

THE LEGACY

A Publication of the Center for Donation and Transplant

Volume 7, Number 2

CDT Announces Appointment of Executive Director

THE CENTER FOR DONATION and Transplant is pleased to announce the appointment of Jeffrey P. Orlowski, M.S., C.P.T.C., as executive director of CDT. Orlowski begins his appointment July 1.

Orlowski previously served as managing director of tissue services at LifeGift Organ Donation Center in Houston, Tx. As such, he was responsible for overseeing all aspects of the tissue recovery program as well as a 24-hour donor coordination call center covering 187 hospitals and a population of 7.6 million people.

"I am very excited to be the new executive director at the CDT," said Orlowski. "I believe we have the opportunity to become a national leader in the donation of organs and tissues and, by so doing, to save or greatly enhance the lives of many throughout our community in New York and Vermont. By working closely with the many fine hospitals in our service area, we will build programs to assure the best possible care for both the donor families and the transplant recipients of our region."

Orlowski possesses 16 years of experience in the fields of donation and transplantation, having also served as regional director of LifeGift's West Texas Office, as well as manager of tissue recovery and processing at Mile High Transplant Bank/Allo-source in Denver, organ recovery coordinator of Colorado Organ Recovery Systems, and as a

transplant coordinator for the Midwest Organ Bank in Kansas City.

"Mr. Orlowski carries a wealth of experience overseeing various functions of organ and tissue procurement at a number of successful organizations," said interim executive director David Conti, M.D. "The CDT is fortunate to find someone of his caliber to take over the oversight of its daily functions and to continue its tradition of success."

Orlowski is board certified by the American Board of Transplant Coordinators, and holds memberships in various organizations including the International Transplant Coordinators Society, the American Association of Tissue Banks and the American Management Association. In addition, he has had numerous works published in several journals including the Journal of Transplant Coordination and Transplantation Proceedings.

Orlowski is a graduate of the University of Kansas with a degree in organismal biology. He also holds a master's degree in management from Regis University, Denver.

In his spare time, Orlowski is a commercial hot air balloon pilot and is a member of the North American Balloon Association and Aircraft Owners and Pilots Association. He and his wife Lorinda have two sons, William and Benjamin.

OPOs Exempted From HIPAA Privacy Rule

UNDER THE Health Insurance Portability and Accountability Act (HIPAA) of 1996, health care providers may use and disclose protected health information for non-living organ, eye or tissue donation purposes. In addition to the Center for Medicare and Medicaid Services' ruling that organ procurement organizations (OPOs) are not covered entities, OPOs are specifically exempted in HIPAA because "persons who make such

donations are not seeking to be treated, diagnosed, or assessed or otherwise seeking health care for themselves, but are seeking to contribute to the health care of others."

Therefore, the release of donor information between OPOs and transplant centers is allowed as necessary to facilitate organ or tissue donation and transplantation.

From the Executive Director

As my term as interim executive director of CDT draws to a close with the arrival of its newly appointed executive director, Jeffrey Orlowski, I would like to take a moment to reflect upon what a positive experience it has been for me to work with such a dedicated staff of individuals to fulfill a common goal.

It is not often that a transplant surgeon has an opportunity to follow the entire donation process from beginning to end, but it has been a privilege to do so. Having myself performed 70 kidney transplants in 2002 alone as a result of the strength and courage summoned by donor families who have just experienced a loss and have made the decision to donate, it is an honor to work more closely with these families and with those who work with donor families on a regular basis.

Overseeing the daily functions of CDT operations allowed me to view the organization in a different light. My previous interactions with staff as medical director had consisted primarily of determination of medical suitability of potential donors and assistance with policy development. I would now be responsible for the supervision of 18 full-time employees and their various responsibilities.

From my observations, what makes the CDT so successful is the teamwork and camaraderie exhibited by its staff. Each employee has

See Executive Director, page 3

In the News

SATURN OF MOHAWK VALLEY celebrated Saturn's National Donor Day in February by inviting CDT staff to participate in a number of media interviews, including the half-hour "Joe Kelly Show" on WKTV and an interview with Clear Channel's KISS-FM. Saturn tied Donor Day in with their current CBS Survivor: Amazon promotions by profiling "real-life" survivors, including a number of local transplant recipients.

