



New Start news

800-642-8399

www.transplantfund.org

2006: A Banner Year for Organ Donation and Transplantation

For the first time ever, the number of deceased donors topped 8,000 in the United States—a 29.6 percent increase since 2002. The result: 24,461 organs were transplanted from deceased donors (accounting for 78.4 percent of the total organs transplanted this year.)

Living donors contributed 6,723 transplanted organs (21.6 percent). In total, 31,184 organs were transplanted.

This preliminary data (released March 23, 2007) was gathered by the Organ Procurement and Transplantation Network (OPTN), which is operated by the United Network for Organ Sharing (UNOS).

The increase in donation might be due to recent policy initiatives and nationwide educational programs aimed at promoting organ donation.

In 2003, the Health Resources and Services Administration (HRSA) joined with key national leaders to launch the Organ Donation Breakthrough Collaborative, to dramatically increase access to transplantable organs by spreading best known practices. The goal: to achieve organ donation rates of 75 percent in 200 of the nation's largest hospitals.

The success of this collaborative led the HRSA to establish the Organ Transplantation Breakthrough

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Young Artists Sell Work To Help Save a Life



Nancy Spooner's first grade art class at St. Paul's Parish Day School.

Listed at UCLA Medical Center, Carla awaits her chance to receive this gift of life, but she does not wait for much else—spearheading her NTAf campaign to raise funds for her medically-related expenses and fighting to spread the word about the importance of organ donation, all while raising two children on her own and maintaining a strong commitment to her church and her faith.

Nancy Spooner's first grade art class at St. Paul's Parish Day School in Ventura, Calif., thought they could give the active Carla a break. (Nancy heard of Carla's story through a friend. She has never even met Carla.)

“Plug your nose and breathe through a straw,” said Carla Brauer. “That’s how it feels.”

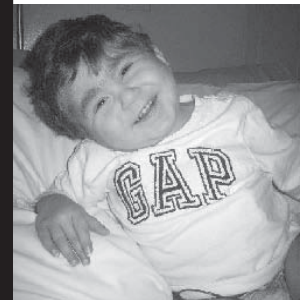
The feeling Carla describes is that of living each day with Chronic Obstructive Pulmonary Disease (COPD)—an end stage lung disease for which she will need a life-saving double lung transplant.

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2006 Annual Report is available:

To read or download, visit the NTAf website (www.transplantfund.org) and click on Publications/Resources.

National Transplant Assistance Fund (NTAF) and Catastrophic Injury Program (CIP)



“your financial link to recovery”

NTAF



Annual Report FY 2006

Oct. 1, 2005 - Sept. 30, 2006

From the Executive Director



25 years is a long time!

As NTAF approaches its quarter century mark, it is appropriate that we take time to reflect on our mission, and the difference we make in the lives of the patients we serve.

Day in and day out, NTAF patient services representatives and financial managers counsel families and communities on the “how tos” of

fundraising for uninsured expenses. Our commitment to help you afford the care you need guides our every action.

As we strive to plan for the future we will be looking to you, our patients, and to you, the professionals who refer us cases, to help us understand how we can better serve you.

You may be asked to participate in a survey and I hope you will take the time to give your candid feedback. Or, just call and let us know how we are doing. We are always looking for additional ways to serve you.

In the last several years we have introduced electronic patient applications, and their popularity

has been unrivaled. To date, we have sent out 269 electronic applications to patients and families that wish to get started fund raising immediately. Electronic communication has the added advantage of allowing the recipient to forward the materials to as many people as he or she wishes. This “viral communication” allows a greater virtual community to support the patient through either online or event-driven activity.

As we seek to respond to long standing patient requests, we are hoping to introduce, in the next several months, a method by which patients or their designees will be able to obtain their contributors lists online.

Technology will continue to give us a multitude of ways to serve patients. The only thing we ask is your patience as we work out any unforeseen kinks in the systems.

Help dream with us and let us know how we are doing.

Best Wishes,

Lynne Coughlin Samson, Esq.

Planned Giving

What is Planned Giving?

What is the secret to making a gift that will benefit both you and NTAF? Part of the answer is careful planning. The best plans are created by deciding what your goals are and determining how to accomplish them.

