

2018
September

be a hero. be an organ donor.



CORE

Center for Organ Recovery & Education

CONNECTIONS

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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



I am excited to announce that CORE has been recognized at the 43rd Annual NATCO Meeting as one of the country's top OPOs in the HRSA Workplace Partnership for Life (WPFL) Hospital Organ Donation Campaign.

NATCO is "The Organization of Transplant Professionals" and brings together clinicians from the OPO and transplant communities. As you know, the WPFL campaign is held in conjunction with the state hospital challenges, with recognition being bestowed on a national platform.

More than 1,200 hospitals across the country participated in the 2018 Hospital Organ Donation Campaign to promote organ, eye, and tissue donation. This reflects a 9% increase over last year's campaign participation. Pennsylvania saw the most participation across the county.

Participants included small and rural hospitals, transplant centers and large health care systems. Working with donation organizations and state hospital associations, the hospitals conducted registration and awareness activities in their facilities and communities between October 2017 and April 2018. During this time, they added nearly 23,700 donor registrations to state registries and the Puerto Rico registry, which includes registrations from the U.S. Virgin Islands. The campaign has generated 443,427 registrations since its inception in 2011.

Being recognized as a top participating OPO truly reflects the work each of you have contributed to increase not only participation but overall donor designation across the country.

I am honored to work with each of you and share this recognition which is the direct result of the excellent collaboration we have experienced for many years.

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.

SEPTEMBER 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 Hospital of Pittsburgh . . . 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.

CORE ADVOCATE CELEBRATES TWO YEARS WITH NEW HEART



Heart Recipient Josh Krull recently celebrated his two year heart transplant anniversary. Earlier this year, on the nationally syndicated television show, *The Real*, he met the parents of the 14-year-old girl who saved his life; telling them that without their selfless decision to donate their young daughter's organs, he may not be here today.



CORE FOCUS

HEART RECIPIENT CELEBRATES WITH TRIP TO MONTANA



For over a year, Michelle Hagerty's life was put on hold while she waited desperately for a life-saving heart transplant. During that time, she had a goal in mind that she wanted to accomplish upon receiving her gift of life. This is Michelle's story:

"Every autumn since 2006, my husband and I would go on a hunting trip out

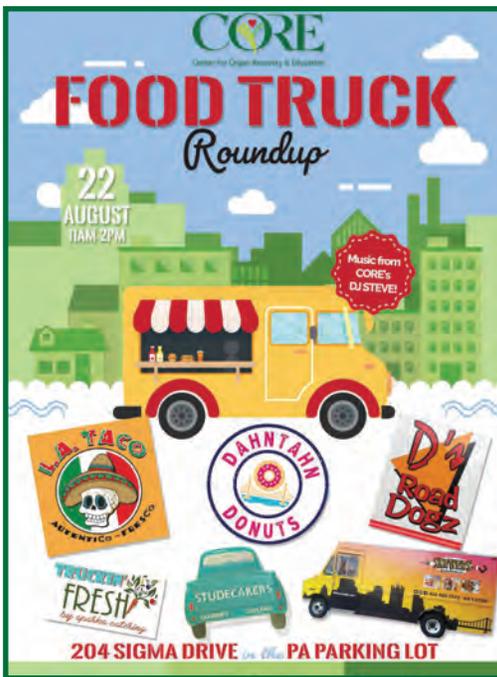
west. My favorite spot is a specific butte in northern Montana. When I was listed for transplant, the tradition broke. Ten months into our wait, I was admitted to the hospital.

I was dying. I accepted this. Yet, if a miracle were to happen and a donor match be found, I vowed to return to Montana and climb my butte. I meditated daily, envisioning myself climbing it. I repeated my mantra multiple times daily: 'You can scream, you can cry, but you cannot quit.' I'd take deep breaths, then walk the hallway for the umpteenth time. It sounds corny, but you have to dig deep and do what's necessary to keep going; to stay focused and positive.

