

2019
Spring

be a hero. be an organ donor.



CONNECTIONS

TABLE OF CONTENTS

Message from the CEO

CORE Focus

Partners in Healthcare

DLA Digest

Advocates in Action

Upcoming Events



A Donate Life Organization

CORE MISSION

The Center for Organ Recovery & Education (CORE) is a nonprofit organization dedicated to promoting donation, education, and research for the purpose of saving and improving the quality of life through organ, tissue, and cornea transplantation.

MESSAGE FROM THE CEO

SUSAN STUART, CENTER FOR ORGAN RECOVERY & EDUCATION CEO



December is often the busiest time of year. There are cookies to bake, latkes to fry, presents to wrap, and stockings to stuff.

For many, it's an exhilarating time filled with comfort and cheer.

For others, like many of our friends at CORE, the flurry of activity can amplify our grief; a spotlight on the absence of someone we dearly miss.

But for better or for worse, the holidays are a time of togetherness.

If there's one thing we're sure of here at CORE, it's that nothing carries us through periods of great joy or great sorrow so swiftly as our ability to work together; our partnerships.

It's the very essence of our mission: working hand-in-hand with others to save and enhance lives through organ, tissue and cornea donation.

In the spirit of the season, this issue of Connections examines many examples of ways we at CORE can come together to create something bigger than ourselves.

We look at how a first responder from the tragic Tree of Life Synagogue massacre has found healing through the generosity of a donor.

We hear a touching story about a donor mother's Thanksgiving meeting with her son's recipients and the gratitude experienced among them.

And in recognition of our year-round collaboration with community health centers, we announce CORE's honor of receiving a Pinnacle Award from Donate Life America.

It's our hope that these stories inspire you to catch some of the holiday spirit and explore new ways we can form even more valuable partnerships in the months ahead.

From all of us at CORE, we wish you happy holidays. We can't wait to continue our work together in 2019.

CORE VISION: Every potential donor will make a *Pledge for Life*.

CORE VALUES

INTEGRITY: CORE would not exist without the trust and support of the community it serves.

COMPASSION: CORE honors its donors and donor families.

QUALITY: CORE exceeds clinical standards to ensure the quality of donated organs and tissue.

RESPONSIVENESS: CORE operates in a fast-paced, detail-oriented manner.

EDUCATION: CORE offers education to uphold public trust and ensure informed donation decisions.

INNOVATION: CORE is a long-standing pioneer in the organ and tissue procurement field.

RESPECT: CORE has respect for both death and life.

LIFE: Most importantly, we value the legacy of life our donors have left and the second chance at life that transplant recipients have gained as a result.

DECEMBER STATISTICS

National Waiting List: 115,017

CORE Waiting List: 2,534

Univ of Pgh Medical Center..... 1,011

VA Pgh Healthcare System..... 696

Allegheny General Hospital 479

UPMC Children's Hosp of Pgh..... 150

Charleston Area Medical Ctr..... 151

UPMC Hamot..... 47

Every 10 minutes, another name is added to the waiting list.

- On average, 20 people will pass each day waiting for their life-saving transplant.
- Ninety percent of Americans say they support donation, yet only 30 percent know the essential steps to take to be a donor.
- One organ and tissue donor can save 8 lives and heal up to 75 individuals.

VOLUNTEERS STRUT THEIR STUFF IN WASHINGTON PARADE



Volunteers from the Washington County Team braved the cold weather to parade through the streets of downtown Washington, PA, in their annual holiday parade. This is the seventh year that CORE has participated in this event.

CORE FOCUS

PA ORGAN DONOR LAW AIMS AT NEW HOPE FOR THOSE WAITING



By Joyce F. Nowell, *The Herald Mail*

Bob Thomas knows what it's like waiting just to have the chance at a life-saving medical procedure. Today, thousands of Pennsylvanians are on waiting lists for organ donations, and a new law that went on the books last month is providing them enhanced hope.

The Franklin County Commissioner knew the importance of organ donation in 2013, when he needed treatment for blood and bone marrow disease.

"When I was waiting for a match for my bone marrow transplant, I was told how many people don't ever find a match," Thomas said. "Ultimately they end up dying because they couldn't find anything."

The Pennsylvania Organ Donation Law, signed by Gov. Tom Wolf in October, works to provide more access to organ donations, including tissue donations. It brings Pennsylvania up to date on the medical side, adding hands, facial tissue and limbs to the anatomical items that can be donated.

"Organ donation gives people the opportunity to live," Thomas said. "It can save a life."

