

Life Goes On

Secretary of State Jesse White • Spring 2015

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

After a seemingly long winter, the weather is starting to break and, we look forward to the summer months. Across Illinois, many communities hold fairs, festivals and other events that include donor drives, which greatly help to increase donor registry numbers. If you see a donor drive in your community this summer, please stop by and take a minute to learn more about organ and tissue donation.

This issue highlights several heart-warming stories of individuals and families who have benefited from donation – including a Naperville donor family who honor other donor families with blankets that have a special meaning, an 11-year-old Streamwood boy who received a liver transplant and a state of Illinois employee who is a living kidney donor to his father.

Our 2015 Be A Hero! Campaign, conducted in cooperation with community colleges, recently ended in April. Look for an announcement in our summer issue of Life Goes On regarding the winning schools as well as information on other April Donate Life Month activities. More than 5.7 million Illinois residents over the age of 18 have said "yes" to donation thanks to the hard work of our facility employees asking the donor question. We thank you for your continued support of our life-saving program.

Jesse White

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Secretary of State

Boy doing well after liver transplant

Ryan Marusich is "back in the game" after lifesaving surgery

Ryan Marusich will be spending this spring and summer doing what many 11-year-old boys do – playing Little League Baseball. Unlike most of his teammates and rivals on the field, Ryan had a liver transplant last fall. His mother and father, Debra and Jay Marusich of Streamwood, Illinois, knew since Ryan was 3 months old that he had compromised liver function because of Alagille Syndrome, a genetic disorder that does not allow the liver to process enzymes and eliminate waste from the bloodstream.

Medication and a high-fat diet kept Ryan healthy for years until a couple of years ago when things began to change. Ryan's numbers were off, and he started to experience fluid buildup. The disease progressed, and the family was told last summer that Ryan needed a liver transplant. Neighbors, family, friends and coworkers united to help the Marusich family while they spent 104 days at the hospital and in the Ronald McDonald House. Finally, in November 2014, Ryan received a new liver. He started back to school in January and things are getting back to normal – the "new" normal, says Ryan's mother. She



Ryan Marusich and his dog, Cocoa.

loves seeing her son active and healthy again.

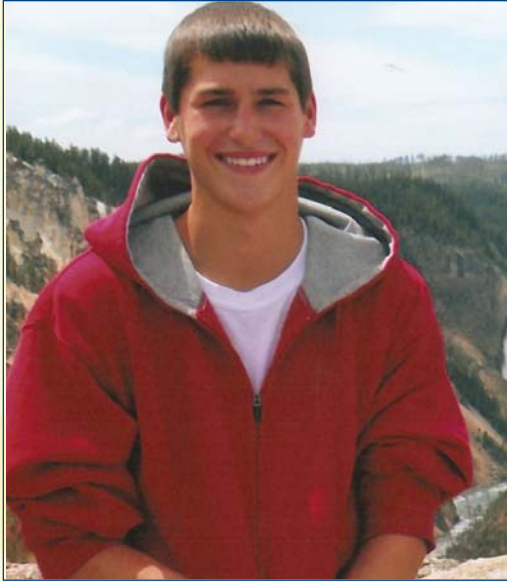
The Marusich family will be helping with an organ, tissue and eye donor registration table on May 30, 2015, at the Streamwood Little League Parade and Celebration. Attendees will be celebrating more than the return of the baseball season – they will be celebrating the return to health of one of their players and teammates.



It's easy to join the Organ/Tissue Donor Registry

- Visit LifeGoesOn.com (it only takes 60 seconds to register online).
- Call the Organ/Tissue Donor Program hotline at 800-210-2106.
- Visit any Driver Services facility and say "yes" to the donor question.
- Complete and mail the registration card on a donor brochure.

Naperville's Zuleg donor family remember son Kyle



Kyle Zuleg Foundation provides scholarships to local high school students

For the Zuleg family of Naperville, the only thing that made sense after the sudden death of their 16-year-old son, Kyle, was to donate his organs so that others could have a chance at life. Tragically killed on a family camping trip in 2010, Kyle had been a student at Neuqua Valley High School in Naperville and an aspiring sports broadcaster. He was a sports referee for baseball and basketball games and was on his high school volleyball team. Kyle's love of sports was evident in everything he did.

(Continued on page 4.)



The Zuleg family of Naperville: Matt, daughter Kristen and wife Jill hold one of their "Forever in our Hearts" blankets provided to donor families going through the donor process.

Donors continue to sign up in Illinois

5.7 million have registered but many still wait...