Planned gifts create opportunities for both NTAF and our contributors. A planned gift from you will help NTAF continue reaching out to patients struggling to afford costly, ongoing medical care. There are a number of easy giving options from which you can choose – from naming NTAF as a beneficiary in your will to more complex tax-advantaged arrangements, such as a trust or insurance policy. A planned gift will allow you to help a cause you feel a passion for in a long-term, meaningful way – a true legacy for the future.

Many people mistakenly think that planned gifts are only for wealthy older citizens. Although certain planned gifts do have minimum financial requirements, others do not. Contributors should consider the financial benefits a planned gift to NTAF can give their family. The benefits to NTAF are certain.

Please call NTAF at 1-800-642-8399 if you are interested in discussing what planned giving options might be best for you. Ask for Lynne Samson.

Patient Reminder

Register on our website to be able to personalize your patient page.

Registering allows you to upload your photo and change the text to tell your story in your own words.

You may also view your guestbook while online, and visit our recently added feature: Message Boards.

**Coming Soon:
Contributors lists accessible online!**

**Visit us on the web:
www.transplantfund.org or www.catastrophicfund.org**

NTAF Moving Forward:

As we approach our 25th Anniversary, and in light of the escalating demand for our help, we are upgrading our technology to better serve you.

We are in the midst of a project to integrate our donor management and accounting functions. One immediate benefit: contributors lists will be available faster than they are now, and will be accessible through patient websites.

Although we have made every effort to avoid glitches, as with any project, there may be some problems along the way. Please be patient as we work through them. The upgrade is part of our ongoing commitment to serve you in a timely, supportive and efficient manner.

Looking Back...
 Dear NTAF:
 You know, I had my lung transplant almost seven years ago now. I received all of your paperwork and just put it aside. I decided I could never bake enough cookies!
 My older daughter, Jennifer, found the papers, filled them all out and just waited for my transplant. The day after my transplant, she typed up a letter telling of my great news, and also about your fund. Little did I realize the friends, family and strangers who heard about my transplant due to the letter and sent in more money than I could have ever imagined!
 Tell those waiting for transplants, that the fund really does work!
 Thank you, Elizabeth C.

National Donor Sabbath

National Donor Sabbath is a weekend dedicated each November to increase awareness of the critical shortage and need for organ, tissue, marrow and blood donation. This year, National Donor Sabbath takes places November 9-11.

Religious organizations of all faiths nationwide collaborate with healthcare communities to raise awareness and encourage individuals to make faith-based decisions to become donors.

Although most religions in the United States view organ donation as an act of compassion and generosity, many people cite religion as a factor for not becoming a donor. Help to change this misconception, by doing your part this Donor Sabbath to encourage people to give the gift of life.

Please contact us, 800-642-8399, to receive National Donor Sabbath materials.

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Banner Year continued from cover

Collaborative in 2005—in an effort to increase the number of organs transplanted per donor to 3.75 or more.

Also, initiated in recent years: the Workplace Partnership, where donation information is made available to employees and members of organizations, corporations and associations of all sizes; and the *12 Weeks Giving* campaign, which resulted in 42,000 new designated donors and reached nearly 750,000 potential donors.

Bellevue Football Team Lifts for Life



The Bellevue High School Football Team, of Bellevue, WA., held a lift-a-thon in May to benefit a local resident in need of a life-saving transplant.

Iliana Romero, a 28-year-old Bellevue mother of three, was diagnosed with Acute Lymphoblastic Leukemia (ALL) in 2005, during her third pregnancy. Iliana endured eight rounds of intensive chemotherapy at Seattle Care Cancer Alliance to combat the leukemia, only to have the cancer reappear in 2006. Her doctors eventually told her that she would need a life-saving stem cell bone marrow transplant.

Without insurance that would cover transplant costs, the Romero family turned to NTAF to fundraise. Their goal: to raise more than \$300,000! Luckily, the Romeros' insurance came through to pay for most of the transplant, but a multitude of expenses still loomed over the family of five, such as: monthly insurance premiums (\$11,000 over eighteen months), donor expenses (travel, hotel, airfare, medication) and post-transplant immunosuppressant medications (up to \$7,000 a month).