Finally, I received my gift of life after waiting 15 months – the last five in the hospital. Now, I was in control and focused on my goal. Every time I was in pain or struggling to walk, I repeated my mantra and envisioned the view from the top of the butte, really putting myself there in my mind. Nine days later, to the astonishment of my team, I went home.

Then, one year post transplant, we made it back to Montana. It was like coming home. My spirit was free. I made it to the top of my butte. Words cannot describe the emotions that overcame me. If it wasn't for my donor and her family making such a courageous decision, I never would be standing up here with this amazing view."

CORE HOSTS NEIGHBORHOOD FOOD TRUCK EVENT



CORE recently held its first neighborhood food truck event for all businesses who are part of the RIDC Business Alliance.

Diners on hand enjoyed not only a variety of foods, but also information about why registering as an organ, tissue and cornea donor is so important.

Among the trucks present was Dahntahn Donuts -- a truck owned, in part, by CORE's legal and legislative advisor Michael Kenney.



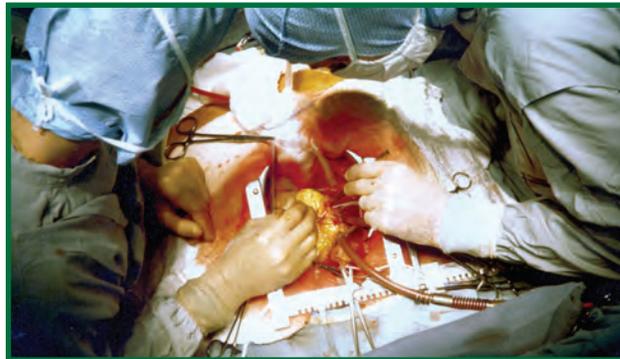
LIVING DONORS NOW PROTECTED UNDER FMLA



For the first time, the U.S. Department of Labor announced measures that protect the job security of living organ donors under the Family and Medical Leave Act (FMLA). With this opinion, any eligible employee who wishes to be a living donor is entitled to unpaid, job-protected leave for the surgery and recovery period. The DOL opinion letter builds upon some existing protections for living donors. Employees of the U.S. government are already permitted 30 days of paid leave for organ donation and seven days for bone marrow donation; many states have similar leave policies for state government employees. Some states extend paid leave to private sector employees as well. Most recently, in May 2018, Colorado passed the Living Organ Donor Support Act, extending paid leave to living donors by providing a voluntary tax credit to their employers. And in March, Maryland passed House Bill 96 which gives living organ donors a tax credit of up to \$7,500 to offset their expenses, joining other states that provide tax breaks to encourage living organ donation. In addition to qualifying living donation under FMLA, the Living Donor Protection Act (H.R. 1270) would also prohibit life, disability and long-term care insurers from denying policies to living donors or charging them higher premiums. Today, more than 114,000 Americans are on the organ transplant waiting list, with more than 96,000 waiting for a kidney. In 2017, of nearly 20,000 kidney transplants, only 5,811 were from living donors.

TRANSPLANT SPOTLIGHT

UNOS/OPTN ISSUE NEW HEART ALLOCATION POLICY



On October 18, the adult heart allocation policy changed.

Heart transplant candidates used to be grouped according to three statuses – 1A (most urgent), 1B (somewhat urgent) and 2 (least urgent). As UNOS/OPTN learns more about heart disease and successful treatment of it, we need more specific criteria that reflects a patient's current health and care they are getting.

UNOS/OPTN changed the heart allocation system on October 18, 2018.

Candidates are now listed according to six medical urgency statuses. Status 1 is the most urgent and Status 6 is the least urgent.

While there are highly detailed criteria for status assignments, several basic factors will be considered:

- Your current treatment is complicated by an infection or clotting, and/or if your treatment requires you to stay in the hospital, then you will generally be in a higher status than those who are not having complications and can leave the hospital.
- Your transplant program must report data to UNOS about your current treatment and symptoms. The program then lists you in the applicable status.

