant?

At first, I didn't think I would ever get the call – I thought the liver tumor would grow to be too big for transplant. Then the call came and the transplant seemed more real. I made a few calls and left the house immediately.

Describe your transplant hospitalization experience.

The staff explained everything to me and what I was about to go through. This was very comforting. I felt better the minute I woke up after surgery. The nursing and medical care was excellent, and I was home in 6 days.

What was the biggest challenge after your transplant?

Trying to take all the different medications at the right times.

What do you most enjoy doing, now that you've had a transplant?

I am back to painting, which I enjoy the most. I am able to do almost anything I want, like spending time with my family and traveling. I feel as healthy as anyone my age, maybe even better. Also, I want to help people who are going through the transplant process.



Painting by Gerry Fellows

Transplant Orientation

The staff at The Transplant Institute offers educational classes for both liver and kidney transplantation.

The **liver transplant** orientation class is held on the second Thursday of each month from 3-5 pm. We require every patient who is being considered for liver transplantation to attend one class. We strongly encourage you to bring a family member or support person to the class as well. Topics covered in the class include:

- Caring for yourself while waiting for transplant
- Understanding your MELD score
- Symptoms of liver disease and their management
- Medications and side-effects
- Nutritional issues and concerns
- Transplant hospitalization and aftercare
- Financial and insurance issues

The **kidney transplant** orientation class is held on the following dates

- February 25, 2009, 2:00 3:30 p.m.
- April 17, 2009, 9:00 10:30 a.m.
- June 16, 2009, 2:00 3:30 p.m.
- September 9, 2009, 9:00 10:30 a.m.
- November 19, 2009, 9:30 11:00 a.m.

All patients who are on the kidney transplant waiting list or who are considering kidney transplant are strongly encouraged to attend this educational session. Topics covered in this class include dialysis, benefits of transplantation, live donor kidney transplantation, and living kidney donation.

To sign up for one of these transplant orientation classes, call The Transplant Institute at (617) 632-9700.

Nutrition Tip

by Asha Kasaraneni, MS, RD Transplant Nutritionist



Did you know...

Probiotics are microorganisms that have been used for centuries as natural components in health promoting foods. Most probiotics come from food sources like cultured milk products, yogurt, fermented and unfermented milk, miso, tempeh, and some juices and soy beverages. Research shows some therapeutic benefits of probiotics, especially with some types of gastrointestinal disorders. There is some evidence that probiotics might be helpful in treating hepatic encephalopathy (confusion, forgetfulness, sometimes coma and death) by altering gut flora and lowering blood ammonia concentrations.

Yogurt is the most commonly recommended source of probiotics. Some recommended brands are Stonyfield Farm, Greek yogurt (Fage, Chobani, etc), Yoplait, and Activia. 1-2 servings of yogurt each day is easy to include in your meal planning – as a snack, a dessert, or added to a milkshake or frappes.

Here's a simple way to turn Greek yogurt into a delicious decadent dessert: Add 1 tbsp granola, 1 tbsp berries (frozen or fresh), and 1 tsp pasteurized honey to plain Greek yogurt. Can use flavored yogurt if preferred and skip the honey.

If you have lactose intolerance, please check with me before adding the above yogurt brands to your diet.

Transplant Trivia

In each issue of Transplant News we'll ask a transplant trivia question. From the correct answers submitted by email, we'll randomly select a winner to receive a Donate Life keychain, magnet, and clock. This issue's question is...

In what year <u>and</u> in what city was the first successful living donor kidney transplant performed?

Email your answer to jrrodrig@bidmc.harvard.edu. The winner will be announced in the next Transplant News.

U.S. Transplant Games

It's not too early to start preparing for the 2010 U.S. Transplant Games to be held in Madison, Wisconsin. Sponsored by the National Kidney Foundation, The Games provide transplant recipients with a chance to compete in a variety of different sports (badminton, bowling, cycling, golf, swimming, table tennis, track and field, etc.). It's also a great time to meet other transplant recipients from around the country, share your transplant story, and honor your donor. Call (866) TX-GAMES or visit www.transplantgames.com for more information.