Illinois residents continue to sign up to be organ and tissue donors, the vast majority do so by saying "yes" to the donor question at Driver Services facilities across the state. Other ways to join include signing up at a donor drive at health fairs or other community events, calling the donor program's toll-free number at 800-210-2106 or visiting LifeGoesOn.com. It only takes about a minute to join the registry – a very easy process to becoming a hero to an individual who is critically waiting for a transplant.

In an effort to expand the registry, the Secretary of State's donor program continues to send out letters to 18-year-old Illinois residents twice a year, providing information on joining the registry, including a registration form. Thousands of 18 year olds join the registry each year through the mailing. The 18-year-old age requirement began in 2006 with the creation of the new legal donor registry. Donor program staff continues to educate young adults through high school and college classroom presentations and regularly attends high school health fairs and awareness events.

The need for more donors continues as more individuals are placed on the waiting list. Patients are listed when doctors have exhausted all other medical processes available. The list is often the last hope for many individuals who are suffering acute organ failure. On average, 21 individuals on the national waiting list die each day.

There are more than 123,000 names on the national waiting list according to the United Network for Organ Sharing (UNOS). Of these patients, 5,300 live in communities throughout Illinois. They could be your neighbor, an acquaintance or the sales associate at your favorite store. More than 80 percent of individuals listed are waiting for a kidney transplant – 102,000 nationally and 4,500 in Illinois. The need for liver transplants follows with more than 15,000 needed nationally, 400 in Illinois.

The need for kidney transplants nationwide by ethnicity includes 37,000 Caucasians, 35,000 African-Americans and 20,000 Hispanics. Most notable is the disproportionately high number of African-Americans on the list. Diabetes, high blood pressure and hypertension all contribute significantly to kidney disease.

Of the more than 15,000 nationwide waiting for a lifesaving liver transplant, doctors use the MELD or PELD score when prioritizing candidates. MELD, Model for End-Stage Liver Disease, is a numerical score based on statistical formulas that are designed to rank patients in need of a transplant who are age 12 and older. PELD, Pediatric End-Stage Liver Disease, is the numeric ranking of patients age 11 and younger. MELD and PELD scores range from less than six to a high of 40, which would be a score assigned to a critically ill liver transplant candidate. In Illinois, 50 individuals with MELD scores higher than 25 wait for a liver transplant.

Please spread the word about the benefits of donation and the life-changing aspect of organ transplantation. Learn the facts from a donor program coordinator today. Lives can be saved one individual at a time.

LIFE GOES ON. BE A

Employee Connection



Zack Pierceall and his father, Van Pierceall.

State of Illinois employee is living donor to his father

We all know organ and tissue donors are heroes. Donors save lives that would be lost otherwise and give individuals hope for a brighter future. Living donors not only save the lives of loved ones, but shorten the transplant waiting list for others.

Central Management Services video conferencing engineer Zacharia Pierceall chose to save a life through living kidney donation. The recipient of his kidney just happens to be his father, Van Pierceall. Zack Pierceall of Springfield donated a kidney to his father in December 2014 at Memorial Medical Center in Springfield.

Zack's father, an iron worker, contracted Lyme disease many years ago. Van suffered for years from a chronic form of the disease. Eventually the disease affected his kidney function, so he began dialysis for his failing kidneys. Finally the disease that had plagued him for so many years was gone, but not before irreversible kidney damage had occurred. Van had been told that he was not a candidate for a kidney transplant while he still had the disease. After Van was cleared, Zack began the long testing process to see if he was a kidney match for his father. It turned out he was a good match.

After their surgeries and a few weeks of recovery, they both have resumed a normal life. Van has received the greatest gift of all – the gift of life – from his son.

"I am so happy to be able to help my father. I couldn't imagine not helping a family member in need. It's just what you do," said Zack.

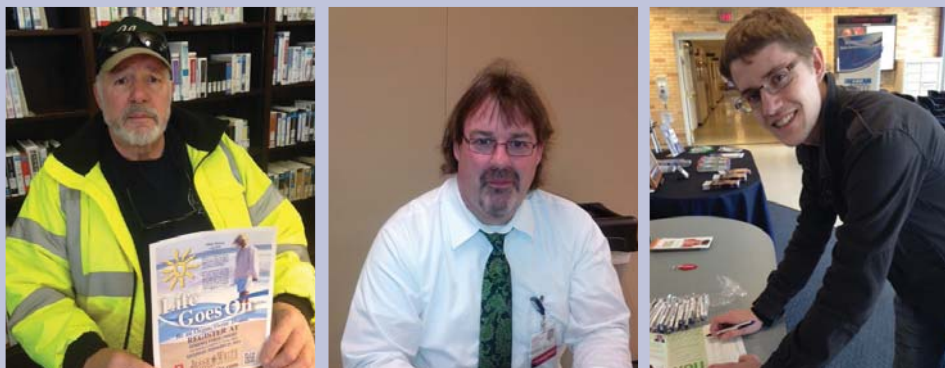


Elgin Community College's Be A Hero team of nursing students sponsored a donor drive complete with a popcorn machine and small table giveaways at their college in March. From left: Ron Russom, Angelica Soto, Lidia Boche, Eric Kaplan, Tirzah Nikolaou, Charles Ramos and Myra Perez.



