The Research Participant Registry connects community members and UPMC patients with researchers at the University of Pittsburgh and UPMC. The registry is a part of the University of Pittsburgh Clinical and Translational Science Institute (CTSI). The registry has enrolled nearly 40,000 adult participants since 2008 and is now opening recruitment to individuals under the age of 18. Parents who enroll their children will learn about research studies in areas of their choosing related to their children’s health.

Evelyn Cohen Reis, MD, a pediatrician, is an associate professor of pediatrics at the University of Pittsburgh School of Medicine. She is also medical director of Pediatric PittNet, the CTSI research network that works collaboratively with Pitt researchers and pediatric primary care practices to improve the health of children. In the following interview, she offers some information about children participating in research.

Why is it important to involve children in scientific research?

Before a medicine, device, or treatment is ever used in the general population, it goes through a lot of safety testing. Then it is tested in adults to see how well it works. But children are smaller, and their bodies aren’t fully developed. Medicine that works well in adults may not always work the same way in children. Some medical conditions, like arthritis, don’t look the same in children as they do in adults. Some diseases only affect children. So, in order to effectively care for children, we have to involve them in the research on diseases that affect them.

“Research is the best way to advance medical care for children so we can learn how to better diagnose, treat, and prevent the diseases that affect them,” says Dr. Reis.

Think of the childhood diseases that used to disable, or even kill, children. “Doctors used to routinely see certain illnesses in children like polio [a highly contagious virus that causes paralysis and death]. In the 1940s and ’50s, polio crippled around 35,000 children a year in the U.S. alone,” says Dr. Reis. “Now, we have a routine vaccine that prevents this deadly disease. Thanks to the hundreds of children who participated in the polio vaccine research here in the Pittsburgh area, no polio cases have been reported in the U.S. in more than 10 years.”

Many of the ways we treat children have been handed down through generations of doctors. For instance, we know that antibiotics treat ear infections. But, until recently, doctors decided how much of the antibiotic to give and how many days to give it based on what had always been done. Researchers, like Dr. Alejandro Hoberman, are now learning which antibiotic treatment courses work best for children so that pediatricians can make such decisions based on facts and evidence, not tradition.

But, why should my child participate in research?

All families benefit from being a part of the research process. Our children are healthier now because of studies done in the past. Children in the future will benefit from what’s being learned in current studies. We need children of different ages, genders, races, and neighborhoods to participate in studies so that doctors know which treatments work best for which groups of children.

Some people could benefit by being a part of a study for a new test of a treatment or drug that isn’t available to everyone else yet. Children may also benefit by seeing specialty doctors who treat their condition. Just as parents are encouraged to take an active role in their child’s regular health care, during a study many parents enjoy the opportunity to learn more about their child’s condition and treatment and give feedback to the researchers.
Is Participating in research safe?

As parents, our children’s health and safety come first. Many studies conducted with children are considered “low risk” studies. The U.S. Office for Human Research Protections defines “low risk” as those risks “encountered during daily life by normal, average, healthy children living in safe environments or during the performance of routine physical or psychological examinations or tests.”

“Any study involving humans has to go through several review steps and approvals,” says Dr. Reis. “All studies offered in UPMC offices have been reviewed and approved by experts at Children’s Hospital of Pittsburgh of UPMC to make sure they’re safe for children.”

Research teams are made up of a group of doctors and health professionals who carefully watch every child in research studies. They monitor how the intervention is working and check for side effects. Most importantly, parents can remove their children from a study at any time for any reason. Participating in research is always voluntary.

What happens when parents enroll their children in the registry?

When parents bring their children to primary or specialty care offices, they will be given information about joining the registry. If they choose to enroll their children, parents will periodically receive news about child health topics. They will also receive information about research studies matched to their interests or to their children’s medical records. Parents can contact the research office if they’re interested in a particular study. Parents will only receive phone calls from research study staff if they’ve asked for more information. The registry will keep your and your child’s information confidential.

“Parents who enroll their children in the registry are only signing up to receive information,” Dr. Reis says. “They can remove their children’s names from the registry at any time. Parents are always in control.”

How can parents learn more about participating in research?

Parents are welcome to contact the Research Participant Registry office at 1-866-438-8230 or researchregistry@hs.pitt.edu for more information.


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If you have a UPMC doctor, you now have more access, more control, and more ways to manage your health care online. With UPMC HealthTrak, you can communicate with your doctor, track your current health issues, review your records or test results, and even have online visits with a real doctor right from your computer. Other useful features include requesting an appointment, chatting online with a customer service agent, viewing your eStatement, and paying your bill online. It’s easy, convenient, and secure, and you can sign up today!

Pediatric proxy allows parents/legal guardians to request doctor’s appointments, communicate with their child’s doctor, manage immunizations, review test results, and more until the child’s 18th birthday.

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