



Life Goes On

Secretary of State Jesse White • Winter 2004
A newsletter for Secretary of State facility employees and other organ/tissue donation advocates

While many people die from incurable diseases and unfortunate accidents, we can do something to save the lives of those who need organ/tissue transplants. We can tell our friends and families about organ donation and encourage those who apply for or renew their driver's licenses to join the Organ/Tissue Donor Registry.

Isn't it a good feeling to know that every day you go to work you may help make a difference in someone else's life? Nearly every person who says "YES" to organ donation has the potential of helping more than 25 people. By asking them that simple question, "Do you want to be an organ donor?", you allow fellow Illinois citizens to take that first step in saving lives. Without Secretary of State employees asking this life-saving question, we would not have nearly 6 million people registered as potential donors — an all-time record.

On behalf of the people waiting for transplants, I thank you for all your help.

Jesse White
Jesse White
Secretary of State

Todd & DeAnne Stille — A donor story to remember

For Todd Stille, time marches on and yet stays frozen, all in the same breath. He knows firsthand the pain of losing someone dear, but also the joy of helping others after his loss.

Todd's wife DeAnne's battle with heart disease began when she was a mere six weeks old. Her mother was told that her baby girl had a heart defect and would probably not live a year. But doctors changed her prognosis after she celebrated several birthdays and they witnessed her will to live. She lived for years with the fact that she could have complete heart failure any day.

Todd, an employee in Central Services at the Secretary of State's office in Springfield, and DeAnne, a former Secretary of State employee in the Special Plates Division, defied many medical odds and married in the summer of 1987. Todd lived with the fact that his new bride may need a heart transplant someday. Numerous trips to the emergency room plagued the couple, but they persevered in the face of all odds. DeAnne's faith kept them going.

By August 2003, DeAnne's health had deteriorated to a point that a pacemaker was her only option. She had been on the transplant list for six years but had been able to maintain a relatively normal lifestyle, so she was not a top candidate for

transplantation. She underwent surgery for a pacemaker on Sept. 2. While she appeared to be doing well immediately following the surgery, she succumbed to complications

two days later. She was only 39. DeAnne was a diehard Chicago Cubs fan and was buried in a Cubs jersey.

Although DeAnne died waiting for life-saving organs, Todd helped her fulfill her wish to become an organ/tissue donor herself. "Through all these years, she always wanted to be a donor," said Todd. "She didn't get hers (transplant), but others did." Many of DeAnne's organs and tissues were donated, including her corneas. "It's comforting

to me that she was able to give because the way I look at it, she is still seeing the world," said Todd, referring to the gift of sight DeAnne's corneas gave to two other people. "I've never had a hero until now."

Plea From a Defective Heart

All I want is to be like everyone else.
"You can't!" they say. "Too sick!" they say.
But they do not know.
I want the problems, frustrations,
burdens of life.
Do not protect me, do not shelter me,
do not keep me here in the dark.
Though you fear I may leave soon
you can do nothing to stop it
and neither can I.
Allow me to be everything I can
While I am here.
Love me, help me,
laugh with me, cry with me.
And when I am gone, miss me, think of me,
laugh about me, cry about me.
I will be fulfilled.

DeAnne M. Stille • Copyright 2003



Coworker Connection

Allan Spain gets second chance at life

Christmas came early in 2002 for Glenn "Allan" Spain of Taylorville — it came on Halloween when he received a kidney from his brother, Gary.

Allan's journey began 16 years ago when he started experiencing nephritis at age 26. "There was nothing they could do for you then," said Allan, who works in the Secretary of State's



Accounting Revenue Department. "All they could do was give you medicine for side effects." As a child, he was diagnosed with low white blood cell count, for which he received medication and was given a stronger version of Advil (Ibuprofen), which in large doses over time can cause kidney damage.

Two years before his transplant, Allan was told he would need dialysis someday and maybe even a kidney transplant. His sister and brother were tested to see if they were matches. Both passed preliminary tests, and Allan was scheduled to receive a kidney from his sister in summer 2002. Three days before the surgery it was discovered that Allan's sister's veins were too small, disqualifying her as a donor. So Allan began the rigorous routine of dialysis the day after his surgery was cancelled.

Allan's brother, Gary, continued to be tested as a possible kidney donor, and on Oct. 31, 2002, the transplant finally took place at Barnes Hospital in St. Louis. In four days, Allan was home with his wife, Jo, recuperating for several weeks. By mid-December, Allan, now 42, was back to work.

"I think the surgery was harder on my brother than on me," said Allan. "But I'm doing well. I have no problems. The only thing I can't do is drink grapefruit juice because it interacts with my anti-rejection medicines," he said, laughing. But if that's the only thing that he's restricted from doing now, Allan said he's more than happy to live without the grapefruit juice.

Our partner — NKF

NKF National Kidney Foundation of Illinois, Inc.

Since 1949, the National Kidney Foundation of Illinois (NKFI) has been committed to providing services, resources and education to dialysis patients and transplant recipients and their families. In addition to working with patients, the NKFI has established programs to help educate the public about the dangers of untreated hypertension and diabetes, ways to prevent kidney disease, and the importance of organ donation.

There are an estimated 800,000 individuals in Illinois living with chronic kidney disease, and most are unaware of it. The foundation's Kidney Early Evaluation Program (KEEP) offers free health screenings to help identify and educate individuals at increased risk — those who either have diabetes and/or hypertension or have first-degree relatives with high blood pressure, diabetes or chronic kidney failure — with the purpose of delaying or preventing the development of chronic kidney disease. Untreated diabetes and high blood pressure are the two leading causes of kidney failure. NKFI will host KEEP screenings in Chicago, Rockford, Peoria and Champaign this year.

