

THE LEGACY

A Publication of the Center for Donation and Transplant

Volume 9, Number 3

2005: Year In Review

2005 was another year of record-breaking achievements for the Center for Donation and Transplant. In 2005, CDT recovered organs from 52 donors. This is the second-highest number of organ donations that CDT has facilitated in its history, and represents an 8.3% increase over 2004. 155 organs were recovered and transplanted from these donors. This achievement ties CDT's record for the greatest number of organs recovered and transplanted in a year, and is an increase of 21 organs, or 15.7% over 2004. In 2005, we also imported and transplanted the largest number of organs in recent history. Twenty-three organs were imported and transplanted at the transplant centers in our region, including 18 kidneys and 5 hearts. The combined local and import number of organs transplanted was 178; this exceeds our previous record of 163 local and import organs transplanted in year 2003 by 9.2% and represents an increase of 25% over 2004. We facilitated 133 tissue donations in 2005, with December being the strongest month of the year for tissue donations. In the past year, CDT recovered organs or tissues

from 35 of the 46 hospitals we serve; 76% of CDT hospitals referred an organ or tissue donor in 2005.

Our two hospitals with Level One trauma centers both achieved conversion rates over the national goal of seventy-five percent. The conversion rate measures the number of actual donors out of all potential donors at a hospital. Albany Medical Center achieved a 75.9% conversion rate in year 2005, an increase of 59% over the previous year. Fletcher Allen Health Care's conversion rate was 100% for year 2005; meaning that every family at Fletcher Allen that was asked, consented to organ donation. Congratulations to both hospitals on their accomplishments.

An increase in organ donors translates into an increase in the number of lives saved every year. We will continue to work hard in 2006 to serve the patients waiting for a life-saving organ transplant and to ensure the final wishes of our donors are carried out. We thank the staff at our hospitals for their excellent care of potential donors as well as the caring and support they give to our donor families.

Speaker Confirmed for Education Day and Awards Dinner

THE Center for Donation & Transplant has confirmed the three speakers that will present at its "2006 Education Day and Awards Dinner" on April 26, 2006 at the Holiday Inn in Saratoga Springs, NY. The educational portion of the day will feature presenters from some of the many different fields of healthcare involved in organ and tissue donation.

Kathleen Goryl, Associate Director of Payer Relations at the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is scheduled to present on, "Joint Commission Initiatives to Increase Organ Donation." The second speaker will be John Harper, PhD, Vice President of Clinical Services at LifeCell Corporation. He will be presenting on the utilization of acellular dermas for abdominal wall reconstruction. The final presenter

will be Antonio DiCarlo, MD. Dr. DiCarlo is an assistant professor of surgery at the University of Vermont and the interim director of transplantation at Fletcher Allen Health Care. His presentation will give a summary of the current state of pancreas transplantation, including life-expectancy data, selection criteria for recipients, surgery overview and an update on current immunosuppression regimes.

This is the second year that an educational program has been added to CDT's traditional "Nurse of the Year" dinner. The educational portion of the day will run from 1:00-5:00 pm, with social hour beginning at 5:00 pm and dinner served at 6:00 pm. Following dinner, recognition awards will be presented to CDT's "Nurse of the Year" and "Health Care Practitioner of the Year." To make a reservation for this event, call CDT at (518) 262-5606.

From the
Executive
Director

The Spirit of Volunteers

ALITTLE OVER two years ago, Lauren Quinn was hired by CDT to be our Public Relations Specialist. At the time, I challenged her to organize, structure, train, and better use the cadre of volunteers we had at CDT. Prior to Lauren there was no formal volunteer program and our utilization of this valuable resource was hit and miss at best.

Thanks to Lauren's talent for working with people and her acceptance of this challenge, CDT today has a vibrant group of volunteers who do literally hundreds of programs promoting organ and tissue donation throughout the CDT service area. These volunteers have all participated in a formal training program and meet routinely to be updated on new information, new programs, and to share ideas. Some have received addi-

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CDT has elected the following two new members to its Board of Directors at its quarterly meeting in December. Susan Baron is an art teacher at Bethlehem Central Middle School. She is also a member of the Albany MOD (Mother of Organ Donors) Squad, a program offering grief support from mothers whose children have died to families who are considering the option of organ donation after the death of a loved one. Julia Cannizzaro is an administrative assistant to Presiding Justice Anthony V. Cardona of the Appellate Division, Third Department. She is also a living donor who donated a kidney to her son at Albany Medical Center in 2003.

