

## EarthAngels Raise Awareness in Memory of Friend

**A**LLISON BARKYOUMB was just like any other 15-year-old girl. She liked hanging out with her friends, dancing with the Spar-kette's Dance Team and playing the saxophone. However, there was something that set her apart. Unlike the other sophomores at Milton High School in Vermont, Allison was born with a heart valve that was too small and had to endure several major heart operations in her lifetime.

On August 9, 2002 Allison underwent a heart valve operation. There were complications afterwards and Allison was urgently placed on the waiting list for a heart transplant. She waited for three and a half weeks but unfortunately one did not come in time. On September 12, 2002 Allison died of a brain hemorrhage.

Two of her best friends, 16-year-olds Kayla Gennrich and Sara Stowell, decided to devote themselves to raising awareness of the need for organ and tissue donation, so that other lives could be saved. They founded "EarthAngels" a group that has grown to 25 volunteers and is dedicated to public education and community involvement regarding organ and tissue donation.

It would appear that people have been paying attention. If you go to their website at [www.earthangel.org](http://www.earthangel.org), there is a listing of events that EarthAngels have participated in including fundraising events, the Milton 4th of July parade,

media interviews and an invite to "Share the Beat," a celebrity fundraiser in California benefiting organ and tissue donation that asked the girls to share their story. EarthAngels have been involved in raising money to help with the medical expenses of people waiting for transplants, and sell jewelry off of their website to help their cause. But their main goal remains getting the message out to the public on the importance of talking to your family about organ and tissue donation, and letting them know what your wishes are. Allison's friends stated, "We found it very sad, shocking and unacceptable



Photo by Dan Steinberg

**EarthAngels (from left) Kayla Gennrich and Sara Stowell at the "Share the Beat" fundraiser in September.**

that with her [Allison]... being at the top of the donor list not one person who passed was a suitable donor. From this experience we learned that many people are unaware of the importance of donating their organs. We want to raise awareness by telling people our story and encouraging them to become donors. That's why we started EarthAngels."

EarthAngels has registered for official non-profit status, which will enable the group to apply for grants and funding. Future plans include a benefit dance in March, a trip to Virginia to visit the Coalition on Donation, and creating a video on the benefits of organ donation that they hope to distribute to schools for educational purposes. "The goal," according to EarthAngels' volunteer Heather Bell, "is for everyone to be a donor." Every fundraiser, every piece of jewelry sold, and every donation story that EarthAngels shares brings them closer to that goal.

### From the Executive Director

## Reflections on 2003

**A**S I LOOK BACK upon the year that just ended, I do so with a profound sense that 2003 was a landmark year in the history of organ and tissue donation in Eastern New York and Western Vermont. While 2003 saw the CDT recover more transplanted organs (155) than in any previous year, the work begun in 2003 will begin to have its true effects in 2004 and beyond.

One of the cornerstone programs initiated this past year was joint participation by the CDT and the Albany Medical Center (AMC) in HHS Secretary Tommy Thompson's Organ Donation Breakthrough Collaborative. Through this project, a team of professionals from the CDT and AMC will be trained and work together to implement national "donation best practices" within the hospital. Included in these best practices is the establishment of an "in-house" donor coordinator. The goal of the project is to increase conversion of potential organ donors to actual recovered donors to a rate of 75%.

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**C**DT Executive Director Jeffrey Orlowski, M.S., C.P.T.C., has been appointed to the New York State Transplant Council by New York State Senate Majority Leader Joseph L. Bruno. The Transplant Council is an advisory board for the State Commissioner of Health, providing information on the allocation, procurement and transplantation of organs and tissues.

- The MOD (Mothers of Organ Donors) Squad program, originally pioneered by CDT, is currently being implemented in other organ procurement organizations. The New York Organ Donor Network is working with Albany Medical Center, the Iowa Donor Network and the Mid-South Transplant Foundation to create a volunteer support program for families facing the death of their loved ones and considering the option of donation. The MOD Squad was launched in Albany in 1997 and provides support and assistance to families from the mothers of organ donors during the time of a loved one's death. Grant funding for this effort was provided by the Department of Health and Human Services.

- On November 20th, the United Network for Organ Sharing (UNOS) dedicated the National Donor Memorial, honoring tissue and organ donors who gave the gift of life. The Memorial is designed to highlight the impact of donation and the importance of increasing donation awareness. The Memorial is located in Richmond, Virginia and will be open to the public on January 30, 2004.
- Heart recipient John Weakley of Mohawk, New York was profiled in The Evening Telegram on his support group's participation in the National Donor Sabbath. The article discussed the efforts of Weakley and the Mohawk Valley Transplant Support and Awareness Group to promote awareness and education of organ and tissue donation.
- Numerous media outlets featured CDT's Donor Memorial Service, held on September 28th, 2003. (Please see page 3 for details).