CDT IS PLEASED to announce that Utica Clear Channel will kick-off their own version of "Got Organs" beginning this summer. The campaign originated with the Albany Clear Channel affiliate in 2001 and proved to be a success, enrolling more than 10,000 people on New York State's Organ and Tissue Donor Registry. Utica's campaign will be modeled after Albany's program, educating the community with the assistance of local transplant recipients and donor families, and setting up booths at all Clear Channel sponsored events throughout the summer. Negotiations are currently underway with potential sponsors of the program in hopes that a two-year lease on a vehicle can be given away at the end of the campaign to one registrant as was done in Albany.

Numerous media outlets in each service area featured organ donation in recognition of National Donate Life Month (see page 5 for details).

Minority Awareness Events Planned

EACH YEAR, organ procurement organizations around the country recognize National Minority Awareness Day, August 1, to raise awareness of donation throughout the minority communities. Minorities are at an increased risk for certain diseases leading to transplantation, such as kidney and heart disease.

To celebrate Awareness Day, the CDT has planned two events with the assistance of Sekou Sundiata, a Harlem-born poet who writes for print and performance as well as music and theatre. Sundiata's latest performance piece, *Blessing the Boats*, is a poetic account of his personal experience with kidney disease and transplant, injury and recovery.

The first event, "Life - Pass It On," is a panel presentation and community dialogue scheduled for 6:30 p.m. Thursday, July 31 in the Huyck Auditorium at Albany Medical Center. Participants will have the opportunity to hear different perspectives on donation from a donor family, an organ procurement coordinator, a transplant surgeon, and a member of the clergy, in addition to Sundiata's perspective as a recipient.

On Friday, August 1, Sundiata will present "An Artist's Journey Through Transplantation," a pres-

Donors Honored on National Donor Memorial Website

RICHMOND, VA - Organ and tissue donor families, transplant recipients and others who have been touched by donation may now honor their loved one or donor on the National Donor Memorial Website, www.donormemorial.org.

The United Network for Organ Sharing (UNOS) is building both a physical garden and a virtual component of the National Donor Memorial to honor organ and tissue donors in the United States.

A new "Tributes" section on the donor memorial website allows visitors to view existing tributes or create new ones. After signing up, visitors who wish to honor an organ donor can create memorial pages that tell that person's "story." Tributes can include words; scanned photos or other images that commemorate the organ donor's life; and his or her passions, favorite places or cherished events. Tools to further customize a tribute include choosing the page layout style and background color.

The site also offers a virtual tour and written description of the National Donor Memorial being built at the UNOS headquarters in Richmond, Va., as well as a calendar of events and news about the memorial.

entation targeted toward medical students and staff. This will include reading selections from his theatrical work, *Blessing the Boats*, discussing the process of making the piece, and showing selected sequences from a videotape of the piece. Medical professionals from throughout our service area are invited to attend the presentation, which will be held at 9 a.m. Friday, August 1 in ME-100 at the Albany Medical College.

The events are planned in hopes of drawing awareness to the critical need for more minorities to donate. Of the 50,000 people waiting for kidneys in the United States, nearly 35% are African-American.

Sekou Sundiata has released two CD's, *The Oneness of Dreams on Mouth Almighty*/Mercury Record label and his second, *longstoryshort*, was released on Righteous Babe Records in 2000. He has received a BESSIE NY Dance and Performance Award and two AUELCO Awards. He was featured on Bill Moyer's PBS series on poetry, "The Language of Life" and is a professor at Eugene Lang College.

For more information on either event planned, please call Sue Ford at (800) 256-7811.

The Legacy

Volume 7, Number 2

Spring 2003

The Legacy is published quarterly by the Center for Donation & Transplant.
218 Great Oaks Boulevard
Albany, New York 12203
Phone 518 262-5606
Fax 518 262-5427

Jeffrey Orlowski, M.S., C.P.T.C.,
Executive Director

Bill McTague,
Manager of Development
Sue (Cain) Ford,
Editor

Catherine McTague,
Staff

Walter Boppert,
Art and Design

**24-Hour Information
(800) 256-7811**

**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 Ford at (800) 256-7811 or via e-mail at sford@cdtny.org

The Legacy is published quarterly.

