

Life Goes On

Secretary of State Jesse White • Spring 2013

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

As we welcome spring and celebrate the renewal of life, it is also a time to turn our attention to those who are waiting for a second chance at life. National Donate Life Month is being observed in April with stepped up efforts to educate others about the critical need for more donors and encourage people to join the donor registry. Donor Program staff and donor advocates have planned events in many Illinois communities throughout the month to "spread the word" about the lifesaving benefits of donation.

Driver Services facility employees on the front lines of donation are especially encouraged to step up their efforts in promoting awareness. More than 90 percent of our registrants come from facility visits. That's why your work is so important — especially to the many men, women and children who are waiting for the gift of life.

This issue of Life Goes On features heartwarming stories about individuals who have been blessed with a second chance at life. On behalf of the approximately 5,000 people waiting in Illinois, we thank you for making a difference!

Jesse White

Jesse White
Secretary of State

National Donate Life Month

During the month of April donor activities and events will be showcased throughout Illinois in observance of National Donate Life Month. Nationally, it's a time to honor donor families, give hope to those on the waiting list, and celebrate with those who have received the gift of life. It also is a time to remember those who did not receive the transplant they were waiting for.

Donor Program staff will be sponsoring donor registry tables at several movie theaters and community events throughout the month, as well as at sporting events and other community venues. Several large high schools also will hold student health fairs where Donor Program staff will be on hand to register students over age 18.

April activities will be launched with the unveiling of the new Secretary of State donor commercial during a press conference with Secretary of State Jesse White.



Donate Life Illinois also will distribute donor-related items such as magnets, posters and table tents with the new tagline, "Your decision. Your gift." Look for the new materials at community Donate Life Month events in your neighborhood.

FACT: Today, more than 112,000 people are on the national waiting list for transplants. Those organs include lungs, heart, liver, kidney, pancreas and small intestines.



Photo courtesy of Martino Tangkar

Secretary of State Jesse White met with members of the Asian American Coalition of Chicago during the 30th Lunar New Year Celebration and Asian American Conference in March at the Hyatt Regency O'Hare in Rosemont. Secretary White was the keynote speaker and addressed participants about the importance of organ/tissue donation among minority populations.

Double lung recipient doing well after 20 years



Janice Earl

Janice Earl of Decatur was born with cystic fibrosis, a lung disease that often is fatal. Fortunately, at age 18 Janice received a double-lung transplant. Her new lungs came from a young woman slightly older than her but she never knew her donor's identity.

Janice recently celebrated her 20th anniversary and is living a happy, healthy life because of a generous donor. "I will be forever grateful to my donor, and I always take a moment to think of her on the anniversary date."

Janice is employed at her family's business and is co-chair of the Macon County *Life Goes On* Committee. "The only way I can pay my donor back is to encourage everyone I see to join the Secretary of State's Organ/Tissue Donor Registry and give someone else a chance," she said. Being a volunteer gives Janice a chance to show that transplants do work and people live normal, healthy lives following transplantation.

Organ/Tissue Donor Program Staff:

To contact a Donor Program staff member in your area, please call the Springfield toll-free phone number at 800-210-2106 or email lgo@ilsos.net.

Program Manager Connie Boatman — Chicago

Assistant Program Manager Sitha Hun — Springfield

Office Manager Karen Kohnke — Springfield

FACT: Last year, 1,622 people received lung transplants, according to the United Network for Organ Sharing.

Spotlight on Minority Donation

In this issue of Life Goes On, we are launching a new feature — Spotlight on Minority Donation, which will highlight issues relating to minority donation. This spring issue focuses on the make-up of the national waiting list, with statistics on minority donation, and one woman's journey on the transplant list as she waits, with optimism, for her gift of life.

Needed: Minority Donors

The need for minority donors is becoming a critical issue. Although there is no guarantee, those of a particular racial or ethnic group have a much better chance of a successful transplant from a larger pool of donors who share their ethnicity. Organ matching (blood type, tissue markers and antigens) is more successful within members of a similar ethnicity.

