



Life Goes On

Secretary of State Jesse White • Fall 2019

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

The summer was an eventful season for the organ/tissue donor program. We observed National Minority Donor Awareness Week with a *Wave Away the Waiting* celebration on Aug. 6 in Chicago. Speakers, entertainment and a health fair raised awareness for the need for more minority donors in Illinois. A minority donor awareness program was also held at HSHS St. Mary's Hospital in Decatur.

In September, the Illinois donor registry climbed to 6.8 million individuals—nearly 90,000 of whom were 16-and 17-year-olds registering for the first time. Many teens are encouraged to register as donors at health fairs and community events after participating in presentations about donation in driver's education classes at their local high schools.

In November, we will observe National Donor Sabbath, a time for religious leaders across the country to recognize the life-giving benefits of organ/tissue donation in their places of worship. Most major religions across the globe support donation because of its ability to provide a healthy life to thousands of individuals every year.

Thank you to the Driver Services facility staff for registering hundreds of individuals as new donors each and every day. Those new donors have the potential to save countless lives.

Jesse White

Jesse White
Secretary of State

National Minority Donor Awareness Week a success in Illinois

Illinois needs more minority donors

On Aug. 6, the Illinois Organ/Tissue Donor Program celebrated National Minority Donor Awareness Week in Illinois. The annual observance promoted the need for more minority donors with a program at the James R. Thompson Center in Chicago. Secretary White held a press conference on the plaza, which featured speeches from transplant recipients and donor advocates. Speakers included Kim Gosell, a three-time kidney recipient and the senior director of Development at UI Health; Vicki Walker, donor mother; and Daniel Perez, kidney recipient. Many donor advocates helped make the day a success by sharing their stories with those in attendance.

"We are working together to end the wait for those in need of organ donation," said Secretary White. "Unfortunately, minorities are in great need of organ transplants, yet they donate at a lower rate. I encourage everyone to

register to become an organ/tissue donor to help give the gift of life to someone in need."

The initiative is supported by Donate Life Illinois. The phrase *Wave Away the Waiting* comes from the critical need for additional donors who might help to "wave away" the long transplant wait list in Illinois.

Nationally, people of color comprise nearly 60 percent of the waiting list for organ transplants, yet account for only about 33 percent of those who donate organs, according to the Organ Procurement and Transplantation Network (OPTN). Statistics from OPTN show nearly 1,500 African Americans on the wait list in Illinois, but only about 120 became donors in 2018. Hispanics demonstrate the same basic trend, with more than 800 on the wait list, but only 60 donating last year. Individuals of color experience illnesses, such as high blood pressure

(cont. on pg. 2)



Secretary White, joined by donor advocates and recipients, addressed the crowd on Aug. 6 at the James R. Thompson Center Plaza for National Minority Donor Awareness Week.

and diabetes, at much higher rates. The larger the pool of donors, the higher the chances are of successful transplants.

In Decatur, a minority donor awareness ceremony was held at HSHS St. Mary's Hospital on Aug. 21. The program included speakers and donor recipients who shared their stories. Following the ceremony, a registration table was staffed by members of the Macon County Life Goes On Committee.

BELOW: Macon County Health Department employees staffed a donor registration table on Aug. 21 at HSHS St. Mary's Hospital in Decatur during a National Minority Donor Awareness Week celebration.



ABOVE: The Jesse White Tumbling Team performed on the plaza at the James R. Thompson Center during the *Wave Away the Waiting* event.

RIGHT: Jackie Green, supervisor of the Food and Nutrition Department at HSHS St. Mary's Hospital in Decatur, presented a poem to honor recipients and donor families during a National Minority Donor Awareness Week observance on Aug. 21. Following the ceremony, the Macon County Life Goes On Committee staffed a donor drive in the hospital lobby.



Wave Away the Waiting Health Fair featured many organizations

Fairgoers had their health questions answered

In conjunction with the *Wave Away the Waiting* program on the James R. Thompson Center outdoor plaza, a 22-vendor health fair was held in the atrium of the Thompson Center. Vendors set up informational tables and interacted with attendees. They also distributed literature, small giveaways and answered questions about services offered at varied organizations. Representatives from Chicago-area transplant hospitals, Donate Life Illinois partners and other organizations participated in the health fair.

