

Share Your Life
Share Your Decision

Life.....Pass It On!

- TSL's 12th Annual Walk-A-Thon—April 22, 2007—Save The Date!!!
- **LIFE: LOVE IT, LIVE IT, GIVE IT!!**



April, 2007

Transplants Save Lives, Inc.

SUNDAY, APRIL 22, 2007
9:45 am SIGN IN 10:30 am WALK
ROCKLAND LAKE STATE PARK
TSL'S 13TH ANNUAL
WALK-A-THON
Free Gifts to first 300 People,
Free Refreshments
ALL FREE
No Cost to Participate
DAVE JENNINGS, Sportscaster and former
All-Pro Punter for the NY Giants and Jets
Bring your Family & Friends
IT IS A WONDERFUL DAY!!



Inside this issue:

| | |
|--------------------------|------|
| TSL's Schedule of Events | 2 |
| Transplant Anniversaries | 3 |
| Members' Corner | 4 |
| Theatre Benefit | 3 |
| Membership Dues Notice | 5 |
| In The News | 8-11 |

TSL'S SCHEDULE OF EVENTS

Mark Your Calendars!



APRIL 22, 2007

13TH ANNUAL WALK-A-THON
ROCKLAND LAKE STATE PARK

MAY 30, 2007

TAKE ME OUT
ELMWOOD THEATRE BENEFIT
Pre-Theatre Dinner at Amici's

JUNE 28, 2007

DINNER MEETING

JULY, AUGUST, 2007

BREAK FOR THE SUMMER

SEPTEMBER, 2007

FIRST ANNUAL GOLF OUTING



Reserve these Dates on your Calendars!

Contact a Board Member with Topic/Speaker Recommendations

**APRIL 22, 2007 TSL'S 13TH ANNUAL WALK-A-THON
CELEBRATE LIFE! TRANSPLANTATION WORKS!**

TRANSPLANTS SAVE LIVES, INC.

We are a non-profit organization for transplant recipients and their families, donor families, and people waiting for transplants and their families. We meet on a monthly basis at Good Samaritan Hospital in Suffern, NY. These meetings are a combination of support and keeping our members up-to-date on all issues of transplantation. Speakers represent all facets of organ donation and transplantation and are foremost in their field. We also enjoy social events together throughout the year.

We Look Forward to Seeing YOU at our Meetings!

**Transplants Save Lives, Inc.
Board of Directors**

| | | | |
|----------------------------|--------------|-------------------|--------------|
| Barbara Blumenthal, spouse | 845-352-5099 | Sue Negrin, heart | 845-627-2240 |
| Nicholas Cinalli, liver | 845-353-3062 | Rick Pascarella | 845-215-5137 |
| Patricia Malone, kidney | 845-354-9737 | Farrah Negrin | 845-627-2240 |

WHO MAKES UP TRANSPLANTS SAVE LIVES, INC.?

WHAT TSL'S PAID MEMBERSHIP LOOKS LIKE TO DATE:

- | | |
|---|-----------------------------------|
| KIDNEY TRANSPLANT RECIPIENTS | LIVER TRANSPLANT RECIPIENTS |
| HEART TRANSPLANT RECIPIENTS | DOUBLE LUNG TRANSPLANT RECIPIENTS |
| CORNEA TRANSPLANT RECIPIENTS | KIDNEY DONORS |
| DONOR FAMILIES | FAMILIES OF TRANSPLANT RECIPIENTS |
| CANDIDATES FOR TRANSPLANT AND THEIR FAMILIES | |
| SUPPORTERS OF ORGAN AND TISSUE TRANSPLANTATION AND DONATION | |

INDIVIDUAL MEMBERSHIPS; FAMILY MEMBERSHIPS

HAVE YOU SENT IN YOUR DUES?

What We Do, Does Make A Difference

Members' Corner

Thank you to **Nicholas Cinalli**, liver transplant recipient, and **Susan Negrin**, heart transplant recipient, for being interviewed on the Steve and Sophia Show on WRCR AM Radio and on Ramapo Town Supervisor Christopher St. Lawrence's Television Show.

