



Heart of a champion  
Remarkable patient  
meets donor's family



James Redford  
Shares the  
beat!

**MEDIA  
PLANET**

DECEMBER 2010

# DONOR AWARENESS



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TIPS

## YOUR GUIDE TO THE GREATEST GIFT

At the National Kidney Foundation Transplant Games, **Larry Hagman** gives back

MAIN: NATIONAL KIDNEY FOUNDATION  
TOP LEFT: JOHN MANIACI, UW HOSPITALS AND CLINICS  
TOP RIGHT: DAN STEINBERG

In **10 minutes**, another person will be added to the organ transplant waiting list.  
In **30 seconds**, you can register to be a lifesaving organ donor at **GiftofHope.org**.

**gift of hope**<sup>SM</sup>  
Organ & Tissue Donor Network

## CHALLENGES

**The first organ transplant ever** performed was a kidney transplant from one identical twin to the other in 1954.

## Giving the gift of life

Since that time, the field of transplantation has rapidly evolved to include liver, intestine, pancreas, heart and lung transplants. As expected, the growth of the field has led to an ever-increasing number of people who need organ transplants, yet there are not enough good organs available.

According to the Organ Procurement and Transplantation Network (OPTN), more than 110,000 people in the United States are waiting for a solid organ transplant, and more than 1,900 of those waiting are children. By comparison, only around 30,000 transplants are performed each year. Every 11 minutes, another name is added to the waiting list, and 18 people die every day waiting for a transplant.

**It takes one decision**

Organ donors have the ability to save or improve the lives of as many as 50 people. Giving the gift of life can also serve to lessen the grief of the donor's own family who will know that the loss of their loved one has saved the lives of others.

To become an organ donor, those interested can register with their state donor registry. Most states, but not all, have donor registries. For more information about a particular state, visit [www.organdonor.gov](http://www.organdonor.gov). You can also choose to designate your decision on your driver's license when you obtain or renew your license. Until you are able to designate your decision on your driver's license or join a donor registry, be sure to carry a donor card with you that states your intentions.

Finally, organ donors should talk to their families about their decision to be an organ donor. Help



**Maryl R. Johnson, MD**  
President, The American Society of Transplantation (AST); Medical Director, Heart Failure and Transplantation, University of Wisconsin Hospital and Clinic

“Organ donors have the ability to save or improve the lives of as many as 50 people.”



them understand your wish before a crisis occurs. This will ensure they are prepared to serve as your advocate for donation.

**Living donors**

The annual number of available deceased donors will not solve the ongoing shortage of organs for transplantation. Fortunately, receiving an organ from a deceased donor is not the only option. Patients in need of some transplants, most commonly a kidney or liver transplant, may also receive an organ from a living donor. Living donors offer an alternative to patients waiting for an organ from a deceased donor.

Anyone interested in being a living organ donor must be in good health. You may not be able to donate if you have high blood pressure, diabetes, or other health problems or if giving an organ puts your long-term health at risk.

## Getting your second chance at life

## INSIGHT

**I worked as a Registered Nurse in Illinois for over 17 years, in Pediatric Intensive Care.**

I was diagnosed with Idiopathic Cardiomyopathy in 1996 and had three Implanted Cardiac Defibrillators (ICD) over the next 10 years, which saved my life several times.

In January 2007, I had open heart surgery for valve repair. To save



**Rachel Angela Moore**  
Heart recipient

my life the doctors implanted a mechanical heart pump (LVAD), hoping my heart would repair itself. Nine months later, the doctors suggested a heart transplant evaluation. In November 2007, I was evaluated at Emory University Hospital in Atlanta, GA., and put on

the heart transplant waiting list.

A heart match is complicated and includes more than matching your blood type. I was told the wait period would be approximately four-six months. However, due to the very small percentage of African-American donors as well as other factors, I waited 14 months. In January 2009, I was very fortunate to receive the gift of a new heart.

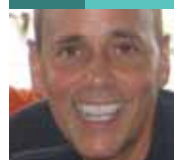
My hope is that organ donation education, awareness and registration would increase, especially

among the African-American population.

I am thankful to the Lord, the donor family, the medical community, my family and friends and the National Foundation for Transplants (NFT) organization. What else can you say to those who are responsible for your second chance at life?

Since my heart transplant 21 months ago, “Blue Skies” have been smiling at me. I can breathe easy, exercise, cook, and sing again. How wonderful is that?

## WE RECOMMEND



**Jeffrey Arnovitz and associates** discuss the role of transplant coordinator.

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## MY BEST TIPS



**David Bosch**  
Communications Director, Gift of Hope Organ & Tissue Donor Network

- 1 Register your decision to be an organ and tissue donor at [giftofhope.org](http://giftofhope.org) or your local Organ Procurement Organization.
- 2 Encourage your friends, family members, neighbors and work associates to do the same.
- 3 Share your decision to be an organ and tissue donor with friends and family members during holiday gatherings.