## New Faces - The Center For Donation & Transplant Welcomes New Staff Members



Jeffrey P. Orlowski, M.S., C.P.T.C., began his appointment as Executive Director of the Center For Donation & Transplant on July 1, 2003. Orlowski previously served as managing director of tissue services at LifeGift Organ Donation Center in Houston,

Tx. He possesses 16 years of experience in the fields of donation and transplantation. 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.

Martin Benoit joined the Center For Donation & Transplant in September 2003 as the finance manager. Marty came to CDT from CGI Management



Consultant's healthcare consulting practice where he was a senior consultant. Previously, he worked at Empire Blue Cross/Blue Shield in such positions as reimbursement and financial analyst, and senior accountant. He received his BA in Business & Economics from State University New York at Plattsburgh and his MS in Health Systems Management from Union College.



Lauren Bould joined CDT in November 2003 as the public relations specialist. Previously, she worked in human resources at Rensselaer Polytechnic Institute and was a recruiter at a staffing firm in New York City. She received her BA in Communication at the State University of New York at Geneseo.

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**We  
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to Hear  
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**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 Bould at (800) 256-7811 or via e-mail at [lbould@cdtny.org](mailto:lbould@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.**

# Donor Memorial Held in September

A DONOR MEMORIAL service was held at Proctor's Theatre in Schenectady on September 28th to honor those who have donated organs and tissue to give the "gift of life." The service remembered more than 1,000 people who have died in the last three years and whose families had donated their tissue, organs or corneas. The 139 families who attended the event came from Ireland and throughout the United States.