THE tissue/perfusion staff at CDT has been identified by Cryolife as having the best recovery technique resulting in fewest procurement errors for heart valve recoveries out of the more than 50 Cryolife programs in the United States. Congratulations to our dedicated team for this significant achievement.

CDT has elected senior organ procurement coordinator Patricia Fuller, RN,

as its 2005 Employee of the Year. Fuller, an employee of CDT since 2001, has taken on several responsibilities in addition to her clinical and hospital development duties, and has proven to be a true asset to the organization.

ACCORDING to UNOS data collected from November 1, 2003 through October 31, 2005, CDT's kidney discard rate (kidneys that were recovered but unable to be transplanted) was below the national average in every category. The discard rates were broken down into the following categories of donors: standard criteria donors, extended criteria donors (recovered from a donor of older age or with a history of health problems) and donors after cardiac death. CDT had the lowest discard rate of all organ procurement organizations (opos) in the U.S for kidneys procured from standard criteria donors, recovering 101 kidneys and successfully transplanting 99 of them. CDT had a zero discard rate for kidneys recovered aftercardiac death. CDT was also below the average discard rate for kidneys

recovered from extended criteria donors.

IN December, CDT senior organ procurement coordinator Patti Fuller, transplant recipient Liz Devivo, and donor mother Karen Dunham appeared on News Channel 34, the ABC affiliate in Binghamton, NY. They discussed the importance of organ donation and Liz and Karen shared their personal connection to donation.

THE "Gotta Have Heart" show with host Bill Colagrande on Kingston's public access television aired a half-hour show about organ donation in January. CDT's PR specialist Lauren Quinn and CDT volunteer and heart recipient John L. Callahan appeared on the show to discuss donation.



A Donate Life Organization

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The Legacy is published quarterly by the Center for Donation & Transplant.
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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 Lauren Quinn at (800) 256-7811 or via e-mail at lquinn@cdtny.org.

The Legacy is published on a quarterly basis and covers the health care community that CDT serves in northern and eastern New York, and western Vermont.

Nominees Sought for "Nurse of the Year" & "Healthcare Practitioner of the Year"

ATENTION HOSPITAL STAFF: do you know a colleague that has gone "above and beyond" in support of organ and tissue donation at your hospital? CDT is accepting nominations for its 2005 "Nurse of the Year" and "Healthcare Practitioner of the Year" awards. Every year CDT honors a nursing professional and healthcare practitioner employed at a hospital served by CDT that have shown exemplary dedication and commitment to donation. The "Healthcare Practitioner of the Year" nominees can include doctors, patient care technicians, respiratory therapists or any hospital staff involved in the donation process. The winners are chosen from nominations provided by physicians, nurses, administrative and support staff. They will be formally honored at CDT's "Education Day and Awards Dinner," held on April 26, 2006 at the Holiday Inn in Saratoga Springs, NY.

You can nominate a colleague for either award by requesting a nomination form from your CDT coordinator. You can also e-mail your nomination directly to CDT at lquinn@cdtny.org. Nominations should include; name, title and phone number of nominee, hospital and unit where nominee is employed, narrative of why you think nominee is deserving of award, and your own (nominator's) name, title, hospital, unit and phone number. Please nominate a deserving nursing and healthcare professional and help us honor a colleague dedicated to saving lives through donation.

Executive Director, from page 1

tional training in public speaking and all, from the most active to the least active, contribute to the mission of CDT and to helping get more names off the waiting list.

In 2005, well over 200 programs, from health fair booths and displays at malls to high school presentations and media interviews, were conducted by CDT volunteers. It is impossible to know how many people were reached by these efforts but it undoubtedly numbers well into the thousands. In addition, uncounted hours were donated to do things like labeling the newsletter you are now reading.

Looking back on the growth of this program, one thing that strikes me is that the importance of volunteers to our program is natural. After all, the very center of what we do, the donation of organs and tissues, is a purely voluntary and selfless act. Those who donate are all volunteers who give of themselves for the benefit of others. For those who receive, and those family members who survive the donor, to give of themselves by giving their time is a wonderful tribute to the gift each donor gives.

And so, we at CDT owe our volunteers a big thank you for their efforts on our behalf. To the donors themselves, a heartfelt and everlasting thanks for giving the gift of life. And to those who live on, this group of recipients, donor family members, and other interested parties who through their enthusiasm for life and for the donation of life spread the message of organ and tissue donation, thank you for all you do!