The foundation offers programs for patients of all ages. Since 1998, it has hosted the "Kids and Kidney Disease" program, providing parents and caregivers information on raising children with kidney disease. Other NKFI programs include "Preparing for Transplantation," "Living with Transplantation" and "Making a Difference," a patient education day for diabetic kidney patients.

The average wait for a kidney transplant in Illinois is four to five years. Over the past year, NKFI and its partners from the Illinois Coalition on Donation educated more than 35,000 Illinois high school students and teachers about organ donation. After attending the program, a survey showed that 85 percent of attendees would say "yes" to donation.

NKFI has a long history of working with the Secretary of State's office to increase awareness of organ donation. The foundation's executive director, Willa Lang, served many years as chair of the Secretary of State's Advisory Panel on Organ Donation and currently chairs the Driver's License Facilities Committee. For more information, call 312-321-1500 or visit www.nkfi.org.

Donor family Jim and Luanna Fuchs show a memorial board and photo album dedicated to their son, Robert James, at a National Donor Sabbath remembrance at Peoria's OSF Saint Francis Medical Center in November.

Photo courtesy of Jason Holman



LIFE GOES ON. BE AN

National Donor Sabbath observed

Churches and clergy across the country celebrated the gift of life that organ/tissue donation provides during the National Donor Sabbath, Nov. 14-16, 2003. The theme was "I am my Brother's Keeper," as indicated on the numerous public awareness materials distributed to churches and religious organizations across the state.

In a letter to religious leaders, Secretary White said, "During this time we ask you to educate church members through sermons, speakers, newsletter articles and bulletin inserts about organ donation....Lack of assurance that the church supports organ donation prevents some individuals from considering it. Your input could make a substantial difference." Secretary White thanked religious leaders for helping spread the word that donation is not only safe but a good example of the Golden Rule.

In Chicago, White attended services at St. Dorothy Parish and Mt. Ebenezer Church. In other areas of northern Illinois, transplant recipients, donor families and friends gathered for the Donor Family Ceremony of Hope, Faith & Remembrance on Nov. 15 at Fitzgerald Funeral Home, Mulford Chapel in Rockford. The evening included a memorial service for donor families, a candle-lighting ceremony, a Gift of Hope quilt display, a memorial wall, a special photo presentation and a reception. In Peoria, a donor remembrance and candlelight ceremony was held Nov. 9 at OSF Saint Francis Medical Center.

Organ Donor staff addresses driver education instructors

The Secretary of State's Organ Donor Program staff recently held a series of 10 seminars aimed at informing driver education teachers about new regulations and updates on the program. Schools will soon be receiving a new video called, "Share Your Life, Share Your Decision: A Student Program on Organ and Tissue Donation." The video and accompanying workbooks were produced by the Illinois Coalition on Donation, of which the Secretary of State's Organ/Tissue Donor Program is a member. Driver Services facilities also will receive a copy of the new video for employees to view.

Training for staff, volunteers and those interested in presenting the new video and workbook to high school students will be held Saturday, Jan. 24, 2004, 9:30 a.m.-1 p.m., at York High School in Elmhurst. For more information on the training, please call Liz Hager at 217-782-0578, Margaret Pearson at 630-579-8711, or Hilary Cichosz Winklehake, National Kidney Foundation of Illinois, at 312-321-1500.

Last year, nearly 35,000 students heard presentations on organ/tissue donation with an overwhelming number of students indicating their interest in joining the Illinois Organ Donor Registry.



Q I want to be an organ donor if something should happen to me, and I am listed on the donor registry; however, my family isn't sure they would agree to donation. Can I be a donor anyway?

A Illinois requires family consent before organs can be donated. The best thing you can do is tell your family how strongly you feel about being an organ donor and that you hope your family will respect your wishes and consent to donation should the opportunity arise.

Q I have heard that some people who have received organs write letters to their donor families. Is this required?

A Many donor family members are happy to hear from those who have received their loved ones' organs. It helps them with the grieving process to know that there are people who are living a better life now that they have received new organs.

Q The last time I was at a Driver Services facility, I said "no" to becoming an organ donor because I needed more information about it. I have since changed my mind. Can I still join the registry?

A Absolutely! You may change your mind about organ donation at any time. Just call 800-210-2106, or visit www.cyberdriveillinois.com and fill out the registry form online. You also may pay another visit to your driver facility to have your name added to the registry.

ORGAN/TISSUE DONOR.

WWW.CYBERDRIVEILLINOIS.COM

Illinois Coalition on Donation officers met in October at the Illinois Eye-Bank in Chicago. Seated from left: Celeste Clark, corresponding secretary, Gift of Hope volunteer; and Liz Hager, vice-chair, Secretary of State's office. Standing from left: Margaret Pearson, recording secretary, Secretary of State's office; and Kara Kelly, chair, Illinois Eye-Bank.



FACTS YOU SHOULD KNOW

- ✓ 12 percent of the U.S. population is African-American, yet 35 percent of patients waiting for a kidney transplant are African-American.
- ✓ This year marks the 50th anniversary of the first successful kidney transplant. In 1954, doctors in Boston performed the first kidney transplant surgery that involved transplanting a kidney from a living donor to the donor's identical twin. One of the doctors who headed the transplant team received the 1990 Nobel Prize for Medicine for his pioneering work in organ transplantation.
- ✓ Of the 82,462 people on the national waiting list, nearly 56,000 are waiting for a kidney and nearly 18,000 are waiting for a liver.
- ✓ Organ/tissue donation is recognized by every major eastern and western religion as a final charitable act of giving from one human being to another. It is considered by most religious leaders to be the ultimate gift one person can give another.

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