

# Take charge of your health today. Be informed. Be involved.

## All of Us Pennsylvania

This month Dr. Steven Reis, associate vice chancellor for clinical research, Health Sciences at the University of Pittsburgh and the principal investigator of the All of Us Pennsylvania Research Program and Esther Bush, president and CEO of the Urban League of Greater Pittsburgh, discussed the impact this research program could have on the future of health and medicine.

**EB:** Good morning Steve, it is a pleasure to take some time and talk with you this month. I have been learning about precision medicine for a year and a half now. I know that you and your team have been working hard to spread awareness about precision medicine and the All of Us Pennsylvania research program. Why is it important for you?

**SR:** Aside from being a researcher, I am also a cardiologist. Part of my job is to prescribe medications. Imagine this: if everyone who is reading this article went to their healthcare provider today with high blood pressure that required treatment, it is likely that most of us would leave with a prescription for the same medication. Why is that? After all, we are all different so why aren't we receiving personalized and precise medical care? The answer is because there isn't enough scientific data to enable individualized approaches to preventing, diagnosing, and treating diseases.

**EB:** Yes, I can follow that. So how does All of Us Pennsylvania fit into changing that type of "one-size-fits-all" care?



ESTHER BUSH

**SR:** I am very excited to announce that the National Institutes of Health All of Us research study, known locally at Pitt as All of Us Pennsylvania, officially opened national enrollment this past Sunday, May 6th. All of Us will be the largest study in the United States. It will enroll one million people nationally. We aim to enroll 120,000 participants here in Pennsylvania. The goal is to create a large database that includes information about people's lifestyles, environment, occupational history, medical history and biological makeup. It's about big data that will lead to scientific discoveries to make disease prevention and treatment more precise and individualized.

The University of Pittsburgh is playing a major role in this landmark study. As of last week we have enrolled more than 5,000

people. Nationally, there are over 27,000 individuals who are currently participating in the study.

**EB:** What an amazing accomplishment! We have been working together for over 10 years now Steve, and because of the Heart Score Study, I have known you even longer. The Urban League of Greater Pittsburgh is so proud to partner with CTSI and All of Us Pennsylvania. I can't stress enough to everyone who I talk to and who is reading this column right now. Diversity in this research study is necessary. What is your team doing to make sure that study participants are diverse, and can truly reflect all differences?

**SR:** That is a great question, Esther, and one that comes up every time I talk about this program. Diversity means so many things. It can be ethnicity, race, health status, geography, lifestyle, neighborhood, sexual orientation, age... and the list could go on. Nationally, the NIH has a goal that 51% of the million people who will be enrolled fall into a category that has traditionally been underrepresented in biomedical research. We want to meet people and work with organizations across our region to spread awareness about this program. It's very important to include diverse individuals from our region so that the results of this study will be relevant to all of us here in western Pennsylvania.

**EB:** I like that. I know that the All of Us Pennsylvania engagement team has come



STEVEN REIS, MD

to the Urban League to talk to our staff and clientele about this opportunity, and that they will be out and about in the community throughout the summer. I am proud to support this effort.

**SR:** Thank you Esther. I can't overstate the importance of Pitt being part of this study so that we can improve the health of our communities. And that includes all of our community and academic partners. We want everyone in our region to hear about this study, and determine if it is right for you. There is more information on this page and anyone can visit our website at [www.joinallofuspa.org](http://www.joinallofuspa.org). Thank you for your time and your continued partnership. I firmly believe that this study is critically important to the health of both Pennsylvania and our nation.

## All of Us Research Program designed to close gaps in health care

In 2015, with the launch of his Precision Medicine Initiative, former President Barack Obama introduced to many of us the idea that health care could be different for everyone based on people's genes, environments and lifestyles. We learned that health care is not "one size fits all" and that our medicines and treatments should not be either. To tailor health care to individuals, we would need to know more about a diverse selection of people on an individual level.

Three years later, the University of Pittsburgh and UPMC, in collaboration with the National Institutes of Health, are announcing the launch of open enrollment for All of Us Pennsylvania, part of the national All of Us research program. The goal of All of Us is to partner with 1 million people who are willing to share their health information with researchers to make sure the newest health discoveries are benefiting everyone.

