

As we celebrate National Donate Life Month in April, we encourage everyone to continue the mission of increasing the number of individuals who are part of the Illinois Organ/Tissue Donor Registry. We are proud to have reached our goal of more than 7 million registrants in 2020, but during these challenging times, the need for donors is more important than ever. Individuals on the transplant waiting list continue to need our help so they can get a second chance at life. Collectively, we can help shorten their wait.

My office recognized African American Heritage Month in February with a video and by recognizing the accomplishments and contributions of African Americans in Illinois. In this newsletter we honor the accomplishments of Dr. Dineen Simpson — the first Black female transplant surgeon at Northwestern Memorial Hospital and the only Black female transplant surgeon in Chicago — who overcame many hurdles on her path to become a trailblazer for African American women in the medical community. I hope you enjoy her story in this issue, as well as the stories about Illinois Senator Christopher Belt and Monica Fox of the National Kidney Foundation of Illinois.

Thank you for all you do each day to continue our lifesaving mission of increasing participation in the donor registry.

Jesse White

Jesse White
Secretary of State

Life Goes On

Secretary of State Jesse White • Spring 2021
A newsletter for Secretary of State facility employees and other organ/tissue donation advocates

April puts donation in the spotlight

During National Donate Life Month in April, we celebrate the success of organ/tissue transplants for those who would not otherwise get a second chance at life. The events this April may look a little different than years past, but the message remains the same — please consider joining the Secretary of State's Organ/Tissue Donor Registry to help shorten the transplant waiting list in Illinois. We have approximately 4,000 individuals waiting for organ transplants in Illinois. The vast majority of individuals are waiting for a kidney. In past years, the department has participated in numerous community events with Secretary of State Jesse White, including an annual press conference to launch April's activities. We have shared displays of transplant stories at Driver Services facilities, planted trees to honor donors and contributed to numerous events across the state. This year, in an effort to limit in-person events, we have pivoted to a virtual message that includes a new campaign on the *Life Goes On* website.

Our office continued its annual tradition of unveiling a new donor awareness campaign each April with a commercial and a brochure featuring former Chicago White Sox player and broadcaster Ed "Farmio" Farmer, a kidney recipient who died last year. Farmer, a tireless supporter of organ and tissue donation, died in April 2020, at the age of 70 from Polycystic Kidney Disease (PKD). This is an inherited condition that also claimed the life of his mother. Farmer — who received a kidney transplant from his brother in 1991 — regularly joined Secretary White for donor awareness events and Chicago White Sox autograph signing sessions. Farmer, who had been a broadcaster for the Chicago White Sox, lived for nearly 30 years because of his gift.

Another way to raise awareness for the April donor awareness campaign is by having Driver Services facility employees wear *Life Goes On* polo shirts. Customers who see staff dressed in

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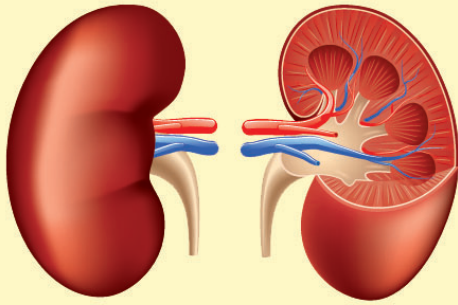
Be an organ/tissue donor

Ed Farmer was an All-Star relief pitcher and the radio voice of the Chicago White Sox. He needed a kidney, and thanks to a lifesaving gift from a donor, he lived nearly 30 more years. Join the registry today.

the coordinating shirts with the eye-catching *Life Goes On* logo may be encouraged to register. Staff also attended a refresher presentation about organ and tissue donation, where they learned new information and to ask questions about the program. Facilities received colorful *Life Goes On* flags to display. Many will fly the flags for National Blue and Green Day

(cont. on pg. 2)

What do kidneys look like and where are they located?



The kidneys are a pair of bean-shaped organs with the job of filtering your blood. Kidneys are the size of an adult fist, located on either side of the spine, just below the rib cage.

What exactly do the kidneys do?

They accomplish a variety of tasks including: removing waste and excess fluid from the body by filtering the blood, controlling red blood cell production, and helping to regulate blood pressure, calcium and potassium. Several times each day, the blood in your body passes through your kidneys.

What can affect kidney function?

Diabetes — This is the leading cause of kidney disease.

High blood pressure (also called hypertension) — This is the second leading cause of kidney disease.

Polycystic kidney disease (PKD) — The most common genetic kidney disease.

Kidney stones and congenital diseases — These conditions, as well as other underlying conditions, such as obesity, smoking, overuse of over-the-counter painkillers, illegal drug use, family history of kidney disease, age, and ethnicity can each affect kidney health.

Many patients will opt for a kidney transplant if doctors think that is the best option for returning the patient to a normal life.

Living Kidney Donation vs. Deceased Donation — Patients can be on the national transplant waiting list for a deceased donor kidney, or they can accept a kidney from a living donor. Patients in need of a kidney that are on the waiting list could remain there for many years, while those who receive a kidney from a living donor may have a much shorter wait. Living kidney donors can live a perfectly healthy life with a single-functioning kidney, which will enlarge to compensate for the missing kidney. Kidneys from living donors may last longer — on average 15-20 years — than those from deceased donors that last about 12 years.