ABOVE LEFT: Secretary of State Jesse White meets with members of the Asian-American Coalition of Chicago at their 32nd Annual Conference on Business and Networking hosted by the Indonesian-American Community at the Hyatt Regency O'Hare in Rosemont in February.

ABOVE RIGHT: Donor program coordinators Margaret Shannon and Jan Eschen staff a donor registration table at the Summit of Hope event in Rock Falls in February. The event, facilitated by the Department of Corrections, is designed to offer resources, services and information to recently released parolees and probationers to help them transition back into their communities.



ABOVE LEFT: Riley Breyman, a 64-year-old heart recipient from Kewanee, visited the Kewanee Library during a recent registry drive to talk about his heart transplant. Riley received his heart in 2009 at the University of Chicago. "I would just like to graciously thank that family for their gift," Riley said.

ABOVE CENTER: Evan Evans shared his living donation story after donating blood at a Memorial Hospital blood drive in Belleville. Evan donated a kidney to his co-worker, Julia Sauls, 10 years ago after he found out that Julia did not have a family member that was a kidney match for her. Even though it was an easy matching process, Evan had to lose some weight before he was allowed to be a donor to Julia. Julia is doing fine, and she named her new kidney Sidney!

ABOVE RIGHT: Patrick Revallo of Bartonville took advantage of the mobile unit at Eastern Illinois University in Charleston to register as a donor. "Thanks for being here," John said. "This was on my list of important things to do."

(More photos on page 4.)

AN ORGAN/TISSUE DONOR.



Springfield's Lincoln Land Community College students Jordan Roach, Corey Kincaid and Isabel Butterfield set up a donor drive and were featured in a commercial with a local car dealership promoting donation as part of their initiative in the 2015 Be A Hero! Campaign.



Heart recipients James Roseman, Gail Henson and Bill Engle set up a donor drive at Moraine Valley Community College in Palos Hills and shared their transplant stories with students who stopped by the table.



The Prairieland Punishers Roller Derby team from Decatur thrilled a crowd of more than 600 as they helped the Macon County Life Goes On Committee kick off National Donate Life Month at the Decatur Civic Center in March.



Heart recipient Gwendolyn Westlund holds a proclamation issued by Westmont Mayor Ron Gunter at the Gwendolyn's Recycled Life event at Westmont High School, Westmont, Illinois, in March. Pictured from left: Rep. Patricia R. Bellock, (R) 47th District; Shane Johnson, co-sponsor of the event; Gwendolyn Westlund and Westmont Mayor Ron Gunter. The day's activities included information about donation, a donor drive and a Lifesource blood drive.

Kyle Zuleg Foundation – (Continued from page 2.)

His mother, Jill Zuleg, an OB nurse at Edward-Elmhurst Healthcare in Naperville, and his father Matt, an education coordinator at Orthopaedic Research Society, asked if Kyle could be a donor right away. (When they arrived home after the donation process, they noticed Kyle's green organ donor wristband sitting on his desk in his room. They had never discussed donation with Kyle; but upon seeing his green bracelet, they knew they had made the right decision for him.) During the long donation process itself – Kyle donated seven organs – Jill and Matt sat by Kyle's bedside as he was prepared for donation. They wished at the time they had been given something to comfort them during the actual donation process. So they decided to provide blankets of warmth, comfort and love to other families undergoing the donor process in the hospital. Embroidered with "Forever In Our Hearts," the blankets provide comfort to the donor family and become a lasting keepsake for the families to take home.

The Zulegs have provided more than 130 blankets to Illinois hospitals since the first one was delivered to a donor family at Edward Hospital in August 2011. Nearly 40 hospitals in Illinois, including major transplant centers in the Chicago metro area and others in Peoria, Urbana, Bloomington and Springfield, have received blankets. The family's goal is to provide a blanket to every transplant hospital in Illinois.

In addition, the Zulegs present scholarships to high school seniors who intend to study media communications in college, which was Kyle's chosen path. So far more than two dozen students have received scholarships through the Kyle Zuleg Foundation. The 3rd "Kyle Shines On" celebration of Kyle's life was held in April in Bolingbrook to raise funds to continue the mission of providing blankets of comfort to donor families and scholarships to students in Kyle's name.