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## INSPIRATION

# Man with reversed organs finds heart transplant through multiple listing

■ **Question:** What is situs inversus?

■ **Answer:** A congenital condition where all of the organs in the chest and abdomen are reversed.

## HOW I MADE IT

Jack Eigel was born different. You might say, in fact, that he was born lucky.

Eigel has a rare condition called Situs Inversus, which means that all of the organs in his chest and abdomen area are reversed. The condition affects less than one in 10,000 people around the world, many of whom are able to lead completely normal lives despite their condition.

Eigel thought he was one of those people. He had a relatively normal, healthy childhood, and had no related complications throughout most of his adult life.

Then he had a heart attack.

### Out of the blue

"I had a cardiac arrest out of the blue after I turned 50. I was at home where, thank god, my partner Ryan found me. The paramedics came, everything worked out at the hospital, and I was able to recover quickly. Before too long I was able to go back to work."

Eigel was in good shape for a year when his health began once again to decline.

He returned to Milwaukee's Froedtert & Medical College of Wis-

consin complaining of shortness of breath, and was told that his heart was failing and that he would need a transplant.

### Astronomical odds

With astronomical odds of finding another Situs Inversus heart donor, Eigel and his doctors focused on finding a compatible heart donor and the surgical expertise to work with his unusual condition.

His doctors advised him to try multiple listing, which involves registering on the wait list at two or more transplant centers.

For Jack, it was the right suggestion. In addition to Froedtert in Milwaukee, he was put on the wait list at the University of Wisconsin Hospital and Clinics in Madison.

In just nine months, he was able to locate a suitable heart.

"By being listed at multiple transplant centers, patients can get an organ earlier. Some centers, like UW for example, have a much shorter wait list than other centers," according to Dr. Niloo Edwards, Chairman of Cardiothoracic Surgery at University of Wisconsin Hospitals.

### Miraculous transplant

Edwards performed the harrowing six-hour transplant procedure, and the results were nothing short of miraculous.

"The biggest challenge was actually putting the heart in. It was like trying to think like Davinci, but in mirror images. It was a technically difficult surgery," said Dr. Edwards.

Eigel has recovered well enough to compete as a swimmer in the most recent National Kidney Foundation Transplant Games in Madison this summer, winning a bronze medal in the 100M breaststroke.

At the games he was able to meet his heart donor Christopher Ramsey's family, and he hopes to continue to honor them in the next Transplant Games.

"It turns out that Chris was himself a competitive swimmer who swam the butterfly, so my goal is to learn that and win a bronze in his honor. His family are such wonderful and supportive people. I've really been blessed."

**RICHARD SHARP**

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INSPIRATION



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TALK TO  
LOVED ONES



A shared  
connection

\* For the first time, Jack Eigel is able to thank the mother of his heart donor, Janet Ramsey, as she listens to her son Christopher's heart beating.

PHOTO: JOHN MANIACI, UW HOSPITALS AND CLINICS

## NEWS

**Question:** What has Larry Hagman been doing since “Dallas”?

**Answer:** Advocating for life-saving organ donations.

TIP

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SPREAD THE  
MESSAGE

# CELEBRITIES GET BEHIND THE FIGHT FOR DONOR AWARENESS



**A LEGACY OF GIVING**  
James Redford pauses for a photo with father Robert at the annual Share the Beat event.

PHOTO: SHARE THE BEAT 2003



In the wildly successful 1980's TV series “Dallas,” Larry Hagman played the nefarious and cut-throat larger-than-life Texas oil man J.R. Ewing, whose sole purpose in life seemed to be the pursuit of filthy oil lucre and making his rivals' lives a living hell.

These days Hagman is applying his booming voice to a far more noble pursuit—advocating for organ donation and transplantation on behalf of organizations like the National Kidney Foundation.

“About 110,000 people are currently waiting for life giving organs and there's great competition to get them,” said Hagman.

### Hagman's transplant

The recipient of a life-saving liver transplant himself in 1995, Hagman understands firsthand the need for organ donation, and for increased education about transplantation.

“There is a great lack of information out there about organ transplantation. One person can save seven lives. And what are you going to do when those people pass on? Don't take your organs to heaven—leave them here where other people can use them.”

Hagman is vocal about the need for those who are on the waiting list to receive transplants to take the necessary steps to maintain



“It's important to me that I remain dedicated to raising awareness for the cause.”

PHOTO: DAN STEINBERG

Awareness (JRI), a nonprofit dedicated to educating the public about the need for organ and tissue donation through film, educational outreach and the web.

After receiving a life-saving liver transplant in 1993, Redford went on to produce *The Kindness of Strangers*, an award-winning HBO documentary film.

“I first went public with a film that captured ordinary people making extraordinary choices to donate life. I went public with my own story in order to increase awareness of the film and its primary focus—raising awareness for organ donation.”