April puts donation in the spotlight (cont. from pg. 1)

on Friday, April 16 — a day for donor awareness at Driver Services facilities and other workplaces.

The Life Goes On website also includes a video link with a personal message from Secretary White and links to the April 2021 television and radio commercials in English and Spanish. There is also a new brochure featuring Ed Farmer, a press release and social media links. A new feature on the website provides information about the three types of donation — organ/tissue, living and whole body — with facts, as well as common myths and misconceptions. Although the Secretary of State's office only promotes registering as an organ/tissue donor, the department is providing additional information on other types of donation for educational purposes. The office is not endorsing any of the featured options.

Black History Month in Illinois

In February, the office recognized the many accomplishments of individuals within the Black community with a video honoring African American Heritage Month. African Americans have contributed greatly to the areas of engineering, science, government, sports, agriculture, literature, entertainment, teaching, medicine and countless other fields.

Illinois is home to a large number of inspirational African American leaders, including Secretary of State Jesse White, the first African American to hold the position in Illinois; former President Barack Obama, the first Black President of the United States; Harold Washington, the late Chicago mayor; former Senator Carol Moseley Braun, the first female U.S. senator from Illinois and the first Black woman to serve in the U.S. Senate; Ernie Banks, the first Black baseball player for the Chicago Cubs; Gwendolyn Brooks, the first Black woman to win a Pulitzer Prize and to serve as Poet Laureate of Illinois; and Jean-Baptiste Pointe DuSable, the founder of Chicago.



Dr. Dineen Simpson

Notably, two Black female transplant surgeons specializing in the field of organ and tissue transplantation have paved the way for others, and are renowned for their medical contributions. **Dr. Velma P. Scantlebury-White, MD**, was the first Black female transplant surgeon in the U.S. and **Dr. Dineen Simpson, MD**, is the only Black female transplant surgeon in Chicago and is Northwestern Memorial Hospital's first African American female transplant surgeon.

Dr. Simpson, assistant professor of surgery (kidney, liver and pancreas transplantation) at Northwestern Memorial Hospital's Feinberg School of Medicine, completed her medical residency at Harvard University. During her surgical residency at Boston's Brigham and Women's Hospital, she observed a living-donor kidney transplant. In her role as director of the African American Transplant Access Program (AATAP) at Northwestern Memorial Hospital, Dr. Simpson focuses on dispelling myths and addressing patient distrust of transplantation, and medicine in general, within the Black community. The program encourages cultural competency, health literacy and offers psychological support to minorities.

Dr. Simpson is the only Black female transplant surgeon in Chicago, yet her position does not reflect the diverse population she serves. The underlying health conditions that often contribute to kidney failure — high blood pressure, diabetes, obesity and more — disproportionately affect the African American community. African Americans have a higher percentage of individuals on the transplant waiting list. According to the



National Kidney Month observed

National Kidney Month is about educating the community about what keeps your kidneys healthy, as well as understanding kidney disease and its effect on the body. Millions of Americans suffer from kidney disease, and many are unaware they have it. It could be related to genetics or underlying health conditions, such as diabetes, obesity and high blood pressure. The National Kidney Foundation of Illinois (NKFI) works with healthcare professionals to improve the lives of those affected by kidney disease. They offer free screenings to detect kidney disease at early stages and help patients understand how to take care of their kidneys. The organization's Kidney Mobile is the first of its kind to travel throughout the state, screening individuals for kidney disease markers.

In celebration of World Kidney Day on March 11, NKFI hosted a virtual event with speakers, presentations, tips for keeping kidneys disease-free, and a healthy, make-it-yourself meal and cooking demonstration.

"World Kidney Day is like the Super Bowl for our organization and kidney patients all over the country," said Jacqueline Burgess-Bishop, FACHE, and CEO of the National Kidney Foundation of Illinois. This is one of my favorite months of the year to lead our amazing team and our partners as we continue to raise awareness about the importance of kidney health and increase awareness of kidney disease and its precursors. At the National Kidney Foundation of Illinois, we are celebrating with a virtual lunch and learn session. Experts in nutrition, nephrology, exercise and organ donation will share updates and demonstrations with hundreds of folks from across the state."

The reality is that African Americans suffer from kidney failure at three times the rate of whites, according to the National Kidney Foundation. They make up 35% of all patients receiving dialysis for kidney failure, despite making up around 13% of the national population. Chronic liver disease and cirrhosis are also among the leading causes of death in African Americans between 45 and 64 years old, according to the Centers for Disease Control and Prevention.



Monica Fox

Finding a new purpose in life

Monica Fox, director of outreach and government relations for the National Kidney Foundation of Illinois, received the difficult news that her kidneys had failed and that she would likely wait for several years for a transplant.

In November 2013, Monica left work because she was not feeling well and went to the emergency room thinking she had a persistent sinus infection, but the diagnosis was much worse. Her kidneys were failing, and she became one of thousands of people in Illinois going to kidney dialysis several times a week, which saved her life until her transplant. Monica took initiative by posting a video about her need for a transplant on social media. She received several offers of a kidney, but there was no match.