Congratulations to new grandmother, **Barbara Blumenthal**, board member, on the birth of her granddaughter, Chelsea..

Congratulations to **Farrah Negrin**, board member, on her recent engagement to David Weitzner.

This newsletter is brought to you through the generosity of **Mr. Gregg Farrell Brie**
1-866-I Don't Know, Inc.

What is I Don't Know, Inc. and How Can It Help You?

I Don't Know Inc. is a free information service. You speak to live operators 24 hours a day, 7 days a week who will assist you in locating services and any other information you need. Finding the greatest merchants and suppliers in the county doesn't have to cost you time and money.

CALL: 1-866-436-6856

You will receive names of people, services to contact.

Any Question Answered.....Any Time.

Any questions, call: 1-866-436-6856

1-866-I DON'T KNOW

GET READY TO WALK ROCKLAND LAKE! TSL'S 13TH ANNUAL WALK-A-THON, SUNDAY, APRIL 22, 2007! BRING YOUR FAMILY & FRIENDS!



THE FIRST 300 PEOPLE TO SIGN IN WILL GET THIS NEW CAP IN LIME GREEN WITH THE DONATE LIFE LOGO ON THE FRONT AND TRANSPLANTS SAVE LIVES ON THE BACK!

LIFE: LOVE IT, LIVE IT, GIVE IT!

NOTICE OF TSL MEMBERSHIP DUES

It is that time of year again when membership dues need to be remitted.

No increase has been taken in the membership dues!

A family membership is \$25

A single membership is \$15

Fill out the form below and send it back with your check to:

TSL P O Box 516 Nanuet, NY 10954

This notice is in lieu of receiving a separate membership dues notice to save on postage.

Name: _____

Address: _____

Telephone: _____

E-Mail Address: _____

Transplant/Hospital/

Anniversary Date: _____

Occupation: _____

| | | |
|--|--|---------------------------|
| I would like to be involved with: | Membership | Website |
| Monthly Speakers | Special Projects | Publicity |
| Speaking Engagements | Board of Directors | Monthly Newsletter |
| NYODN | Greater NY area Coalition on Donation | |

Be An Advocate for Organ and Tissue Donation

Join the TSL Family!

They say it takes a community to help raise a child — it takes a member of TSL to help raise the awareness in our community!

SPONSORS FOR THE 13TH ANNUAL 2007 WALK-A-THON

To date:

**ASTELLAS PHARMA
NOVARTIS PHARMACEUTICALS
ORANGE & ROCKLAND UTILITIES, INC.
CABLEVISION
I DON'T KNOW, INC.
WESTCHESTER MAGAZINE
NEWS12 HUDSON VALLEY
IRA WICKES ARBORISTS
DEBBIE MCGUINNESS STATE FARM INSURANCE
AL SEDOTTO MEMORIAL FUND
MAC ALBUS SCHOOL OF KARATE
LIFE IS GOOD
SNYDER SNACKS
BARRETT DISTRIBUTORS WISE CHIPS
MARTINS BREAD
GLASS GARDEN SHOPRITE
PATHMARK
WRCR RADIO ROCKLAND
SUPERVISOR CHRISTOPHER ST. LAWRENCE'S T.V. SHOW
COSTCO
FRIEHOFERS
NEW YORK ORGAN DONOR NETWORK**

**A FULL LISTING OF SPONSORS WILL BE DISPLAYED AT THE
WALK-A-THON AND PRINTED IN TSL'S MAY, 2007 NEWSLETTER!**

LIFE: LOVE IT, LIVE IT, GIVE IT!

