Transplant Guidelines Too Late For Rabies Victim

David Dishneau, Associated Press

Experts say a Maryland man who died last month of rabies might have been spared under transplant recommendations that hadn't yet been published when he got a kidney from an infected donor in 2011.

The guidance from the federally funded United Network for Organ Sharing came out in June, nine months after organs from the Florida donor went to four patients. The guidelines urge caution when considering donors with encephalitis, a brain inflammation that is one symptom of rabies. The Florida donor suffered from the condition.

The only other known U.S. case of rabies transmission through a transplant occurred in 2004 in Texas. Four organ recipients died, and the case helped stir the creation of a UNOS committee dedicated to reducing disease transmission through transplants. The Disease Transmission Advisory Committee was formed in 2006 as part of a government agreement with the private group, based in Richmond, Va.

The committee says it took so long to publish the encephalitis guidelines partly because it had to gather and analyze enough data about rare transmission events to provide a solid basis for its recommendations.

The committee also decided to address more common diseases first.

In 2010, it issued guidance on influenza, suggesting that lungs and intestines from donors infected with the H1N1 virus not be recovered for transplant. In 2011, the panel published guidance on the cancer-causing HTLV-1 virus, and last November, recommendations on tuberculosis. The group now is working on guidance for West Nile virus.

The encephalitis document urges organ banks and transplant surgeons to be cautious in considering organs from donors whose symptoms suggest a central nervous system infection, such as rabies. It urges "extreme caution" when the encephalitis appears to be from a virus. The document lists the rabies virus as one possible cause of encephalitis.

When the donor — 20-year-old William Edward Small — died in September 2011, doctors at Sacred Hearth Heath System in Pensacola, Fla., thought his symptoms were caused by a food-borne toxin, ciguatera, carried in saltwater fish, said Kathy Giery, director of LifeQuest Organ Recovery Services, which approved his organs for transplant.

She said nobody suspected the donor had rabies until after the Maryland recipient died. If they had, the organs wouldn't have been offered, she said.

"The guidelines from 2012 were different from what was in place in 2011, when this took place, so for our cases today and going forward, I think everyone would be looking at this through a different lens," Giery said.

Dr. Michael Green, a University of Pittsburgh pediatrician and chairman of the Disease Transmission Advisory Committee, said a concern for rabies in potential donors would call for extreme caution. But he said every transplant carries risk.

"In every instance, the transplant team must weigh the rare risk of donor disease transmission against the possibly greater risk that a candidate will die without a transplant opportunity," Green wrote in an email.

Compared with other diseases, rabies is rare. It kills just a handful of U.S. residents a year. Usually transmitted by a wild animal bite, it's almost always fatal once symptoms appear. But the disease can be stopped if a bitten person gets treatment, including a series of vaccinations, soon after exposure. The people in Florida, Georgia and Illinois who also received organs from Small have shown no symptoms and are getting the vaccines.

Thirty-two other people in five states who had close contact with the recipients or donor also have been urged to get the vaccine, according to the Centers for Disease Control and Prevention.

Committee member Dr. Timothy Pruett, surgical chief of the University of Minnesota transplant programs, said deaths from transmitted diseases are horrible events — but part and parcel of the organ donation system.

"The risk of dying without an organ still is so much greater than the risk of dying with a transmitted disease, but I don't want to be cavalier about it — it's something no one wants to see," he said.

The eight years it took for the rabies guidance seems unreasonable to Jennifer Hightower of Gilmer, Texas, whose 18-year-old son Joshua was among those killed by rabies-infected transplants in 2004.

"I think it took way too long," she said. "I believe any time there's signs of encephalitis or any kind of anything wrong with the brain that they can't point to, they shouldn't use them."

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