

# THE LEGACY

A Publication of the Center for Donation and Transplant

Volume 6, Number 3

## Visit Our New Website!



People who wish to donate can do so by printing a donor card or New York State Organ and Tissue Donor Registry enrollment form, or by completing the enroll-

**V**ISITORS TO CDT'S NEW website have access to a wealth of information about organ donation and transplantation as well as upcoming events and activities at CDT. The new site at [www.cdt.org](http://www.cdt.org) was launched in June.

"With so many people using the Internet as an educational resource today, we decided that we had to revamp our site to make it more thorough and user-friendly," said Sue Cain, public relations specialist for CDT.

The website provides answers to common questions such as religious views, the truth behind myths and what can be donated. For those who want to learn even more, the definition of brain death and the entire donation process from the point of referral to placement of the organs is detailed. A number of personal testimonials submitted by donor families and transplant recipients help to put a face on the process.

ment form online and clicking "submit." There are also tips to help people discuss donation with their family members.

Hospitals and other organizations or families who work with CDT can learn about the services provided, the service area covered and employment opportunities available, and can view photos of staff. A list of upcoming events and archived issues of CDT's newsletter are also accessible.

If anyone is unable to find the answer to their question on this extensive new site, they can try visiting any of the helpful links provided to transplant centers in our area and other organizations such as the United Network for Organ Sharing or the Department of Health and Human Services, or can submit their question to staff via email under the link "Contact Us."

Please take a minute to visit the site and email us with feedback.

## CDT Welcomes Three New Transplant Surgeons

**C**DT WOULD LIKE TO EXTEND A WARM WELCOME to three newly appointed transplant surgeons at its area transplant centers.

Abrar Khan, M.D., C.M., M.Phil, joins Fletcher Allen Health Care to oversee the newly created Division of Transplantation Surgery and Immunology. In this role, he plans to address such issues as organ rejection and the processes leading up to it.

Dr. Khan recently completed a transplantation/surgical fellowship at the University of Pittsburgh Medical Center. He received his medical degree from McGill University and completed postgraduate training and research, including a postdoctoral transplant immunology fellowship at Harvard Medical School and is currently enrolled in the graduate studies program in immunobiology at Yale University.

The Division of Transplantation Surgery and Immunobiology began evaluating transplant patients in early July and will begin providing kidney, pancreas, and kidney/pancreas transplants over the course of the next few months.

The Albany Medical Center has appointed two new transplant surgeons. Andrew Isenberg, M.D., who received his medical degree from the Boston University School of Medicine, completed his surgical residency and transplantation fellowship at Albany Medical Center before going on to complete a pancreas transplantation fellowship at the University of Minnesota. He is credited with numerous presentations and publications.

Francisco Escobar III, M.D., F.A.C.S., will join the staff at Albany Medical Center later this month from Oregon, where he served as a private general and vascular surgeon. He previously served as an abdominal transplant surgeon for twelve years and as head of the division of vascular access surgery at Henry Ford Hospital. Dr. Escobar completed a fellowship in kidney, pancreas and liver transplantation at the University of Minnesota Health Sciences Center and a mini-laparoscopic fellowship at Staten Island University Hospital. He received his medical degree from Brown University.

CDT looks forward to working with each of you.

## In the News...

**E**ACH OF THE FOUR TELEVISION news stations in the Albany market covered CDT's Re-Cycle for Life event in June. The event was also covered by the Times Union, WROW, WGY-810AM and WPYX-106.5FM, who broadcast live.

CDT representatives Jody Thompson, organ procurement coordinator, and Sue Cain, public relations specialist, talked about organ donation on WKNY Radio in Kingston.

Hometown Radio, WIRY 130 in Plattsburgh, helped to organize the Melissa Lahtinen Penfield Golf Tournament with Champlain Valley Physician's Hospital in July. For more information, turn to page 4.

The Leader Herald in Gloversville published an article about organ and tissue donation after Nathan Littauer Hospital announced its excellent compliancy rates in reporting all deaths to CDT.

### Lobby Efforts Successful

Thanks to numerous CDT volunteers and organ procurement and transplant professionals, our lobbying efforts early this spring were a tremendous success.

