

Take charge of your health today. Be informed. Be involved.

Confronting the myths about organ donation

This month, the "Take Charge of Your Health Today" page focuses on organ donation and the importance of becoming an organ donor. Vianca Masucci, health advocate at the Urban League of Greater Pittsburgh, and Esther L. Bush, president and CEO of the Urban League of Greater Pittsburgh, exchanged ideas on this topic.

VM: Good afternoon, Ms. Bush. Are you as excited as I am to advocate for organ donation?

EB: I am, Vianca. Folks may be surprised to know that there are great racial and ethnic disparities in organ transplantation. Simply put, people of color, which includes African Americans, Asians, Native Americans and Latinos, are more likely to need an organ transplant than their White counterparts. But only a small percentage of organ donors are people of color. This has caused a national shortage of organs for people of color. I'm glad we're talking about this.

VM: This is, indeed, a problem. I don't think people realize the consequence of checking "no" next to the organ donor question at the Department of Motor Vehicles.



ESTHER BUSH

The conversations that folks have in the community about organ donation are shadowed by myths, superstition and even urban legend. We've all heard the story about the guy waking up in a tub full of ice with his kidney missing.

EB: Of course we all have. But what we

need to be hearing about is the 120,000 people waiting for organ transplants. We need to be hearing about the 22 people who die every day waiting for the organs that could've kept them alive. We need to be confronting these myths that scare people away from donating and present them with the facts.

VM: Great idea, Ms. Bush. Why don't we do that now? The first one we can bust is this idea that organ donors get worse health care because doctors want them to die so that they can take their organs. When you go to doctors, they are focused on helping you. Health care professionals have very clear ethical guidelines they must follow. Doctors will never take your organs before you die. In fact, organ donors actually undergo more tests than nondonors to make sure that they have died.

EB: Yes, and these tests come at no charge to the donor. In fact, the donor will never be charged for any medical services related to organ donation. So you don't have to worry about your family being stuck with a huge medical bill in addition to funeral

costs.

VM: Speaking of funeral services, a lot of folks are concerned about organ donation interfering with an open-casket funeral. It does not. Clothes will cover any of the scars created by organ donation.

EB: Thank you for saying that so openly, Vianca. One of the things that makes organ donation so hard to talk about is addressing death. It can be hard to think about your own death and imagine what will happen to your body after you pass away. But that shouldn't be the focus. When I think about organ donation, I don't think about death. I think of the many lives that I could save by donating my organs. I think of leaving a legacy of caring behind to the persons I love and families I save.

VM: What a great legacy it would be! Thanks for taking time to talk with me about such an important issue, Ms. Bush. I look forward to hearing your thoughts next month as we discuss chronic disease prevention and healthy aging.

For more information about this month's topic, e-mail partners@hs.pitt.edu.

Understanding the organ donation process

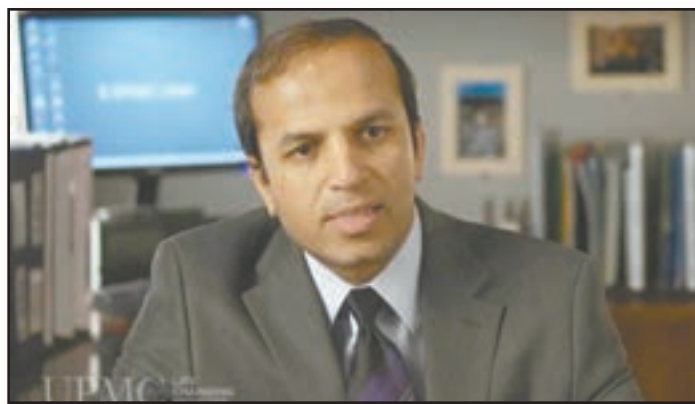
When an organ stops working correctly because of injury or illness, it needs to be replaced. Doctors are able to replace many organs in the body using organs from living or deceased donors. Organ transplantation sounds like a straightforward process. But the wait for a compatible donor can be long, and many myths persist and keep people from becoming organ donors.

