REALHEALTH™

Tailored To Fit

Dara Richardson-Heron, a doctor and breast cancer survivor, works with the All of Us Research Program, which aims to customize medical treatment for individuals.

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On a rainy day more than 20 years ago, Dara Richardson-Heron, MD, learned that she had breast cancer at age 34. Although she was a physician, she was devastated by the news.

Prior to her diagnosis, she had noticed a lump in her breast after doing a self-exam. While she wasn't initially worried, she knew that the lump should be evaluated, so she scheduled an appointment with her physician. During her physical exam, she mentioned what she'd felt to her doctor, and he agreed that an evaluation should be done. But he told her that he doubted there was anything to be concerned about because she was so young.

Richardson-Heron's mother, however, had been diagnosed with breast cancer 10 years earlier. Because of this history and her medical training, she insisted on getting further tests. Consequently, her doctor agreed to give her a referral for a mammogram.

"Sometimes women—in particular, women of color—are not taken as seriously as we should be when we go to the doctor," she says. "I always tell women that if you don't get the response you feel is appropriate when you present your health concerns to your physician or caregiver, it's very important to move on to someone else."

After the mammogram, she was even more certain something was wrong. Richardson-Heron reached out to a former professor of hers, an oncologist at New York University Medical School, who evaluated her case and subsequently managed her treatment.

"I was diagnosed with breast cancer a month after my wedding," she says. "The experience was unbelievably surreal, devastating and life-altering."

Richardson-Heron recalls that at that time much of the literature indicated that the chances of surviving five years were slim for individuals under age 35 who were diagnosed with invasive breast cancer.

"I was scared that I was going to die," she says. "I knew that I would almost certainly need chemotherapy because that was the treatment of the day. But I had seen many patients die from the side effects of chemotherapy, not necessarily from the disease, and that was pretty scary."

Today, because of research efforts, doctors now have an arsenal of treatments to choose from based on the type of tumor a woman has.

Currently, Richardson-Heron is the chief engagement officer and scientific executive for the All of Us Research Program, an initiative created by the National Institutes of Health to help advance individualized medical care.

The goal of this historic effort is to collect data from 1 million or more people living in the United States and use the information to study how people's lifestyles, environments and biological makeup influence health and disease.

"The more information and data that we gather, the more we'll know about what makes people unique, which we hope, in turn, will pave the way for more customized preventive health approaches and medical breakthroughs," she says.

Richardson-Heron hopes more personalized and effective treatments will become available because of enhanced participation in clinical studies by different people, particularly those who have historically been underrepresented in biomedical research. The program also aims to make data broadly accessible to diverse groups of scientists.

"Many women, including me, are alive today because of research that has been done to enhance treatment effectiveness and decrease side effects. Breast cancer changed my life immensely. And while I wouldn't ever want to experience it again, I can say without equivocation that the experience made me a much better person, physician and leader and also helped me to focus more clearly on what's really important in life."

More About "All of Us"

This research program aims to improve health and treat disease with individualized care.

As part of the Precision Medicine Initiative conducted by the National Institutes of Health, the data collected from participants in the All of Us Research Program will provide a national resource for research studies spanning a wide variety of health conditions.

To reach participants, All of Us has partnered with many organizations to forge strong connections to communities of color. (More than 75 percent of participants are from underrepresented populations.)

"Essentially, these organizations are increasing awareness and excitement in our programs," says Dara Richardson-Heron, MD, the chief engagement officer and scientific executive for All of Us.You might see them showcasing our program at their national conventions, or they might be tabling at workshops or hosting round tables and be including information about our program in their social media channels."

Richardson-Heron says the collected data are being strictly safeguarded to ensure privacy and security for individuals' information.

In addition, the program is making concerted efforts to address the distrust many people of color may have toward medical research and acknowledging the documented abuses of science experiments that took place years ago, such as the Tuskegee Study of Untreated Syphilis among Black men.

Says Richardson-Heron, “At the All of Us Research Program, we truly want everyone to be part of the research so that everyone can benefit from the medical advances and cures.”