

Registry law boosts organ donation

But education could minimize distrust and misconceptions about procurement process

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SPRINGFIELD — The day after her husband fell off his motorcycle and suffered a severe head injury, Dee Paquette struggled with her feelings about organ donation.

When the issue was raised at Peoria's OSF St. Francis Medical Center, where she and other family members gathered in the hours after the accident in November, emotions swirled in her mind as her husband lay unconscious in a nearby hospital bed.

"I actually didn't want to go through with it," she said.

She worried that Arthur Paquette, 54, would feel pain during when the organ was taken, even though doctors told her that the accident on a two-lane road in Morris had left her husband — who wasn't wearing a helmet — brain-dead.

Dee Paquette, 46, said she is not opposed to organ donation, but the thought of surgery to remove his organs repulsed her at the time.

Those types of concerns in the past have led Illinois families to say no to donation 40 percent of the time, even though national surveys indicate that more than 90 percent of Americans support the concept of organ donation.

In Arthur Paquette's case, his family couldn't have stopped organ donation from taking place, even though his wife, four adult children and three siblings ended up supporting the idea when they gathered at St. Francis.

First-person consent

A few months before the accident, Arthur Paquette, who lived in Tinley Park, had obtained a license to ride a motorcycle. At the same time, he signed up for Illinois' new "first-person consent" registry for organ donation.

The registry, established in January 2006 by the Illinois General Assembly, allows drivers to make binding decisions to allow for organ donation upon their death.

There is anecdotal evidence that the law has led to organ donations that in the past might not have taken place.

But the law hasn't yet shown an effect on the overall number of organ donors, which hovers around 300 statewide each year. That's because it will take between four and eight years for the 6 million drivers in the previous organ-donor registry to be

transferred to the new "first-person consent" registry as they renew their driver's licenses, according to Dave Bosch, spokesman for the Gift of Hope Organ and Tissue Donor Network.

So far, 1.5 million drivers have signed up for the new registry — mostly at secretary of state driver facilities, though they also can sign up online at www.lifegoeson.com. Gift of Hope plans to kick off a major sign-up campaign this month that includes a special Web site, www.IAmAreYou.org.

"We have a long way to go before we can compare apples to apples," Bosch said.

Wishes could be ignored

The first-person consent law replaced a system in which Illinois drivers could indicate in a state-operated registry that they wanted to donate. They also could sign the back of their drivers' licenses outlining their wishes. But those wishes could be ignored.

Before the law changed, families refused to give consent 16 percent of the time, even after being told their loved ones had signed up for the registry, according to Elmhurst-based Gift of Hope.

Illinois joined a growing list of states with first-person consent registry to address the chronic shortage of donated organs nationwide.

In Illinois, 4,600 people are on waiting lists for organ transplants through hospitals that include Memorial Medical Center in Springfield and St. Francis in Peoria. The other transplant centers are at Loyola University Medical Center in Maywood and several Chicago hospitals: Children's Memorial, Northwestern Memorial, University of Chicago, University of Illinois and Rush University Medical Center.

Between 200 and 300 Illinoisans die each year on the waiting lists.

Officials from Gift of Hope have estimated that first-person consent could lead to at least 30 more organ donors each year, a 10 percent increase, when the new registry is filled.

100 more donor organs a year

Because several organs can be procured from each donor, the new law could lead to 100 more donor organs becoming available for transplants each year, Gift of Hope officials said. The agency works with hospitals and families to procure organs from the 1 percent to 2 percent of people who die in ways that make organ donation an option.

Jack Lynch, Gift of Hope's director of community affairs, said first-person consent has "without a doubt" made more organs available for transplant.

He said he knows of at least 10 to 15 deceased organ donors in 2006 — all of them black — who wouldn't have become donors if they hadn't signed up for the first-person consent registry.

Lynch, who is black, said he discussed organ donation with those donors' families and believes the families would have canceled the donations if they had the final say.

Distrust fuels opposition

Some of the families would have turned down donations because they were overwhelmed with grief, distrusted the medical system or mistakenly believed that blacks were unlikely to receive their loved ones' organs, he said.

Lynch said blacks are just as likely as whites to support organ donation if they are educated about the process.

Even if families don't agree with a loved one's choice to join the first-person consent registry, Lynch said he doesn't know of any situations in which families felt mistreated or offended during the procurement process.

Gift of Hope officials take care to make families feel involved, he said.

"You must master the art of talking with families rather than talking at them," he said.

Paquette's heavy burden

Dee Paquette had been separated from her husband for several months at the time of his motorcycle accident. The couple had been married for 16 years and operated a business buying and selling railroad freight cars and related equipment.

But Dee Paquette said their estrangement didn't make the organ-donation discussion any easier.

"It was a pretty heavy burden," she said.

She learned last week that one of Arthur Paquette's kidneys was successfully transplanted into a 53-year-old man. The other kidney went to a 46-year-old married man with one child. Arthur's liver went to a 54-year-old married man with three children.

Dee Paquette said it was "really nice" to hear that children somewhere would be able to see their parents live longer because of her husband's organs. But the news also rekindled her grief.

"It's still so close to his death," she said. "It makes you feel kind of good, but it also makes you sad."