The New York Gift of Life Donor Medal Bill {Senate Bill 2820-A (Hannon, et al), Assembly Bill 10753 (Hoyt, Conte)} has passed both the senate and the assembly and is awaiting Governor George

Pataki's signature. This legislation establishes the creation of a medal by the Department of Health to be given to families of donors in recognition of their gift of life. Discussions are underway as to how this initiative might be implemented.

Additionally, the legislature added \$250,000 to the State budget for the New York State Task Force to Increase Organ and Tissue Donation. This will assist the Task Force in expanding public awareness and professional education efforts.

### Discussions Underway for Vermont Registry

The Vermont General Assembly has approved the implementation of an organ and tissue donor registry. CDT is currently working with the New England Organ Bank, the Vermont State Health Department and the Vermont Department of Motor Vehicles to develop the registry.

### Change in Statistics

The number of patients who die each day without the organs they need has increased from 16 to 17, while the number of minutes between new names added to the waiting list has decreased from 14 to 13. The number of men, women and children awaiting organs in the United States has surpassed 80,000.

## Motorcyclists Rally For Donation

**M**ORE THAN 55 MOTORCYCLE enthusiasts turned out for the third Re-Cycle for Life ride in June. The event is held in conjunction with Americade, the world's largest multi-brand motorcycle touring rally, to raise awareness of organ and tissue donation.

Donor father Bob Vaniglia and liver transplant recipient Skeeter Todd addressed the crowd about the healing and life-saving benefits of donation before leading a caravan of motorcyclists on an hour-long scenic route from Seymour's Motorized Sports in Latham to King Neptune's Lounge in Lake George, where a number of raffle prizes were awarded.

Special thanks to our hosts, Seymour's and King Neptune's, to Trooper Paul LeClair for leading the ride, and to our sponsors: Berkshire Motor Works, Hoffman Car Wash, Quick Response Restoration, Wilson's Yamaha Country, McDermott's, Coca Cola Bottling Company, Grecian Gardens Restaurant, Kirker's Steak and Seafood, Romano's Italian American Restaurant, McDonald's of Clifton Park, Hannaford Wolf Road, Price Chopper Central Avenue and Guilderland,



**Among those who led the caravan of motorcyclists to Lake George are committee member Larry Moyer, Assemblyman Dan Burling (R-Warsaw), Assemblyman Jim Conte (R-Huntington Station) - a kidney recipient, and New York State Trooper Paul LeClair.**

Howard Johnson's Restaurant, Martha's Dandee Crème, Café Nora and Bella Napoli.

## The Legacy

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**We  
Want  
to Hear  
From  
You!**

**If you are a member of an affiliated hospital who would like to advertise an upcoming event or submit an article to the Legacy, contact Sue Cain at (800) 256-7811 or via e-mail at [scain@cdtny.org](mailto:scain@cdtny.org). The Legacy is published quarterly.**

# Excellence

By Carol Madeiros, in memory of her husband Larry

**"E**XCELLENCE IS THE RESULT of caring more than others think is wise, risking more than others think is safe. Dreaming more than others think is practical and expecting more than others think is possible."

These are the words inscribed on a poster that I recently purchased. I bought it because the sentiment expressed my husband's personal creed; the way he lived the 39 years of his life... That he lived in this way is not ordinary. In fact it is astonishing given the considerable personal health obstacles that he confronted during the course of his life. Larry was born a hemophiliac, his blood was deficient of clotting factor required to form a firm clot. As a child, he endured frequent hospitalizations. He was forced to infuse blood product containing the missing clotting protein and was infected through tainted blood product in the early 1980's with the HIV virus and hepatitis. Still, he refused to spend life on the sidelines. He biked, hiked, went white water rafting and enjoyed all sports and games. He was competitive, and always expected to win. Often the physical activity had its price - he was sometimes bruised for days - but for him, this was well worth the cost. After all, excellence is the result of risking more than others think is safe.