Tell Your Story, Save a Life

Did you know that telling your personal story could save one or more lives? Whether you are a transplant recipient, someone waiting for a transplant, a living donor, or a deceased donor family member, your story could be the key to someone else signing up to be an organ donor.

There are now more than 100,000 children and adults on the national transplant waiting list. As someone touched by transplantation, your personal perspective is critically important in helping others to understand the importance of organ donation.

The New England Organ Bank has an excellent volunteer program that does a lot of educational activities and events in local communities throughout the region. The NEOB staff trains volunteers to raise organ donor awareness by

- speaking at faith-based organizations, schools, and civic groups
- staffing information tables at fairs, blood drives, and walks
- distributing educational materials in your local community
- participating in interviews with local media

For more information or to sign up as a volunteer, call Jennifer Cray at (508) 363-9682 or email her at jennifer cray@neob.org.

"To the world you may be one person, but to one person you may be the world."



Staff Profile *Martha Pavlakis, M.D., Medical Director of Kidney and Pancreas Transplantation*

Dr. Pavlakis is a recognized leader in the field of kidney and pancreas transplantation. She has served on numerous regional and national committees and boards, including the Region 1 (New England) Renal Transplant Oversight Committee, the American Society of Transplantation's Women's Health Committee, and the American Society of Nephrology's Transplant Advisory

Group. While our patients are very familiar with her high quality of clinical care, they may not know that she is a very accomplished teacher and researcher. Many residents and fellows whom she has trained are now providing care to patients with kidney diseases at medical centers and transplant programs around the country. Also, she has published 50 scientific articles and book chapters.

As medical director of the kidney and pancreas transplant programs since 1999, Dr. Pavlakis has cared for hundreds of patients with kidney disease and diabetes, as well as many living kidney donors. "In addition to the intellectual challenges that kidney and pancreas transplantation presents to me, I enjoy getting to know my patients and working together with them in a partnership for their health," said Dr. Pavlakis, reflecting on the rewarding aspects of her profession. "Each patient brings a unique story and perspective to the transplant clinic. I feel honored to be a part of such an important aspect of their lives."

"Dr. Pavlakis gives me the feeling that if we hit a bump in the road with my transplant she will do what needs to be done to get the answers, to weigh the options, so that together we'll get through it. I am confident that she will always be there for me."

Joel, kidney and pancreas transplant recipient

Waiting for a kidney transplant is one of the most difficult challenges her patients confront. She is sensitive to the uncertainty and anxiety of waiting, not knowing when transplantation might occur. Dr. Pavlakis encourages patients to work on understanding and preparing for the challenges of transplantation while they are waiting, including trying to identify a potential living donor. "A living donor kidney transplant has many medical advantages, and it will certainly shorten the waiting time for a transplant," she notes. Regardless of whether a patient has a living donor, she stresses the importance of maintaining a positive attitude, having family or friends who provide emotional and practical support, being your own health advocate, and adopting a healthy lifestyle (not smoking, exercising, and maintaining a healthy body weight). "Working towards these goals can help a patient keep hope alive and well while they wait," Dr. Pavlakis emphasizes.

It is sometimes difficult for patients on dialysis and in need of a kidney transplant to imagine what life will be like with a new functioning kidney. As a transplant specialist for many years, Dr. Pavlakis knows what difference transplantation can make in the lives of her patients. "After transplantation, most patients feel so much better and see an improvement in their overall quality of life," she notes. "They now have to take antirejection medication every day, but it's less restrictive than kidney failure or dialysis for most patients. After transplant, patients are freer to pursue their goals and dreams - they feel better with a functioning kidney and they have more time – and that's what transplantation is all about!"

