



# Life Goes On

Secretary of State Jesse White • Fall 2016

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

The Organ/Tissue Donor Program strives to educate everyone in Illinois about the importance of signing up to be donors. In early August, we targeted this message to minority groups in Illinois as we celebrated National Minority Donor Awareness Week statewide. Minorities in particular need to consider donation as many ethnicities are, sadly, affected by the need for a transplant in their lifetime. Many remain on long waiting lists, but are less likely to register as donors. An ethnically diverse donor pool increases the odds of a successful transplant for everyone waiting.

As we head into fall, we thank those who have registered their donor decisions at numerous summer events throughout Illinois. Donor staff registered donors across the state this summer at schools and universities, health care facilities and hospitals, and many health fairs and festivals. Each new registration means that more lives may be saved through transplantation — a win for everyone.

*Jesse White*

Jesse White  
Secretary of State

## “Wave Away the Waiting”



Secretary of State Jesse White addresses the crowd on the plaza of the James R. Thompson Center in Chicago on August 3 at the 4th annual “Wave Away the Waiting” event for National Minority Donor Awareness Week. Standing behind Secretary White are: Jose Betancourt, kidney and liver recipient; Jack Lynch, African-American Task Force Director of Community Affairs and Community Outreach for Gift of Hope Organ and Tissue Donor Network; Anthony Diaz, cornea recipient; Terry Christopher Lee, living kidney donor; Kevin Cmunt, CEO of Gift of Hope Organ and Tissue Donor Network; and Charmin Edwards.

Waiting for an organ transplant affects thousands of people each year, including numerous minority candidates, many of whom will not get the transplant they need in time. In August, we celebrated “Wave Away the Waiting,” an event that brought attention to the need for more minority donors in the state.

“The need for a transplant can be great in many minority communities,” said Secretary of State Jesse White. “If we increase the number of minority donors, we can increase the pool of donors for many who are waiting. Many times a better organ match comes from within one’s own ethnic makeup.”

On August 3, hundreds gathered at the James R. Thompson Center in Chicago to observe “Wave Away the Waiting,” showcasing the need for more minority donors.

Performances by several groups included the Jesse White Tumbling Team, Kalapriya Center for Indian Performing Arts and Dawn the Dancing Diva. A large vendor area inside the Thompson atrium and another outside on the plaza featured organ donor registration tables and other vendors. Organ donor staff answered individuals’ questions about donation and encouraged many to sign up.

According to the United Network for Organ Sharing (UNOS), 57 percent of those waiting for transplants are minority, but less than 40 percent actually donated organs. Many minorities are disproportionately affected by illnesses, including hypertension and diabetes, which often can lead to the need for a kidney transplant in their lifetime.

During the program, Secretary of State  
(continued on page 2)

## Rock River Valley LGO Committee member receives tissue transplant



Shirley Pincus

For Rock River Valley Life Goes On Committee member Shirley Pincus, the pain in her left foot was becoming unbearable. Shirley's ability to enjoy an active life was slowly disintegrating. A swelling ankle and intense pain were ruining her ability to live a normal life. A scan of her foot revealed significant nerve damage in three areas of her left leg. Luckily for Shirley, a surgeon explained to her that she could receive a nerve transplant, a surgical procedure called nerve decompression with Allograph, a tissue provider. During surgery, the damaged nerves were removed and replaced with donated decellularized human nerve tissue. After surgery, Shirley's pain was gone. "Today I work hard to promote organ and tissue donation. Without my surgery, I would not have discovered my purpose in life – to promote donation and educate others about what a gift organ and tissue donation is," said Shirley.

**LIFE GOES ON.  
BE AN  
ORGAN/TISSUE  
DONOR.**

## "Wave Away the Waiting" (continued from page 1)

Jesse White spoke to those gathered outside at the James R. Thompson Center plaza, expressing the need for more minority donors. He also confirmed that the Illinois Donor Registry had reached the 6 million mark earlier in the summer. Cornea recipient Anthony Diaz, living kidney donor Terry Christopher Lee and liver and kidney recipient Jose Betancourt joined Secretary White at the podium.

"I encourage everyone to sign up to be a donor. A single donor can save or enhance the lives of as many as 25 individuals," said Secretary White.

Many vendors gave out informational handouts at the event inside the Thompson Center. Health care material and brochures were distributed to the crowds inside. Many individuals registered to be donors at the event, and countless attendees took home valuable health care information to discuss with their families.

Those present were treated to a special performance by the Jesse White Tumbling Team on the plaza during the program. Attendees were also encouraged to discuss organ and tissue donation with family, friends and co-workers.



The Jesse White Tumbling Team thrills the crowd gathered on the plaza at the James R. Thompson Center on August 3 for "Wave Away the Waiting," part of National Minority Donor Awareness Week.



Team Illinois members who participated in the Transplant Games in Cleveland in June stand with Secretary White at National Minority Donor Awareness Week. From left: Lisa Givens, kidney recipient; Nicole Brown, kidney recipient; Gwendolyn Westlund, heart recipient; and Anthony Diaz, cornea recipient.



## National Minority Donor Awareness Week



HSHS St. Mary's Hospital in Decatur hosted a National Minority Donor Awareness Week donor drive to encourage minorities to register as donors. Also assisting the drive were the Macon County Health Department, Be The Match (national bone marrow donor registry), Macon Life Goes On Committee members, Gift of Hope Organ and Tissue Donor staff and St. Mary's staff.