He worked tirelessly on the local and national level as an advocate for the bleeding disorder community. He lobbied Washington for the passage of Ricky Ray, a bill that provided aid to those individuals infected by the tainted national blood supply. Larry was the co-founder of Positudes, Inc., the first non-profit pharmacy in the country. His concept was to provide fellow hemophiliacs the blood factor and drugs they needed, while helping them manage their chronic disease by sharing his personal knowledge and positive attitude. His commitment to Positudes was so strong that he responded to calls any time of the day or night. After all, excellence is the result of caring more than others think is wise.

Together, Larry and I pursued having children of our very own. Most doctors, while sympathetic, refused to consider the possibility of Larry fathering his own children because he was HIV positive and I was negative. Even this did not daunt Larry's dream to become a dad. His research led us to a doctor in Milan, Italy who had developed a method to remove all traces of HIV from semen. In over 500 inseminations carried out by his laboratory,

not one had infected the mother, and in the 200 resulting pregnancies, not one infant was infected. Larry's persistence was rewarded when we became the first HIV discordant couple in the USA to safely secure parenthood. Ashley, now 4 and Taylor, now 2 are gorgeous, healthy and HIV-free. But then again, excellence is the result of dreaming more than others think is practical.

Tragically, Larry lost his life not as a direct result of his HIV, as most would expect. He developed an infection in his leg, which he was unable to beat due to his compromised liver function. (Both a side effect of his HIV drug regimen and hepatitis.) He fought to gain a spot on the liver transplant list, and we moved to Pittsburgh Presbyterian Hospital, one of the only hospitals in the country to perform a successful liver transplant on an HIV positive hemophiliac. On September 28, 2001, Larry became one of the 17 people that die each day while waiting for an organ transplant. Larry would want people to know that it is possible for a single donor to help or save as many as 100 recipients, and that the average age of organ recipients is 39 for kidneys, 45 for hearts, 43 for lungs, 36 for livers and 35 for pancreas - In other words, young people in the prime of their lives; most of them mommies or daddies, like him.

In the months since his death, I've thought a lot about our lives together, and yes, in spite of everything, I consider myself lucky - Lucky to have had 17 excellent years with Larry. I've established a scholarship in his memory to be awarded to graduating seniors pursuing their education. I've also planned the first annual bike/run/walk-a-thon to be held September 21 to help fund the scholarship.

I've incorporated walking, biking and running in order to ensure that anyone and everyone who wishes to participate may find a way.

My hope is that it will raise hemophilia and organ donation awareness and be a lot of fun for everyone...

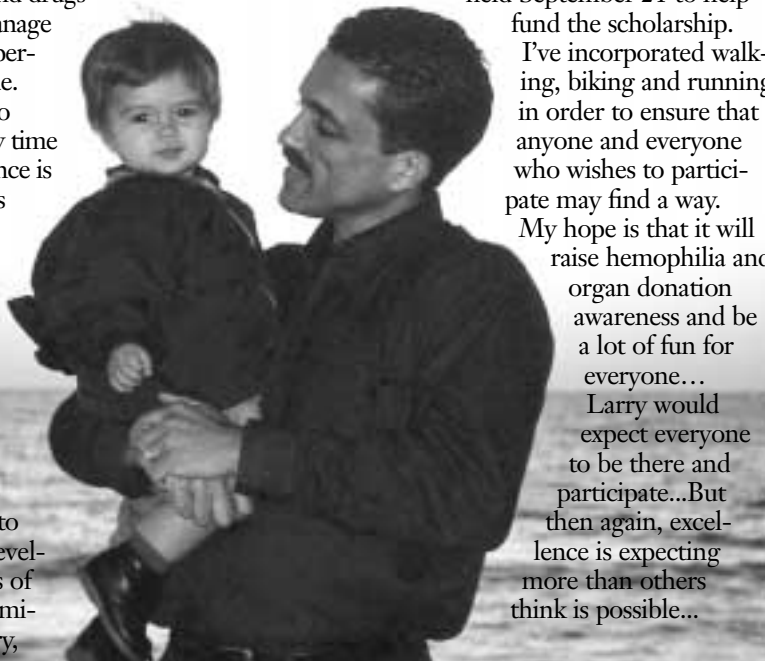
Larry would expect everyone to be there and participate... But then again, excellence is expecting more than others think is possible...



