



Life Goes On

Secretary of State Jesse White • Fall 2020

A newsletter for Secretary of State facility employees and other organ/tissue donation advocates

Many exciting things are happening within the Organ/Tissue Donor Program this year. I want to thank everyone who has continued to promote organ and tissue donation over the last few months.

On Aug. 25, the Illinois Secretary of State's Organ/Tissue Donor Registry reached a record 7 million registrants. This is important because the need for donors is critical. Many men, women and children are waiting for lifesaving hearts, lungs, livers, kidneys, pancreases and intestines. Thousands more need life-enhancing tissue transplants.

In August, we celebrated National Minority Donor Awareness Month. We developed a virtual program to share with cultural centers, health departments and many other organizations so that we could continue to educate minority communities about the need to register as donors. Facility staff members are on the frontlines of this important program, and organ donor staff will help refresh everyone's donor program knowledge this fall with an informative presentation. We want facility personnel to be aware of changing laws and statistics to better serve customers.

Your efforts in spreading the word about donation, whether it be in your workplace or through public outreach, are appreciated by those who are waiting for that lifesaving gift. Thank you for helping us reach our goals.

Jesse White

Jesse White
Secretary of State

Donor Registry Reaches 7 Million

Milestone celebrated this summer



The Illinois Donor Registry has reached 7 million registrants, making it one of the largest donor registries in the nation.

"I am proud that Illinoisans continue to show their giving spirit and commitment to others by signing up for this lifesaving program," said Illinois Secretary of State Jesse White. "Our mission is to strengthen the Organ/Tissue Donor Program through outreach and registration initiatives. We want to end the waiting for the approximately 4,000 people statewide. Each year about 300 people die waiting for a transplant in Illinois."

Of the total number of people who can register as donors in Illinois, 65% have chosen to participate in this program. In addition, more than 155,000 16- and 17-year-olds in Illinois have registered as donors since 2018, as part of a law initiated by Secretary White.

"Now more than ever, people should consider registering as donors so that everyone waiting for a transplant has a better chance at receiving one," said White. "Nationwide, donors are saving lives even in the midst of a pandemic."

Secretary White is encouraging people to join the 7 million Illinoisans who have said "yes" to donation. Registering only takes a minute at www.LifeGoesOn.com, and up to 25 lives can be saved or improved by a single donor.

WHERE ARE THEY NOW?

St. Louis teen says life is good after third liver transplant

For Annika Tiede, 19, a third liver transplant she received at age 8 is allowing her to pursue her dream of becoming a transplant nurse. Annika was born with biliary atresia, a liver disease. After two liver transplants failed as a toddler, Annika had her third transplant at the Ann and Robert H. Lurie Children's Hospital in Chicago.

Annika was unable to attend her first two years of elementary school because she was waiting for her third transplant, but a new liver allowed her to attend second grade. Annika recently graduated from high school, and is now attending Coe College in Cedar Rapids, Iowa. She is majoring in nursing, with plans to become a pediatric transplant nurse.

Annika ran cross-country in high school, volunteered for the St. Louis Zoo education program and was an intern for the city of Richmond Heights, Missouri, where she worked at the local library, public works and the police department. She also traveled as part of the zoo volun-

teer program to Panama and Belize, where she had the opportunity to work at an ecological research station. Annika also loves creative writing and is currently working on her first novel, tentatively titled "The Raven's Heir."

Annika's mother, Moreena Tiede, an IT specialist at Washington University in St. Louis, worked as a regional coordinator for the Secretary of State's Organ/Tissue Donor Program for several years before moving to St. Louis.

Annika recently gave a speech encouraging teens to sign up for organ/tissue donation. "In Illinois, teenagers can now sign up to be organ donors, which is pretty great," said Annika. "But you have to be sure to talk to your family, because they need to know about your decision. It's kind of hard to talk to your own family about death, because it's a terrible thing to think about, but this is a time when teens are learning to talk about hard things. We have a lot of hard things happening in our world. I want my family to know that I care about this world and the people that are left in it, even after I am gone. I want to be an organ donor because life is precious."



Eight-year-old Annika Tiede, center, and her mother, Moreena Tiede, left, visit with Illinois Secretary of State Jesse White in Springfield in 2008 shortly after Annika's third liver transplant.



Annika Tiede, 19, after her recent high school graduation.

Chicago and Lake Zurich Residents Receive Double Lungs as Northwestern Memorial Hospital Performs First COVID-19 Transplants

This summer, surgeons at Northwestern Memorial Hospital in Chicago performed the first two double-lung transplants in the nation on two area patients suffering lung damage from COVID-19. Mayra Ramirez, 28, of Chicago and Brian Kuhns, 62, of Lake Zurich received double-lung transplants. According to doctors at Northwestern, COVID-19 can damage lungs beyond repair, so transplants are an option for some patients. Ramirez, a paralegal, became ill with COVID-19 and sustained lung damage very quickly. Her surgery was in June, while Kuhns had his transplant in July. Both are grateful for their transplants.

August Marks National Minority Donor Awareness Month with New Virtual Campaign

During August, the Organ/Tissue Donor Program observed National Minority Donor Awareness Month with a comprehensive virtual campaign aimed at educating those in minority communities about the importance of registering as donors.