Words of Thanks: A Donor Family's Thoughts

This letter was written to a CDT coordinator from 16 year-old Maura Gracey, whose uncle Doug was an organ donor in November 2005.

Jennifer,

I just wanted to drop you a line and tell you how much help you were to both me and my family during our difficult time of need. I don't think there would have been another person in the world that could have made us feel more at peace with the fact that we were losing someone that meant the world to us. I am SO glad that we decided to donate my uncle's organs; I don't think he would have wanted it any other way. You and your team of angels were amazing!!!! It is so comforting to know that even though it was the end for my uncle that it was somehow the beginning for another, what a happy thanksgiving those people must have had. Before this event had occurred in my family I knew so little about what it truly meant to be an organ donor. I had thought about it in the past myself but had no idea all that went into the process and how much an organ could truly mean to another. Even though I am only 16 I feel I have learned a life long lesson from this experience and have some how grown up from it. You and your team are amazing people, more than you will ever know!!!!!! I can't stress enough how grateful I am!!!! Losing my uncle so suddenly hurt inside, but being able to have a few short hours with his body somehow made me feel better about where his spirit was and where it was somehow going. To me it's as if somehow he is still alive within the individuals that received his organs. I hope that we will be able to meet some of these individuals in the future.

Please thank the other two individuals that were with you that day, I can't seem to remember their names, which I apologize for and would love to know if you could provide me with them, but they too were a great help to me and my family during this time. You are my angel!!!!!! It may sound funny but in a way you are, you and every other individual involved in the organ donating process!!! I hope that you had a great Thanksgiving and a wonderful Christmas holiday as well.

Thank you again for everything!!!
Sincerely,

Maura Gracey and the Gracey Family
~In memory of Doug Gracey~

At right staff and volunteers mingle at CDT's office open house in January. The reception was held to show visitors CDT's newly remodeled office space.

From left, Eileen Rooney, transplant coordinator Marta Taylor, Jennifer Dudley and Public Relations Specialist Lauren Quinn.



Gift of Life Becomes Gift of Friendship

EILEEN ROONEY has never felt the nausea and fatigue that accompanies dialysis. She's never waited patiently along with tens of thousands of people for a donated organ. She's never even had a family member face the news that they need an organ transplant in order to live. Nevertheless, on November 15, 2004 Rooney entered Fletcher Allen Health Care in Burlington, Vermont for surgery. She donated one of her kidneys to a complete stranger.

Rooney had always considered organ donation a positive act, but was never touched by donation directly until six years ago. While working as an evening manager for the Ronald McDonald house in Burlington, she befriended the parents of a young patient. The boy had just rejected his second kidney transplant and desperately needed another donated kidney. Rooney began exploring the option of donating her kidney to him, but the boy died before she was able to do so. In honor of his memory, she decided to continue pursuing the option of donating her kidney to someone in need.

Rooney began going through the vigorous physical and psychological testing required of all living donors. "We run extensive tests in order to ensure that all living donors are not only medically able to donate a kidney, but are psychologically prepared to do so and that they are donating the kidney altruistically," said Marta Taylor, the transplant coordinator at Fletcher Allen who worked with Rooney. During her initial testing, a benign tumor was discovered on her liver which needed to be removed before she could donate. At another point after passing the hospital's tests, Rooney was set to donate to a potential recipient but the transplant was canceled due to concern over the histocompatibility between donor organ and recipient.

As Rooney was going through the evaluation process, another woman in Vermont was battling kidney problems that had plagued her since childhood. Jennifer Dudley, born and raised in England, was diagnosed with kidney cancer at 18 months old and had a tumor and one of her kidneys removed as a baby. Years later in 1997, after moving to Vermont with her American husband, she was told she had developed polycystic kidney disease (PKD) in her remaining kidney. Dudley made the appropriate lifestyle changes to accommodate the disease, but

still needed to be added to the waiting list for a donated kidney. Her name was added to the UNOS list in August of 2003.

Although there are now more kidneys donated by living people than by deceased donors, living anonymous donors or "Good Samaritan" donors who choose to donate to a stranger are still rare. From January 1, 2005 through October 31, 2005, there were 59 kidneys transplanted from live anonymous donors in the U.S. in 2005. Out of the 16,004 kidney transplants performed in 2004, 85 of them involved living anonymous donors. In most cases, when kidneys are recovered from living donors they are transplanted into the donor's family member or close friend. Eileen Rooney's donation was the first living anonymous donation performed at Fletcher Allen Health Care. Since then, there has been one more organ recovered at Fletcher Allen from a "Good Samaritan" donor.



