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**FOR IMMEDIATE RELEASE**

### **80,000 American's on Medicine's Death Row Seek Answers on the Internet**

Oct. 5, 2007, Deerfield Beach, FL -- America's need for organs is growing five times faster than the rate of available donations. Meanwhile, desperate Americans are going online, renting billboards, passing out leaflets and even joining organ donor clubs in a bid to find someone – anyone - who will keep them alive.

People routinely wait up to seven years for an organ. Most of them will never get one. Nearly 7,000 of them die each year. Meanwhile they wait – prisoners in their own home, bound to nearby hospitals and doctors, often bed-ridden, stuck in a dialysis unit every other day – for the rest of their lives.

#### **"It's like a prison. It's terrible."**

Steve Spitzer spends idles away his time reading a book about dog training. He's been on the transplant list for 3 1/2 years for kidney disease. For more than a year and a half he's spent most of the day for two days each week sitting in a chair getting dialysis. Without dialysis, or a transplant, he won't survive.

#### **Tomorrow may never come**

"I am leading half a life now," says Phyllis McGill. She reads mysteries to her 88-year-old mother while they wait for a kidney. Three days a week she gets up at 4 am and spends the day taking her mother to dialysis. Mom has been on the national organ transplant list awaiting a kidney since 2001. The odds are not good - 92,000 people (2/3rds of them kidney patients) are waiting for organs from deceased donors. Less than 10,000 kidneys are available each year. Meanwhile, every 13 minutes a new name is added to the waiting list.

#### **The Day the Music Died**

Ken Novikoff, 60, has lived with a genetic form of kidney disease his whole life. For decades it's been in remission, but he always knew that some day the inevitable would happen. Doctor's now only give him weeks before he becomes what he calls "a prisoner of dialysis." Desperate, like thousands of other patients, he's turned to the Internet looking for a donor. With a small retirement from his days as a high school music teacher, he's investing as much as he can on the Internet in a gamble that he'll be chosen by a stranger for a kidney donation. He's even had an organ donation information page added to his website, where he shares his love for the music and singers of the twenties ([www.KenNovikoff.com](http://www.KenNovikoff.com)). With a collection of over 10,000 rare 78 rpm records, and an almost photographic memory for music, Ken has been sharing his music with students, friends and audiences for generations. Trapped in a dialysis chair, many of these activities will die, even if he doesn't. "If I can't share my music with people, I might as well be in a jail cell," Ken said, " or even dead. What do I have to live for now?"

#### **Gambling on the Internet**

The huge disparity between available organs and the size of the waiting list creates a lot of frustration. In desperation some patients turn to the Internet to bypass lengthy organ donation waiting lists and find donors themselves. But as the competition for organs on the Internet heats up, so does the debate over the ethics, or lack thereof, of the online competition for organs. Online databases of potential donors and recipients act like medical dating services, trying to match up those in need with people willing to part with part of their anatomy ... sometimes for a price. Further, like everything else on the Internet, there are people trying to exploit both donors and patients, people trying to cheat to jump ahead on the legitimate organ lists and of course the inevitable black market in organs.

#### **The Price of Compassion**

Many experts say patients who receive organs from people they meet through Internet or “human interest” stories through the media are cheating. Some surgeons even refuse to operate on patients who have met a donor online. Douglas Hanto, M.D., chief of transplant surgery at Boston's Beth Israel Deaconess Medical Center, is one of them. "People should not jump ahead of others on the organ list just because someone likes their picture or is moved by their story," he says.

Some doctors think that since donors moved by an Internet contact were not planning to give, you didn't take away an organ that would have gone to someone else. But the problem is nobody knows yet whether this practice increases the organ supply or not.

The major factor limiting the number of organ donors is the low percentage of families who consent to donation. A 1995 study of families of donor-eligible patients found that 86.5% were asked to donate but only 47.3% gave consent. Only 40% of suitable individuals donate their solid organs after death. On the other hand, the demand for organs has been risen 400% in the past decade. Despite 20 years of aggressive educational campaigns to increase organ donation by government and non-profit agencies, donation rates have not significantly.

### **Tomorrow may never come**

Dialysis is so frustrating that some people would rather die than go on living that way. With dialysis, a life can be preserved for ten years or more. But for many kidney patients, that's worse than death because it means spending the rest of your life on “Death Row,” two or three days every week dragging yourself to a dialysis appointment for hours at a time. In fact, about one in five patients prefer to quit dialysis, rather than go through this – which of course is the ultimate death sentence, usually ending their suffering within a week or so. Between 1995 and 2002, according to government data, more than 60,000 people died like this, mostly in their seventies, rather than continue living on medicine's death row. And the rate of people on dialysis is increasing alarmingly, with 100,000 new patients each year.