According to the U.S. Department of Health and Human Services (HHS), about 79 people receive organ transplants every day. However, an average of 22 people die every day because of a shortage in available organs. Every 10 minutes, another person is added to the national transplant waiting list. One organ donor may be able to save eight lives.

All of these statistics add up to the fact that the number of people who need an organ transplant is much greater than the number of people signed up to be organ donors.

Many myths about organ donation still exist and affect people's decision to become donors. Understanding the organ donation process can help overcome some of the anxiety surrounding donations and transplants, according to Abhinav Humar, MD, Thomas E. Starzl Professor of Transplantation Surgery and chair of transplant surgery at the University of Pittsburgh School of Medicine and clinical director of the Thomas E. Starzl Transplantation Institute.

To dispel the myth that people receive worse medical care once they consent to be organ donors, Dr. Humar says that there are safeguards against this. "First, doctors act in the best interests of their patients. Second,



ABHINAV HUMAR, MD

the process for organ donation isn't even started until it's determined that the donor has met or will most likely meet the criteria for being brain dead. Third, the team that removes the organs and gets consent from the donors or their families is separate from the team that's looking after the patient.

There's a separation of the two teams so that there's no conflict of interest. The doctor who's looking after the patient has no vested interest or benefit from that person being a donor," he says.

"People should know that we see no downside for a deceased person to be an organ donor," says Dr. Humar.

The other way for someone to be a donor is through the live donation process. A live donation is when someone is donating one organ or part of one. "Commonly it's done with kidneys," says Dr. Humar. "We have two kidneys, and most people can do fine

with just one kidney. People can also donate part of their livers because the liver is an organ that can regrow."

There are racial and ethnic disparities with regard to organ donation and transplantation. HHS research shows that "African Americans, Asians and Pacific Islanders and Hispanics/Latinos are three times more likely than [Whites] to suffer from end-stage kidney disease, often as the result of high blood pressure and other conditions that can damage the kidneys. Almost 34 percent of the more than 101,000 people on the national waiting list for a kidney transplant are African American. African Americans are the largest group of minorities in need of an organ transplant."

Organs from donors are not specifically matched by race or ethnicity to recipients. But HHS reports, "Compatible blood types and tissue markers—critical qualities for donor/recipient matching—are more likely to be found among members of the same ethnicity."

If people think about the great need for organ donations and decide they want to become donors, Dr. Humar encourages people to discuss their wishes with their families. "If people feel strongly about being a donor, they should let their families know. It's always easier to talk about it up front.

We also often find that people are reluctant to ask others to be a living donor for them. We'd like to have people feel more comfortable doing that."



PA DOT Donor Registration

The Pennsylvania Department of Transportation (DOT) works with the Gift of Life, CORE and the Department of Health to increase awareness of organ and tissue donation in Pennsylvania. If you are older than 18 and are interested in becoming an organ donor, you can sign up in person at your local DOT office or register online at www.dmv.org/pa-pennsylvania/organ-donor.php.

For more facts about organ donation, visit <http://www.organdonor.gov/whydonate/facts.html> or <https://www.core.org/understanding-donation/dispelling-the-myths/>.

Pittsburgh man receives 'the gift of life'

The lives of people on the organ transplant waiting list can be difficult. Most patients spend years hoping for the gift of life while carrying on with their daily lives as normally as possible.

While serving in the National Guard, Moses Hart discovered that he had an enlarged heart and that it was probably caused by a virus. In 2000, Hart was diagnosed with cardiomyopathy, which means his heart doesn't pump enough blood. The disease weakens the heart muscle and often leads to heart failure.

Because his heart didn't pump enough blood, doctors inserted a ventricular assist device into Hart to help him stay alive. The device is attached to the heart. He carried the pump and power source outside of his body in a fanny pack. He even slept with it.

In January 2015, Hart received his first call from the transplant center. Unfortunately, the heart that was available wasn't suitable for him. In the meantime, he volunteered at the Center for Organ Recovery & Education



(CORE) and Allegheny General Hospital. In January 2016, Hart received his heart. He waited approximately four years for his gift of life but will tell you that it was certainly worth the wait.