For several years, the donor program has held a "Wave Away the Waiting" event in August at the James R. Thompson Center in Chicago. This event traditionally featured a press conference held by Secretary of State Jesse White, a 22-vendor health fair, entertainment, speakers and a performance by the Jesse White Tumbling Team. Since an in-person event was not possible this year, a virtual web-based campaign was created to educate those in minority communities about the need to register as organ/tissue donors.

"This year we held 'Wave Away the Waiting' a little differently. But regardless of the format, the message was still the same—register to become an organ/tissue donor," said Secretary White.

The virtual campaign included a flyer, donor fact sheet, letter and video message from Secretary White, and PowerPoint presentation that included general donor information, as well as specific information aimed at minorities. Many of the diseases that commonly affect minority communities, when left untreated, can lead to the need for a transplant. Minorities represent large numbers on the transplant waiting list (both nationally and in Illinois), but are less likely to register as donors.

"Building our registry in order to give others a second chance at life is extremely important, especially in minority communities," said Secretary White. "By sharing this information with cultural centers, public health departments and other outreach organizations, we are encouraging individuals in minority communities to register as organ donors in order to build an even more diverse donor registry, which will benefit those waiting," said Secretary White.

The virtual campaign was posted on the Organ/Tissue Donor Program's website at www.LifeGoesOn.com and was distributed as an educational tool throughout the state to encourage donation within multi-cultural communities.



Family Friend Receives Ultimate Gift

The Organ/Tissue Donor Program's 2020 public service announcement and brochure featured the story of a young woman who was a heart donor to a friend of her family. Chicago resident Domonique "Nikki" Smith passed away at age 18. A friend of her family, Tanisha Basham, was in need of a heart transplant at the time of Nikki's death. Tanisha was suffering from congestive heart failure, and doctors told her the only way she was going to live was to receive a heart transplant. Her heart was functioning at just 9 percent before her transplant. A healthy donor heart that matched her blood and tissue type was her only hope.

Fortunately, Nikki was a match for Tanisha. Today, Tanisha advocates for organ/tissue donation with her donor's mother, Vicki Walker, and together they speak about the need for more people to register as donors. They focus their efforts especially in minority communities where the need is great, but fewer people register as donors.



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October is National Liver Awareness Month

October is National Liver Awareness Month, a time to learn how the liver functions and how to keep it healthy. According to the American Liver Foundation, nearly 33,000 Americans die from liver cancer each year. Diseases and conditions that may cause the liver to fail include chronic viral hepatitis, obesity, Primary Sclerosing Cholangitis (PSC), alcoholism, cirrhosis, and poor diet and lifestyle choices. In 1963, the first liver transplant was performed by Dr. Thomas E. Starzl, a pioneer in the world of liver transplantation.

Two of the donor program's regional coordinators are liver transplant recipients. Angelique Marseille of Beecher received her liver transplant in 1992, when she was just 23 years old. The reason for her liver deterioration is still unclear.

"I ask everyone if they are a registered organ and tissue donor," said Angelique. "I encourage those who have not registered to make the donor decision to save or enhance a life by giving the gift to someone. My life will be forever changed by that act of generosity."

Gavin Dillon of Libertyville received his liver transplant in 2016 at Northwestern Memorial

Hospital in Chicago when he was also 23 years old. Gavin suffered from Primary Sclerosing Cholangitis (PSC), a narrowing of the bile ducts that lead to the liver, the same disease that took the life of former Chicago Bears running back Walter Payton in 1999.

"I know how lucky I was to receive my new liver more than four years ago now," said Gavin. "It was certainly a gift of life for me. I am enjoying being part of the Secretary of State's Organ/Tissue Donor Program and being able to share my personal story with many individuals. If I can encourage people to sign up because of my story, I am happy to share it."

What does the liver do?

The liver is the second largest organ in the body and sits under the rib cage on the right side of the body. At just 3 pounds, it has many necessary functions such as eliminating toxins, producing energy and helping with digestion. To keep it healthy, people are advised to watch their weight, eat a balanced diet and exercise regularly. Environmental toxins can also damage liver cells. People are advised to drink alcohol in moderation, read labels on medications, such as pain relief medicines, and avoid taking illicit drugs.

What is a liver transplant?

If a person's liver is damaged by disease or an unknown cause, doctors will sometimes suggest a liver transplant. The damaged liver is replaced, most commonly, by a healthy liver from a deceased donor. In some instances, a person can receive a partial liver, which will grow into a full-sized functioning liver within a couple of months. A healthy individual can also donate a section of their liver to a person in need, which is called a living liver donation.

According to the Organ Procurement and Transplantation Network (OPTN), more than 12,000 individuals are currently waiting for a liver transplant nationally. Of those individuals, 240 are under the age of 10. Last year, there were nearly 8,900 liver transplants performed in the United States. Of those who received transplants, 551 were under the age of 18.

In Illinois, five of the 271 individuals currently waiting for a liver are under the age of 10. Of the 323 liver transplants performed in Illinois last year, 19 were performed on individuals under the age of 18.



Daru Smith, triple transplant recipient, center, presented the Chicago South Driver Services facility staff with a new countertop display featuring his transplant story at the facility on Aug. 29. Daru is one of two individuals to receive a rare triple transplant (heart, liver and kidney) at the University of Chicago Medical Center in 2018. Standing with Daru are facility zone manager Nykeba Gardner, left, and facility supervisor Pamela Smith.

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