“After all, excellence is the result of risking more than others think is safe...

After all, excellence is the result of caring more than others think is wise...

But then again, excellence is the result of dreaming more than others think is practical.”



## Champlain Valley Physician's Hospital: Community, Staff Pull Together to

**D**EEP IN THE HEART of the Champlain Valley on a warm summer day, nearly 140 people gathered on the lush greens of the Bluff Point Golf and Community Resort for a day of golf, camaraderie, and remembrance.

The event is called the Melissa Lahtinen-Penfield Golf Tournament, and is held in memory of Melissa Lahtinen-Penfield, a popular teacher and swimming instructor who lost her battle with cystic fibrosis following a lung transplant. The tournament benefits organ donation awareness efforts and assists families who need to travel for transplants or for living donation.

"This year put us over the top," said Hannah Hanford, Director of Development for the Foundation of Champlain Valley Physician's Hospital (CVPH) of her third year organizing the event with Hometown Radio, WIRY 130 AM.

Bob Pooler of Hometown Radio was inspired to raise awareness several years ago when he learned about a young girl in Plattsburgh who was waiting for a lung transplant.

The seventeen-year-old girl and her family, who were forced to relocate to California for three

months for her care, did not have the income to cover their travel expenses. Pooler and his coworkers at WIRY 130 coordinated "Apples for April," a 24-hour radiothon at which they sold apples donated by local orchards to help raise money for the family and to raise awareness.

"There are so many people who don't understand donation and we hope to educate them," said Pooler. "You need to make the people around you aware of what you want."

According to Pooler, more than \$40,000 was raised for the family. Still, while the event was a success, the transplant tragically was not enough to save April's life. Hometown Radio continued their awareness efforts when the community lost its second young victim – Melissa.

Some awareness efforts the proceeds are used toward include a weeklong display in the local shopping mall during National Organ and Tissue Donation Awareness Week and funding for the traveling quilt exhibit.

The Foundation isn't the only department at CVPH that is dedicated to raising awareness of



**Members of the Melissa Lahtinen-Penfield Tournament planning committee include (from left to right): Hometown Radio staff Theresa Langlois, Carol Santa, Ann Tarasavage, Kerry Rafferty of the Foundation of CVPH and Bob Pooler. Not pictured: Eleanor Lahtinen, Melissa's mother, and Dan Santa.**

# Raise Awareness

donation. Wanda Flynn, Director of The H.K. Freedman Renal Center of CVPH and Heather Crandall, unit clerk, recognize the importance of organ donation, as they work with kidney dialysis patients on a regular basis. Dialysis is often used as a means of cleansing the blood by filtering wastes and excess fluids when both kidneys have failed while the patient awaits a kidney.

The Center coordinates various awareness efforts including a weeklong display at the Clinton County Fair and presentations with groups such as the Senior Citizen Council and the Boy Scouts, to name a few. They, too, are instrumental in coordinating the traveling quilt display.

Other CVPH employees are credited for ensuring that the donation process is a success.

Brain Millsaps, R.N., who works in the emergency department, was one of the first nurses to obtain consent for tissue donation from a family after attending a Tissue Requestor's Workshop facilitated by CDT. Successful completion of the program qualifies a medical professional to obtain consent legally under the Medicare Conditions of Participation and under State Department of Health requirements.

One CDT employee cites Kathleen Carey, R.N., ICU nurse manager, as being "extremely instrumental and hospitable in assisting us to coordinate a donation earlier this summer."

CVPH is licensed as a 356-bed acute care hospital and 54-bed skilled nursing facility serving the north country of New York State.

## Device May Increase Number of Transplantable Lungs

A new device recently acquired by CDT may help increase the number of transplantable lungs by improving airway clearance. Lungs are at a higher risk for deterioration than any other transplantable organ. Nearly 4,000 people are awaiting lungs in the United States, but fewer than 1,000 receive them annually.

According to Jonathan Fenimore, CPTC, the device, called The Link™, serves two purposes. "One is to improve blood gases, oxygenation and perfusion. The other is to improve lung function so that we can transplant more lungs," said Fenimore.