If you are in the new Status 1 or 2, you are in the most urgent need for a heart transplant. As a result, you would be considered first for heart offers from a wider geographic area (up to 500 miles from the donor location) before candidates with Status 3, 4, 5 or 6.

Your status may change if your symptoms get better or worse, or if your form of treatment changes. If you had been in a higher status but no longer meet the criteria for it, your transplant team will change your status as appropriate.

Your transplant team is the best source of current information regarding your status and any treatment options.

Only medical information is used to determine how urgently you need a heart. No other personal information, such as your insurance type or cause of your heart disease, goes into deciding your status.

Your transplant team will report any major change in your medical condition or the treatment you are getting. This information could change your urgency status.

It is important that your transplant center has your most current information and test results. Please work with your transplant team to schedule appointments and tests that will allow them to keep your information up to date.

If you are at the highest level of medical urgency, your transplant team must frequently re-certify your information. This is done to ensure that patients in that status are still in urgent need of a transplant. Other status criteria require re-certification of medical information every few weeks or months.

Children younger than age 18 will continue to have the three statuses 1A, 1B and 2. The medical criteria used to prioritize them is somewhat different from the adult criteria.

The transplant system is designed to be flexible and allow for improvements. New forms of treatment, and new understanding of patient care, help us learn how to save more lives and help enhance people's quality of life through transplantation.

Transplant professionals review the heart allocation system regularly and adjust it to better meet the needs of transplant candidates. Your transplant team will keep you informed of changes in the system and what they may mean for you.

You should contact your transplant team first if you have questions or concerns. They will have the most detailed information about your medical status and treatment options. You may also contact UNOS Patient Services at 1-888-894-6361.

PREPARE FOR NATIONAL DONOR SABBATH IN NOVEMBER

National Donor Sabbath is an interfaith celebration of life and thanksgiving. It is a special time for congregations across America to learn about the critical shortage of organs and tissue and to celebrate the greatest blessing of all – LIFE.

National Donor Sabbath will be observed November 9-11. We invite you to use the following downloadable resources within your local communities and houses of worship by visiting www.donatelife.net/nds/.

If you are interested in hosting an event in your local community, want to find out how to get involved in an existing event, or would like more information, contact Lisa Upsher at lupsher@core.org.

BE A SYMBOL OF HOPE FOR THOSE WHO ARE WAITING.

Donation helps restore health, sight and mobility. Consider providing hope to the more than 100,000 people in need of lifesaving organ transplants and the hundreds of thousands more in need of corneas and tissue.

Learn more about organ, eye and tissue donation and register today. core.org/register

DLA REACHES INSTAGRAM MILESTONE

DLA's Instagram account has reached 10,000 followers! As a verified organization at Instagram's 10K follower mark, DLA will now be allowed to include links in Instagram story content. Taking an action to register from Instagram just got easier. Follow DONATE LIFE: @donatelifeamerica.



PARTNERS IN DONATION

CORE DONORS CRITICAL IN ALZHEIMER'S, AUTISM, HIV RESEARCH



The National Disease Research Interchange (NDRI) has been awarded more than \$7 million in grants for research focused specifically on Alzheimer's disease, Autism Spectrum Disorder (ASD) and HIV/AIDS.

CORE provides donated tissue to NDRI for these critical research projects.

The first supplemental award focuses on Alzheimer's disease and its related Dementias (AD/ADRD).

The second supplemental award focuses on Autism Spectrum Disorder (ASD). NDRI will provide the NIH's Neurobiobanks with post mortem brains recovered from donors with a history of ASD that will further research into the etiology of the disorder.

HIV/AIDS is the focus of the third supplemental award with an objective to develop an HIV Human Tissue Resource for Large Scale and Cohort-Specific HIV Studies. Through this grant NDRI will provide federally-funded investigators access to a rigorous and uniform collection of human biospecimens obtained from defined cohorts of HIV positive donors with the intent of yielding consistent and reproducible experimental results for ground-breaking studies.