Transplant Institute Meets New Medicare Criteria

Medicare has requirements that all U.S. transplant centers must meet to be a Medicare-approved transplant center. Transplant centers must perform successful transplants, deliver quality patient care, and have sound policies and procedures. Medicare wants to be sure that a transplant center has all of the clinical support needed to manage the complexities of end stage organ disease and transplantation and that all of these supports are available 24 hours a day. In early 2008, a team of transplant experts chosen by Medicare made a surprise 3-day visit to the BIDMC Transplant Institute. The survey team toured the Institute and inpatient units; they spoke with nurses, doctors, social workers and the nutritionist – and to patients; they reviewed all of our policies and some patient records to make sure that we follow our policies. In July 2008, The Transplant Institute received word that we once again met criteria to be a Medicare-approved kidney, liver and pancreas transplant center!

The Gift of Life

An interview with Claire Young, a living kidney donor

Donating a kidney to a person in need – be it a loved one, friend, or stranger – is a wonderful and courageous gift. Each year in the U.S., over 6,000 adults willingly give this gift of life. In February 2008, Claire gave her husband an unusual Valentine's gift – her left kidney.

Describe why you decided to become a living donor.

My first thought was we needed to do this to keep our family together. My husband's previously transplanted kidney was failing. Either he needed dialysis or a new donor. We went through the process 8 years ago and it was successful, so why not do it again.

What information was most helpful to you?

The information packet that was put together by The Transplant Institute was the most helpful. It let us know what to expect and what the potential risks were. Time spent on the phone and in person answering my questions was invaluable and much appreciated. The donor nurse coordinator (Nancy Salonpuro) handled the situation with grace and patience, even when I wanted to move faster than the process would allow.

What surprised you most about donation?

The biggest surprise was that my husband was able to bounce back quicker and was on the go much sooner than after his last two transplants.

What was the biggest challenge after surgery?

Going back to work. I wanted to start working again, but I had spent so much time being just a mom...it was such a hard thing to pull away from.

What is most satisfying about being a donor?

Watching my husband lead a normal life, which is the reason I did this. Our family is now able to do some of the things other families do all the time, like go camping. I am watching my husband do activities that used to be limited because of his health.

What recommendations do you have for others who are thinking about becoming a living donor?

Get all the information you can and listen to everything the staff has to say. Ask questions, even if you think they are silly. I would recommend to anyone that is thinking about this challenge to seriously consider the wonderful opportunity you are giving the recipient to live a "normal" life. I have been truly blessed by doing this for my husband.



Jonathan and Claire Young, their children, and Donald

Transplant Institute Receives Federal Grant to Reduce Racial Disparities

African Americans are more likely to develop chronic kidney disease and to need a kidney transplant than those of other races. However, they wait longer for a kidney transplant and die at a higher rate on the waiting list, in part because they are not as likely as White patients to get a live donor kidney transplant. Research has shown that African Americans know less about the benefits of live donor kidney transplantation and they are more reluctant to ask others to be a kidney donor.

Recently, the National Institute of Diabetes and Digestive and Kidney Diseases awarded Beth Israel Deaconess Medical Center a \$750,000 research grant to study which educational approaches work best to increase the likelihood that African American patients will consider and also receive a live donor kidney transplant.

African American patients who enroll in the study receive either standard transplant education, a group education session with other patients, or a home visit by transplant health educators. These sessions address common concerns about live donor kidney transplantation and provide information about how to approach others about kidney donation.

For more information, visit <u>www.clinicaltrials.gov</u> or contact Dr. Jim Rodrigue (617) 632-9700.

Carbon Monoxide May Hold Transplant Benefit

Douglas W. Hanto, MD, PhD, Chief of the Division of Transplantation, has focused his laboratory research on the ability of carbon monoxide (CO) at low concentrations to be protective in organ transplantation models. Animal model research has shown that low concentrations of CO can protect kidneys against ischemia-reperfusion injury (process occurring during organ donation), prevent organ rejection, and improve organ survival. The goal of Dr. Hanto's research is to perform critical experiments that will allow CO to be studied in human clinical trials of organ donation and transplantation.