Of the 6,000 donors who contribute organs annually, only 15 percent yield transplantable lungs. Retained secretions in a donor's lungs physically obstruct pulmonary airways and can cause problems such as bacterial growth, ciliary dysfunction or mismatched ventilation. Chemical damage can result in mucus hypersecretion, edema or intensified inflammatory response. Donor lungs with evidence of excessive mucus retention cannot be used for transplantation. Although lungs with significant inflammation or bacterial contamination might still be accepted for transplantation, recipient outcomes may be compromised.

To preserve the viability of donor lungs, organ procurement organization staff must call in a respiratory therapist to perform some form of airway clearance such as chest physical therapy (CPT), which consists of frequent manual percussion and vibration of the chest wall and positioning of the patient to facilitate secretion drainage. This technique is often difficult to perform given its physical demand and the therapist's responsibility to patients needing similar treatments.

High-Frequency Chest Wall Oscillation (HFCWO) using The Link™ has the potential to increase lung procurement. The device, approved by the Food and Drug Administration in 2001, consists of an inflatable vest connected by two tubes to an air-pulse generator. The generator rapidly inflates and deflates the vest, oscillating the donor's chest wall to create airflow within the lungs. Clinical studies have shown the Link's ability to stabilize or improve pulmonary functions, airway patency and gas distribution and to prevent respiratory infections caused by mucus plugging.

CDT will use the device on a trial basis for one year at hospitals where it has been approved by the technical support department, and only on suitable lung donors (up to the age of 65).

## Contact CDT

**if you  
desire to:**

- **OBTAIN INFORMATION** pamphlets and donor cards
- **ENROLL** in the New York State Organ and Tissue Donor Registry
- **REQUEST SPEAKERS** for civic or professional groups

Call or write to:  
The Center for  
Donation  
and Transplant  
218 Great Oaks  
Boulevard  
Albany, New York  
12203

**(518) 262-5606**  
**(800) 256-7811**

## A Personal Perspective

Marcia Schultz, Donor Family Member

**“All his vital signs are failing. If your husband is an organ donor, we have to know now.”**

**A**T 12:45 a.m., January 20, 2000, that's what Art's doctor told me over the telephone. I had no idea he would die so soon.

“How long do I have before I must make this decision? Ten minutes? I have to ask my daughter. I have to call our son in San Francisco.”

I had talked about organ donation to Art a few years before, when little Nicholas Green from California was killed in Italy in 1994 and became a donor to worldwide acclaim. I knew that I wanted to be a donor - but Art was not one to talk about his feelings, and he didn't then.

Art was a healthy 57 year-old. He ran regularly when he wasn't cross-country skiing, swimming, hiking, biking...He watched his diet. He saw his internist regularly for medication, which controlled his high blood pressure, his only health concern. The day after returning from the Virgin Islands, I went to talk to him but found him on the floor, his right side paralyzed by a stroke, unable to speak. Now, three days later, he was dying.

Becky told me that organ donation was OK with her, and Dan said the same. I made the decision. Art would be an organ donor. Becky and I met with an organ donation representative, who asked my permission for every organ.

On February 1, a large envelope came from the Center for Donation & Transplant (CDT) in Albany. A letter explained that a 67 year-old man received his heart, a 70 year-old man the liver, a 56 year-old man one kidney, and a 35 year-old man the other, and that they were all doing well. There was information on grieving, a certificate from the U.S. surgeon general thanking the family for donating, and a survey on the donation experience.



**Since she met Bob Hill (pictured here), the recipient of her husband's heart, Marcia Schultz has dedicated much of her time to raising awareness of the benefits of communication.**

And that was all. What now? The days and weeks dragged on. In addition to the grief from losing Art, I was tormented by my decision to donate. Had I made the right one? Didn't Art have to make that decision? What were his wishes? I'd never know. Who could I talk to? I finally called CDT, but I couldn't talk about these doubts. Instead I asked about the recipients. How were they doing? Would I ever hear from them? CDT told me that it was up to them to write to me. In some cases it might take years. In some cases they never wrote.