KAISERNETWORK.ORG. 3/23/2007

[CMS](#) on Thursday announced new standards for organ donation programs that would remove federal funding from failing programs, the [Los Angeles Times](#) reports. The rules, which took two years to finalize, aim to prevent "poor or marginal performers" from receiving Medicare funding, according to a report that accompanied the new rules. Under the new rules, transplant programs would be required to do the following to continue to receive funding:

- Perform an average of 10 transplants a year;
-
- At least match expected survival rates, accounting for the national average and unique situations in programs and patients;
-
- Reveal to potential recipients how many patients and organs have survived or functioned at least one year after surgery, along with how many were expected to do so;
-
- Notify patients in programs with only one transplant surgeon that the surgeon might not be available at the time of the transplant, in addition to stating whether provisions have been made to find a substitute surgeon (Weber/Ornstein, *Los Angeles Times*, 3/23);
-
- Use donor advocates to inform living donors about medical and psychological risks; the surgical procedure, including post-operative treatment; and availability of alternative treatments for the recipient;
-
- Use donor advocates to inform living donors that donation-related future health problems might not be covered by the donor's health insurance and that they might have problems obtaining health, disability or life insurance in coming years (Meckler, *Wall Street Journal*, 3/23); and
-
- Immediately alert Medicare if the program is not meeting these standards.

Under old rules, which were not strictly enforced, heart and liver centers were required to perform 12 transplants annually; lung and intestine centers were required to perform 10; and kidney centers had to perform 15 transplants within four years of opening. Centers also had to meet set survival rates without taking into account complicating factors. A *Times* analysis determined that if the new rules were strictly applied today, 64 transplant centers -- nearly 13% of the nation's 500 programs -- would lose approval and funding, including 29 centers for heart transplants, 21 for kidney, seven for liver, six for lung and one for intestinal transplants.

Implementation

The CMS transplant rules will take effect in 90 days. Centers will have six months to seek approval of their programs, and those that do not meet the minimum requirements will have a "reasonable time period" to correct problems. Once approved, centers will be up for review every three years. Medicare officials expect 2% of centers, or 10 per year, to lose certification (*Los Angeles Times*, 3/23). Leslie Norwalk, acting administrator of CMS, said, "This is a major milestone in our efforts to make sure that people needing transplants get the best possible care" (*Wall Street Journal*, 3/23).

KAISERNETWORK.ORG. 4/3/2007

DOJ ISSUES MEMO ALLOWING KIDNEY PAIRED DONATIONS

The [U.S. Department of Justice](#) on Wednesday issued a memo stating that federal law does not prevent kidney paired donations, a procedure in which donors give a kidney to an unrelated recipient in exchange for a relative or loved to receive a kidney from another donor, the [Baltimore Sun](#) reports. The procedure was developed at [Johns Hopkins Hospital](#) in 2001, and so far, about 140 have been performed. The practice has "remained rare" because of the 1984 Organ Transplant Act, which made it illegal to donate an organ for "valuable consideration," the *Sun* reports. The original intent of the law was to prevent people from buying and selling kidneys. According to the memo, nothing in the law prevents kidney paired donations. The memo will be posted on the DOJ Web site on Tuesday. About half of the 6,000 people waiting for a kidney could receive one as a result of the ruling, according to Robert Montgomery, an associate professor of surgery and director of [Hopkins' Comprehensive Transplant Center](#). William Lawrence, director of patient affairs for the [United Network for Organ Sharing](#), and Montgomery said they are optimistic that Congress will pass [legislation](#) that would specifically allow kidney paired donations. The House and Senate have approved such measures, but differences in language must be resolved, according to Lawrence. Richard Freeman, chair of the legislative committee of the [American Society of Transplant Surgeons](#), said, "It's going to make [a] dramatic difference in removing barriers we've all faced trying to perform paired transplants" (O'Brien/Emery, *Baltimore Sun*, 4/3).

MAN HAS 3 HEARTS IN 1 MONTH. LEAVES HOSPITAL. 46-YEAR-OLD HAD ARTIFICIAL HEART BEFORE RECEIVING DONOR ORGAN. ASSOCIATED PRESS. 3/23/2007.