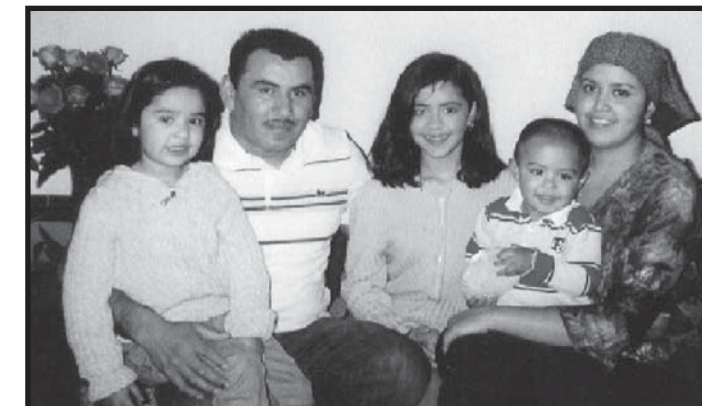
After hearing of Iliana's story through a friend and teacher at Sherwood Elementary, where Iliana's oldest daughter attends school, Wesley Warren, Bellevue Football Defensive Coordinator, decided to get the team

involved.

Wesley developed a four-page informational packet regarding Iliana's story and distributed it to the team.

"The kids could see right away that they were really going to make a difference in helping someone who really needed to be helped, said Wes.

We decided to use the strength and backbone of our football program—weightlifting!"



The Romero family. (Far right: Iliana Romero.)

The eight team captains (for the 2007 season) divided the 60-man roster into teams to tackle eight different sections of the downtown Bellevue Business District for pledges for the lift-a-thon. The team also sought donations going door-to-door in their neighborhoods, as well as asking friends, family members and teachers to

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Will cord blood replace bone marrow transplants?

New Study Suggests It's a Possibility

Transplanted blood cells from umbilical cords appear to offer better results than bone marrow transplants in the treatment of leukemia, according to a new study published in the June 9 issue of *The Lancet*, one of the world's oldest peer-reviewed medical journals.

The study of 785 children under age 16 found an almost equal five-year survival rate from both types of transplants. The benefit of a cord blood transplant: only six antigens need to be analyzed and four need to match, rather than the eight required for a successful bone marrow transplant.

"With cord blood you can find a match for most patients, where with marrow you cannot," said Dr.

John E. Wagner, director of the bone marrow transplant program at the University of Minnesota and lead researcher (*Health Day News*).

Currently, bone marrow matches cannot be found for half of all leukemia patients who need to undergo transplantation, said Wagner.

"From my point of view," he said, "it now demonstrates that cord blood can be considered a first line therapy and not an afterthought.

The take-home message is that when cord blood is so promising, it should have an impact on public policy" (*Health Daily News*).

John's Story

"When the world says, 'Give up,' Hope whispers, 'Try it one more time.'"—Author Unknown

John Merkins, Jr.'s world has said to him "Give up" several times throughout his 34-year existence on this earth, but somewhere along the road, between battling cancer and coming to terms with spinal cord injury, John found the hope to "Try it one more time."

"I'm not living the life that in my dreams I thought I'd be living," said John, "but I am happy with the life I'm living."

And the life he is living has proven to be a model of human endurance at its best, persevering not once, but twice, in the face of misfortune—eventually finding peace and a purpose.

John's Story

At age 16, while at a high school football practice, John felt a pain in his right leg considerable enough to choose to see his family doctor. Little did the healthy 6'2" teen know, this trip to the doctor would change his adolescent years indefinitely.

What was first thought to be just a case of torn ligaments was later diagnosed to be a rare bone cancer, osteosarcoma, a diagnosis that would call for grueling hours of chemotherapy and the removal of John's femur.

"When I was first diagnosed, it didn't really hit me," said John. "I thought, 'When am I going to play football again?' It was hard...I was young, just hoping, looking forward to a bright future."

Unfortunately, John would not play football again; instead, he would spend his adolescence receiving aggressive chemotherapy and surgery, spend a year walking with a cane, and only be well enough to complete two hours of school work a day at home. During this time, John would also be told the cancer had metastasized to his lungs, requiring yet more chemo and leaving John with more lost youth.