Then two days before Thanksgiving in 2016, she received a directed donation from a friend's family at the University of Illinois Chicago Medical Center. It was a perfect match. She knows her donor's name and feels a very special connection to him. Monica takes anti-rejection medicines daily to keep her body from rejecting the new kidney, and found a new purpose for her life — as an advocate for organ and tissue donation, first for The Gift of Hope Organ & Tissue Donor Network and later, the National Kidney Foundation of Illinois.

"Because my donor, Milton, said yes to organ donation, I have had the opportunity to see my daughter, Olivia, grow into a wonderful young woman, meet my grandchild, spend time with my family, and hopefully make a difference for others who wait for their gift just like I did," said Fox. Every day I wake up feeling grateful for this precious gift of a lifesaving transplant, and that I realized a new path for my life — advocating for organ donation and educating about kidney disease."

In 2018, Monica participated in the Transplant Games of America, an Olympic-style athletic competition held every two years. Monica stresses the importance of registering as a donor and making your wishes known to family, as her donor did.

LIFE GOES ON
BE AN ORGAN/TISSUE DONOR
REGISTER AT LIFEGOESON.COM

Organ Procurement and Transplantation Network, Blacks make up just 14% of the total population in Illinois, but 40% of those are waiting for a kidney.



Senator Christopher Belt

State Senator Christopher Belt (D-Centreville) is an advocate of organ and tissue donation. He received a kidney transplant in 2010 at Barnes Jewish Hospital in St. Louis after years of high blood pressure (also known as hypertension), a leading cause of kidney failure. Sen. Belt had been battling high blood pressure since his mid-20s. In 1996 (when he was just 24), he was told that his kidneys showed signs of damage. Many of his family members also suffered from hypertension. He kept his high blood pressure under control, and he was fortunate that his kidneys continued to function where he did not need kidney dialysis until a year before his transplant.

"I made up my mind I had to continue to do this (dialysis) to keep going," Sen. Belt said. "I kept working, doing normal things."

He received three calls regarding a kidney transplant, but the first two did not materialize. The third call was for the kidney he received on Jan. 24, 2010. He was released from the hospital two days later. The quality of his life improved dramatically after the transplant.

"The Black community is not as educated on transplants, it's all about education," said Sen. Belt. Even though Belt did not have a living kidney donor, he believes in living donation. Coincidentally, Sen. Belt's predecessor in the senate, Sen. James Clayborne, Jr., also received a kidney transplant.

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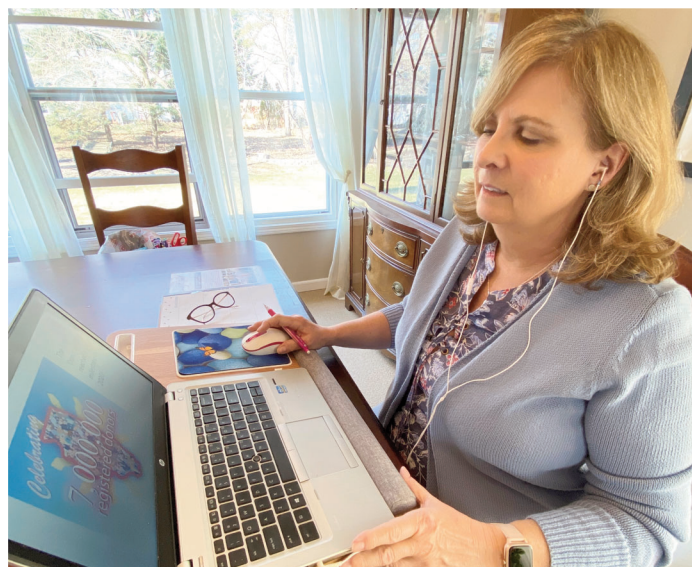
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Organ/Tissue Donor Program coordinator Margaret Pearson addresses York High School driver's education students in Elmhurst via zoom in March. Margaret presented donor classroom presentations for two days with Leah Gleason, whose daughter, Lucy, a liver transplant recipient, graduated from York.

DID YOU KNOW?

- Both a human kidney and heart are each about the size of a closed fist.
- The right kidney is slightly larger than the left because the liver also sits on the left side of the body taking up more space.
- Each day the kidneys filter 45 gallons of blood in the average person.
- The liver is a very large and heavy organ (about 3.5 lbs.) that regenerates in both the donor and recipient if a section is removed from a living donor and transplanted.
- The heart pumps about 2,000 gallons of blood each day in the average person.
- Although the human heart weighs less than one pound, a man's heart generally weighs 2 oz. more than a woman's heart.
- About 4,000 people in Illinois are on a waiting list for a lifesaving organ transplant.
- There is no waiting list for those waiting for a tissue transplant (corneas, skin, bones, tendons, ligaments and veins).
- The cornea is the most commonly donated tissue with a 95% success rate.
- A living donor can donate a section of the small intestines, which is much longer than a person is tall (10 feet).
- Laughter is good for the heart!



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