Study Shows Albany Med's Renal Transplant Program is One of Nation's Best

ALBANY MEDICAL CENTER'S Renal Transplant Program has been recognized as the only program in New York State and one of only 14 programs nationwide to show statistically significantly better results than expected in one-year graft survival rates in adult patients. The Scientific Registry of Transplant Recipients, based upon information received from the United Network of Organ Sharing (UNOS) and the Organ Procurement Transplantation Network (OPTN) also shows that wait times for kidney transplantation at Albany Med are significantly lower than the national average.

The report collected data from the country's 254 renal transplant programs between January 1999 and June 2001, and analyzed graft and patient survival at one month, one year, and three years following transplantation. The findings showed a 97 percent graft survival rate at Albany Med as compared to an expected 91.5 percent survival rate after one year. Only 13 other programs in the nation achieved statistical significance in graft survival after one year, placing Albany Medical Center's Renal Transplant Program among the nation's top six percent.

"The first year after a renal transplant is the most critical and complicated period for a kidney transplant recipient," explained David Conti, M.D., chief of general surgery and chief of the section of abdominal organ transplantation. "Thus, graft success at one year is the best indicator that the patient will survive with adequate kidney function for the long term."

The findings for graft survival at one month and three years and patient survival at one month, one year and three years all showed survival rates higher than expected, although these positive variations were not considered to be statistically significant.

"We are very proud of these results," said Conti. "We attribute our success to the tremendous support provided to our program by Albany Medical Center and the multidisciplinary approach we take

in caring for patients with end stage kidney disease. Our transplant team, unlike most, provides care to the recipients for several years following the transplant. This continuity of patient care is critical to the patients' well-being."

In addition, the report shows that the transplantation time for waitlist patients is significantly lower than that of the national average. According to the report, 50 percent of Albany Medical Center patients are transplanted at a median time of 20.2 months, as compared to the national average of 35.3 months.

"The longer a patient has to wait for a transplant, the greater their risk of death," said James J. Barba, chairman of the Board of Directors and president and CEO. "Albany Medical Center is fortunate to have Dr. Conti and an extraordinary team of physicians, nurses and support staff in the Renal Transplant Program, as well as the support of the Center for Donation and Transplant helping to keep the waiting time for transplantations down and the likelihood for positive results strong."

The study was adjusted for risk factors, including variances in patient populations, organizations, interventions and other appropriate factors.

The Renal Transplant Program at Albany Med was established in 1969. Approximately 100 patients are evaluated each year and 80 patients undergo kidney transplantation.

In 1999, Albany Med's Renal Transplant Quality Improvement Team placed first in the nation in the health care category of the prestigious "Quality Cup" competition. Sponsored by the Rochester Institute of Technology and USA Today, the Quality Cup recognized teams who made significant contributions to the improvement of quality care in their organization. In addition, the Department of Health and Human Services cited Albany Medical Center's Kidney Transplant Program as having one of the best success rates in the country in 1997.

Executive Director, from page 1

worked diligently to improve relations with hospitals and communities, to better his- or her-self professionally and to offer the support and care that donor families and medical professionals need at the time a donation occurs. It is this support to each other and to each family and professional that they work with that has been so essential to the CDT's success.

During my term, I had the opportunity to witness such proud occasions as the national expansion of CDT's Mothers of Organ Donors program

(MOD Squad) as it received a grant in the amount of \$4.3 million, and the seventh annual Nurse of the Year Award and Appreciation Dinner, to the diligence in readying for an audit from the United Network for Organ Sharing (UNOS).

To my delight, CDT staff made my transition an easy one, and I am certain that Mr. Orłowski will experience the same welcome as I.

David Conti, M.D.
Interim Executive Director

CDT CELEBRATES NATION

ORGAN PROCUREMENT Organizations around the country celebrated National Donate Life Month for the first time this April following the designation by U.S. Secretary of Health and Human Services Tommy Thompson. Traditionally, the third full week in April had been recognized as “National Organ and Tissue Donation Awareness Week.”