Vendors included: the Illinois Department of Public Health's Center for Minority Services, which offered several key health screenings; Loyola Medical Center; the Ann & Robert H. Lurie Children's Hospital of Chicago; Premier Urgent Care-Hyde Park; Rush Medical Center; UI Health UIC; Chicago Center for Sports Medicine/Orthopedics; 100 Black Men; Build

Chicago (minority youth organization); POP on Youth Violence; and the Pulmonary Fibrosis Foundation. Donate Life Illinois partners included: Vitalant (formerly Lifesource); the National Kidney Foundation of Illinois; Eversight Illinois; Gift of Hope Organ & Tissue Donor Network; and Team Illinois. The Illinois Treasurer's office

hosted an I-Cash table to help reunite individuals with unclaimed property, and the Secretary of State's Organ/Tissue Donor Program distributed literature and registered new donors. Other vendors included Henna Tattoo and Live One Day At A Time, which offered acupuncture and reflexology.



LEFT: Dr. Airron Richardson, Premier Urgent Care-Hyde Park, talks to a health fair participant during the *Wave Away the Waiting* health fair at the James R. Thompson Center. RIGHT: John Valencia, transplant strategic outreach coordinator, Rush Medical Center, helps a health fair attendee with services offered at Rush during *Wave Away The Waiting*.



National Donor Sabbath to be observed Nov. 15-17, 2019

Worship leaders encouraged to speak about donation on this weekend

One of three national observances for organ/tissue donation is National Donor Sabbath, a weekend set aside for clergy to speak to their parishioners about the lifesaving benefits of organ donation. The weekend is observed in mid-November, and religious leaders are encouraged to ask members of their congregation with a transplant to share their stories with their fellow worshipers. Most major Eastern and Western religions support organ donation, citing the lifesaving benefits of transplantation. Many churches host a donor registration drive during Donor Sabbath weekend to register those who have not yet made the donor decision.

Secretary White traditionally visits several churches and speaks about donation during this weekend. The Secretary encourages anyone with ties to a place of worship to speak to the leader and ask if a donor registration table can be set up or literature distributed to those attending services during the observed weekend. There is a great need for more donors in Illinois and raising awareness could mean a larger donor pool available for those who are currently on the waiting list.

Illinois and DuQuoin state fairs promote organ/tissue donation

Two Illinois state fairs drew tens of thousands of attendees in Springfield and DuQuoin in August. In Springfield, Secretary White walked in the Illinois State Fair Twilight Parade on Aug. 8 to celebrate the opening of the fair. Each year, the Springfield Life Goes On committee sponsors a float decorated in blue and green donor colors to promote donor awareness. Secretary White joined committee members, donor advocates and volunteers for the parade. The participants were dressed in green Donate Life t-shirts. At the DuQuoin State Fair, Secretary of State employees and volunteers staffed a table to distribute literature and small giveaways and to answer questions about organ/tissue donation.



ABOVE: Secretary White (far left) joins a group of organ/tissue donation supporters and Springfield Life Goes On Committee members at the Illinois State Fair Twilight Parade. BELOW: Secretary of State's office employees and volunteers staffed an informational table, which included organ/tissue donor registration materials, during the DuQuoin State Fair.



Decatur toddler receives new heart

Secretary White presents story at facility

Giannah Patricia Nichole Wilkins of Decatur was born on Oct. 23, 2017. When her mother, Katrina Gramigna, was 31-weeks pregnant, she was told there was a problem with her unborn daughter's heart. Doctors told the family that the baby was suffering from congenital cardiomyopathy and that her chances for survival were slim. After Giannah's birth, her family was prepared for the long wait she might have for a new heart. On Dec. 16, 2017, Giannah's family was told there was a heart for her and she underwent surgery for her transplant the next day at St. Louis Children's Hospital.