Richard Stadelmann of Chicago stops by the donor registration table on August 6 at the Morton Arboretum in Lisle during the arboretum's Destination Asia Festival. Richard shared his family's story of his sister serving as a cornea donor and the impact it had on the recipient's life.



Diane Langley, who is currently waiting for a kidney, stopped by the donor registration table at the Morton Arboretum in Lisle during its Destination Asia Festival on August 6-7.



Mikaela Libby registers at the donor registration table at the East St. Louis Driver Services facility during National Minority Donor Awareness Week to show her support for donation and sign up.



The recently reorganized Champaign County Life Goes On Committee attended a National Minority Donor Awareness Week event at Carle Foundation Hospital in Champaign with Secretary White. From left: Frank Veach, Liz Hager, Tim Battershell, Amy Bandy, Lola Lewis, Secretary White, Donna Battershell, Jim McFarlin and David Freeman.

## Champaign LGO Committee registers 151 donors

University of Illinois at Urbana-Champaign students turned out in force August 20 for the annual Block Party and Quad Day events on campus to celebrate the beginning of the academic year. The Champaign County Life Goes On Committee and volunteers participated by staffing donor information and registration booths at both events. This year, a total of 151 students and faculty joined the donor registry. Several minority donors were excited to be part of the program and expressed interest in helping spread the word about the importance of being an organ and tissue donor. Motivated by their mission, Champaign Life Goes On members educated many about donation, showing them how easy it is to register. The Champaign Life Goes On Committee is led by donor program regional coordinator Liz Hager.

## Donor symbol remains on new Illinois driver's license and state ID card



Earlier this year, the Secretary of State's office began issuing a newly designed Illinois driver's license and state ID card to Illinois residents. The new Central Issuance licenses and ID cards are a more secure identification document, bringing Illinois closer to becoming REAL ID compliant, which is a federal mandate by the U.S. Department of Homeland Security. The small, red, state of Illinois donor symbol is visible on the front of the new license, just to the left of the smaller photo in the bottom right corner. Individuals who receive the new license or state ID card are still in the donor registry and should note the new location of the donor symbol.

# National Donor Sabbath to be celebrated November 11-13, 2016

National Donor Sabbath is celebrated annually during the second weekend in November – this year November 11-13, 2016. This three-day weekend observation of donation brings to the forefront the need for more organ and tissue donors to alleviate the crushing number of individuals who wait for transplants. The extremely long waiting lists not only impact Illinois, but affect the entire country as well. Worship leaders everywhere are asked to take a few minutes during the worship services of this observed weekend to talk about donation and the need that exists in their community. Clergy are also encouraged to invite individuals who have had transplantation touch their lives or who are a member of a donor family or currently on the waiting list join them to share their personal story to fellow worshipers.

One of the pervasive myths about organ and tissue donation is that religious preferences may prevent many from becoming donors. In fact, all major Eastern and Western religions embrace donation in many ways. They agree that

leaving organs and tissues to others upon death is a compassionate choice. But they all agree that donation is an individual choice and that worshipers are encouraged to make the decision they are comfortable with.

For example, Catholicism believes that donation is an act of charity and love, and that transplants are lifesaving measures and are fully advocated by Catholic leaders. Islam embraces donation and states that transplantation offers "clear positive results" to those for whom a transplant is needed according to the U.S. Department of Health and Human Services. In principle, Judaism sanctions and encourages donation in order to save lives and considers it an act of kindness. Other major religions such as Hinduism, Buddhism, Mormon and Christianity also embrace the lifesaving gift of a transplant. There are many references that support organ donation in Hindu scriptures. Daan is the original word in Sanskrit for donation meaning selfless giving. "Organ donation is in keeping with Hindu beliefs as it can help to save the life of others," according

to the late Mr. Om Parkash Sharma MBE, president of the National Council of Hindu Temples. Central to Buddhism is a wish to relieve suffering and there may be circumstances where organ donation is viewed as an act of generosity.

More than 122,000 individuals wait nationally for organ transplants -- 1,000 of them are under the age of 10, according to Donate Life America. Nearly 60 percent of those waiting are minorities, but minorities are vastly underrepresented on donor registries. The average wait for a kidney from a deceased donor is about 3-5 years. But living donors (those who donate a kidney to someone) can alleviate the wait for many. Nearly 35 percent of all deceased donors are age 50 or older, according to Donate Life America. An additional 5 percent are over age 65.

We encourage everyone who attends a worship service to talk to his or her clergy and encourage them to educate the public about donation at services during National Donor Sabbath.

## Rent One Park baseball game



Secretary of State Jesse White meets with former Southern Illinois University Salukis Women's Basketball coach and donor family member, Julie Beck, at organ and tissue donor night during the Marion Miners baseball game at Rent One Park on May 19 in Marion.



Secretary of State Jesse White throws out the first pitch on May 19 during organ and tissue donor night at the Marion Miners baseball game at Rent One Park in Marion.



Secretary of State Jesse White meets with Glenn Poshard (former president of Southern Illinois University and former U.S. senator) during organ and tissue donor night at the Marion Miners baseball game at Rent One Park in Marion on May 19.