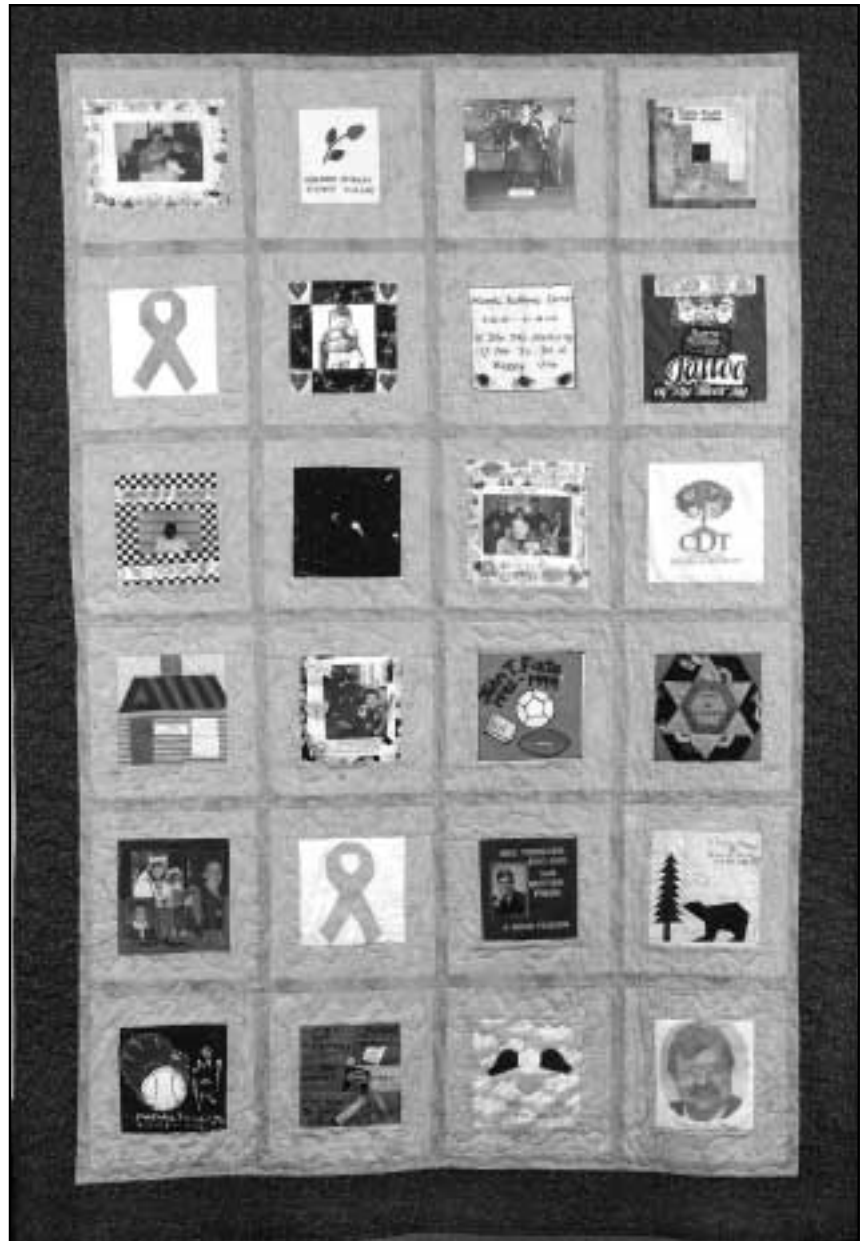


**Dr. Kenneth Moritsugu delivers his speech at CDT's Donor Memorial Service.**

The evening's keynote speaker was Dr. Kenneth Moritsugu, U.S. Deputy Surgeon General. "For some of us this is a day of sadness as we reflect on the memory of our loved ones," Moritsugu said. "We remember with sadness, we rejoice with life." Dr. Moritsugu made the decision to donate his wife's organs after she died in an automobile accident in 1992. Six

years later, he donated his daughter's organs after a separate accident claimed her life. He learned that his wife helped to save the life of a retired police detective and a 12-year-old girl. The donation of his daughter's organs benefited a mother of five and a 59-year-old man. Other presenters included Retired Col. Wayne Boy, a liver recipient and associate director of facilities at the College of William and Mary, Dr. David Conti, Medical Director of CDT, and Jeff Orłowski, Executive Director of CDT.

Family members were presented with the "Gift of Life" medal, a symbol of the tremendous gift given by donors and a reminder of the importance of organ and tissue donation. Guests were also able to view the recently completed "Kaleidoscope of Memories" patchwork quilt, created with patches that donor families submitted in memory of their loved ones.



Speaker Retired Col. Wayne Boy emphasized the importance of donation to the recipients. "My life hasn't simply been prolonged, it's been transformed." Boy said, "You have saved our lives. What you do makes a difference you can't even begin to imagine."

**CDT's "Kaleidoscope of Memories" quilt was unveiled at the Donor Memorial. The quilt is made up of patches created by donor families and pays tribute to the individuals who gave the Gift of Life.**

## Executive Director, from page 1

Another cornerstone was the establishment of a true "in-house" donor coordinator at Fletcher Allen Medical Center (FAMC) in Burlington. Our in house staff will be working with FAMC staff to establish many new programs within the hospital. Among these programs are early referral, team approach for consent, and immediate follow-up/debriefing following all organ referrals.

In addition to these and other hospital-focused programs begun in the past year, the CDT is also building for

the future from within. Work teams have developed and expanded internal quality assurance programs, created new CDT staff training modules, and compiled hospital profile books, among other projects.

In closing then, let me reiterate that we at the CDT are very excited by the achievements of the past year and are looking forward to even greater accomplishments in the year to come. As we set out on the path before us, we look forward to working with each of you to make the dream of shorter transplant waiting lists and fewer deaths while waiting for transplant a reality.

## Albany Medical Center Participates in "Organ Donation Breakthrough Collaborative"

**A**LBANY MEDICAL CENTER has been selected as one of 200 hospitals in the nation to participate in U.S. Health & Human Services Secretary Tommy G. Thompson's "Organ Donation Breakthrough Collaborative" designed to increase organ donation rates in hospitals with the highest potential for organ donors. These 200 hospitals account for 50% of eligible organ donors in the country. The Breakthrough Collaborative is designed to save thousands of lives by increasing the national conversion average from 46% to 75%. Conversion is the percentage of medically suitable potential donors who actually become donors.

Albany Medical Center, in conjunction with The Center For Donation & Transplant, has formed a multidisciplinary team composed of organ procurement coordinators and hospital health care professionals to attend training sessions from September 2003 through April 2004. The team is working with others from across the country to study the best practices of hospitals with donation conversion rates of 75% or above. They will then replicate those programs in Albany Medical Center, and refine organ donation procedures in order to increase rates of donation. Team members include CDT professionals William McTague, manager of operations and Maureen Teal, organ procurement coordinator, and Albany Medical professionals Lyn LaBarre, administrator of emergency services and Karen Sigond, nurse manager in the Medical Intensive Care Unit.

