

By Stephanie R. Conner

Illustrated by Jackie Besteman

**W**hen her 11-year-old daughter, Grace, died, Janie Chambers mourned as any mother would. But she also knew she could help prevent other mothers from losing a child that day. Chambers, a critical care nurse manager at North Florida Regional Medical Center, donated young Grace's organs.

It was 1993, and Grace had suffered a brain aneurysm and was pronounced brain dead before she arrived in the emergency room. The physician showed Chambers her daughter's CT scan and suggested they let Grace die there. But Chambers, who has been a registered nurse for nearly 25 years, refused.

"I told him to take her to the pediatric ICU and call whoever he could," Chambers says. She wanted Grace's organs to go to people who needed them, which meant keeping the child on a ventilator until recipients were found. Despite some initial resistance, the physician agreed, and 11 people ultimately received Grace's organs and tissue—liver, heart valves, kidneys, pancreas, eyes—and skin and bone tissue.

"At least some good came from Grace's death," Chambers says.

One of Grace's kidneys went to a 19-year-old man, Chambers says. About a year later, Chambers and her husband received a letter from the organ procurement organization (OPO) saying the recipient wanted to meet them.

When NFRMC nurse manager Janie Chambers lost her daughter, she did the only thing she knew would help. **She donated the 11-year-old's organs**—and saved lives.

"It was obvious that, psychologically, he needed to meet us," Chambers says. So, she and her husband met the young man and his wife. Before the transplant, they had both been forced to quit school, but the transplant changed their lives. Ten years later, the Chambers keep in touch with the grateful couple, who now both have master's degrees and two boys who might never have been born if not for Grace.

"That's the one thing that's given us comfort in losing Gracie," Chambers says. "We are our brother's keepers. You give what you can to others, and you're blessed if you can do that."

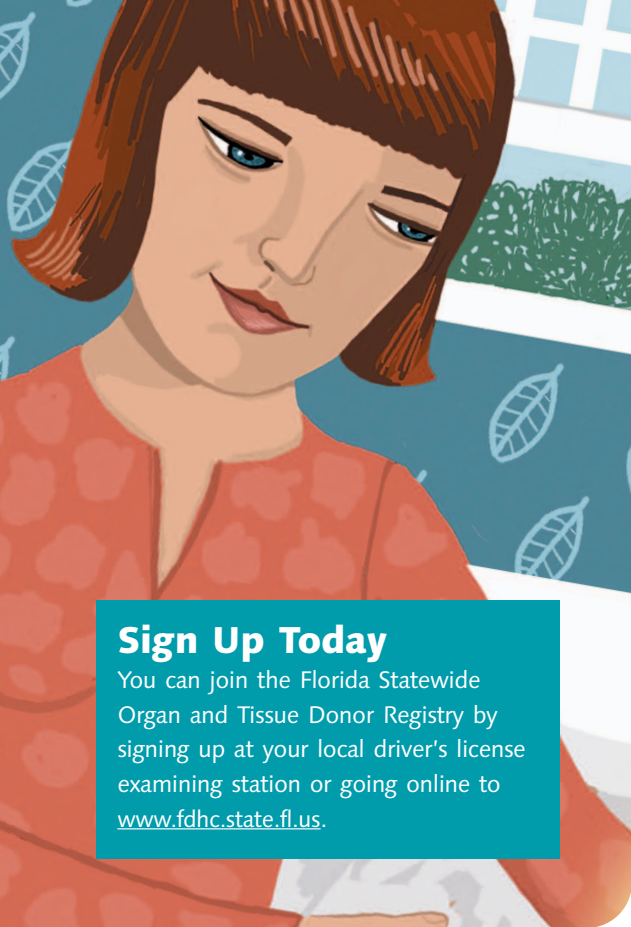
### How Organ Donation Works

Since this experience, Chambers has been an activist for organ and tissue donation in Florida and her home state of Georgia. She speaks from two perspectives—as a donor mother and as a critical care nurse.

"I encourage people to do it because it's the one thing that made me feel better [when Grace died]," she says. "It gives you comfort."

And with more than 80,000 people on the national waiting list for organs, including more than 2,800 people in Florida, Chambers has her work cut out for her.

She regularly speaks to groups on behalf of LifeQuest, the OPO serving North Florida Regional Medical Center's region of the state, and the Southeast Tissue Alliance, its tissue procurement counterpart. She also speaks in front of



## Sign Up Today

You can join the Florida Statewide Organ and Tissue Donor Registry by signing up at your local driver's license examining station or going online to [www.fdhc.state.fl.us](http://www.fdhc.state.fl.us).

organizations and at community events to encourage people to make a difference through organ donation.

"Janie and her whole family are just really delightful people," says Kathy Giery, spokesperson for LifeQuest. They can talk about something that's very personal and very painful in a way that...I don't even know how to describe it. They're just so passionate about their beliefs in donation."