We are happy to announce that human clinical trials using CO have begun. Studies using low concentrations of inhaled CO for a short duration of time in healthy volunteers have been completed and reviewed by the U.S Food and Drug Administration (FDA). Based on the safety outcomes from healthy volunteers, the FDA has extended approval to further investigate inhaled CO in kidney transplant recipients. Kidney transplant recipients at BIDMC will soon have the opportunity to participate in a new nationwide clinical trial utilizing inhaled CO. The objective of the trial is to learn the most appropriate dose (safe and tolerable) of CO to be delivered to kidney transplant patients and whether its administration affects short-term kidney function.

To learn more about this study or transplant clinical research at BIDMC, contact Robyn Chudzinski, PharmD, Transplant Clinical Research Administrator, at (617) 632-9841 or visit www.bidmc.org/transplant.

We Care About Transplant Caregivers

Caregivers are a very important part of the success of transplantation. A caregiver can be a spouse, adult child, a family member, or a close friend. Caregivers help to monitor your health, help you with basic living needs (cooking, bathing), drive you to appointments, help keep track of your medications, and help make healthcare decisions, among other things.

For these reasons, it is important for the caregiver to meet the transplant team and to be an active part of the whole transplant experience. Caregivers also should learn as much as they can about your illness and the transplant process.

We recognize that caregiving can be very time consuming and stressful. Caregivers experience their own unique form of stress as they balance the demands of their loved one's illness and other life responsibilities. We encourage caregivers to talk more with their social worker and/or psychologist about any concerns or worries. Our behavioral health professionals can work with you to learn effective stress management strategies and to help you find the resources you need. For example, many caregivers benefit from joining caregiver support groups and participating in their own mental health treatment.

Visit our website <u>www.bidmc.org/transplant</u> to learn more about transplant caregiving and to download a podcast of stress management strategies for caregivers.

Advanced Vascular Care Center Opens in Brighton

Maintaining vascular access is critical in the care of patients who are on dialysis following kidney failure. When vascular access complications occur, many Boston area patients seek care in hospital emergency departments. Lengthy delays in receiving care may prevent patients from returning promptly to dialysis. The Advanced Vascular Care Center was founded to achieve superior outcomes by providing quick, patient-centered care in a convenient, dedicated facility. It is staffed by surgeons including Drs. Douglas Hanto, Seth Karp, and Yael Vin and interventional radiologists including Drs. Salamo Faintuch, Boris Nikolic, and Dmitry Rabkin, all from BIDMC. Patients receive quick, expert services because the Center's sole focus is vascular access care. They use the latest, minimally invasive surgical techniques. The Center is conveniently located in Brighton, and parking is free. For more information, visit www.advancedvascularcare.com or call (617) 783-5200.

BIDMC Organ Donation Efforts Recognized

By Jerry Berger

For the fourth year in a row, BIDMC has received the U.S. Department of Health and Human Services' Medal of Honor for Organ Donation.

"This award reflects the commitment of numerous BIDMC departments and individuals here and at New England Organ Bank (NEOB) to the many patients awaiting a transplant," said Linda Lentz, Director of Transplant Services at BIDMC's Transplant Institute. "As a representative of the transplant team, I am grateful for the hard work that is done prior to our receiving an organ for one of our patients."

Lentz said every hospital in the country is considered a donor hospital, but only 90 have received the Medal of Honor for Organ Donation four years in a row. Hospitals and organ procurement organizations earn this designation for consistently achieving adjusted donation rates of 75 percent or higher in a single continuous 12-month period, according to Barbara Levine, Hospital Relations Coordinator at the NEOB.

Donation rates refer to the number of patients who are medically suitable to be considered for donation, who actually become donors. For the past four years, BIDMC has met or exceeded this 75 percent rate.