The surgery lasted five hours and Giannah was hospitalized for nearly a month. She recovered at home with her mother, four siblings and grandmother. Now 2 years old, Giannah is a happy, healthy toddler who is learning to walk and reaching developmental milestones like other children her age. Her family hopes that someday they will meet their donor family and thank them in person for their Christmas miracle.



ABOVE: Heart recipient Giannah Wilkins, now age 2, with her mother, Katrina, and Secretary of State Jesse White at the Decatur facility. BELOW: Giannah Wilkins gives Secretary of State Jesse White a kiss on the cheek after he presents her countertop display story at the Decatur facility.



Employee Connection

Naperville Driver Services facility employee's father has heart transplant



Heart Recipient Frank Badus, Jr., seated center, with his family: (from left) son, Frank; wife, Mary; and daughters, Nicole and Michelle.

Michelle Morris is a Public Service Representative at the Naperville facility. Her father, Frank Badus, Jr., 72, recently celebrated the 25th anniversary of his heart transplant. Frank has been there to see his family grow, and has several grandchildren and great-grandchildren. Frank is a retired heating and air conditioning specialist. Before he received his lifesaving gift of donation, he was suffering from heart failure and was placed at the top of the transplant waiting list for a new heart. His wife, Mary, and Michelle, as well as the rest of the family prayed that a heart would become available for him. On Sept. 1, 1994, Frank received a new heart at Rush Medical Center in Chicago. Frank has been there to walk two of his children down the aisle at their weddings and to be a part of his six grandchildren's and two great-grandchildren's lives because of his incredible gift. Michelle explained how the transplant brought their family closer together. The family values each year they have had with Frank. Michelle advocates for organ/tissue donation as part of her job at the Naperville Driver Services facility. She believes that registering new donors will give others a chance at life, just like her father.

First Ladies Health Initiative *We Move* a success

Secretary White spoke about the importance of registering as an organ/tissue donor to hundreds of participants of the First Ladies Health Initiative *We Move* 5K Run/Walk on Sept. 7 in Chicago. The event, held at Oakwood Beach in Burnham Park, featured speakers including Toni Preckwinkle, Cook County Board chair; Amy Eshleman, spouse of Chicago Mayor Lori Lightfoot; and many others.

The First Ladies Health Initiative is a consortium of more than 200 pastors' wives (First Ladies) from across the United States. Its mission is to increase awareness and prevent chronic diseases that are disproportionately affecting the African American and Latino communities. The group partners with more than 900 healthcare providers, volunteers, and public and private health-related organizations.

The *We Move* 5K Run/Walk is a family-friendly annual event to celebrate and improve Chicagoans' health. The day's activities included the run/walk, a health fair featuring dozens of physicians offering valuable advice on a number of health-related topics, an organ/tissue donor registration table, fitness demonstrations, important health screenings, and healthy food samples.



Secretary White supported the First Ladies Health Initiative with (from left): First Lady Shauntai Stowers, chair, First Ladies Health Initiative Chicago Chapter; First Lady Jamell Meeks, national chair, First Ladies Health Initiative; Toni Preckwinkle, president, Cook County Board; Secretary White; Tracey Alston, executive director, First Ladies Health Initiative; John Gremer, director of communications, Walgreens; Val Warner, host of Windy City LIVE, ABC7 Chicago.

OTS 29th annual Anniversary Celebration honors members

Organ Transplant Support held its 29th annual Anniversary Celebration at a brunch on Sept. 8 at the DoubleTree Hotel by Hilton in Naperville. Dozens of OTS members were in attendance, many with their families, to network with others. OTS members have received transplants, are part of donor families, or are caregivers for family members and friends waiting for a transplant. OTS president Carol Olash, a heart recipient, emceed the special recognition awards ceremony, including the "Spirit of OTS" awards. This year's "Spirit of OTS" award winners were Judy Bruni, a 21-year pancreas recipient from Schaumburg, and David Gustafson, an 11-year liver and kidney recipient from St. Charles. Judy and David each exemplify and live the OTS mantra that "No one should go through this alone." This fall, a mentoring program entitled You Are Not Alone began signing up OTS transplant recipients to help those going through the transplant journey. Mentors will provide psychological and social support, as well as practical advice to transplant families.



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