Pennsylvania was seen as a front-runner in organ-donation laws in 1994, but it has taken nearly 25 years for an update to get through the legislature. The law brings the commonwealth into the group of 47 other states that have adopted the Uniform Anatomical Gift Act.

"This is the first change to our PA laws regarding organ donation in over two decades," said Dr. Peter Jablin of Summit Pulmonology, who serves as Chambersburg Hospital's Critical Care Services medical director and whose daughter, Kate Haswell, is an Organ Procurement Coordinator at CORE.

"This is a victory for the nearly 8,000 Pennsylvanians on the national transplant waiting list who now have renewed hope of a second chance at life," said Susan Stuart, president and CEO of CORE, which is the federally designated not-for-profit organ procurement organization that serves western Pennsylvania, including Franklin and Fulton counties.

While the Chambersburg Hospital doesn't perform organ transplants, it does recover organs for surgery elsewhere. Jablin believes the positive impact of the law will be right in our own backyard.

"The people who benefit live here, in our community," Jablin said. "These are our neighbors who can finally walk down the aisle when their children marry, can finally see their grandchildren, can finally sing in church and live a life free of the constraints of dialysis."

The law will now require a coroner to issue a written statement providing the reason he or she intends to deny recovery of all eligible organs when a death is under investigation. It also allows a transplant surgeon or designee to attend a meeting regarding denial of organ recovery.

"The update respects the authority of state coroners and protects criminal investigations, while also safeguarding the wishes of each donor or their family," according to Stuart. "I believe the more rigorous documentation and discussion required for a denial, which this law outlines, will translate into more organs available for transplant."

The law sets in motion additional opportunities for people to become an organ donor. A Donate Life PA Registry will be established to allow people to register as a donor online.

"We believe it was important to update the state's organ-donor laws in order to continue to encourage organ donation in Pennsylvania," said Nate Wardle, press secretary with the PA Department of Health. "There is a lot of work currently being done by DOH and PennDOT, among many other groups and organizations, to encourage organ donation"

"Awareness within our community is crucial," Jablin said. "Almost 50 people can benefit from one donor with gifts of lungs, heart, kidney, liver, pancreas, intestines, corneas and tissue.

This story was originally published in the *Herald Mail*. To see the story in its entirety, [click here](#)

75

As a reminder, CORE along with our national partners at AATB, RSA/DoT, AOPO, EBAA, NATCO, UNOS, NKF and DLA at a recent roundtable, encourage anyone discussing tissue donation to cite the accurate figure of 75 when referring to the number of people who can be helped by a single donor. This number was updated from 50 in 2016.

THE HEALING POWER OF TISSUE DONATION: KNOW THE FACTS

- Donated heart valves can replace damaged valves, or correct a baby's congenital defect, allowing the heart to function normally.
- Grafts help patients with spinal deformities live normal lives.
- Musculoskeletal tissue can save limbs from amputation and be used to replace bone, tendons and ligaments lost to cancer, severe trauma, degenerative joint disease, arthritis and other conditions.
- Recovered skin can save the lives of burn victims and improve the lives of patients with significant soft tissue defects.
- Tissue allografts play a key role in restoring function and mobility and, since research shows that physical activity reduces the risk of chronic health conditions, empower patients to live healthier, more active lives.
- Injured joints or degenerated discs cause pain, hinder mobility and dramatically decrease quality of life.

Source: AATB

PARTNERS IN HEALTHCARE

PENNSYLVANIA AND WEST VIRGINIA HOSPITALS BEGIN 2019 HOSPITAL ORGAN DONATION CAMPAIGN

More than 1,000 hospitals across the country are expected to participate in The Health Resources and Services Administration's (HRSA) Workplace Partnership for Life 2019 Hospital Organ Donation Campaign, which officially began on October 1 and runs through April 2019. The campaign has enrolled more than 443,430 organ donors since its launch in June 2011.

West Virginia and Pennsylvania hospitals will, for the first time, both participate in state hospital challenges that run at the same time as the HRSA campaign.

In 2018, Pennsylvania had the special distinction of being the state with the largest number of participating hospitals that were recognized — 105 in total.



FEDERAL GOVERNMENT IMPLEMENTS NEW RULES AIMED AT DECREASING NUMBER OF DIALYSIS PATIENTS, INCREASING NUMBER OF KIDNEY WAITLIST PATIENTS



Starting in 2020, the Centers for Medicare & Medicaid Services (CMS) will start tracking the percentage of dialysis patients who are placed on kidney transplant waitlists; the measurement will, in turn, become standard for Medicare certification, specifically Medicare payments to dialysis facilities and the quality measures for which the dialysis facilities are held accountable. Advocates believe this is positive for chronic kidney disease patients conducting dialysis because now their dialysis centers have an incentive to help patients get listed on a National Transplant Waiting List, which has been a challenge in the past.