From left, Eileen Rooney, transplant coordinator Marta Taylor and Jennifer Dudley.

In November of 2004, Dudley learned that she would be receiving a kidney from a living anonymous donor. She was excited and happy, but a little apprehensive about the surgery. "I knew that if a total stranger could give up a kidney for me, this would be my best chance to get my life back," recalled Dudley. The transplant took place immediately after Rooney's kidney was

recovered, to minimize the time that the organ was outside of the body. The kidney began working as soon as it was transplanted and both women recovered quickly from the surgery.

For ethical and privacy reasons, Fletcher Allen withheld Rooney and Dudley's identities from each other until after the surgery. Prior to the transplant, Rooney merely knew that the recipient was a patient at Fletcher Allen Health Care. After the surgery, both women expressed a desire to meet each other. "I always hoped we would meet in person," said Rooney. "I think it would be only natural to want to meet, but you do have to enter the process knowing that you may not meet, and you also have to enter it knowing that you can't decide what kind of person it is that you're donating to."

As soon as they met, both women connected and have formed a strong friendship. They stay in close contact and get together frequently. Dudley even changed her license plate to read, "UK99PCT," in

reference to her new “American” kidney. Both women are also active participants in Fletcher Allen’s support group; open to donors, donor families, transplant recipients and those waiting for a transplant. As part of the group, they give presentations to educate Vermont residents about the importance of organ donation.

In the end, Rooney’s act of generosity benefited both women far more than they thought possible. Sharing her thoughts on being a living donor,

Rooney said, “In my heart as well as in my mind, I knew it was something I could do to make a difference. And the end result, my meeting Jenni, developing a very unique friendship with her and hearing how her quality of life has improved, has been a far more affirmative experience than I ever could have imagined.” Dudley added, “I now have energy and am able to do things I never thought I could do again. Best of all, through this wonderful gift, I have made a wonderful friend.”

Donor Family After Care Program Revised and Expanded

WITHIN the past year, CDT staff has carefully reviewed its existing donor family aftercare program, including CDT literature, activities and events designed for families that made the decision to donate. As a result of this analysis, CDT is expanding and adjusting its support program to ensure that the needs of donor families continue to be met.

CDT will be adding a new event for both donor families and transplant recipients. The first annual “Celebration of Life” family picnic will be held in late spring of 2006. This event will allow donor family members, transplant recipients, and health-care professionals to come together on a Sunday afternoon to enjoy some barbeque, share stories and memories, and get to know one another in a relaxed and informal setting.

Donor families will no longer have to wait up to one year to receive the New York State Gift of Life donor medal. The medal will now be sent to families along with a keepsake chest within one month of their loved one’s date of donation. CDT’s annual donor memorial, traditionally held in New York and Vermont during the summer, will now be held at one location in the capital region in early fall.

Previously, the memorial was held for families in the first year of their loss. Recognizing that some donor families require additional support beyond the first anniversary of their loved one’s passing, invitations to the memorial will be expanded to include families that made the decision to donate up to three years ago.

The current aftercare packet that CDT sends to families following donation will be replaced with grief support literature created by CDT specifically for its donor families. The packet will address the concerns and feelings that donor families experience after the loss of a loved one. The literature is meant to be helpful and meaningful to families as they travel through the grieving process and begin to heal.

CDT will continue to offer families the option of participating in such activities as adding a square to the donor family quilt, volunteering for community education activities and writing letters to their loved one’s transplant recipients. More information will follow in the Legacy and in mailings to donor families as the new events draw closer. It is the hope of CDT staff that the aftercare program will continue to provide comfort and support to families dealing with loss.

New York State Revises Brain Death Guidelines

NEW YORK STATE has issued a revised set of guidelines for declaring brain death in order to clarify the process for healthcare practitioners. Although the previous guidelines were stringent in protecting the patient, they contained certain provisions that were considered unnecessarily cumbersome and allowed for variability in how the guidelines were applied. For example, under the previous guidelines, the recommended timeframe between first and second declaration was vague and there was variation from hospital to hospital of anywhere from 6 hours to 2 days. The new guidelines close the variation in time, stipulat-

ing that six hours is a sufficient time frame between first and second declarations. This establishes a firmer timeline for physicians and eliminates what could be an unnecessarily long wait for the families of those patients. The purpose of these revisions is to ensure the process of declaring brain death is clear and straightforward, benefiting healthcare professionals, the patients, and the patients’ families, and to maintain consistent applications of the guidelines throughout the state. New York hospitals have been informed of these changes and training on the new guidelines will be held across the state.

