Seeking a better base for studying infertility

If you’ve got 15 minutes to spare—and you’re already happy with your car insurance—you could contribute to the advancement of scientific knowledge. Fifteen minutes is about how long it takes to fill out a survey developed by DMS researchers to learn more about the long-term health effects of assisted reproductive technologies (ART).

In vitro fertilization and other types of ART are used in about one percent of all births in the U.S. But, says Judy Stern, Ph.D., the director of DHMC’s human embryology and andrology lab and the leader of the research effort, surprisingly little is known about the potential consequences of such treatments, either for children born with ART or for their parents.

**Risks:** “The majority of people who go through these things are fine,” Stern says. “But we don’t really know whether there are small risks that we hadn’t initially thought of.”

Research on the subject so far has raised more questions than it has answered. For newborns, potential risks include low birthweight and certain genetic risks. For parents, there are hints of a potential link between infertility and an increased risk of some types of cancer. There are also questions about whether women who donate eggs are at an increased risk of cancer.

But Stern says it’s not known if these health risks are related to ART treatments, to some factor associated with infertility, or to some other cause. “Even if we see some risks, we don’t know if it’s the underlying disease or the treatment,” she says.

To try to find some answers, Stern has created a registry that will track the health of people who have used ART as well as of children born through ART. The registry is recruiting participants at about 75 ART clinics in the U.S. and Canada. The online survey is very secure, says Stern, so the information people provide will remain confidential. The survey can be accessed at https://www.ifrr-registry.org.

The initial information asked of participants includes data on types of fertility treatments they have used as well as background health information. Even this basic information will be useful, Stern says, but in some cases researchers may want to ask additional questions of a subset of participants. In that case, Stern would act as a gatekeeper, contacting certain participants to ask if they would be interested in participating in an additional study. She also hopes that participants will return to the site over time to update the information about their health and the health of their children.

**Data:** The registry is also open to men and women who have had children without fertility treatments, so their data can provide a baseline comparison.

And, once the registry is large enough, Stern would like to be able to provide participants with feedback about how their situation compares to that of other participants. For example, if a woman using IVF gives birth to twins, she would be able to see the overall outcomes for other women who have had twins born with IVF.

“There is a whole lot that we really need to learn,” Stern says.

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