“Each year, the month of April brings springtime and nature’s renewal,” said Secretary Thompson. “Now, each April will remind all Americans of their own ability to renew and enhance life through the gift of donation.”

Ulster County

Joseph Roberti, Chairman of the Public Health Committee and member of the Ulster County Legislature sent the ball rolling that helped to make April proclaimed “Organ Donor Month” in Ulster County. County agencies including: Ulster County Health Department, Kingston and Benedictine Hospitals, Diamond Productions, Kingston Lions Club and Stop DWI programs supported the efforts to increase organ donor enrollment in Ulster County.

All Ulster County office workers received a New

York State Organ and Tissue Donor Registry Enrollment form with their paychecks to kick-off the event. In addition, a panel presentation addressing donation was taped at Kingston Hospital and shown on public access television stations, a table was set up at a local mall, ads were placed in the Kingston *Daily Freeman* and a banner was hung from a train trestle overlooking a main street in Kingston.



From left, Jason Wolstenholme, organ procurement coordinator and Sue Cain, public relations specialist, accepted a proclamation designating April “Organ Donor Month” from legislator Joe Roberti, right, at an Ulster County legislative meeting.

Legislative Education Day

MORE THAN 20 CDT staff and volunteers kicked off Donate Life Month by visiting legislators on April 1. The effort was led by the New York Alliance for Donation in hopes of educating legislators and obtaining support for three specific agenda items, including: the establishment of a Gift of Life Trust Fund through use of special license plates and/or voluntary donations with a driver’s license renewal (A. 6393-B); the maintenance of state funding for public awareness and education about organ and tissue donation; and the passage of

legislation (A 4574/S. 791) that would establish the New York State Organ and Tissue Donor Registry in state law and provide funding for a statewide donation awareness effort.

Senator Kemp Hannon, chair of the Senate Health Committee and Assemblyman James Conte, a kidney recipient, handed down resolutions declaring April “Organ and Tissue Donation Awareness Month” in New York State at an afternoon presentation for participants.

Nurse of the Year Award and Appreciation Dinner



Doris Kalohn, a liver recipient, holds a photo taken during a visit with her donor family in Japan.

EACH YEAR at the “Nurse of the Year” award and appreciation dinner, CDT recognizes individuals or organizations in the community who have supported our mission to facilitate the gift of life.

At the seventh annual event, CDT recognized Schenectady County Sheriff Harry Buffardi with a community service award. Sheriff Buf-

fardi assisted us in the emergency transport of life-saving organs for transplant.

The second community service award was presented to Kelly Zinicola, a public relations specialist at Faxon-St. Luke’s Health Care. Zinicola was recognized for going above and beyond in promoting organ and tissue donation in the Utica area.

The distinguished service award was given to Vermont Assemblywoman Johannah Leddy Donovan for her efforts to implement a Vermont State Organ and Tissue Donor Registry to educate Vermont residents. As the wife of a heart recipient, Assemblywoman Donovan has offered support to our efforts on countless occasions.

The “Nurse of the Year” Award was presented to Linda Boussey, R.N., of Alice Hyde Medical Center (see related story, page 7).

Around the Community

DONATE LIFE MONTH was celebrated throughout our communities by various organizations and civic groups. Beff’s Restaurant sponsored an organ donation drive and presented an Irish pub crawl trip to one person who enrolled on the New York State Organ and Tissue Donor Registry. Albany Medical Center’s heart transplant program celebrated its third anniversary, and the kidney transplant program sold “Don’t Take Your Organs to Heaven” mugs in the cafeteria. Various organizations including Aetna, Enterprise Rent-A-Car and the Waterford Lion’s Club enrolled as Workplace Partners through Secretary Tommy Thompson’s Workplace Partnership Initiative.



Kelly Zinicola says heart recipient John Weakley, shown here, has inspired her to raise awareness of organ donation.

In the News

THE Glens Falls Post Star’s announcement that April was Donate Life Month prompted Enterprise Rent-A-Car to sign on as a Workplace Partner.

Utica’s WKTV profiled Kelly Fox, a kidney recipient and WUTR profiled heart recipient John Weakley to draw attention to the life-saving benefits of donation.