The team has already taken steps to implement three of the best practices. The first practice involved assigning an organ procurement coordinator to work full-time in the hospital. Coordinator Maureen Teal, will be working in-house at Albany Medical to educate and assist the medical staff in organ donation. Having a full-time coordinator will allow Albany Medical Center to be more proactive in identifying potential donors and managing their care.

The second practice being implemented is the establishment of clinical triggers that will allow medical staff to more easily identify potential donors. Medical staff will be trained to recognize these triggers, such as neurological injuries and

dependency on a ventilator, and contact CDT immediately. Federal law states that hospitals must report all deaths or imminent deaths to their OPO, but the calls need to be made as quickly as possible to allow for the option of donation to be fully and properly explained.

The third component involves the education of medical staff concerning a team approach to speaking with families about donation. "Our goal is to approach the family in the most caring, supportive and compassionate manner possible," says CDT Executive Director Jeff Orlowski, "The concepts we've implemented thus far work to allow people to aid communication with the families. Medical staff will be trained to allow families have their wishes relative to donation fulfilled while allowing us to provide the best support we can to surviving family members as well as hospital staff."



**CDT and Albany Medical Center Collaborative team (from left) Lyn LaBarre, Karen Sigond, Maureen Teal and Bill McTague**

Albany Medical Center was chosen to participate based on the annual number of brain deaths at the hospital. A panel composed of experts in the field of organ procurement is leading the initiative. Each team participating in the Organ Donation Breakthrough Collaborative submits monthly data to track the impact of their testing efforts.

The Breakthrough Collaborative is the first program to acknowledge the joint effort needed by both hospitals and organ procurement organizations to increase donation rates. Orlowski states, "This initiative is focusing on both hospitals and OPOs working together to better their community. We have the same purpose in fostering awareness and saving lives and the collaborative will allow us to encourage each other to reach that common goal."

# "Life - Pass It On" License Plates

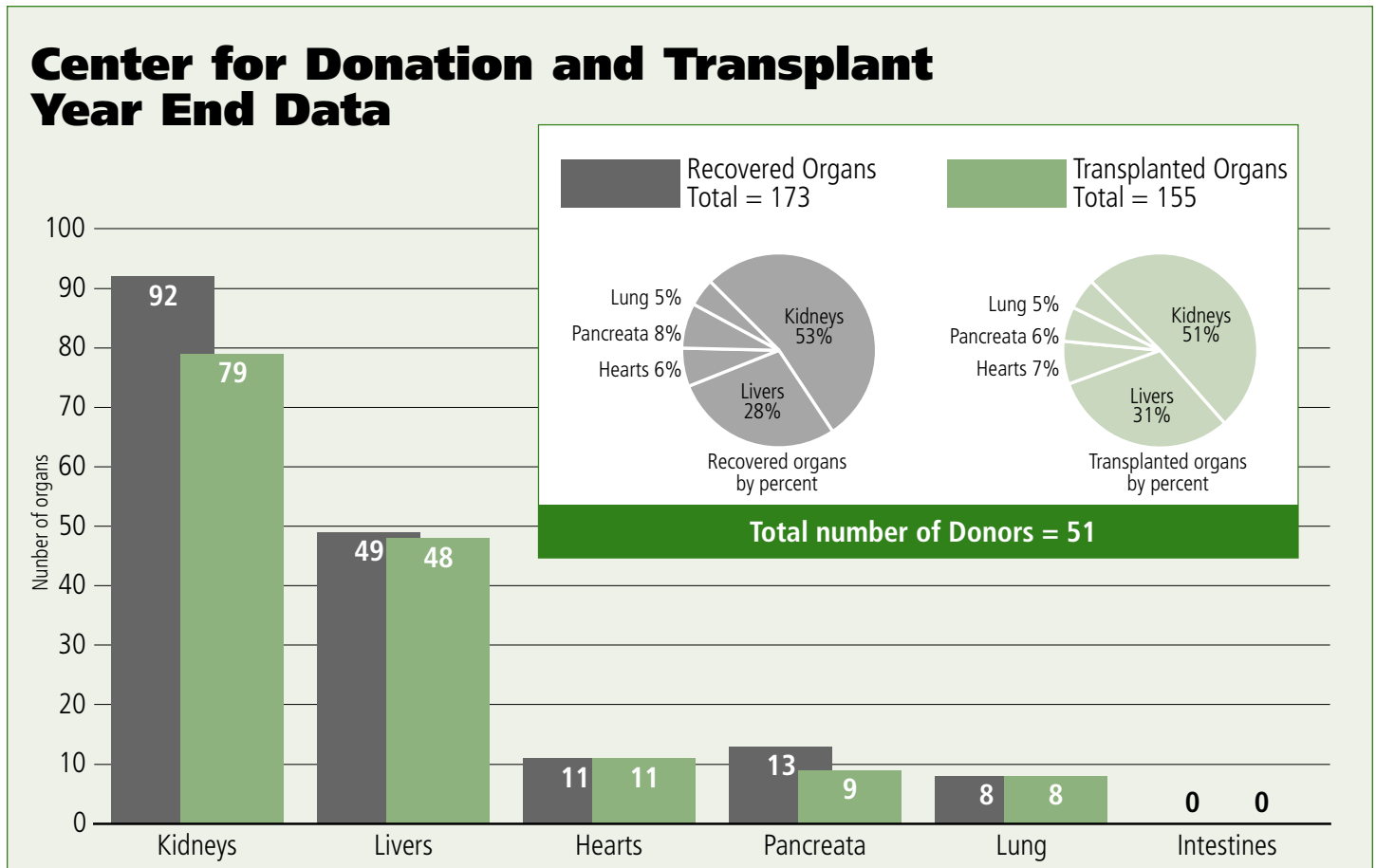
**G**OVERNOR GEORGE E. PATAKI has signed legislation into law allowing the creation of the first New York custom license plate promoting organ and tissue donation. The "Life-Pass it On" plate will be available in 2004 and proceeds from the annual service charge will be deposited into the "Life - Pass It On Trust Fund" used for research, education and efforts to raise awareness of organ and tissue donation.