PHILADELPHIA - A 46-year-old man whose body was powered by three separate hearts in the span of a month walked out of the hospital Thursday and said he felt like competing in a triathlon. "I feel like a million dollars, actually," said patient Gary Onufer. "I feel like a whole new person." Accompanied by his wife and hospital staff, Onufer took slow steps out of the Hospital of the University of Pennsylvania as a donor heart beat in his thin frame. The organ replaced a temporary "Total Artificial Heart," a mechanical device that doctors said Onufer was the first person to receive in the Northeast.

"I feel like I could do a triathlon right now," said Onufer, an insurance agent from Ambler. Onufer was "deathly ill" when he arrived at the Penn hospital in early February, said Dr. Michael Acker, one of his surgeons. Though doctors still aren't sure why, the seemingly healthy and active man was suffering from congestive heart failure and needed a new organ.

Most patients in that situation would have a device implanted in their ailing hearts to keep them alive until a donor can be found, health officials said. But doctors thought Onufer's heart, even with artificial help, was too weak to last the two months Acker said is normally needed to find a donor. So they asked Onufer if he wanted to be a pioneer of sorts by undergoing the region's first implant of the Total Artificial Heart, made by Arizona-based SynCardia Systems. Onufer said yes. "My choices were very limited," he said Thursday. "I would have slowly died." The apparatus, approved by the federal Food and Drug Administration in October 2004, is a modern version of the one invented by Dr. Robert Jarvik and first implanted in a patient 25 years ago.

For Immediate Release
Office of the Press Secretary
March 28, 2007

National Donate Life Month, 2007 **A Proclamation by the President of the United States of America**

Donating organs, marrow, and tissue is a kind and compassionate act that can protect and enhance the precious gift of life. During National Donate Life Month, we recognize the generosity of donors and raise awareness of the importance of donating.

In recent years, there has been great progress in this important effort, and the rate of organ donation has steadily increased -- helping save thousands of lives. Despite this success, more than 95,000 Americans currently await organ transplants, and hundreds more are added to the transplant list each month. My Administration strongly supports organ, marrow, and tissue donation, and we are working with public and private groups to help more citizens understand the impact of organ donation.

Americans who wish to become organ and tissue donors can register with their State's donor registry, designate their intent on their driver's license, and sign and carry donor cards, which are available at organdonor.gov. I urge all citizens to consider becoming donors and encourage all donors to inform their loved ones of their decision so their wishes can be fulfilled. Every human life holds inherent dignity and matchless value, and National Donate Life Month is an opportunity to celebrate our country's organ and tissue donors. The decision to donate the gift of life demonstrates the compassionate spirit of our Nation.

NOW, THEREFORE, I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim April 2007 as National Donate Life Month. I call upon health care professionals, volunteers, educators, government agencies, faith-based and community groups, and private organizations to help raise awareness of the urgent need for organ and tissue donors throughout our Nation.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty-eighth day of March, in the year of our Lord two thousand seven, and of the Independence of the United States of America the two hundred and thirty-first.

GEORGE W. BUSH

WWW.TRANSPLANTSSAVELIVES.COM

'A STRANGER'S HEART,'

A HALLMARK ORIGINAL MOVIE
PREMIERING SATURDAY, MAY 5

Peter Dobson, Kevin Kilner and Mary Matilyn Mouser Also Star In
The Inspiring Story About Living in the Moment

(HealthNewsDigest.com) - Samantha Mathis stars as a young woman who gets a new lease – and a new outlook – on life after receiving a heart transplant in "A Stranger's Heart," a Hallmark Original Movie premiering Saturday, May 5 (9/8c). She rethinks her workaholic lifestyle, and finds a chance at happiness with a fellow transplant recipient, played by Peter Dobson. Although the film portrays individuals who received a single organ from a donor, up to eight lives can be saved from one donor, a remarkable legacy for any one person to leave.

More than 90,000 patients currently await a life-saving organ transplant. An average of 19 people die each day because not enough organs are available to meet the need. Procedures vary from state to state, but online registration is available in many states. Demand for transplants among minority populations is disproportionately high and traditional minority representation among donor pools needs to be strengthened.