In Memory Of

CDT gratefully accepts financial donations that we use to fund programs to educate the public about donation and to support our donor families. Often, the contributions are given in recognition of a CDT organ or tissue donor. Below is a list of people who were honored through donations given to CDT in 2005. We would like to express our appreciation to all contributors for their support.

Georgette Tremblay
Michael Belawski
Kendall MacFarland
Barbara Davis
John Kelly
Jean Phillips
Jean Phillips
John Heim
David Yarrington
John Schempp
Douglas Gracey
Eric Lawrenz

CDT would also like to thank the following organizations for their support:
Beff's Restaurant
Charity Golf Tournament; Verizon Volunteers Employee Program; Memorial Society of the Hudson Mohawk region; United Way (Golub Corp Employees Donation); Greek Orthodox Ladies; "Ride for Tommy Rally" Tammy & Lawrence Mitchell fundraiser; Eagles 2586 Bell Jar.

Amy Bindelglass Memorial Scholarship

For the fourth year, CDT is offering the Amy Bindelglass Memorial Scholarship to high school juniors and seniors. The scholarship will award \$500 as first prize and \$200 as second prize to two students that write a convincing, persuasive essay of a minimum 1,000 words on the topic below. Entries should be sent directly to CDT and need to be postmarked by March 15, 2006. Winners will be notified on March 31, 2006 and will be invited to CDT's awards dinner held on April 26, 2006. For more information, call 1-800-256-7811.

THERE ARE OVER 90,000 people waiting for an organ transplant in the U.S. Historically, the donation of organs has relied upon the generosity of families that choose to donate their deceased loved one's organs, and the voluntary donation of certain organs from living donors. Because of the urgent need for transplantable

organs, the medical community has explored different ways to increase organ donation. One option is to offer a financial incentive to families that donate their loved one's organs after they have died. This incentive could be in the form of a tax deduction, reimbursement for funeral expenses, a donation to a charity of the family's choice, or a direct payment to the family.

Critics say that giving donor families any type of financial stipend is "paying" them for organs. They are afraid financial incentives will be the first step in the buying and selling of organs, which is illegal under the National Organ Transplant Act. Proponents counter that the current method of relying on families to say "yes" to donation because of goodwill and generosity is not working, and that offering a financial stipend would increase organ donation while expressing gratitude to the donor family.

What do you think? Should families be offered a financial incentive to donate their loved one's organs after death? If so, is one form of stipend (paying funeral expenses, a tax deduction, direct payment to family) more ethical and just than another?