"It (chemo) not only kills your bad cells, it runs your

whole system down," said John. "It makes you feel like you are dying."

After a 7-year battle to combat the cancer, at age 22, John finally went into remission.

"The date came up when the doctor said, 'Alright, you don't have to keep making these doctor visits. Come once every five years. You have a clean bill of health,'" said John. "He told me my chances were just as good as anyone else."

I started just wanting to live my life, make up for lost time...do the things I missed out on, just going out with friends and having fun."

But John would only have three months to regain his adolescence, before misfortune would strike again.

While drinking at a party with friends, John, then 23, accepted a ride home from a friend who had arrived late to the party.

"There were three of us (friends together at the party). We were drinking; we knew we couldn't drive," he said. "This person (the driver) had arrived at 11 p.m., we left at 11:15 p.m. He said, 'Of course I'm okay. I told you, I just got off work.'"

The four teens made it two blocks before hitting a side street, where the driver dramatically increased his speed.

"He started laughing, saying, 'I got this,'" remembers John.

John, unfortunately, would never make it home that night.

It would take four hours for the rescue team to pry the teens out of the demolished car, which had bounced off several parked cars, jumped a high curb and flipped a few times, said John. The crime scene investigator estimated the speed of the vehicle at the time of the crash to be between 85-95 mph.

"Every so often I'd feel the bright light on me and I'd blink my eyes," he said, describing the waiting time to be removed from the car. "It was a cold night. I had a warm feeling on my body; I couldn't feel my body."

John was rushed to Thomas Jefferson University Hospital, of Philadelphia, where he would later be told the fate of his world for a second time.



John Merkins, Jr. in a motorized wheelchair, which he controls with his head. He uses a mouth piece to control his phone and computer.

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Carla's story continued from cover

Based on an art history lesson on Claude Monet, Spooner decided to surprise Carla by having the children make ceramic water-lily tea lights and sell them to benefit NTAF Southwest Lung Transplant Fund in honor of Carla Brauer.

"We liked what the lotus/water lily represented," said Spooner. "We thought it was much of what C.J. (Carla) has to go through...The life of a water lily begins at the bottom of the pond with its seeds down deep in the mud. Its focus is to make its way through the muck and mire to bloom on top of the water in full and radiant splendor."

The children also made ceramic bumble bee and ladybug plates, which they sold along with the tea lights at two different venues: The City of Ventura Spring Art Walk in Ventura's Downtown Cultural District and Grandparents Day and Special Friends Day at St. Parish Day School.



The ceramic tea lights were sold for \$20 each and the

plates were sold at \$30 each. The result: \$1,200 in funds raised for Carla.

"We're just very excited to be able to help Carla," said Spooner. "They (the children) just exploded with this. If it was up to them, we would still be making water lilies for C.J."

Once the money was collected and all the pieces sold, the class put together a package for Carla, which included: biographies of all the children, a CD of photos showing the children making the ceramics, a *Most Important Thing* poem, as well as a ceramic fairy necklace for Carla for the days when she isn't feeling well.

"You can just touch it and think of us, and we will love you right back," said Ula, a contributing first-grade artist.

"To look at them, and see their young, happy faces," said Carla... "This book and their bios are all going to California (where she will have her transplant) with me."

As for her fairy necklace: "I'm saving its power for when I don't feel so good," said Carla.



Students making a ceramic baseball trophy for Carla's son Jon because they didn't want him to feel left out.

John's story continued from page 5

"I don't remember the doctor telling me," he said. "Eventually, I guess I realized that my life was never going to be the same, and I was paralyzed literally from the neck down."

The driver escaped the vehicle unscathed. In fact, he left the scene of the accident. He was later found two blocks away with a blood alcohol level twice the legal limit. John has not spoken to the driver since.

"The four of us that were in that car were pretty tight," said John, "I don't have any ill feelings. I know he (the driver) didn't set out to do what he did."

John, now 34, has found a purpose to all of this. While at Inglis Foundation, a facility for adults with disabilities, John discovered that despite his spinal cord injury (SCI), he still had a lot to offer with his mind.