Health care is based on research. Medications are developed through research, under rigorous review and with people agreeing to participate in research studies. By joining All of Us PA, participants will provide information to the All of Us research program from their electronic health records, personal history and bio samples (urine and blood for genetic testing, weight, height, blood pressure, etc.). Participants



A research technician at the University of Pittsburgh Medical Center prepares to collect a blood sample from a participant in the "All of Us" research program. DAKE KANG/AP

will have opportunities over many years to provide data about themselves that will help researchers learn more about how indi-

vidual differences in lifestyle, environment and biological make-up (such as genetic background) influence health and disease.

This information is expected to lead to new treatments tailored to individual patients.

Precision medicine is an essential approach to disease treatment, especially in underrepresented populations. "One of the main goals of precision medicine is to close gaps in care," says Mylynda Massart, MD, PhD, assistant professor of family medicine at Pitt and medical director at UPMC Matilda H. Theiss Health Center.

In the past, research did not always include people from all racial and ethnic backgrounds. Also, historically, people from certain racial and ethnic backgrounds have been reluctant to participate in research. Therefore, research has been done on limited patient populations. Now, researchers want to study, for example, whether a cholesterol medicine that was tested and works well in White men also successfully treats African American women. Doctors would even be able to look at our health data and determine which medications are best for our conditions.

If you are interested in knowing more about the All of Us PA research program, visit [www.joinallofuspa.org](http://www.joinallofuspa.org) or call 412-383-2737. Also, watch for the All of Us PA engagement team at community events, libraries or even at your pharmacy or health care provider's office.

### Ask how to get a



and be one in a million.

Be one in a million by participating in a research study that may change the future of medicine.

The All of Us Pennsylvania study is part of a National Institutes of Health nationwide precision medicine study that will give doctors and researchers the tools needed to pave the way for the discovery of more individualized approaches to health care.

#### How do I join?

Call (412) 383-2737 or visit [joinallofusPA.org](http://joinallofusPA.org) to find out more and schedule your appointment.

You can also start your journey by going to [participant.joinallofus.org/#/register](http://participant.joinallofus.org/#/register) website:

- Click "Sign Up" to enter your e-mail and password so that you can then complete your online consents and surveys.
- Call (412) 383-2737 to schedule a clinic visit and finish your enrollment.
- All participants receive a \$25 gift card upon completing their clinic visit.

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## All of Us: An Opportunity for Our Future Health Care

by Rev. Paul Abernathy

Director, FOCUS Pittsburgh

Many times, we in the community discuss health inequity with great frustration. We are always thinking about when the opportunity for us to expand access to health care and an improvement in the way health care is delivered in our communities will come. It is important that we do not miss the opportunities we have asked for, for generations. The All of Us research program is perhaps one of the greatest opportunities that our community has been presented with in decades. All of Us gives us the opportunity, through participation, to pave the way for improved health care—not only us but for our children and our children's children. It is time that we take responsibility in embracing this opportunity with the future of our community in mind, with the realization that, if we do so, lives in our community will be greatly improved generations from now. It is our hope and our prayer that the dedication that we have demonstrated by participating in this research will lead to healthy living that creates a new norm for culture and life in our community.

I think it is important that we approach this research in the same spirit of our ancestors. In fact, I'm reminded of Abraham Lincoln, who said, "The struggle of today is not altogether for today." He was referring to the freeing of the slaves. Freedom from slavery would not just end racism in the nation. Rather, there would be many decades after 1865 before we could even have civil rights in this nation. We have to understand that there are steps that must occur across multiple generations before change can truly happen. We may not receive the benefits from the steps we take. Just like our ancestors before us, we have



REV. PAUL ABERNATHY

to understand that the struggle of today is not only for today. We have to take steps while bearing in mind our descendants to come and the responsibility that we have to them.

I am always reminded of the Iroquois League, our Native American brothers and sisters, and their "seventh generation principle." One thing that they consider before making a decision is how this decision will affect them seven generations from now. Now, we ask, "How will participating in this research affect us seven generations from now?" We are a community, and communities exist over generations. I think we have to be honest and say that our community seven generations from now will probably be better off because of this step that we took.