As one of 58 federally designated not-for-



MOSES HART

profit organ procurement organizations (OPOs), CORE works closely with donor families and designated health care professionals to deliver the gift of hope by coordi-

nating the surgical recovery of organs, tissues and corneas for transplantation.

As a Minority Organ Tissue Transplant Education Program (MOTTEP) site, CORE features programming for minorities to help bridge the gap between potential donors and the national transplant waiting list.

MOTTEP's mission is to decrease the number and rate of ethnic minority Americans needing transplants. CORE supports MOTTEP in its goal to facilitate a national information and education campaign that emphasizes both prevention and intervention strategies.

According to Donate Life America, there are currently 77,633 patients from minority backgrounds waiting for transplants in the United States. In Pennsylvania, there are more than 4,000 minorities on the waiting list.

For more facts about donation, visit www.core.org or www.unos.org. To register as an organ, tissue and cornea donor, please visit www.core.org/register.

Renewed life: Father meets son's organ recipients

by Kaylan Thompson

PADUCAH, Ky. (AP)—Despite hushed whispers, the tapping of nervous feet, the clicking of iPhone cameras, all was silent for West Kentucky Community & Technical College's men's basketball coach Michael Chumbler on Feb. 27 as he stood to meet two complete strangers in the campus gymnasium.

The three men were already connected, however, by one common factor, the life of 20-year-old Kam Chumbler, Michael's son who passed away last May. Michael was meeting for the first time the men who are living because of his son's organ donations.

"I can feel Kam here," Michael Chumbler said, looking toward Paul Mattingly, the recipient of Kam's lungs. "When I stood to hug him, his lungs were breathing, in and out. I could feel them."

A few weeks ago, Chumbler mailed personally written letters to each transplant re-

ipient, asking them to attend a basketball game being played in Kam's honor so he could see the lives his son saved.

"I couldn't not come. It has all come full circle," Mattingly said. "We lost our son, an organ donor, in 2008, so on the way down to the hospital to get the transplant I knew what someone was going through. It just eats your heart when you lose someone. So for Kam's sake, I block that out and grab life a lot harder."

Mattingly, from Louisville, had suffered from idiopathic pulmonary fibrosis, a sort of cancer on the lungs, for over three years. When he received a double-lung transplant, he knew it was a gift, a second chance, from a stranger.

"That weighed heavy on me, knowing that someone else's lungs were in me to help me keep going. I had to come meet Michael today, knowing that I received Kam's lungs," he said, looking toward Michael.

"Thank you, from the bottom of my lungs."

Mattingly's wife, Julie, said she is thankful for Kam's brave decision to become a donor. Because of that choice, her husband has a renewed life.

"There are so many emotions following a transplant, and he's been feeling depressed the past few months, but as soon as that letter came with videos of Kam, it has given him new motivation," she said.

"I just wish I could thank him for making that one simple choice."

Kam's donations saved the life of another Louisville resident, Ed Ice, who received a liver transplant after combatting ulcerative colitis for over 40 years. Because of the transplant, he was able to live to see the birth of his grandson in July.

"For me, it is surreal," Ice said. "It was tough for me to make a decision to have a transplant. I thought that these were the parts I came in with, and these were the

parts I needed to come out with, but finally I decided to do it. It still messes with your head a bit because the only reason I'm here is because of Michael's son."

For Chumbler, meeting with the recipients of his son's donation was a vital step toward healing.

"I wasn't ready to meet them before," he said. "I needed some time, but I'm grateful to them for coming. It never stops hurting, but this will help heal. Nothing will ever make the pain completely better, but this is a step in the right direction, for sure."

For Mattingly and Ice, being the recipient of an organ donation makes them mindful and thankful each day.

"It really affects you when you think that, for us to live, somebody else died," Ice said. "So every morning when I get up, I thank God, and I thank Kam."

Information from: The Paducah Sun, <http://www.paducahsun.com>