A year to the month that John moved into Inglis, he moved out to lead an independent life and to

spread his found message: "That they can overcome it (SCI). It's not the end of the road."

Since 2000, three years post-injury, John has traveled to youth groups, schools and has been a guest speaker at court-appointed classes for DUI offenders to raise awareness of the dangers of drinking and driving.

"I just feel if I can help touch, motivate one life, then it's all worth it to me to donate my time," said John. "It inspires me to go into these schools. You can hear a pin drop."

I am happy I am making a difference. It's not just going in one ear and out the other. Students are taking notice."

John began his speaking engagements free-of-charge. He now charges a small fee to cover his costs (web page, publications and travel expenses). John is currently fundraising with NTAF for a modified van for his speaking engagements.

For more information on John's story and speaking engagements, please visit his patient page at www.catastrophicfund.org or his personal site <http://www.johnsvoice.net>.

Lift for Life continued from page 4

contribute. The team raised \$7,000 through their efforts.

“Finally, what made the event really special was watching the expressions on the players’ faces when Iliana’s sister spoke to them and thanked them at the conclusion of the lifting,” said Wes. “It isn’t often that young people are faced with an opportunity to help someone like Iliana and the Romero family. However, it was quite evident that Iliana’s story, and the overwhelming support shown by all those who know and love Iliana, truly inspired the 2007 Bellevue High School Football team to look at the bigger picture in life, and strive to be great players on the field, but even better people off of it.”

Community Choice Act

Introduced by Sen. John Harkin (D-Iowa) in March 2007, the Community Choice Act builds on the “*Money Follows the Person*” concept to make changes to the federal Medicaid laws to put an end to the forced institutionalization of people with spinal cord injuries, diseases and other disabilities living in the United States (More than 2 million people are currently residing in nursing homes and other health facilities and institutions.)

As stated by 1)ADAPT, a leading proponent of the bill, “The Community Choice Act provides an alternative and will fundamentally change our long-term care system and the institutional bias that now exists. Once they are deemed eligible for the institutional services, people with disabilities will be able to choose where and how they receive services.

1) ADAPT (www.adapt.org/) focuses on promoting services in the community instead of warehousing people with disabilities in institutions and nursing homes.

Scientists making progress in study of stem cell research

Scientists have long awaited a solution to the controversial embryonic stem cell issue. A recent study offers hope that an alternative solution may one day be found.

Three independent teams of scientists recently reported producing the equivalent of embryonic stem cells in mice using skin cells. If this could be replicated in humans using human skin cells, and scientists stress the *IF*, it would be a huge advance for medical treatments.

Bush Pairs Veto With New Cell Initiative

As expected, President Bush vetoed a measure promoting embryonic stem cell research June 20, making this his second veto on the stem cell issue during his presidency.

Just as Bush vetoed the measure, he introduced a new cell initiative. The goal: to promote research into producing cells with properties like those of human embryonic stem cells without destroying embryos in the process. Bush issued an executive order directing the Health and Human Services Department to promote research into such cells.

As stated by domestic policy adviser, Karl Zinsmeister, to the *The New York Times*: “This is a product of a lot of really hard, earnest work on this policy. It is a real sincere effort to open up a new scientific solution to a vexing problem.”

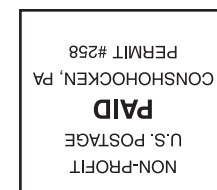
But advocates for stem cell research are not convinced this initiative has any real value. Why? Research of this kind already exists and there is no “new” money attached to this initiative.

Parts to the Initiative:

- The registry of embryonic stem cell lines eligible for research with federal tax dollars will be reconfigured as the “human pluripotent stem cell registry,” with the intention of allowing other types of stem cells to become eligible for federal financing if they have the same properties as embryonic stem cells.
- Order Michael O. Leavitt, secretary of health and humans services, to support alternative techniques and develop a plan detailing how to go about getting new stem cell lines approved for the registry.

Though experts are encouraged by the achievement, further study is needed, and research into embryonic stem cells should not be abandoned.

Researcher Konrad Hochedlinger, who led one of the three teams involved in the study, said, “We simply don’t know which approach...will work the best.”



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