# For an experienced research participant, a potentially life-saving personal discovery

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On the first of May, 2015, Angelique Bell waited in a hair salon, reading the weekend section of the newspaper. She noticed an ad for a health research study that needed participants who had risk factors for diabetes. Since she met the criteria and had some time to pass, she decided to call about the study right then, from the salon chair. It was her 45th birthday.

"I don't have diabetes, but I have a strong family history of diabetes and some of the risk factors, and I thought that the information from this study could be something that could benefit me in the future," said Bell.

She didn't expect, however, that her impromptu birthday decision to call about the study would potentially save her life.

As part of the screening for the study, Bell had to do bloodwork and an EKG—standard tests to get baseline health data. Her results, however, were anything but standard: they showed extremely low levels of potassium and an arrhythmia in her heart that could be fatal if not treated.

"When she came in, she was having a lot premature ventricular contractions, which is potentially dangerous because your heart could suddenly go into ventricular tachycardia or fibrillation, which can kill you," said Dr. Philip A. Kern, director of the University of Kentucky Center for Clinical and Translational Science and principal investigator of the diabetes study in which Bell participated.

At the time Bell was taking two medications to help control her blood pressure. One medication was a diuretic, which, unknown to Bell, was causing her to lose too much potassium through her urine. The resulting potassium deficiency was causing the arrhythmia in her heart.

Kern and the research team sent Bell to the UK Gill Heart Institute for further evaluation and treatment. She was taken off the diuretic, had to wear a heart monitor for 48 hours, and received potassium supplements.

"I was 45 years old at the time and I had to wear this heart monitor. Three-fourths of my grandparents had heart attacks. My mother had congestive heart failure. So it was a scary," said Bell. "I was relieved to find out that the condition had not gotten to a point of causing damage. A really serious problem was averted."

Once the arrhythmia was resolved, Bell, undeterred by her own health scare, went back to Kern and participated in the diabetes-related study that she had originally phoned about.

The study was not Bell's first experience as a research participant, nor was it her last. She had previously participated in two asthma-related studies at other institutions, motivated by her own diagnosis as a child, and she subsequently volunteered again at UK as a healthy participant in a study examining how our bodies process fat intake. Through each experience she learned more about her own health.

"That is one of the good things about being in the study—a lot of times when people get in studies, they find out about other issues with their health. There's a pretty in-depth amount of testing done, and it could uncover something that wouldn't be found in a routine exam."

Bell was also familiar with health research through family members' experiences. Her father participated in a longitudinal study on gout, and

her uncle was a researcher with the Centers for Disease Control and Prevention ("he was very excited about science"). Exposure to both researcher and participant experiences has convinced Bell of the importance of empirical, evidence-based information, as well as the need for research participants.

"Having people around who do research, you see how important it is for them to get people in their studies so they have enough evidence," she said.

She additionally emphasizes the importance of racial and gender diversity among research participants, in order to understand how health conditions and treatments affect people differently, but she simultaneously acknowledges the legacy of the infamous Tuskegee experiment conducted between 1932 and 1972. In the course of that study, hundreds of poor, African American men were knowingly left untreated for syphilis.

When the Tuskegee story was uncovered, it created an understandable distrust of health research, particularly among African Americans. At the same time, however, the story initiated a host of stringent federal regulations enacted to protect research participants. In 1974, Congress passed the National Research Act and created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which developed guidelines for human subject protection, including the landmark Belmont Report.

Health research involving people is now "very highly regulated, with multiple layers of protection," said Kern. Studies require a process of informed consent and communication of diagnosis, as well as reporting of the study results. Institutions like UK that conduct health research must have institutional review boards (which include community members) to review the plans for all studies. UK also has an Office of

Research Integrity that can answer questions and support research participants.

"Because of Tuskegee I think a lot of African Americans are leery of participating in research studies," said Bell. "But if you don't participate in the research then the data that relates to you is not there. Some things do have a genetic factor, and some things might affect people of African descent differently than people of European and Asian descent."

If there is residual distrust about health research, there is also a great deal altruism that motivates many people to participate. According to Roxane Poskin, participant recruitment manager at the UK CCTS, a large percentage of volunteers join studies as way to give back to society and contribute to discoveries that improve health for others and future generations. This is particularly true for healthy participants, who don't have a health condition they hope to address through a study but who are essential to research that broadens our understanding of what Kern calls "the basic mechanisms of disease and how the body works." While participants receive information about their health and sometimes receive compensation for participating, they don't always receive a direct health benefit for themselves.

"They want to be involved and help others even, if it doesn't help them directly," Poskin said. "If we didn't have volunteers, we wouldn't be able to accomplish research studies. Even the smallest things have been researched, like thermometers and crutches."

Bell, who has spent her career in non-profits organizations (she currently works with Kentucky Refugee Ministries and ITNBluegrass), says she doesn't personally know many people who participate in studies, but that she would encourage anyone to participate, either for their own benefit or to advance medical knowledge that could help others.

"We have to have evidence-based research," she said. "And you get a lot more information about your health than you would in a normal physical."

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