"Each year countless lives are saved through organ and tissue donation," said Governor Pataki. "The creation of the "Life - Pass It On" license plate will encourage new organ and tissue donations by increasing public awareness, while also providing critical support for important further organ transplant research."

In addition to the regular registration fee, the initial cost for a standard "Life - Pass It On" plate will be \$43 with an annual renewal fee of \$25. For every plate sold, \$20 of the \$25 renewal fee will be placed in the "Life - Pass It On Trust Fund." Drivers may also purchase a personalized license plate with up to six characters for \$68, with an annual renewal fee of \$50. The renewal fees are billed every two years.

New York State Department of Motor Vehicles Commissioner Raymond P. Martinez said, "The Life-Pass It on" plate will join the other cause plates that the state has to offer, which provide an opportunity for all of us to display publicly our support for this, and other important programs." Presently, there is not an exact release date for the license plate, although it is expected to be in 2004. Interested parties should check the New York State Department of Motor Vehicle's website at <http://www.nydmv.state.ny.us> or call 1-800-364-PLATES for availability.

Currently, there are over 8,000 New Yorkers waiting for a life-saving organ transplant. In June of 2000 Governor Pataki established the New York State Organ and Tissue Donor Registry. Since its creation, over half a million New Yorkers have registered with an average of 20,000 new enrollments per month over the last three years. If you are interested in registering your intent to become an organ or tissue donor, visit [www.cdtny.org](http://www.cdtny.org) or call 1-800-256-7811.



# The Amy Bindelglass Memorial Scholarship Open to Students

**J**ANUARY IS THE KICK-OFF month for CDT's Amy Bindelglass Memorial Scholarship, created in memory of Amy Bindelglass, who lost her life in a tragic accident at the age of two. By making the decision to donate her organs, her fami-

ly helped save the life of a five-year-old boy who needed a new heart. This \$500 scholarship is open to high school juniors or seniors attending high school in the counties of New York and Vermont that are served by CDT.

## Applicants are asked to present an argument and write a persuasive essay on the following topic.

Many countries in Europe such as Spain, Austria, Belgium and Sweden, follow a policy of "presumed consent" for organ donation. Presumed consent assumes that people have agreed to be an organ donor upon death unless they have specifically stated that they do not wish to donate. People unwilling to donate have to "opt out" of the system. This is very different from the United States, where people who wish to be organ donors upon death "opt in" by enrolling in a state registry, or signing a donor card or the back of their driver's license. Some states, including New York and Vermont, require that families of potential donors make a decision whether or not to donate, even if the potential donor has expressed a wish to donate. Countries that follow "presumed consent" on average have a high percentage of people who donate and a low percentage of the population that "opts out." Currently there are over 83,000 people in the United States waiting for a transplant, and an average of 17 people die every day while on the wait list. Should the United States adapt a policy of presumed consent? What would be the implications of that change?