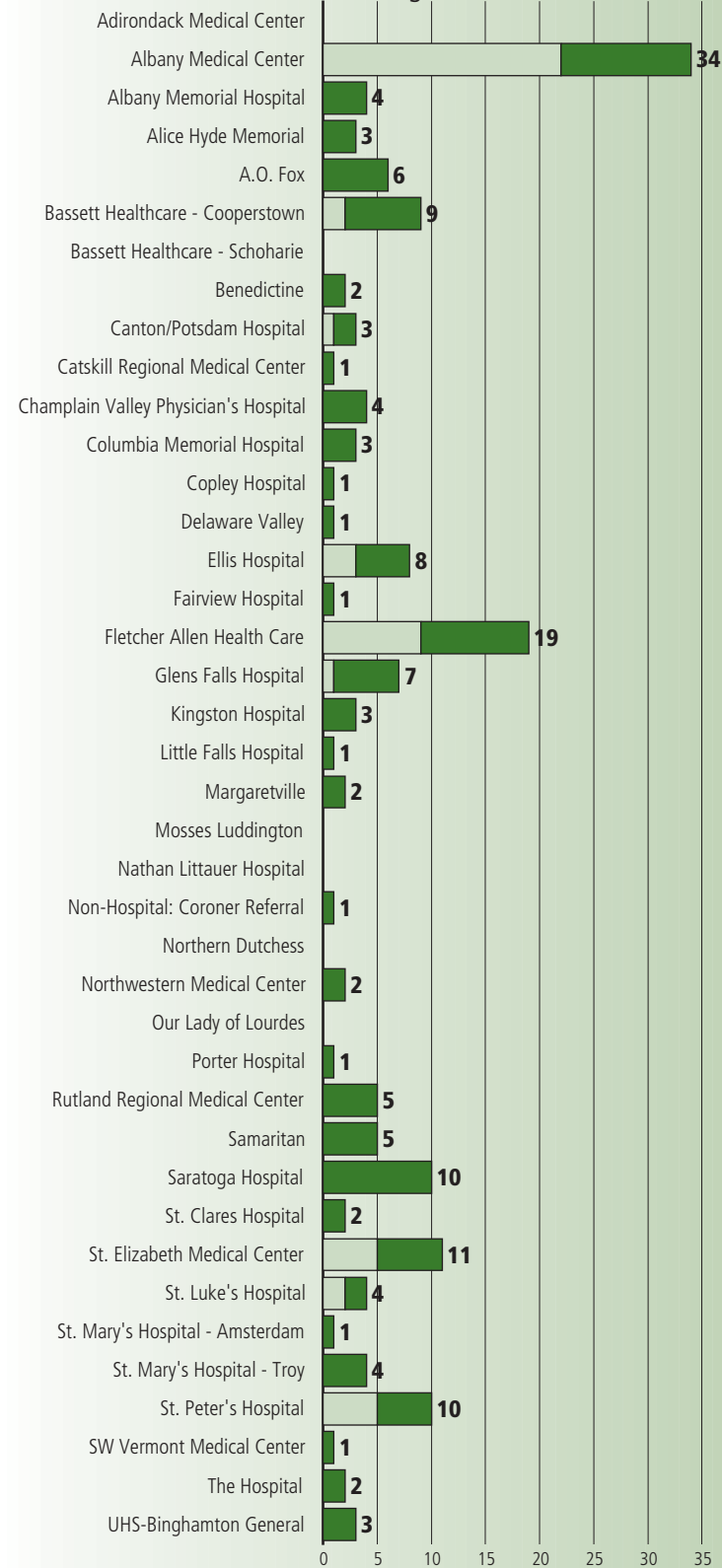


CDT tissue perfusion/technician Christina Collins explains how to operate a kidney perfusion machine at CDT's new pump room. The room, located at Albany Medical Center, allows staff to perfuse kidneys in a sterile environment. Kidneys that are perfused after recovery often have a higher rate of success in transplantation.

Donor Activity by Hospital

January 1 through December 31, 2005

133 total tissue donors, 52 total organ donors



Organ Donors Tissue Donors

NYAD and NYSNA Offer Free CEUs for Organ Donation Education

The New York Alliance for Donation (NYAD) and the New York State Nurses Association (NYSNA) have collaborated on a specialized educational program for nursing professionals on the role of the nurse in organ and tissue donation. This continuing education program has been approved for 3.4 contact hours by NYSNA, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. It is currently available in booklet form.

Upon completing the course, the learner will be able to:

- ◆ Discuss the need for organ and tissue donation.
- ◆ Discuss challenges regarding organ and tissue donation.
- ◆ Describe the process of organ transplant for the organ recipient.
- ◆ Identify the benefits of organ and tissue transplantation on the recipient.
- ◆ Discuss the laws and regulations that impact organ and tissue donation.
- ◆ Distinguish between cardiac death and brain death and how they relate to organ and tissue donation.
- ◆ Identify critical aspects of the consent process.
- ◆ Discuss the role of the registered nurse in organ and tissue donation including referral, donor management, recovery and aftercare.

To receive a free printed copy of this program, please contact your hospital's assigned organ procurement coordinator or call the Center for Donation & Transplant at 1-800-256-7811.

Contact CDT if you would like to:

- ENROLL in the New York State Organ and Tissue Registry
- OBTAIN INFORMATION or donor cards
- REQUEST SPEAKERS for schools, civic organizations or health fairs
- BECOME A VOLUNTEER and help raise awareness of donation!

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

Or visit www.cdtny.org



Center for Donation & Transplant
218 Great Oaks Boulevard, Albany, New York 12203
Phone 518 262-5606, Fax 518 262-5427
P2301



Upcoming Events and Important Dates

March 15Deadline for Amy Bindelglass Memorial Scholarship

March 15UNOS Region 9 Meeting, New York, NY

March 31Deadline for "Nurse of the Year"
and "Health Care Practitioner of the Year" nominations

April 1Start of National Donate Life Month

April 26Education Day & Awards Dinner, Saratoga Springs, NY

If you have any questions about our upcoming events,
please contact Lauren Quinn at (800) 256-7811.