"The combined public health impact of Alzheimer's disease, Autism Spectrum Disorder and HIV/AIDS is staggering," said Bill Leinweber, President and CEO of NDRI. "We look forward to supporting these critical research efforts with the expertise and competencies NDRI has demonstrated through our HTORR program."

"It is indeed a privilege for NDRI to be awarded support from the NIH to further leverage the impact of our long-standing efforts to support investigators with the biospecimens needed to advance discovery," said Mary Hendrix, PhD, President of Shepherd University and Chair of the NDRI Board of Directors.

The National Disease Research Interchange (NDRI) is the nation's leading source of human tissues, cells and organs for scientific research. A not-for-profit 501 (c) (3) organization founded in 1980, NDRI is funded in part by the National Institutes of Health, public and private foundations and organizations, pharmaceutical and biotechnology corporations. By serving as the liaison between procurement sources and the research community, NDRI is uniquely positioned to support breakthrough advances and discoveries that can affect advances in the treatment and cure of human diseases.

INDIANA COUNTY CORNER ACCEPTS AWARD FOR PARTNERSHIP THAT SAVES LIVES



At a luncheon held at the Indiana Country Club, CORE recognized Indiana County Coroner Jerry Overman Jr. as forensic leader of the month by the Association of Organ Procurement Organizations. The organization cited Overman for demonstrating outstanding leadership and innovative practices to make a difference in donation and transplantation.

According to CORE CEO Susan Stuart, this was a recognition that's not only well-deserved, but also, a long-time in the making. She said, "Throughout his career, Jerry has taken great measure to ensure that donation is an

opportunity for families who may not otherwise have the option. In doing so, he has saved and enhanced the lives of so many in this community and well beyond."

Specifically, Overman created software that is making non-hospital electronic referrals possible, ultimately increasing donation. By doing this, he's giving grieving donor families the ability to create a lasting and meaningful legacy for their loved ones. He's served as a vocal supporter for organ, tissue and cornea donation in Harrisburg, advocating for the Donate Life PA Act.

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, September 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

YOU'RE INVITED

This is what a
HERO LOOKS LIKE

Are you a heart transplant recipient, waiting for a heart transplant or caring for someone who is? The Center for Organ Recovery & Education (CORE) would like to invite you to a special meeting where you'll have the chance to connect with other recipients, waiting list candidates and caregivers to share your story and learn more about promoting the Donate Life™ cause!

Heart Transplant Support Group

Saturday, October 27, 2018
11 a.m. - 1 p.m., lunch will be provided
204 SIGMA DRIVE, PITTSBURGH, PA 15238

Please RSVP by Thursday, October 18 to kmetz@core.org

(coping with grief)
during the holidays

It takes courage to grieve and to honor the pain we carry – particularly during the holiday season when our sadness is intensified and the world is celebrating around us. Please join us in listening and talking with others as they share their stories and how they continue to cope during the holiday seasons.

{ Tuesday, Nov. 6th, 2018 }
7:00 p.m. - 8:30 p.m.
CORE
204 Sigma Drive, Pittsburgh, PA 15238

{ Every Tuesday from Nov. 20th, 2018 - Dec. 18th, 2018 }
6:00 p.m. - 8:00 p.m.
Hospice Care of West Virginia
1606 Kanawha Blvd., Charleston, WV 25387

(rsvp)
Rose Grondwalski at
412-963-3550 or rsvp@core.org

Advocate KICK-OFF

NETWORKING LUNCH KEYNOTE EDUCATION

SATURDAY, JANUARY 5, 2019 10AM-2PM
CORE HEADQUARTERS IN PITTSBURGH, PA
WVU HEALTH SCIENCES CENTER IN CHARLESTON, WV
TEAM ALLEGHENIES TRANSPLANT MEETING IMMEDIATELY FOLLOWING KICK-OFF

Invitation to Follow



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.