



Life Goes On

Secretary of State Jesse White • Winter 2014
A newsletter for Secretary of State facility employees and other organ/tissue donation advocates

With the whirl of the holidays over, we can reflect on the blessings in our lives like family, good friends and good health. But for many, good health is not a reality as thousands of people wait on a seemingly endless waiting list for an organ transplant. And for many, that call will not come in time.

The national waiting list consists of more than 120,000 men, women and children who cling to the hope that they will receive a transplant in time. To put that number in perspective, 120,000 people would fill Chicago's Soldier Field twice or Wrigley Field three times!

The stories and photos in this issue represent hope for those on the waiting list. From the heart recipient who spoke to her congregation during National Donor Sabbath, to the kidney recipient who walked 90 miles for donor awareness, to the second-grader who navigates her world cheerfully with limited sight and a cornea transplant, to the fifth-grade class that took on donation as their class service project, these courageous individuals are testament to the lifesaving potential of donation.

Jesse White

National Donor Sabbath "Let the Music Continue for Others"



Secretary White was joined by faith leaders and the Irons family of Maroa as he kicked off National Donor Sabbath with a press conference in Chicago on November 15. Grace and Gillian Irons (center) were featured in the Secretary of State's public service announcement that aired on religious radio stations during the month. The girls' mother, Leslie, is at far right.

Secretary of State Jesse White and religious leaders joined together to show religious support for organ/tissue donation during National Donor Sabbath, November 15-17. The national observance helps to educate faith organizations about the benefits of donation. Joining Secretary White at a press conference at the James R. Thompson Center in Chicago were leaders from Christian, Muslim, Jewish, Buddhist and Sikh faiths.

"People often cite religious beliefs as a reason for not signing up for the state's organ/tissue donor registry," said Secretary White. "The faiths represented here show how many different religions support this lifesaving act."

This year's Donor Sabbath theme – "Let the Music Continue for Others" – was reproduced on posters, church bulletin inserts and bookmarks and distributed at many houses of wor-

ship, where Donor Program staff and other donor advocates staffed donor registration tables.

The Secretary of State's office produced a 60-second public service announcement for Donor Sabbath that was distributed to religious radio stations statewide and featured sisters Gillian and Grace Irons of Maroa. Nine-year-old Gillian received a kidney transplant at age 3, and her sister, 4-year-old Grace, also will need a kidney transplant.

Secretary White visited two churches during Donor Sabbath Weekend: Victory Christian International Ministries in Markham, where he heard Nicole Brown's compelling heart transplant story (see page 2), and Oakdale Covenant Church in Chicago, where he spoke about donation and the importance of joining the registry.

Donor presentation given to Morgan Park High School students

Last September, Donor Program regional coordinator Gail Grabczynski gave six classroom presentations to more than 200 driver education students at Morgan Park High School in Chicago. The students were eager to learn about donation while having some of their concerns and fears about the subject resolved.

Students watching the award-winning Donate Life Illinois classroom video, "Share Your Life; Share Your Decision," listened as a former York High School, Elmhurst, student Robert Manion discussed his kidney dialysis routine and how difficult it was to try to live a normal teenager's life. Another student in the video is heart recipient Rebecca Harper, a former Morgan Park High School student. The students were amazed that someone from their own school had benefitted from organ/tissue donation.

After the video and classroom presentation, the students seemed eager to not only learn more about donation but to do something about educating more people. A few students even discussed creating a student club to continue educating people about the benefits of donation.



Driver education students at Morgan Park High School in Chicago watch the Donate Life Illinois student organ/tissue donor video.



Join the Illinois Organ/Tissue Donor Registry today at

LifeGoesOn.com

Heart recipient inspires others during Donor Sabbath

Nicole Brown of Markham was an active 34-year-old young woman last year, loving life and enjoying time with friends. Unbeknownst to her, a heart transplant was looming in her future.

Nicole had the chance to tell her recent heart transplant journey at Victory Christian International Ministries Church in Markham during National Donor Sabbath weekend. Nicole and her mother, Kip Dixon, recounted the startling turn of events for Nicole, including her being taken to the hospital and learning that she had experienced heart failure due to a sepsis infection in her heart as well as in her entire body. After numerous surgical procedures and efforts to restore her heart function, the doctors determined that Nicole's heart was not strong enough to function on its own and that she needed a heart transplant.