Students should present a clear and convincing persuasive argument either for or against the idea of adopting the presumed consent policy in the United States. The essay must demonstrate a clear understanding of the rules, regulations and ethics surrounding donation.

Essays should be a minimum of 1,000 words and be typed and sent with the student's name, address, phone number, grade, social security number and the name of the student's high school to:

Memorial Scholarship  
The Center for Donation & Transplant  
218 Great Oaks Boulevard  
Albany, NY 12203

Submission deadline is April 1st and the winner will be notified by April 15th. For more information, call Lauren Bould at (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](http://www.cdtny.org)

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



## Help to Make Children's Wishes Come True

**I**N OUR PROFESSIONAL and personal lives, many of us have relationships with children facing life-threatening illnesses. There is a way for you to help make these children's dreams come true. By telling families, colleagues, and other community members about the work that your local Make-A-Wish chapter does in communities you let them know that a wish may be possible for a sick child. In turn, these people (or yourself!) may refer a child for a wish and begin a journey that will create hope, strength, and joy in the lives of that child and his or her family.

Children between the ages of 2 1/2 and 18 who are living with life-threatening medical conditions are eligible for a wish. Making a referral is as simple as picking up the phone and calling the Make-A-Wish foundation toll-free at 1-800-722-WISH (9474). There is no consideration given to a family's financial situation when determining eligibility.

For a child with a life-threatening medical

condition there is nothing like the power of a wish, and you can be an integral part of making those wishes come true! There are several local chapters of the Make-A-Wish Foundation in New York and Vermont. Please call the above number or go visit [www.wish.org](http://www.wish.org) for further details.

## Nominate A Nurse

**T**HE TIME HAS COME to send in nominations for CDT's "Nurse of the Year" award, given in April to recognize the exemplary efforts of a nurse committed to organ and tissue donation. If you have a nurse in your area that you feel has gone "above and beyond" in support of donation, please ask your CDT coordinator for a nomination form.

## Congratulations!!!

With the dedication and assistance of our hospitals, CDT has surpassed its goal of 50 organ donors for the year 2003 with a total of 51 donors. This is only the second time CDT has ever met or exceeded the 50-donor mark. This allowed us to recover 173 organs, 155 of which were transplanted. This is the largest number of transplanted organs CDT has ever procured and, most importantly, allowed 22 more people to receive the Gift of Life in 2003 than the previous year. CDT would like to congratulate and thank all of you for your commitment to donation and your excellent care of potential donors. Let's continue our hard work in 2004!

One nurse will be chosen for the award based on the nominations from physicians, nurses, administrative and support staff. The 8th annual Nurse of the Year Award and Appreciation Dinner will be held April 29, 2004 at the Century House in Latham, NY. The dinner honors individuals in the medical profession and greater community dedicated to supporting efforts of organ and tissue donation.

## Basketball Star Brings Attention to Need for Donation

**A** LOT OF MEDIA ATTENTION has been generated by the case of Alonzo Mourning, the basketball star who announced in November that he was retiring from the Nets due to kidney disease, and would need a new kidney to survive. This sparked a national discussion when several people stepped forward and inquired about becoming a potential donor for Mourning, raising questions about living donors and bringing awareness to the urgent need for organ donation.

The Kidney and Urology Foundation of America fielded close to sixty calls from people offering to be tested as potential donors for Mourning. Ultimately, Mourning found a donor who is an unidentified family member. Most living donors are family members, because of the physical compatibility of

the organs, and the magnitude of the gift being given. All potential donors, along with testing for physical compatibility, are screened to determine the reason for their donation. If it is something other than true altruism, that person will be turned away.

Although there has been controversy about the strangers willing to donate an organ to a celebrity, the most important issue to be raised from Mourning's media attention is the dire need for organ donors. There are currently almost 57,000 people on the UNOS waiting list for a kidney; 83,000 people in total are on the list for an organ transplant. If the publicity generated from this case causes people to consider the idea of donation, maybe we can lower the average of 17 Americans who die every day waiting for a transplant.



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P2301



# Upcoming Events

- January 26 .....Amy Bindelglass Memorial Scholarship Kick-Off
- February 14 .....Saturn Donate Life Day
- April 1 .....Start of Donate Life Month
- April 14 .....Legislative Education Day
- April 29 .....Third Annual Nurse of the Year Award & Appreciation Dinner
- May 1 .....AMC Neighborhood Challenge

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