"The award speaks to the committed and coordinated efforts of an entire team of people at BIDMC from administration through line staff," Levine said. "An effective donation process is complex and requires knowledge of the process, commitment and a high degree of coordination and collaboration within BIDMC and between BIDMC and NEOB.

High conversion rates certainly have everything to do with families who consent to donation, but before that can happen, we need hospital staff that understand and carry out the best practices that support a donation event."

Levine said BIDMC has many practices in place to facilitate meeting this goal year after year. The Organ Donation Council meets quarterly and includes staff from the intensive care units, the Emergency Department, the operating rooms, Social Work, Ethics, Pastoral Care, Interpreter Services, Administration and the NEOB.

Surgeon Jonathan Critchlow, MD, chairs this council, which reviews all donation activity and makes process improvements when necessary. Levine said a monthly subgroup meets to identify and work on challenges and improvements in a more grass roots effort. Various other subgroups work on related projects, all with goals of process improvement and quality end-of-life care decision-making.

Reaching the conversion rate is a team effort. Levine said staff from the ICUs, Emergency Department, Social Work, Pastoral Care, Respiratory Therapy and other clinical departments work in collaboration with NEOB to complete the donor testing, medically manage the donor, and evaluate and support potential donors and their families. Then the Transplant Institute staff work with the patients who are recipients of organs that are transplanted. "It is the success of this work that is reflected in the Medal of Honor award," Levine said.

The Liver Transplant Support Group

Where support and community meet compassion and hope

The Liver Transplant Support Group provides patients at BIDMC who are listed for and who have had a liver transplant the opportunity to meet others liver transplant patients. The Support Group is open only to patients and provides a comfortable and confidential setting to discuss the many facets of the liver transplant process, including:

- Challenges with each stage of the transplant process
- Managing symptoms and medication side effects
- Having hope while facing uncertainties on the waiting list
- Asking for and accepting support from family and friends

The group is co-led by Amanda Reed, LICSW, liver transplant social worker, and Maureen Doherty, LCSW, Farr 10 social worker. The meeting is held in the solarium on Farr 10, the dedicated inpatient transplant unit, every Wednesday from 12 noon to 12:50 p.m. There is no cost and no need to sign up. Whether you live close to the hospital, are in Boston for a medical appointment, are admitted to Farr 10, or come to the hospital just for the support group, your participation is welcomed! Please call 617-632-9700 if you have questions.

Walking For Fun... Walking for Life

Patients, staff, and their families from The Liver Center, Farr 10, and The Transplant Institute at BIDMC pounded the pavement to raise awareness and funds for liver disease prevention and treatment. The American Liver Foundation's *Liver Life Walk* is an annual family-friendly event designed to help put an end to liver disease, which affects more than 30 million people in the United States.

Several liver transplant survivors from The Transplant Institute walked with their family members, as well as the transplant healthcare team who cared for them. As a team, they raised several thousand dollars to advocate for more education about liver disease and to support more research that will benefit others. "The walk for research is a fun way for Team BIDMC to show support for patients and commitment to conquering liver disease through the support for research," said Dr. Michael Curry, Medical Director of Liver Transplantation at BIDMC. Kim Sullivan, one of the liver transplant nurse coordinators, laced up her sneakers and set a good pace for the team. "I look forward to this walk every year. It gives me the chance to interact with my dedicated colleagues outside the office in a fun and relaxed environment. But the most rewarding part of the Liver Walk is seeing our patients walking with their team of loved ones. They are so happy to be alive and have the chance to give back by raising awareness and money for the ALF," Sullivan said. "Seeing them outside of the medical setting is great for all of us!"

The American Liver Foundation 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, including hepatitis. To learn more about liver disease, the ALF, or the *Liver Life Walk*, contact the ALF's New England Chapter at http://www.liverfoundation.org or call (617) 527-5600.

The Transplant Institute Beth Israel Deaconess Medical Center 110 Francis Street, 7th Floor Boston, MA 02215

> Name Address City, State, ZIP