There are 59 federally designated OPOs in the United States

that serve 259 transplant centers. LifeQuest's role is "one of professional education and clinical participation," Giery says. "We go in and educate the intensive care units, emergency room staff and administration on what organ donation is, how to identify a potential donor and how to implement the referral process."

Hospitals like North Florida Regional Medical Center work with LifeQuest coordinators. "When there's a potential donor, we evaluate the suitability for donation, talk to the family and obtain consent for donation. Then, we arrange the recovery operation," Giery says.

As with Grace Chambers, one person's organs can potentially benefit many recipients. So it's possible that the recipients are not at North Florida Regional Medical Center. In such a case, the recipient's physician will come to the donor, perform the operation and take the organ back to the recipient's hospital. The operation is performed within 24 hours of the family consenting, Giery adds.

### 'God Is Telling Me Something'

When she donated Grace's organs, Janie Chambers was trying to do the one thing she could to make herself feel better—and to make Grace's death somehow seem less senseless. But when she donated her time and energy to raise awareness of organ donation, she had no way of knowing it would come full circle.

Today, a decade after Grace's death, the Chambers family is facing another test of their strength and courage. Last December, Janie's husband, Bill, was diagnosed with renal failure. He needs a kidney transplant to survive.

Blood type is the leading indicator of whether the body will accept a new organ. Janie's blood type matches her husband's, so she has volunteered to be a living donor and give him one of her kidneys.

However, his condition stems from a congenital defect. It has been passed on to their 16-year-old daughter, who will need a kidney transplant someday.

## What You Can Do

Signing a card for the United Network of Organ Sharing or denoting your wish to be an organ donor on your driver's license are both good first steps, but there's more you need to do.

"You can sign a million and one papers, but if you come to the hospital and your family says no, it doesn't matter," says Janie Chambers, critical care nurse manager for North Florida Regional Medical Center. "Nobody is going to supersede what the family wants."

Here are Chambers' recommendations:

- Even though the conversation may be uncomfortable, share your decision to donate your organs with your family. "We should talk about all sorts of these things with our families—not just organ donation," Chambers says.
- Explain to your family that you've made the situation easier for them. By expressing your wish to donate your organs, you've taken the burden off them to decide what to do should that time come.
- Insist they honor your final wishes.

There are two additional legal forms you should consider signing to ensure your decisions are carried out properly. Called advance directives, these include a living will and a medical power of attorney.

**Living Will:** A living will gives instructions about the use of medical treatments at the end of life. It can state

"You give what you can to others, and you're blessed if you can do that."

"He won't let me give my kidney, because our daughter might need it," Chambers says. Her husband is now on the waiting list for a kidney.

When she reflects on this and her involvement in organ donation education, Chambers says, "God is telling me something."

Chambers' story is a touching one, Giery says. "Here's a family who believes in organ donation, and now it's once again part of their life," she says.



which treatments are wanted and which are not. The document's purpose is to guide physicians and family members on how aggressively to use medical treatments intended to delay death.

**Medical Power of Attorney:** A medical power of attorney appoints a particular person to make medical decisions for you should you no longer be able to make decisions for yourself.

Both of these advance directives are in effect only when you are unable to make decisions. Should you regain your ability to communicate, you will resume responsibility for making decisions on your healthcare. For more information, visit Last Acts, a national coalition to improve care and caring near the end of life, at [www.lastacts.org](http://www.lastacts.org), or speak with an attorney.

### Dispelling Myths

Even though Chambers considers other people's perspectives, it's difficult for her to understand why anyone would not be an organ donor. LifeQuest notes that more than 80 percent of the public supports the concept of donation in polls and surveys, but the national consent rate is only 50 percent. There are several reasons people don't want to donate, but many of those reasons are actually myths.

For example, contrary to popular belief, all major Eastern and Western religions either support organ donation or leave the decision up to the individual. "No religion is opposed to it," Giery says.

Other people worry about disfigurement and funeral delays. Giery, however, notes that organ donation is not disfiguring, so an open-casket funeral is still an option, and the donation process won't delay funeral arrangements.

Finally, there's concern that a physician or EMT will not make every effort to save a person's life if they know the patient is an organ donor.

"That's the silliest one of all," Giery says. "Everyone in healthcare is working to save your life. Organ donation is only discussed after all life-saving efforts have been exhausted."

When those efforts have been exhausted, it's devastating. But Chambers knows there is a way to make it better. "I was able to help a lot of people make that decision," she says. Her authority doesn't come from her years of nursing experience or her schooling. It comes from her firsthand experience with organ donation 10 years ago.

For Janie Chambers, the loss of her daughter has left a hole in her life. And while nothing can bring her daughter back, in many ways, organ donation has allowed Grace to live on. ❖



### Save a Life

To learn more about organ donation, call LifeQuest at **(800) 535-GIVE** or **(352) 338-7133**, or visit online at [www.lifequestfla.org](http://www.lifequestfla.org).