Samantha Mathis ("An American President,") and Mary Matilyn Mouser ("NCIS",), star as a woman who gains a new perspective on life after receiving a heart transplant and the young girl whose mother was the donor, in "A Stranger's Heart", a Hallmark Original Movie premiering Saturday, May 5 (9/8c). Peter Dobson ("Forrest Gump") also stars.
Photo: Eric McCandless/© 2007 Crown Media.

Premiering Saturday, May 5th

Missed Opportunities: The Institute of Medicine Report: Organ Donation: Opportunities for Action

By **Richard J. Howard** Am J Transplant. 2007;7(1):14-16. ©2007 Blackwell Publishing Posted 03/23/2007

The shortage of organs is *the* problem confronting transplantation. Patients are being added to the waiting list — currently one every 11 min — at a faster rate than organ procurement organizations (OPOs) can recover donor organs.^[1] In 2004 the Department of Health and Human Services (DHHS) and the Greenwall Foundation asked the Institute of Medicine (IOM) to review 'the current efforts and proposals to increase organ donation from deceased donors, including but not limited to educational activities, media campaigns, financial incentives, and presumed-consents From these meeting they generated the report: Organ Donation: Opportunities for Action. Four principles guided the committee as it considered various options.^[3] The first is a trustworthy system. A trustworthy system is also a completely transparent system. The second principle is appeals for donation should be based on such acceptable motivations for donation such as altruism, community spirit, and reciprocity. Other acceptable motives include a sense of obligation, a desire to find redemptive meaning in a tragic situation, and a desire for praise and honor. The third principle is respect for persons: (1) respect for the dignity of each individual; (2) respect for the right of everyone to govern the disposition of his or her body after death, including whether to donate organs for transplantation; (3) respect for cultural and religious practice concerning the remains of human beings; and (4) respect for the wishes of families. The final principal is fairness. Policies and practices designed to increase the organ supply need to be fair in the distribution of both benefits and burdens, with particular attention to their impact on disadvantaged groups. It is not surprising that ethical considerations carry such great weight in this report. The report is helpful in discussing virtually all aspects of efforts and proposals to increase deceased organ donation. Much of the report, however, is disappointing in that the committee seems to have lost sight of the goal of organ donation: to save the lives of those in need. The committee appears to have been dominated by ethicists, and their views of ethics, in turn, dominated the deliberations. But is it ethical to continue to permit patients to die waiting for organs when their lives might be saved? The IOM report does note the number of individuals dying on the waiting list, but evidently the committee gave only minimal ethical weight in their deliberations to individuals who die due to lack of an organ. In view of the great need it was disappointing that the committee was unwilling to take any risks to increase organ donation. In many places the document says that many considerations are not proved or established and that more data are needed before various actions can be tried or permitted. And yet the committee is against

**JOIN TSL
FOR OUR
13TH ANNUAL
WALK-A-THON
SUNDAY
APRIL 22, 2007
9:45 AM SIGN-IN
10:30 AM WALK
ROCKLAND LAKE
STATE PARK
NORTH PARKING LOT**



organ donation would work in the United States. Even the American Medical Association Council on Medical Ethics is in favor of a pilot project of presumed consent.^[8] Presumed consent and incentives for donation may not work in this country. One or the other might cause a backlash that would result in decreased organ donation. On the other hand, they might also increase organ donation. But without any data, we will continue to act blindly and will still be having a debate about these efforts years from now.

The committee thought that presumed consent would exploit the poor who would donate but might not have access to transplantation because of inadequate health insurance. Certainly it is shameful that many citizens do not have access to transplantation in the richest country on earth, which spends more on health care than any other country. But should this be a reason for the poor not to participate in presumed consent? If the committee was so concerned about the ethical issues involved in this exploitation of the poor, should they not have suggested that OPOs inform potential donors or their families that while they can donate, they would be unlikely to be transplanted if they were in need?