Three months after Art's death, I received a letter from Bob, who had received the heart. He expressed sorrow at my loss, he wrote how he prayed for his unknown benefactor, he thanked me. I cried with relief and joy. At last, I had the emotional validation that Art's donation had been right to do. This was no longer a vague, slightly unreal, “anonymous” act. Bob was enjoying a new life,

playing with his little granddaughter. Art wasn't alive, but because of him, Bob was!

I called CDT to tell them how thrilled I was to receive Bob's letter. They would continue to forward our letters anonymously, no full names or addresses. CDT in Albany and Mt. Sinai Hospital in New York City (for Bob) would also screen all our letters. As I composed a reply, I decided to take the initiative to write to the other recipients: "Dear Organ Recipient...I want you to know that my husband had a massive stroke and died from swelling on the brain three days later...He did not die in order to help you. He just died...I wonder if your transplant has been successful, if it has helped you have a better quality of life. I pray for you and your future well-being." To Bob I added, "Your letter comforted me and made me feel that the most overwhelming decision of my life was the right one."

The liver recipient, K.C. from NYC, and Joe, the kidney recipient from Schenectady, replied within one year. Each thanked me and wrote of his new chance at life. I replied. It was fine that neither expressed a desire to meet. However, Bob wrote that he wanted to thank me in person; I also wanted to meet him. It took a long twenty months after the transplant for this. Bob, his wife Carol and I have now met several times. We e-mail and write each other. We want to work to increase knowledge about organ donation. More education is necessary. More awareness. And, more information to assist the recipient and the donor family to communicate with each other. A simple, heartfelt "thank you" from Bob turned my doubt and guilt into comfort and joy at his well being.

I am not trying to convince anyone to be an organ donor, but to say that I could have been spared months of anguish if Art and I - and our children - had talked to each other about organ donation. No one expects to die. But, we all do, and some of us under circumstances that lend themselves to organ donation.

It's an act of kindness to let your family know your wishes about organ donation so that your wishes - whatever they are - will be respected.

What a waste to have let Art's organs be buried with him! They brought life to four people! No, Art does not live on with his organs. But the memory of this good man lives on. And the conviction that I made the right decision.

## Guidelines for Communication Between Donor Families and Recipients

**S**HORTLY AFTER their loved one's donation, donor families receive a letter from CDT thanking them for their donation and offering them generic information as to where the organs were placed, such as the age, sex, occupation and city in which the recipient resides.

If they choose, donor families have the option of writing to their loved one's recipients through CDT. They might wish to write to find out more about the recipients and to talk about their loved one.

We ask that correspondence is kept anonymous for at least one year to protect the privacy of everyone involved. Donor families can send their card or letter directly to CDT in an unsealed envelope. CDT will then forward the letter to the recipient(s) if the center at which they were transplanted allows communications to occur.

Transplant recipients can write to donor families to express their gratitude in a similar fashion through their transplant center if it is allowed. Each organ procurement organization or transplant center has its own guidelines concerning the communications process.

The reasoning behind anonymous communication is to ensure that both the donor family and the recipient feel comfortable communicating and to prohibit any unwanted direct contact should anyone find that it is too emotionally difficult to communicate at that time and wish to discontinue contact. If after one year, both parties have expressed an interest in direct communication, we will ask the donor family and the recipient to sign a consent form allowing us to release their last names, addresses and/or phone numbers to each other.

Many donor families have said that a personal note from a recipient offers some comfort, and many recipients appreciate having the opportunity to personally thank the family for choosing the option of donation. Whatever the case, it is important for both to understand that choosing whether or not to communicate is a personal decision and must be made when the time is right.



Center for Donation & Transplant  
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 P2301



**Upcoming Events**

**October 1.....UNOS Region 9 Transplant Forum**

Doubletree Club Hotel, North Syracuse, NY

**October 21 .....Registered Nurse Advisory Council Meeting (RNAC)**

The Century House Inn, Latham, NY

**Transplant Speakers International (TSI) Volunteer Program**

CDT Offices, Albany, NY

**November 12 .....CDT Volunteer Training**

CDT Offices, Albany, NY

**November 15-17 .....National Donor Sabbath**

If you have questions about any of our upcoming events, please call Sue Cain at (800) 256-7811.