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Facebook Is Urging Members to Add Organ Donor Status

By **MATT RICHTEL** and **KEVIN SACK**

Nearly 7,000 people in the United States die each year while waiting for an organ transplant. It is a number that [Facebook](#) hopes to lower with its vast network of 161 million members in this country.

The company announced a plan on Tuesday morning to encourage everyone on Facebook to start advertising their donor status on their pages, along with their birth dates and schools — a move that it hopes will create peer pressure to nudge more people to add their names to the rolls of registered organ donors.

It is a rare foray by Facebook into social engineering from social networking, and one with a potentially profound effect, according to experts in the field of organ donation.

They say people declaring on Facebook that they are organ donors could spur others to sign up at motor vehicle departments or online registries. But these experts say Facebook could create an informal alternative to such registries that could, even though it carries less legal weight, lead to more organ donations.

That is because a disclosure on Facebook could provide the evidence of consent that family members need when deciding whether to donate the organs of a loved one, said Dr. Andrew M. Cameron, the surgical director of liver transplantation at Johns Hopkins Hospital.

“This is going to be an historic day in transplant,” said Dr. Cameron, adding that people who die for want of an organ do so mostly because there are not enough organ donors, not because of any shortcomings in medical technology. “The math will radically change, and we may well eliminate the problem.”

Dr. Cameron estimated that millions of people could shift their donation status overnight.

Previous efforts to encourage organ donation have struggled, Dr. Cameron said, because the issue is sensitive and personal and because the decision is made at the motor vehicle department, where many people may not want to focus on the prospect of dying. Fewer than half of adult Americans have signed up to be an organ donor.

“We have attempted to have a sensitive conversation, one that addresses your mortality, at

the D.M.V.,” Dr. Cameron said. “Now we move the conversation into your own home or office with 120 of your closest friends on Facebook.”

Under the Facebook plan, members will be able to declare and update their organ donation status. The status will appear with other biographical information in a section called Health and Wellness, which includes, for example, updates on whether a person has recently lost weight or ever broken a bone.

This feature will also lead to links to state online donor registries, where people can change their donor status; or they can still do so the traditional way, by visiting the local motor vehicle department.

Facebook is introducing the change not only in the United States but also in the United Kingdom, where it has around 30 million members. The company says it plans to add it in several other countries in the coming months. Globally, Facebook has about 900 million members.

Some experts in the field of organ donation agreed that Facebook could substantially help to change the culture, but they emphasized that the Web site would not become a de facto registry.

Charlene R. Zettel, chief executive of [Donate Life California](#), an arm of a national advocacy group that promotes organ donation, noted that when someone signs up with an official state registry, it is a legal declaration that allows their organs to be donated without family consultation.

In a situation where the deceased is not in a registry, organ procurement specialists often contact the family to persuade them to grant consent and often are able to do so.

If people were to declare themselves organ donors on Facebook, Ms. Zettel said, it might simplify and hasten the decision for families to approve a donation.

“I think that it would certainly provide direction and comfort to the family,” she said. “Whether it would be legally defensible if a family wanted to challenge it, that’s a whole new arena.”

She added: “We do not want people to feel that all they have to do is put their decision to donate on Facebook. We really need to encourage people to go to their state registry.”

Dr. Cameron played a role in the change at Facebook. A 1991 graduate of Harvard University, he had written about his transplant efforts — and the struggles to find donors — for a class reunion booklet.

That was read by a former classmate and friend, Sheryl Sandberg, the chief operating officer

at Facebook. At a reunion last May, Dr. Cameron recalled standing at a mixer when Ms. Sandberg told him that she had read about his efforts and had been thinking about the struggle to get more organ donors.

“She said: ‘I think we can fix that,’ ” Dr. Cameron recalled. “It was a chills-up-the-spine moment.”

[BJ Fogg](#), who studies how technology can change attitudes as director of the Persuasive Technology Lab at Stanford University, said the prominence of organ donation on the Facebook site “will trigger people to make an important decision about whether to be an organ donor, a decision most people in the last year haven’t even considered.”

Dr. Fogg added: “If you see all your friends do it, or have the illusion all your friends are doing it, it sets up an expectation of sorts and it may become a social norm.”

This is not the first time Facebook has tried to use its network to address a social issue. Late last year it launched a service called “lifeline” that allows people to make contact with a suicide-prevention counselor or report someone through Facebook who they fear might be suicidal. That year, the company also introduced tools to discourage bullying and allow people to report episodes of bullying.

Several Facebook initiatives have engendered a negative reaction over the years, and longtime Facebook observers noted that there might be some people who do not support the idea of organ donation and would try to persuade others in their Facebook postings to pledge not to donate their own organs .

There are currently 114,000 people waiting for organ transplants, according to the federal government’s Organ Procurement and Transplantation Network. Most of them — 92,000 — are waiting for kidney transplants, a procedure with a high rate of success.

But there is a vast shortage of organs to meet the need, with only 28,535 transplants performed last year. Between 6,000 and 7,000 patients have died in each of the last 13 years while waiting for organs. Because the growth in organ donations has not kept pace with the growth in needed transplants, the gap between supply and demand has been growing.

The median wait for a kidney nationally is about four years, according to data collected for the government by the [Scientific Registry of Transplant Recipients](#). But waiting lists are maintained on a regional basis, and in areas with high rates of organ failure and low rates of organ donation, the wait can extend much longer. The [most recent data available](#) puts the median wait for a [kidney transplant](#) in California at six and a half years.

Four-fifths of organs transplanted last year came from deceased donors, who typically indicate on their driver’s licenses or in other instructions that they are willing to donate.

Donation rates have been increasing steadily, with 43 percent of those 18 or older designating themselves as organ donors last year, according to [Donate Life America](#). Donation rates in 2010 ranged from 7 percent in Texas to 76 percent in Alaska, according to the group.

Ms. Zettel, the chief executive of Donate Life California, predicted that Facebook's move would lead to "an explosion of registrations."