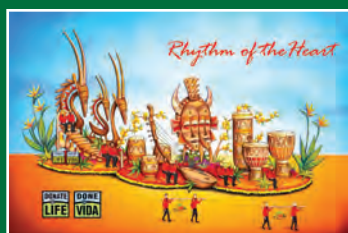
"Informing patients about their waitlist options and helping patients learn about living organ donation, which can greatly reduce their time waiting for a kidney transplant, are essential to improving the quality of life for dialysis patients. No patient should believe that they must face a lifetime of dialysis if they are eligible for a transplant," The National Kidney Foundation (NKF) said in a press release. "NKF will work closely with our patients, transplant professionals and dialysis care professionals to develop robust, feasible recommendations to CMS and we look forward to helping CMS on this issue."

In the United States, 30 million adults are estimated to have chronic kidney disease — and most aren't aware of it. One in 3 American adults are at risk for chronic kidney disease. Risk factors for kidney disease include diabetes, high blood pressure, heart disease, obesity and family history.

SET YOUR DVR!



Don't forget to tune in when the Donate Life float sails down the streets of Pasadena during the 130th Rose Parade® presented by Honda on Monday, Jan. 1, 2019, at 11 a.m. (EST). For additional information about the Tournament of Roses, please visit the official website at tournamentofroses.com. You can watch the parade live on the Hallmark Channel. Celebrating its 16th year, The Donate Life Rose Parade® Float continues its mission to save and heal lives by sharing the gift of life and delivering the message of organ, eye and tissue donation to the world. Families of deceased donors are honored to see their loved ones' floral images highlighted as part of the float. Living donors and recipients bring the float to life by riding or walking beside the float. This year's parade theme, The Melody of Life, celebrates the power of music in bringing us together. The 2019 Donate Life Rose Parade® Float, Rhythm of the Heart, highlights the musical diversity and rhythms of Africa. Djembe drums from Senegal, along with a Kuba drum from the Congo will carefully integrate 44 floral portraits in their beautiful design, honoring the brave lives of deceased donors. Overlooking the floragraphs is a dramatic double Senoufo mask from the Ivory Coast that gives thanks to ancestors and remembers those who have gone before.



DONATE LIFE DIGEST

THREE YEARS OF HOPE: TRANSPLANTS FROM HIV-POSITIVE DONORS INCREASE DRAMATICALLY



Three years after the implementation of the HIV Organ Policy Equity Act (the HOPE Act), transplant opportunities for HIV-positive candidates willing to accept organ offers from HIV-positive donors continue to rise.

Transplants allocated through the HOPE Act have more than doubled over last year. Organs from donors that initially test positive for HIV have been transplanted into HIV-positive recipients since 2016; 50 of them in 2018. This indicates that more and more HIV-positive people are becoming aware that they can leave the legacy of life through organ donation.

UPMC's liver and kidney transplant program is a HOPE Act participating transplant center.

UNOS has been supporting HIV-positive candidates through the HOPE Act since its implementation. "The HOPE act has provided the ability to transplant organs from individuals not previously considered as donors. This has increased the opportunity for HIV+ recipients on the waiting lists to be transplanted," said UNOS Chief Medical Officer David Klassen. "The HOPE Act program was slow to get started but in recent months as more transplant centers have initiated HOPE Act transplant programs and OPOs have identified additional donors, the number of transplants has increased substantially."

Signed into law November 2013 and implemented November 2015, the HOPE Act opened the door for HIV-positive candidates to receive and donate organs. The act allows research on transplantation of organs from donors identified as HIV-positive into HIV-positive candidates under approved research protocols.

Organ procurement organizations can run matches for HIV-positive donors. The only candidates who will appear on match runs for these donor offers will be those listed at transplant programs that have an IRB-approved protocol, and whose HIV status and willingness to accept an HIV positive kidney or liver has been confirmed.

Any participating hospital must conduct transplants under IRB-approved research protocols conforming to the Final Human Immunodeficiency Virus (HIV) Organ Policy Equity (HOPE) Act Safeguards and Research Criteria for Transplantation of Organs Infected with HIV, developed by the National Institute of Allergy and Infectious Diseases, one of the National Institutes of Health.

Transplanting organs from HIV-positive donors into HIV-positive candidates shortens the waitlist, increasing the organ availability from HIV-negative donors for HIV-negative recipients. In addition, it gives hope and comfort to the family of donors, knowing their loved ones have saved the lives of other HIV-positive patients.

