2011

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National Transplantation Pregnancy Registry Celebrates 20th Anniversary

This year marks the 20th anniversary of the National Transplantation Pregnancy Registry (NTPR). Established at Jefferson, this unique registry is a voluntary study, in which transplant recipients (both men and women) report their experiences with conception, pregnancy, childbirth, and the health of the recipient. The NTPR was founded by Principal Investigator Vincent Armenti, MD, PhD, a Jefferson alumnus and former transplant fellow with a dual faculty appointment as Professor in the Department of Surgery (Transplantation Division) and the Department of Pathology, Anatomy, and Cell Biology.

Dr. Armenti’s interest was sparked two decades ago when a transplant recipient told him she had terminated a pregnancy after transplant. “I realized then that if our goal after transplant was to restore recipients to health as fully as possible, we needed reliable data to provide better counseling,” he says.

Transplants and pregnancy may sound like a dangerous combination for the mother as well as the fetus or newborn. But in the past 20 years the Registry has collected data on 1,940 pregnancies—1,185 female transplant recipients and 1,224 pregnancies fathered by 811 male transplant recipients. “These data have helped to establish patterns of risk factors and inform us of the impact that certain anti-rejection drugs are having on pregnancies,” he says.

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Dr. Armenti and his staff, which includes research coordinators Faith R. Carlin, Lisa A. Coscia, RN, BSN, CCTC, and Carolyn H. McGrory, MS, RN, and data coordinator Dawn Armenti, analyze a number of variables to identify risks factors of pregnancy, which vary according to what kind of organ has been transplanted. “After a kidney transplant, recipients facing graft failure (loss of transplant function) can go back on dialysis, if necessary,” Dr. Armenti explains. But for liver, heart, and lung recipients, he says, the consequences are more severe given that the only alternative therapy is retransplantation. High blood pressure and diabetes, which can develop during pregnancy, also pose threats for the pregnancy, in addition to rejection.

By collecting and analyzing information on all types of solid organ transplant recipients, the Registry can use these data to help provide guidelines for counseling. According to the NTPR, many transplant recipients are able to maintain pregnancy, with the majority resulting in a healthy live birth, and continue with stable transplant function. However, exposure to the immunosuppressive mycophenolic acid (MPA) products during pregnancy was associated with a pattern of structural birth defects, an observation reported to the FDA and responsible for the required “black box” warning about the drug.

On May 7, 2011, the NTPR held a 20th anniversary celebration for 100 members of the Registry—transplant recipients and their families—in conjunction with the Gift of Life Donor Program here in Philadelphia. Nobel laureate Dr. Joseph Murray, 92, who performed the world’s first kidney transplant in 1954, surprised the attendees by video conferencing into the event from Massachusetts, to address the group and answer questions—a real “full circle moment.”

Dr. Armenti commented that the event was “a wonderful opportunity to bring all of these people together for the first time, to meet the children and talk about our plans to follow these children as they mature. The more data we can collect and measure, the greater difference we can make for future generations.”

For more information about the NTPR, visit www.jefferson.edu/ntpr.