Various events such as the Nurse of the Year Dinner and Albany Medical Center’s heart transplant program’s anniversary celebration were covered by Capital News 9, the Times Union and WXXX-Fox News.

Poster Contest Winner

SOPHIE BICK, an eighth grade student from Shelburne Community School in Shelburne, Vt., designed the winning entry for CDT’s Vermont poster contest.

Sophie received a \$150 gift certificate to University Mall and an ice-cream party for her class, attended by Kathy O’Brien from CBS’s Survivor: Marquesas series.



From Small Hospitals Come Big Ideas: Alice Hyde Medical Center



Linda Boussey, R.N., with Linda McClarigan, R.N. and David Conti, M.D., after being named CDT's Nurse of the Year.

BILLBOARDS. Ads. Commercials. These were just some of the ideas discussed at the first meeting of the CDT's Registered Nurse Advisory Council (RNAC) as methods to increase awareness of donation. But Linda Boussey, an R.N. at Alice Hyde Medical Center, knew that the possibility of getting any of the three accomplished in her area would be nearly impossible.

Nevertheless, she was determined to find a way to raise awareness in the small rural community of Malone, New York. Using what she learned through the RNAC, Linda approached some of her area's largest employers; Alice Hyde Medical Center, the Franklin County Court House and Barehill, Franklin and Upstate Correctional Facilities. She obtained permission from key executives to supply informational materials and organ donor cards to be put in each employee's paycheck, reaching nearly 3,000 people.

For her efforts, Boussey was selected from 15 nominees as CDT's Nurse of the Year. In nominating her for the award, vice president of patient care Linda McClarigan, R.N., said, "Through her efforts of education to the community, I believe there will be more individuals who are willing to contribute their organs or their loved ones' if the time comes."

Canton-Potsdam Hospital

AT A LATER MEETING of the RNAC, Debby Kent, R.N., of nearby Canton-Potsdam Hospital was inspired to educate her community about donation after hearing two representatives from Transplant Speakers International share their personal stories.

Jack Locicero explained how he donated his daughter Amy's organs after she was a victim of the Long Island

Railroad shooting, and Pete Radigan spoke about his experience as a heart recipient. At the same meeting, Secretary Tommy Thompson's Workplace Partnership was introduced to the group and Kent felt that it would be a great opportunity to raise awareness while also producing positive public relations for her hospital.

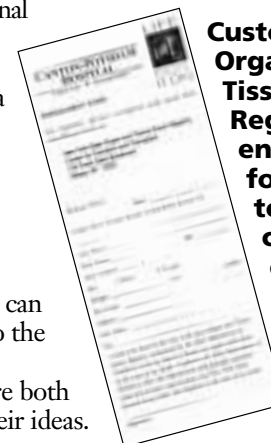
"My goal of course is to get as many people to sign organ donation cards as possible, but more importantly, I just want

people to talk to their loved ones about such things as organ donation and health care proxies," said Kent.

Kent shared her ideas with Hospital Vice President Cliff Westerling, who suggested that they invite other businesses and organizations to join them in the campaign, including: Reynolds, Alcoa, Corning, area clergy, Rotary and Knights of Columbus groups, and the four area colleges; Clarkson, SUNY Potsdam, SUNY Canton and St. Lawrence University. Potsdam is considered the area's "cultural and educational center," with a population of 8,000 swelling to 11,500 each school year.

Kent has begun her campaign by presenting information at management groups and brief inservices at several different department meetings. To help track the effectiveness of her campaign, she had New York State Organ and Tissue Donor Registry enrollment forms printed with the Canton-Potsdam Hospital logo, which she has placed in the lobby, dining room and other areas along with literature. After she has finished educating staff at meetings, she plans to remind them about the importance of donation through the in-house mail system and at the hospital benefits informational fair. If the campaign is successful, area corporations and organizations will be encouraged to participate.

These efforts can be credited to the efforts of the RNAC, where both nurses got their ideas.



Customized Organ and Tissue Donor Registry enrollment forms help to track a campaign's effectiveness.

“The RNAC was formed to help people put great ideas into motion, and I’m pleased to see that happening,” said Patti Fuller, R.N., an organ procurement coordinator at CDT and organizer of the RNAC.