Current estimates suggest that more than 1.2 million people are HIV-positive; 35,000 people are newly infected every year. While life expectancy of HIV positive patients nears that of the general population, end-stage liver or kidney disease is expected to increase as the population ages, creating an even greater need for more organs. It's critically important for transplant surgeons to educate HIV patients about the HOPE Act and organ donation if the availability of organs is to grow.

KNOW THE TRUTH CAMPAIGN AIMS TO SET THE RECORD STRAIGHT ON ORGAN DONATION



African Americans make up nearly 30 percent of the national waiting list for life-saving organ transplants, but account for less than 15 percent of actual donors, according to data from the Organ Procurement and Transplantation Network (OPTN). The disparity comes from cultural and social misconceptions, along with a distrust of the healthcare system. This results in African Americans being underrepresented on state registries. It's time to know the truth.

Southwest Transplant Alliance, the nonprofit organ procurement organization (OPO) based in Dallas, has launched KNOW THE TRUTH, a public information campaign aimed at providing education, resources and awareness about the need for organ donation in the African American community. KNOW THE TRUTH highlights real-life stories of African Americans who have undergone transplants and busts the myths that permeate communities.

While ethnicity, social status, income, or culture are never factors in determining who receives organ transplants, similar ethnic backgrounds between organ donors and recipients do make matches more likely. To learn more, visit www.knowwhatstrue.org.

TREE OF LIFE
VICTIM, FIRST-
RESPONDER
HERO FINDS
HEALING WITH
THE HELP
OF A TISSUE
DONATION;
BONE GRAFT



Successful surgery! All because of a bone donation from a total stranger one month after the deadly Tree of Life Synagogue mass shooting in Squirrel Hill, the family of injured Pittsburgh Police Officer Daniel Mead say they're optimistic he will now make a full recovery. In early December, the Zone 4 Officer — who came face-to-face with the gunman that day — just had pins removed from his hand where they also put in bone grafting. Officer Mead and his sister Diane are holding up a card indicating his surgery included the use of donated bone. According to Diane Mead, Daniel's sister, "Want to say THANK YOU to the donors that made it happen. We are SO grateful!"

NATIONAL MAKE UP
YOUR MIND DAY:
DECEMBER 31



Make up your mind to save a life.
MAKE UP YOUR MIND DAY | DECEMBER 31
[Register today](#)

ADVOCATES IN ACTION

AN INCREDIBLE BOND: LAWRENCE COUNTY MAN'S ALTRUISTIC GIFT CHANGED BEAVER FALLS WOMAN'S LIFE



By Marsha Keefer, *The Beaver County Times*

Eleven years ago, CORE Advocate Robert Rice of West Pittsburg donated one of his kidneys to a woman he'd never met. Called nondirected altruistic kidney donations, they are rare and extraordinary. To date nationally, less than 2 percent have occurred since 1988.

Every day was a slog. Perpetually tired, she could barely make it through the day. Her complexion wan, weight down to 100 pounds, it was obvious Colleen McGovern Sempf was ill. Still, she maintained a full-time job as an instructional support aide at McGuire Memorial, a care facility in Daugherty Township serving people with intellectual and physical disabilities. And was single mom to a teenager.

Three times a week — Monday, Wednesday and Friday — when her shift ended at 3 p.m., Sempf drove nearly 10 miles to a dialysis clinic in Baden where for three to four hours she was tethered to tubes and hooked to a machine that substituted for her kidneys, the bean-shaped organs just below the ribs that filter waste from blood. And then she'd drive home to Beaver Falls and collapse.

"I had a lot of complications," the now 50-year-old said. "I was losing my eyesight."

Her best option was a kidney transplant. None of her relatives was a suitable match. Sempf was placed on a national transplant waiting list for a cadaveric kidney. And then she got a phone call at work that spring that would change her life.

Nondirected altruistic kidney donors — kidney donors who give to someone they don't know and without benefiting someone else — a rare and extraordinary gift. To date nationally, 64 percent of living-donor kidney transplants were directed donations between biologically related pairs; 34 percent were directed donations between people who were not biologically related; and less than 2 percent were altruistic nondirected donations, according to data provided by Katelynn Metz, communications and marketing coordinator for the Center for Organ Recovery and Marketing.

Robert Rice falls into the latter category — one of the ultimate do-gooders. Eleven years ago, Rice, now 48, of West Pittsburg in Lawrence County, worked as an activities assistant at Southwestern Veterans Center in Pittsburgh's Highland Park that provides health care and related services to veterans who are disabled, chronically ill or in need of specialized care. Every day he saw patients on dialysis.