Through his non-profit, Redford is actively involved in Share the Beat, an annual event held in collaboration with the American Society of Transplantation that uses music and storytelling to raise awareness and funds for the benefit of the transplant community.

As with Hagman, for Redford it's all part of honoring transplant donors and educating the public about why organ donation is so important.

“It's important to me that I remain dedicated to raising awareness for the cause. My hope is that events like Share the Beat will help provide others the same gift of life I was lucky enough to receive.”

their health in order to assure a successful procedure.

“Exercise as much as you can, quit smoking, of course, because you will be under sedation for a long time and your lungs need to be in good shape. Although you will feel tired all the time, you have to keep exercising no matter how tired you feel. Staying in good shape will help a lot more than you think,” said Hagman.

### Redford's gift

Hagman is not the only one using his famous name to help raise awareness for organ transplantation.

Robert Redford's son James Redford is Founder of The James Redford Institute for Transplant

RICHARD SHARP

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# PANEL OF EXPERTS



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**Question 1:**  
What is the greatest challenge to overcome to achieve higher rates of organ donor participation nationwide?

**There is a critical shortage** of organs available for transplantation in the United States. Each month hundreds of people are added to transplant waiting lists, and thousands of potential recipients die annually while waiting for organs. The greatest challenge to overcome is increasing awareness of those facts. People must be educated so that they can turn their own tragedies into opportunities for life for others through the gift of organ donation.

**There are** so many “great” challenges that it is hard to rank them and put one above all others as “the greatest.” I would agree with one of the other experts who noted that increasing public awareness is one of the great challenges. Along those same lines, one of the great challenges is to get people to let their families know that they wish to donate their organs. Unfortunately too often a family member will not give permission for donation because he or she did not realize that their loved one wanted to donate their organs. As well the family member may be so traumatized and shocked by the unexpected death of their loved one that he or she may be unwilling or unable to agree to donation at that time. And since the potential deceased donor is no longer with us and cannot speak for him or herself, the family is left to make the final decision. If the potential deceased donor had spoken with that family member before his or her death, then the family member left to make the decision is more likely to agree to donation.

**Question 2:**  
What is one myth about organ donation that you would like to dispel?

**Unfortunately,** there are many myths surrounding organ donation. One of the main myths that needs to be dispelled is that healthcare workers will not work as hard to save a patient’s life if he or she is a potential donor. This could not be further from the truth. If you are severely ill or injured, your medical team’s main focus is saving your life. Additionally, to avoid any conflict of interest, the doctor treating a potential donor is not directly involved in the decision process of whether the patient’s organs will be transplanted.

**Rules for allocation/donation.** While the waiting times for organs differ in regions of the country, there are strict rules that govern the allocation or distribution of organs. The transplant community is committed to creating a system that is just and fair. Any changes are carefully considered and we make every effort to increase donor awareness and donor rates. By increasing organ donation from both deceased donors and living donors, we can decrease the geographic disparities across the country. It is important for people to know that there are several ways to consider becoming a donor and one does not need to be a blood relative to donate.

## A vital role: Exploring transplant coordinators



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**Successful transplantation requires a dedicated team of professionals who provide care throughout the transplant process—from when the patient initially considers a transplant to long-term follow-up after transplant.**

The transplant nurse coordinator is a key team member who supports the patient and family. The transplant nurse promotes comprehensive, ethical, and evidence-based care.

A transplant coordinator has extensive experience in transplantation and specializes in the area of either donor or recipient care, but not both. This role separation allows the nurse coordinator to advocate for the patient and family as well as maintain confidentiality in care. The transplant nurse coordinator is also involved in efforts to increase awareness among community groups and other health care providers regarding organ donation and transplantation.

According to the “Scope and Standards of Transplant Nursing Practice” (American Nurses Association, 2009) co-authored and

developed by the International Transplant Nurses Society (ITNS), the transplant nurse coordinator is unique to the transplant community and most are registered nurses.

**The role of the transplant nurse coordinator falls into one of the following categories:**

■ The procurement nurse coordinator provides and ensures compassionate and confidential care for all deceased donors and their families, allowing them to fulfill their final wish to donate the gift of life.

■ The living donor nurse coordinator works with people who wish to donate an organ to ensure they are fully prepared for their experience and followed closely long-term to optimize their outcomes.

■ The recipient nurse coordinator provides care to the patient both before and after their transplant occurs.


Although there are many health care professionals included in the transplant team, the transplant nurse coordinator has the unique opportunity when providing care to patients and their families. One transplant nurse coordinator

summarized the role said, “It is an honor to provide nursing care to patients and their families as they move through the transplant process. My most satisfying moments are when a patient, who was so ill prior to transplant, returns for a visit feeling healthy and happy, with an improved quality of life. This is what transplant nursing is all about.”



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