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Out of Grief Sprouts a Life-Saving Legacy

By JANE E. BRODY

You don't have to be rich, famous or even an adult to leave a memorable legacy that can change lives.

Just ask Stacey Oglesby of Lockwood, Mo., whose 15-year-old daughter, Colbey, died in a car accident in 2001. Colbey had told her mother that when she got her driver's license, she was going to sign up to be an organ donor. So when hospital personnel asked about organ donation, Ms. Oglesby said, "we had no hesitancy."

Seven people got Colbey's organs. Her lungs went to Valerie Vandervort, a 29-year-old Oklahoma woman with cystic fibrosis. In the nine years since, Ms. Vandervort has run three 5K races, hiked a mountain, danced at her sister's wedding, doted on her nieces and nephews, and won medals in swimming at the 2010 National Kidney Foundation United States Transplant Games.

Ms. Oglesby also befriended the recipient of Colbey's heart, Judy Kaufman of Chesterfield, Mo., who was near death with congestive heart failure. When they met, Ms. Oglesby took a stethoscope to listen to the beat of her daughter's heart.

Ms. Oglesby, who speaks often about Colbey's legacy, said she has inspired others to become potential organ donors. If not for donating her daughter's organs and connecting to the recipients, she said, "it would have been hard to get through the grief."

A Widespread Need

At any given time in the United States, more than 100,000 people are waiting for donor organs, more than 10 times as many as become available. Some die waiting; others get sicker and sicker, sometimes too ill to survive when a suitable organ finally becomes available.

In addition to kidneys, heart, lungs, liver, pancreas and intestines, donations can include tissues like corneas, skin, heart valves, bone, veins, cartilage, middle ear, tendons and ligaments that can be stored in tissue banks and used when needed.

Most donations come from people who die suddenly, usually from an accident, a gunshot or a brief illness that resulted in brain death. (A small but growing number of donations follow cardiac death.) Some adults indicate their wish to be donors by signing the back of their driver's license or a donor card or simply telling their next of kin. For minors, hospital personnel often ask the distraught parents if they would consider donating their child's organs.

But when 6-year-old Katie Coolican died in 1983 from an undiagnosed heart malformation, it was her mother, Maggie, a nurse, who asked about donating the child's organs — "to make some sense of it all," Ms. Coolican, of East Hampton, Conn., said in an interview.

"We were willing to donate anything," she added, "but at the time all they could use were Katie's corneas and kidneys."

Likewise for Julie Schlueter of Winsted, Minn., whose daughter, Missy, 10, died of a cerebral hemorrhage in 1992: donating the girl's organs meant her loss was not in vain.

Missy's liver and one kidney went to a man who four years later won a silver medal in the Summer Olympics in Atlanta; he sent the medal to the Schlueters to thank them for enabling him to live. Two toddlers, one from Italy and the other from Colorado, got Missy's heart valves. And an Iowa woman, then 47, got her other kidney and is still doing well 18 years later.

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Rose D'Acquisto of St. Paul said that donating all her husband's usable organs "has led to things I'd never imagined."

Her husband, Tony, died in 1996 at age 35 when an undiagnosed brain tumor hemorrhaged and left him in an irreversible coma. Ms. D'Acquisto said the recipient of his liver — an Indiana man near death with a rare liver disease — had now been married more than 30 years and has three grown children.

And the Minnesota farmer who got one of Tony's kidneys got his life back; he had spent three years traveling three hours a day three times a week for dialysis.

Ms. D'Acquisto, now remarried, says she continues to write and speak about organ donation as love's greatest gift. Along with Ms. Schlueter, she was among more than 7,000 people who attended the Transplant Games last month in Madison, Wis.

When Katie Coolican died, there was no follow-up care for families who donate the organs of their loved ones. After a few years of struggling with grief, her mother wrote about her experience in The American Journal of Nursing and began speaking about organ donation all over the country.

She went back to school, got a master's degree and wrote a booklet, "For Those Who Give and Grieve," that was published by the National Kidney Foundation. (The foundation also publishes a quarterly newsletter with that title, edited by Ms. D'Acquisto.)

"Katie's had a wonderful legacy that continues to this day," Ms. Coolican said. In 1992 she founded the National Donor Family Council for the kidney foundation to help grieving families that donate loved ones' organs and tissues. The two-year follow-up program she created for families has become a model for organ donation programs throughout the country.

(To read more "gift of life" stories about organ donation, see the Web site org/gift/index.html.)

Who Is Eligible to Give?

Do not rule yourself out as a potential donor because you think you may be too ill or too old. Only a few circumstances, like pervasive infection or active cancer, absolutely preclude organ donation, and there is no age limit. People in their 80s and 90s have been successful donors of certain tissues, as have newborns. But for anyone under 18, a parent or guardian must approve the donation.

Even if a person dies after an illness that precludes organ donation, or if too much time elapsed after death for organs to be viable, there is still the opportunity of whole-body donation to a medical college, where the body can be used in research or to help students learn anatomy.

While it is best to register one's interest in whole-body donation with a medical school in advance of death, after death it is up to the next of kin to make it happen. You no longer own your body after you die. If this is something you would want for yourself, discuss it with your spouse and children, who must agree with your wishes.

Most religions support organ donation as a charitable act, although some may not condone whole-body donation. Check the Web site www.organdonor.gov and click on "Religious Views on Donation" for guidance.

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