After being added to the national donor waiting list, Nicole went through a series of tests and had to be supported by a ventricular assistance device. Support from family poured in, and love from friends served as a comfort to Nicole.

"Not only was my church supporting and praying for me, but churches across the country supported me and prayed," said Nicole.

"There were days I was so scared I couldn't see straight, wondering if I would die before I got listed to receive a heart," she said. "I wondered how long I would have to wait, and I had a million other questions and thoughts, but something inside me kept me fighting."

Then, one day around 4:30 a.m. Nicole heard her phone ring; the call she had been waiting



Secretary White with heart recipient Nicole Brown (center), her mother, Kip Dixon, and Pastor Carl White of Victory Christian International Ministries in Markham during a National Donor Sabbath celebration.

for. "The transplant team told me to get ready to come to the hospital. Through my tears I unplugged my machine, pushed my way into my parents' room and gave them the news."

Soon after arriving at Advocate Christ Medical Center, Nicole was taken into surgery and received her gift of life on Feb. 2, 2013.

"It feels great to be able to get back to life as I knew it; to get back to living a normal life and do most things I did before," said Nicole. "I have much more energy, stamina and strength. My new heart has allowed me to have the freedom I so desperately wanted back."

Not only is Nicole taking her life back, she also is writing her own blog, "Matters of the Heartttt" (mattersoftheheartttt.blogspot.com) and a corresponding Facebook page, "An Open Heart." She loves inspiring others who are going through similar ordeals in their lives.

"My life is now about making the most of the life that God has given me. I know I am blessed and am forever grateful for my second chance at life."

Customer Service Week

Many Driver Services facilities across the state pulled out all the stops to welcome customers to their facilities in October during Customer Service Week. From refreshments to community donor drives, many facilities thanked customers for their business during the festive week. Awards were given in two categories: smaller facilities with 12 or fewer employees and larger facilities with more than 13 employees. Winners included:

First place: Chicago West and Wheaton facilities

Second place: Secretary of State Police and Greenville facility

Third place: Lombard and Plano facilities

Employee Connection

For Jerry Maillard, his family's decision to donate his mother-in-law's organs when she passed away involved a family discussion. A senior manager at the Libertyville Driver Services facility, Jerry admits that not everyone in the family had the same views on donation. But after much discussion the family agreed that if she could help others live a better life by passing life along, they would consent to donation. In the end it was the best decision the family could have made, Jerry said.

Jerry's mother-in-law, Mary Ann Starkey of Mundelein, had died unexpectedly of an aneurysm. Jerry and his wife, Mary, were pro-donation and the whole family, including Mary Ann's husband and her siblings, had to make a decision quickly. They finally consented to donation and it was a very positive decision, according to Jerry. The best part was when Jerry's father-in-law began receiving letters from the recipients of his wife's organs. The heartwarming letters about the lives restored confirmed that consenting to donation was the right thing to do. The family was helped through their grief knowing that Mary Ann continued to live on through others.

Another Libertyville employee and donor advocate, Glenda Hatchett, recently lost her husband, Tony, who was a kidney recipient several years ago. You could say that supporting donation "runs in the family" at the Libertyville facility.



Jerry and Mary Maillard

Beecher City resident walks 90 miles for donor awareness

Kidney recipient Don Stuckey, age 59, received a kidney transplant in August 2013 at Memorial Medical Center in Springfield. It was a life-changing experience for him and he wanted to let the world know about it. Don decided to walk 90 miles across Central Illinois in honor of his transplant as a way to promote organ/tissue donor awareness and raise money for the Memorial Medical Center Transplant Team's Patient Assistance Program.

Finding himself in renal failure three years ago, Don had to admit he was sick and was placed on dialysis because of his failing kidneys. Don said it was a "surreal experience" when he finally got the call that there was a kidney for him. He doesn't know the identity of his donor but knows it was a Chicago-area resident who was 12 years younger than him.

Don walked 90 miles from Effingham to Springfield over a 10-day period beginning September 19 and ending September 28, 2013, just six weeks after his transplant. The last leg of the journey coincided with Memorial Medical Center Transplant Services' Annual 5K Run/Walk at Washington Park in Springfield.