African-Americans, Asian and Pacific Islanders, and Hispanics suffer from renal failure in much greater numbers than do Caucasians — nearly three times more. They tend to suffer end-stage renal failure more often and from kidney-damaging high blood pressure and diabetes.

According to the U.S. Department of Health and Human Services (HRSA), of the more than 90,000 people waiting for a kidney nationwide, 34 percent of them are African-American — the largest group of minorities in need of kidney transplants. This is a disproportionately large number considering the national general population of African-Americans is just 14 percent. And the total number of kidneys received by African-Americans in 2011 was 4,300 of the 16,800 total performed, or 25 percent.

In general, the national waiting list (as of June 2011 according to HRSA) is comprised of 45 percent Caucasian; nearly 30 percent African-American; 18 percent Hispanic/Latino; 6.4 percent Asian; and 0.5 percent Native Hawaiians and Pacific Islanders. African-Americans are twice as likely to be diagnosed with diabetes as non-Hispanic whites. And while nearly 30 percent of the total candidates currently waiting for transplants are African-Americans, they comprised just 16 percent of all deceased donors in 2011.

How Can You Help?

Please encourage minorities to register as donors at health fairs, donor registration drives and Driver Services facilities. Ask minority customers why they are hesitant to register as donors when so many minorities are waiting for a transplant. Assure them that signing up to be a donor *does not mean* they are being asked to become donors right away. People who join the registry need to understand that donation is a long way down the road for the vast majority of registrants.

In addition, help dispel the Top 4 myths about donation (see below) and assist people in spreading the word within their own communities that without donor organs for transplant, no one on the waiting list gets a transplant.

Myth: If I am in an accident, the paramedics will not try to save me if I can save 25 other lives.

Truth: Paramedics and emergency personnel ALWAYS try to save a life.

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LIFE GOES ON. BE A

Donation across the state



ABOVE: Nursing students from North Park University in Chicago met with Secretary White at the Asian American Conference in Rosemont in February.



ABOVE LEFT: Kara Kelly of the Illinois Eye-Bank and Lynn Reed of the Illinois Coroner's Association attended the Basic Coroner Training Course in Springfield in January. Kara and Brian Bush of the Donor Program presented a program on the coroner's role in the donation process, and donor registry access forms were provided to all the coroners.

ABOVE RIGHT: Brian Bush (right) of the Donor Program shared the vital message of organ/tissue donation at an Eldorado Rotary Club meeting. With Bush is Ryan Gray (left), president of the Eldorado Rotary, and Bill Hartley, Rotary program chair.



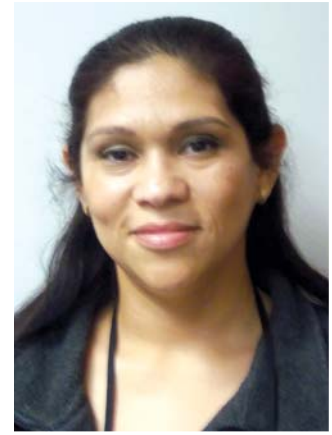
ABOVE: Ty Warner (center) a student at Lincoln Trail Community College in Robinson, with nursing students Megan Millsbaugh (left) and Toni Hart at a health fair at the college. At last year's fair, Ty was waiting for a second kidney transplant after rejection from his first surgery. This year, he was happy to report that he had received a second kidney!

ABOVE RIGHT: Triton College in River Grove is partnering with the Donor Program at six health fairs throughout the year where students can ask questions about donation and join the registry.



LOWER RIGHT: Morgan D'Organ is flanked by Donna Stout (left) and Cassie Stanley, transplant recipients from the same donor at a Yorkville High School boys basketball game in January. Donna is a heart recipient and Cassie a two-time double-lung recipient.

Employee Connection



Sanjuana "Juana" Saenz

With young children to care for, Sanjuana "Juana" Saenz, 38, struggled to keep up with everything in her life, including a diagnosis of Lupus. As her aggressive strain of the disease advanced, it destroyed her blood platelets and she had her spleen removed. The disease also attacked her kidneys and she found herself in kidney failure and in need of dialysis. She also underwent six months of chemotherapy in an effort to derail the increasingly aggressive disease.