### **A Question of Ethics**

Though most kidney transplants come from cadavers, these have failed to meet the growing demand. Buying and selling organs on the so-called “black market” has long been viewed unethical in the U.S., where it is actually illegal. But there are some ethical issues even concerning otherwise legal donations because doctors must risk the life of a healthy person to save or improve the life of a patient. According to the United Network for Organ Sharing (UNOS), almost half of all kidney donors in the U.S. are living donors. UNOS is the government-sanctioned organization (<http://www.unos.org>), which maintains waiting lists, determines the priority of patients on the lists, and places available organs.

There are three categories of living donations: (1) directed donation to a loved one or friend; (2) non-directed donation to the general pool (goes to the recipient on top of the waiting list); and (3) directed donation to a stranger, such as someone you met through the Internet. Finally, there is a fourth category, which is relatively new – donor exchanges. There are two types of exchanges. With Deceased Swap Donation (or a three-way kidney exchange) a non-matching relative or friend donates a kidney to the general waiting list then their relative or friend would have priority on the waiting list for the next available kidney. With the Living Donor Paired Exchange, a patient with a donor that isn't compatible exchanges with another patient with an incompatible organ, thus getting two compatible transplants.

Each type of donation has its own ethical concerns. Directed donations can put intense pressure on loved ones who may feel emotionally compelled to donate. With non-directed donations, doctors worry about the for making a life-threatening sacrifice for a total stranger – is the person mentally ill, compensating for depression or low self-esteem, seeking media attention, or harboring hopes of becoming involved in the life of the recipient?

Directed donation to a stranger also raises difficult questions. Patients advertising for an organ on the Internet or in the media have been strongly discouraged by many doctors who believe it unfairly bypasses the waiting list. In addition, without pre-screening, donated organs could go to patients who will die soon anyway. These donations also favor rich people with the resources to pay high fees, and they often go to the most attractive patients or those with the most moving story rather than to those most in need. Finally, some of these donors may be secretly paid, which is illegal.

Proponents of directed donations through the Internet, however, express sympathy with the difficulty that patients and their families experience during the long, difficult and frustrating process of waiting for an organ. This is particularly true for patients on dialysis – waiting on a virtual death row! They argue that when patients find living donors, these organs that otherwise would not be donated and people on the waiting list aren't hurt. In fact, whenever someone gets a directed donation, everyone still on the waiting list gets to move up closer to the top. Some also point out that we have a right to donate to political parties and charities of our choice, so we should be able to choose to whom to give our organs.

In 2004 Paul Dooley from Canton, MA and Dr. Jeremiah Lowney, co-founded <http://www.MatchingDonors.com> due to the huge shortage of available organs when Mr. Dooley's own father couldn't even get on the waiting list. They believe that there are thousands of altruistic and compassionate people willing to consider live organ donation if they were made more aware of the opportunity to help their fellow human beings. MatchingDonors.com gives people in need of organ transplants the ability to search for live organ donors over the Internet.

For patients like Ken Novikoff, there is no question. "I am a people person. My life has always been about teaching and sharing music. I can't do that imprisoned in a dialysis chair every other day! I am on the waiting list, but that could take years. It's like just giving up and waiting to die. I can't do that. I've got to have hope. The best chance I have is to tell my story and maybe find a donor myself, perhaps someone who loves music as much as I do."

## **RESOURCES:**

### **MatchingDonors.com**

A web site created to give people in need of transplant surgery an active way to search for a live organ donor.

<http://www.MatchingDonors.com>

### **U.S.Department of Health and Human Services Secretary's Organ Donation Initiative**

Internet Address: [www.organdonor.gov](http://www.organdonor.gov)

### **United Network for Organ Sharing (UNOS)**

Phone Number(s): (888) 894-6361

Internet Address: [www.unos.org](http://www.unos.org)

### **Coalition on Donation**

Phone number(s): (804) 782-4920

Internet Address: [www.donatelife.net](http://www.donatelife.net)

### **Office of Minority Health, Office of the Secretary**

Phone Number(s): (800) 444-6472

Internet Address: [www.omhrc.gov](http://www.omhrc.gov)

### **Children's Organ Transplant Association**

Phone Number(s): (800) 366-COTA (2682)

Internet Address: [www.cota.org](http://www.cota.org)

**New York Organ Donor Network**

132 West 31st Street, 11th Floor

New York, NY 10001

<http://www.donatelifeny.org>

Phone: (646) 291-4459,

Fax: (646) 291-4602