Don, who has run the Chicago Marathon twice in the past, talked to people along the way about his experience and the need for donor awareness. He also took donations and sold drink cozies and bracelets, raising nearly \$3,000 for the Transplant Team's Patient Assistance Program.

Fifth-graders promote organ/tissue donation

While most fifth-graders are diligently working on their nightly math homework, playing soccer and going to movies and sleepovers, the students in Holly Latas' fifth-grade class at Alden-Hebron Elementary School in Hebron were concerned about the number of people on the transplant waiting list. So much so that they researched and designed a

presentation to be given to the driver education classes at Alden-Hebron High School.

During the six-week project, students did extensive research, learning donor facts, talking to experts and ensuring they had a professional-looking, factual presentation before presenting it to the students. An added bonus for their efforts was a visit by Secretary of State Jesse White in November, who met with the students at the Woodstock City Hall and congratulated them for their efforts.



Secretary White with fifth-graders from Alden-Hebron Elementary School.

In addition, many facilities and SOS offices were awarded with Certificates of Excellence:

- 69 W. Washington Express facility
- Aurora facility
- Chicago Central and Chicago East facilities
- DeKalb facility
- Olney facility
- Melrose Park facility
- Naperville facility
- Deerfield facility
- Elgin facility
- Libertyville facility
- Schaumburg facility
- Waukegan facility
- Budget and Finance Office
- Vehicles Special Plates Division
- Index Department



Wheaton facility manager Linda Dorner (left) and supervisor Gina Cozzi stand next to a donor registration table during Customer Service Week.



Don Stuckey, kidney recipient.

Chicago second-grader inspires others

Eight-year-old Liliana Vujic didn't mind when her mother, Kimberly, told her that she couldn't have the birthday sleepover she had been anticipating because she had to get up early the next day to participate in the Illinois Eye Bank's 3rd annual "I Can Make A Difference" 5K Walk in Wheaton. Liliana remarked that the walk at Danada Forest Preserve might be more fun than a sleepover!

Liliana, a second-grader at Mitchell Elementary School in Chicago, knows that some things are more important than others in her life. She and her family and friends were participating in the 5K Walk as "Team Liliana" to promote awareness for eye health. Liliana has an eye condition known as Peters Anomaly. She has very limited sight and underwent a cornea transplant in April 2010 in her right eye. She wears a contact lens in her left eye, which she must wear along with eyeglasses.

"Liliana loves learning but has many challenges," said Kimberly. "She loves school and her new closed-circuit TV. And she has a new vision teacher this year so she uses her teacher's iPad with a program to enlarge the text." Liliana can read enlarged text in books and on a computer screen so she can keep up with reading and schoolwork. But her vision makes participating in sports and many other extracurricular activities difficult.

Liliana met Secretary White two-and-a-half-years ago when he was photographed with her and other young children with eye conditions for the Illinois Eye Bank's 2011 poster.



"Team Liliana" included 8-year-old Liliana Vujic (front with glasses) and her family and friends.

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

Early transplant surgeon paved way for others

In 1963, Dr. John Bergan was changing the lives of many as a transplant surgeon at Northwestern Memorial Hospital in Chicago. His passion led him to many discoveries and advances in transplant technology. Although he made progressive steps for science, he also made a huge impact with his family, namely his daughter, Betsy Altman.



Betsy Altman

"He was a surgeon at Northwestern in 1963 but went to Denver to train with Dr. Starzel, a fellow transplant surgeon," said Betsy. "Afterwards he brought what he learned back to Northwestern to share with his colleagues. My father later set up one of the first registries at the American College of Surgeons in a vacant office using index cards."

At age 86 and enjoying his second year of retirement, Dr. Bergan is still the heroic father his daughter remembers him to be. "My father always thought, how can we do this better?"

Asked what she would say to someone who was on the fence about being a donor, Betsy said, "Organ donation is so essential. We must be willing to share." To those on the waiting list and faced with the uncertainty of finding a match, Betsy encourages to "keep your hope."

"Thanks to a donor, these children can see a bright future ahead. You can help others too."

- Jesse White, Illinois Secretary of State



Photo courtesy of John Reilly Photography, www.johnreillyphotography.com

Restore sight. Change lives forever.
Join the Illinois Organ/Tissue Donor Registry today.
www.LifeGoesOn.com