One of the committee's justifications for ruling out financial or other incentives is that they might crowd out altruism. Certainly, we think of altruism as a more praiseworthy motive than taking incentives for organ donation. If we are to increase organ donation and incentives might work, however, who is to say that altruism is such a worthy motive that others should not be allowed or even tried? Unless we are willing to try a pilot program we will never find out if incentives will work. Do we so value altruism—even above saving more lives through transplantation—that we should not even try a pilot program to see if incentives work? Evidently the committee believes this is indeed the case, since they are against even trying a pilot program. It should be noted that even trying a pilot program involves some risks. Such a trial would be difficult. If such a program were unsuccessful, it is not assured that we could go back to the way things were previously. Future donors might expect payment as a matter of course.

One of the more troubling statements of the report is: 'one result of the current supply–demand approach is the perception that the goal of the donation request process is to get *consent* rather than to offer the dying patients or their families the *opportunity* to consider donation as a natural part of dying and death'.^[12] It is troubling because the IOM committee suggests that OPO personnel should merely tell donors and their families about donation and transplantation without trying to get them to agree to donation. But the job of organ procurement coordinators who ask for permission to recover organs for transplantation is to get the families to agree to donation by offering the family information on organ donation that will lead to a decision to donate. The interaction between coordinators and families must, of course, be done with great care, understanding, and empathy. Coordinators are taught how to approach families, and organ procurement organizations develop strategies to encourage donation and to get potential donors and families to agree to donation. The Organ Donation Breakthrough Collaborative was designed to share and improve these strategies. The committee is in favor of informed choice rather than informed consent, because 'the decision concerns the disposition of the body after death rather than the survival or the quality of life of a living person', although it is difficult to discern precisely what the difference is.^[13] The goal of the coordinator is more than to merely give the family the opportunity to consider donation, and it should be.

Despite its shortcomings on the issues of presumed consent and incentives, the report has a great deal of good advice and recommendations that the transplant community would be good to heed. Public awareness and education are never-ending responsibilities of the transplant community. More attention should be paid to making donation an end-of-life consideration. We must strive to make transplantation a more trustworthy endeavor, especially in view of several recent negative articles in the newspapers. We must also convince the public that allocation of organs is fair. DCD, although many transplant centers are now using organs from these donors, can still be further increased. All avenues to increase organ donation must be tried simultaneously. The DHHS and the Greenwall Foundation are to be applauded for asking the IOM to undertake a thorough review of organ donation. In the end, the committee essentially recommends we maintain the *status quo*. It has much faith that the Organ Donation Breakthrough Collaborative will go a long way toward solving the donor shortage. It could have taken risks, such as suggesting the National Organ Transplantation Act be amended to permit a trial of incentives or that presumed consent be tried in some places. Much remains to be done.

Dreaming the Big League Dream, Again. Drafted by the Reds, a Prospect Soon Learns He Needs a New Kidney. THE NEW YORK TIMES. April 5, 2007. By Pat Borzi.

His red uniform top and white pants hid the fist-sized lump on his right hip and the surgical scar across his abdomen. Occasionally, Carson Kainer said, another player notices the scar and asks about it. Then he shares his remarkable story. Last Sept. 12, Kainer had a kidney transplant. His father was the donor. Kainer, 22, is believed to be the first person to play professional baseball with a transplanted kidney. Kainer learned he needed the transplant two weeks after the Reds chose him in the 14th round of the draft last June, and the day before he was set to sign a contract. The surgery went well, the Reds remained interested and Kainer signed a contract in October. Like most transplanted recipients, Kainer takes daily antirejection medication and takes precautions for a diminished immune system. Besides washing his hands frequently, Kainer makes his own lunch to control his salt and nutritional intake. He wears a molded plastic pad when he plays to protect the kidney. The Reds, being cautious, gave Kainer his own hotel room and his own row of lockers in the clubhouse.

ELMWOOD THEATRE BENEFIT

WEDNESDAY, MAY 30, 2007

TAKE ME OUT

CONTACT NICK CINALLI: 845-353-3062 FOR TICKETS

Transplants Save Lives, Inc.

P. O. Box 516
Nanuet, New York 10954

Phone: 845-627-2240
Fax: 845-627-7804
E-mail: newheart93@aol.com

*What We Do Does Make
A Difference*