Juana was placed on the national waiting list for a kidney for about a year until her younger sister was determined to be a match. In July 2003, Juana received a new kidney from her sister Maricella, a living donor who was just 22 at the time. Maricella, who served in the U.S. Army, was deployed to Afghanistan just three months after the surgery that saved her sister's life.

An employee at the Joliet Driver Services facility, Juana of Joliet is forever grateful to her sister who, remarkably, was a perfect kidney match. This summer Juana will celebrate 10 years with her new kidney, an event that changed her life. "I never dreamed of seeing my grandchildren," said Juana, who has a 4-month-old granddaughter. "I never really dreamed about even having a future before. But it gives you the opportunity for a future, and the quality of life for me is a 360-degree turn."

FACT: More than 5,000 men, women and children in Illinois are on the waiting list.

AN ORGAN/TISSUE DONOR.

Minority Donation (continued from page 2)

Only after doctors have done everything for you but you are too critically injured to be saved is your family approached about donation. The Secretary of State's office does not provide access to the donor registry to medical personnel in an emergency situation.

Myth: My religion doesn't support donation.

Truth: ALL major eastern and western religions leave the donor decision up to the individual.

Myth: I have always heard my family will be charged for the removal of my organs if I am a donor. I don't want them to have to pay if I am a donor.

Truth: A donor's family is NEVER charged for organ removal.

Myth: I want an open casket at my funeral. I am told I can't have this if I'm a donor.

Truth: Organ retrieval from a donor is done as a very careful and respectful procedure where the organs are removed surgically and the body carefully restored afterwards. If you choose to have an open casket, no one would have any idea you had been a donor.



Sheila Swain

Woman remains hopeful for kidney, pancreas

Since age 6, Sheila Swain of Chicago has fought juvenile diabetes and joined the national waiting list just three years ago. Sheila has lived a fulfilling life with diabetes — she married, had children and enjoyed a career. In 1997, she had double bypass surgery and experienced cardiac arrest due to complications from kidney dialysis. She now has a defibrillator, but nothing has

derailed her dream of someday receiving the gift of life from a perfect stranger.

"My husband got tested for me. Unfortunately he was not a match," said Sheila. "I have hope that one day someone will step forward and I will get the transplant that I need. In the meantime, I'm doing what it takes to live. I am striving for the best. I don't dwell on my sickness. I know one day I'm going to get what I need."

In an effort to match more people in need of a kidney, many hospitals are pioneering a "kidney swap" program where a fam-

ily member in need of a kidney, but having no match within their own families, may find a match within another family in the same situation. Sheila said she is interested in this scenario if she and her family qualify to be part of such a program. This helps many waiting list candidates find living donors, thereby saving lives and freeing up a place on the waiting list for someone who doesn't have a living donor.

The advice Sheila gives to others on the waiting list is to "just keep going ... until you get what you need. Be encouraged! There's a lot of information, help, counseling, reading materials, classes and support for those on the waiting list." And, above all, Sheila emphasizes, you are not alone.

Join the Illinois Organ/Tissue Donor Registry today at LifeGoesOn.com.

Yes, you can be a living donor!

Many people may receive a transplant from a living donor someday. These are the organs that can be transplanted from a living donor.

Kidney — The most common, living donors who donate a kidney do not experience much change to their kidney function, although it will be slightly decreased. Living kidney donation has now surpassed deceased donation!

Liver — Living donors can donate a segment of their liver. The liver can regenerate itself, so the donor's as well as the recipient's liver segments will grow into full-size functioning livers.

Lung — A lobe (or section) of one lung can be transplanted from a healthy living donor.

Intestine — Although not done often, a section of a living person's intestine can be donated.

Pancreas — In an effort to help more people suffering from diabetes, transplantation of a portion of the pancreas from a living donor is now being done.

Source: United Network for Organ Sharing