"I would see them come back from dialysis like three times a week and saw how they were very drained. They looked very sickly. I just thought maybe I could help somebody out there," he said. "I just had the urge to help somebody because of what I saw every day at work," he said.

Sempf was even more astounded when she received the phone call from her transplant coordinator telling her a stranger wanted to part with one of his kidneys.

"I was like are you kidding me? I couldn't believe it."

Surgery was set for June 20, 2007, at UPMC Presbyterian/Montefiore. Sempf was up and moving within a day.

"It worked so perfect," Rice said. "It's her kidney now. I'm still doing good. I'm happy about that."

"No more dialysis," she rejoiced. "I felt wonderful. My skin went back to a pink color. I just felt — I don't know how to express it. I felt alive. Like I slept forever and woke up and rejuvenated."

Reflecting on the experience, Rice said "it's probably the greatest thing I've ever done — other than getting married. I better say that 'cause I'll get killed from the wife. It's one of the best things I've ever done. It was."

They've remained friends ever since, Sempf said, keeping in touch regularly.

Metz said theirs is "an incredible story of giving. It's really great," and one that even though occurred more than 10 years ago, is worth retelling during this season of thanks and giving, "I think this really outlines what true giving is and the effect somebody can have on another person's life," she said. "The likelihood of a purely outright, altruistic donation — those are few and far between. He's a hero."

"Tell my wife," Rice joked.

"She knows," Sempf said. "Tammy is an amazing woman, too, to let him do this."

"We wish there were more Roberts around," Metz said. "How many people could be saved if there were more of him in the world?"

"That's true," Sempf said. "I was one."

This story was originally published in the *Beaver County Times*. To read the full story, [please click here](#).

WESTERN PA KIDNEY SUPPORT GROUPS



The Western PA Kidney Support Groups needs your support. Bringing together more than 10,000 people in the region, we hold support groups to share experiences and provide vital information for our members. In addition to connecting with our 600 members through our support groups, we provide phone line support, and host seminars and conferences, as well as attend events to raise awareness of our organization. For each donation of \$20 or more, you will receive a free T-shirt of your choice plus a button and bumper sticker. We have a limited selection of sizes from S-3XL. To make a donation, please call 412-427-2969 or email Jack Silverstein at silverjacki@yahoo.com and include your address, as well as which shirt size you would like. Upon receiving a check, your shirt, button and bumper sticker will be shipped to your home free of charge.

HEART TRANSPLANT SUPPORT GROUP



Saturday, December 28 • 12pm

Panera Bread Meeting Room
3401 Blvd of the Allies
Pittsburgh, PA 15213

The meetings are open discussion; bring your personal victories to share, your concerns, and your questions.

Our goal is to provide support to pre-transplant and post-transplant individuals in the physical and emotional areas through discussion. The information shared is personal and should be kept private within the support group.

To attend, please contact Tom at t.meshanko@verizon.net.

UPCOMING EVENTS

CORE CALENDAR: core.org/calendar-of-events

Living Donor Champion

The Journey Starts Here

Living Donor Champion Workshop

If you are in need of a liver transplant, every moment spent on the waiting list is critical. A living donor transplant may be a lifesaving solution to getting you off of the waiting list and back to being healthy.

A Champion may be a friend, family member, co-worker, or anyone else who is willing to provide emotional support for someone on the transplant waiting list. They can help by taking the lead in finding and securing a suitable living donor.

A Champion's role includes:

- Finding a living donor in a timely fashion
- Connecting and talking with as many people as possible so that an appropriate match can be found

• Offering support and inspiration through this difficult journey

You and a family member or friend are invited to attend a free educational workshop to learn about the living donor transplant process, the benefits, and the resources available to find a living donor.

To learn more and for updates on upcoming Champion events, please visit UPMC.com/LivingDonorChampion.

Like us on Facebook and join the conversation about living donor transplants. Facebook.com/LivingDonorTransplant

Advocate KICK-OFF

NETWORKING LUNCH KEYNOTE EDUCATION

SATURDAY, JANUARY 5, 2019 10AM-3PM

NOW IS YOUR CHANCE

LIVE & GIVE

HELP SAVE LIVES. BECOME AN ORGAN DONOR.

Register today, and you can help save as many as eight lives and help countless more through organ, tissue and cornea donation.

MAKE A DIFFERENCE IN A MEANINGFUL WAY.

Register today at core.org/register.

ERIE OTTERS

DONATE LIFE GAME

JANUARY 26, 2019



Make a difference in the lives of those waiting, donor families and recipients all over western Pennsylvania and West Virginia by becoming a CORE Advocate. To register, contact the CORE volunteer coordinator at 412-963-3550.