Other hospitals are encouraged to participate in campaigns similar to those that Alice Hyde and Canton-Potsdam have implemented. For more information, please call Sue Ford at (800) 256-7811.

New York State Implements Safeguards for Living Liver Donation

FOLLOWING the death of a 57-year-old New York State man who donated part of his liver to his ailing brother at Mount Sinai Hospital in January of 2002, NYS Commissioner of Health, Antonia Novello, M.D. appointed a Committee on Quality Improvement in Living Liver Donation. David Conti, M.D., interim executive director of CDT, was chair of that committee.

A key proposal in the committee’s recommendations is a donor advocate team consisting of an internist, a nurse and a social worker, each of whose main focus must be centered on the well-being of the donor, ensuring that the individual understands

the medical, psychosocial and financial implications of the procedure.

In addition, committee members unanimously rejected calls for a moratorium on living-liver donor transplantation, recognizing that the 10-15% mortality rate of patients currently waiting for livers due to the lack of available organs would make such a moratorium morally and ethically unacceptable.

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

Or visit www.cdtny.org

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

IN THE LAST ISSUE of “The Legacy,” heart recipient and CDT volunteer John Weakley of Herkimer was profiled in the Hospital Spotlight section for his efforts with Faxton-St. Luke Health Care’s Volunteer Association. Not long after the article appeared, Weakley heard from the family of his 19-year-old donor for the first time, 11 years following his transplant. Elsie, his donor Stephen’s mother, wrote this poem:

THE GIFT OF LOVE, Elsie, donor mom

I remember well the night my son, you sat upon my bed.

I’m going to be a donor mom, upon renewal, you said.

Who would believe I’d ever heed, those words you were to say.

Or that the time would come so soon, when you would go away.

Before God came to take you, He had put it in your mind,

To choose a “GIFT OF LOVE”, my son, leave part of you behind.

You would be “BLESSING” others, with another chance at living;

We pray that they appreciate, your unselfish act of giving.

They have no way of knowing, how special they must be,

For God had already chosen them, before that time you see.

Those lucky ones He’d chosen to receive the gift of sight,

Will see the world more clearly, through your blue twinkling lights.

So many others gifted, by your sweet unselfish choice,

That night you came to tell me, in that calm, steady voice.

Now you were lying silent, and they asked what we would do?

There was no need to ponder, for I’d been prepared by you!

These gifts had been pre-wrapped my son, the day that you were born,

We gave them over lovingly, from this package sadly torn.

Your gifts were ever precious, for they’d been housed in you;

Our need for them no more, my son, we’d had the gift of you.

We’d been gifted by your presence, while you were here to love;

Had shared that precious package, God sent down from above.

That night you came to tell me, you took my breath away,

Your words imprinted in my mind, when we were asked that day.

We knew that we had played a part, in God’s unfolding plan,

To raise you from a baby, to this grown unselfish man.

The one who has your heart now, may know he has the best;

For we knew that heart in purity, before that fatal test.

Some may have thought you just a shell, with gifted parts all gone,

And wondered at the whole of you, as we sent you home;

But a heart beats for you in Heaven, it stood a test of time;

You did not go without one son, you took a part of mine.



Upcoming Events

- July 7Melissa Lahtinen Penfield Memorial Golf Tournament**
Plattsburgh, NY
- July 31“Life... Pass It On”**
Panel presentation, Albany Medical Center, Albany, NY
- August 1“An Artist’s Journey Through Transplantation and Recovery,”**
Sekou Sundiata to Speak in Recognition of National Minority
Awareness Day (see page 2 for details)
Albany Medical Center, Albany, NY
- August 1 - 3Binghamton Hot Air Balloon and Spiedie Festival**
Binghamton, NY
- August 13Tissue Requestor’s Workshop**
CDT Offices, Albany, NY
- September 11Tissue Requestor’s Workshop**
Cooperstown, NY
- September 132nd Annual Adirondack Spintacular Bike-a-Thon**
and 5K Race/Walk for Awareness
Mayfield, NY
- September 28Donor Memorial Service**
Proctor’s Theatre, Schenectady, NY
- October 14Tissue Requestor’s Workshop**
Kingston, NY

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