

**PROFESSION****Transplant experts question impact of Facebook's organ-donor registration push**

With more than 90,000 U.S. patients needing kidneys, only a dramatic expansion in living donations would meet the growing demand for organs.

By **KEVIN B. O'REILLY**, *amednews staff*. *Posted May 28, 2012.*

Facebook's move to allow users to add their organ-donor registration status as a "life event" on their profile pages led to a surge in donor sign-ups and earned the company plaudits from physicians and other professionals in the transplant community.

But experts warn that the social-networking behemoth's action will not be enough to solve the U.S. organ shortage and could pose ethical problems for patients and families while trivializing the decision to donate.

As of mid-May, Facebook reported that more than 100,000 of its users had publicly declared their status as organ donors with the site's new functionality.

To post donor registration as a life event, users are asked to specify where they had registered and when they signed up. If they are not registered, Facebook members can click a link that will take them to their state's donor registry site. As with other updates to the site, users can decide whether to share the information with everyone or only a few friends.

More than 33,000 Facebook members were newly registered as donors in the week after the site's announcement, said Donate Life America, a national alliance of registries and organ procurement organizations that is participating in the social network's initiative. Forty-three percent of U.S. adults already were registered as donors before the Facebook action.

Many states saw huge jumps in registrations. In Illinois, for example, 540 people signed up as donors between January and April. On May 1, when the Facebook policy was announced, 748 people registered through Donate Life Illinois, said Dave Bosch, the group's spokesman.

The early results are wonderfully encouraging, physicians said. They added that the publicity afforded by Facebook's pervasive presence in U.S. life — one in two Americans is a member of the service, and 60% of members check the site daily — could greatly increase the number of people willing to donate their organs after they die, while raising awareness of the organ shortage.

About 115,000 Americans are candidates on the United Network for Organ Sharing waiting list.

"The visibility of it is great," said Benjamin Hippen, MD, a transplant nephrologist at Carolinas Medical Center in Charlotte, N.C. "How often do you pull out your driver's license? Almost never. Here, it's almost like walking around with a big 'Donate life' button on. The only people I know who do that are transplant professionals."

Minimal effect on wait lists expected

Even if harnessing the power of social media can help dramatically boost the willingness of Americans to donate their organs after death, it is unlikely to solve the organ shortage, experts said.

That is because nearly 40% of the approximately 14,000 people who donate organs each year are living donors. And, despite efforts to increase the number of donations after cardiac death, about 90% of the cadaveric donations come from patients who die of brain death.

Of all U.S. deaths annually, only about 14,000 decedents are potential brain-dead donors whose organs are healthy enough for transplantation, said an Aug. 14, 2003, study in *The New England Journal of Medicine*.

"People on Facebook now can say they'd be willing to donate their organs if they died," said Alvin H. Moss, MD, a nephrologist and director of the Center for Health Ethics and Law at West Virginia University in Morgantown. "The problem is that very few people end up being brain dead in this country. The number of people who die from drug overdoses and motor-vehicle accidents — which are the most common causes of death for cadaveric donors — those numbers are decreasing, because cars are getting safer and we have an improved driving environment."

The Facebook move is "unlikely to make a dent in the era of severe organ shortage," said Henkie P. Tan, MD, PhD, director of living donor renal transplantation at the University of Pittsburgh's Thomas E. Starzl Transplantation Institute.

About 80% of those on the organ waiting list need kidneys, and nearly 5,000 patients died while waiting for a kidney transplant in 2011, according to the National Kidney Foundation.

"The main issue is that we don't have enough donors, whether cadaveric or living," said Dr. Tan, a transplant surgeon. "There should be a push for more living donors. If Facebook could push for more living donors, it might make a dent."

Several other transplantation experts agreed that Facebook should consider exploring a way to let users publicize their status as living organ donors or their willingness to donate a kidney or participate in an extended donor chain. The company did not respond to a request for comment on the proposal by this article's deadline.

People who need kidneys already are using Facebook to seek out donors. A study presented at the National Kidney Foundation's Spring Clinical Meetings in May found that at least 91 English-language patients had solicited kidneys on the site.

"There are definitely some dangers involved in doing this," said Alexander Chang, MD, senior author of the study and a nephrology fellow at Loyola University Medical Center in Maywood, Ill. "Three percent of these patients had multiple posts from people trying to sell kidneys to them, mostly from developing countries. And there were very few mentions of the costs of the donation when signing up to donate the kidney, despite the possible risk of death and the financial burden."

"A huge decision"

At least one medical ethicist has raised concerns about Facebook's organ-donor update. The site's members ought to be exposed to some information about the donation process and should be encouraged to talk with their families about their decision, said Summer McGee, PhD, co-editor-in-chief of *The American Journal of Bioethics*.

Now, Facebook members can declare their intent to donate with a few mouse clicks. The state registries Facebook links to do include information about procurement and transplantation, but users are not required to read it before signing up.

McGee suggested that individual users be prompted to share their decision to become an organ donor with family members using Facebook. She also advised organ procurement officers to avoid using a deceased patient's Facebook life-stream update in talking with families about whether to approve donating their loved ones' organs.

"There was a lot of excitement, and rightfully so, when Facebook made this announcement," McGee said. "But once the hype is over, the question is: Did they build a system or a pathway for people to responsibly educate themselves about being an organ donor? It's a huge decision. This isn't just as simple as saying you went on a trip to Washington, D.C., last month or had a great dinner with friends last night, or to equate it with a whole number of other things you put on your Facebook status."

Despite concerns about the ethics and effectiveness of using social media to increase cadaveric organ donation, the value of Facebook's effort will be crystal clear to patients, said Dr. Tan, associate professor of surgery at the University of Pittsburgh School of Medicine.

"For many potential organ transplant recipients, the fight for life is a personal one," he said. "To that potential individual recipient, even the increase in one transplant is the fight for his or her life."

ADDITIONAL INFORMATION:

WEBLINK

"Estimating the number of potential organ donors in the United States," *The New England Journal of Medicine*, Aug. 14, 2003 (www.ncbi.nlm.nih.gov/pubmed/12917304)

"Organ Donation: Friends Saving Lives," Facebook, May 1 (newsroom.fb.com/News/Organ-Donation-Friends-Saving-Lives-15f.aspx)

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