

All of Us RESEARCH PROGRAM

The
Precision
Medicine
Initiative



Henry Ford Health System (HFHS) has been selected as one of only ten elite organizations to partner with the National Institutes of Health (NIH) as part of its *All of Us* Research Program. *All of Us* aims to enroll one million participants in a research effort to improve clinicians' ability to prevent and treat disease based on individual differences in lifestyle, environment, and genetics.

HFHS ambulatory patients and employees began participating as early enrollees this past summer and the program is ramping up enrollment prior to the planned national launch in spring 2018.

An inpatient recruitment pilot program has recently been approved and is now underway at Henry Ford Hospital, as well as enrollment sites at Henry Ford Hospital, New Center One, 1 Ford Place, and Henry Ford Medical Center-Detroit Northwest.

The privacy of participants is important and the following steps will be taken to protect it:

- Information about participants will be stored on protected computers.

- The NIH will limit and keep track of who sees the information.
- The *All of Us* Research Program has Certificates of Confidentiality from the United States government. This will help fight any legal demands (such as a court order) to give out information that could identify participants.
- The transfer of participants' electronic health record (EHR) information to the *All of Us* program will be performed by authorized individuals only, through an electronic process.
- Standard personal identifiers: Name, date of birth, address and phone numbers will be removed and replaced with a code which will be kept separate and secure.

You can join the *All of Us* Research Program by calling **1-(844) 893-3908** to get an enrollment code, or request more information by visiting www.HenryFord.com/JoinAllOfUs

BE ONE IN A MILLION

Together, we can discover what matters to you

PATIENT ADVISOR SPOTLIGHT

JOYCE MCKEE

Joyce McKee joined the PERC team as a Patient Advisor in March of 2017, after her HFHS doctor encouraged her to share her experience as a member of the Transplant Living Community. The Transplant Living Community, known as the TLC, is a program conceptualized in 2008 by patients for patients to address unique life style issues that confront transplant recipients and their families. Joyce provides real time support and lifestyle education in her role as a Lifestyle Coach to all organ and bone marrow recipients and their caregivers. Ms. McKee has an inspiring story, she received an LVAD (left ventricular assist device) in 2012, and then underwent a heart transplant in 2013, and today, as a PERC Patient Advisor, McKee gets to share her experience while helping others.

As a member of TLC, Ms. McKee learned the benefits of self-care and a fighting attitude. “I learned about making healthy choices, the importance of following my doctor’s instructions, and finding the balance between rest and exercise. These are crucial, life changing choices, and having a professional support team, in addition to friends and family, made me feel like I had a personal army of love and support behind me. I was able to connect with relatable people, talk about our shared experiences, and ultimately I realized, that I wasn’t in this alone, and if I kept the right attitude and followed through with my treatment, I would achieve my best health.”

Ms. McKee explains that while undergoing a transplant is a very emotional and painful, the experience humbly reminds us that we are all connected- through experience, through feelings, and through community groups like TLC and PERC – which create exceptional bonds and provide unparalleled support, which is why Ms. McKee became a Patient Advisor.

“I really enjoy talking to patients, especially those going through heart transplants because I understand their pain and am able to support them through day to day guidance, and in the end, we always become friends because our relationships are based on strength, understanding, and compassion. It is so important that patients feel like they have someone on their side, because it allows them to feel less fear, less pain, and I am able to facilitate proper care from my personal experience, providing guidance they may not get from another friend or family member.”

“I am honored to be a Patient Advisor for the PERC team because I help to encourage others to have a healthy lifestyle. When I engage with patients, I help them change their attitudes, to help them fight, to instill hope, and I have learned to be this way from my own experience, but also through the tools I have received in my Patient Advisor Training. Being a Patient Advisor has been a wonderful experience because we are all helping each other with our health while forging lasting, meaningful relationships.”

A WORD FROM THE PERC DIRECTOR

CHRISTINE JOHNSON, PhD



We are off to a great beginning in 2018! In this issue of the PERC Newsletter you can read about our Community Partner, the Women’s Inspired Neighborhood Network, dedicated to finding effective, long-term solutions to reduce infant mortality and decrease racial disparities in birth outcomes throughout Detroit. Joyce McGee, a

patient advisor who belongs to the Transplant Living Community, shares her heart transplant story and why she loves to encourage others to live a healthy lifestyle in the Patient Advisor Spotlight. Finally, you can find out more about the All of Us Research Program with a goal of helping researchers understand more about why people get sick or stay healthy. With a national launch planned for this spring, we are always looking for patient advisors to be participant partners to work with us on this groundbreaking project. You can email allofus@hfhs.org for more information.

Happy Reading!

Christine Cole Johnson

COMMUNITY

THE WOMEN-INSPIRED NEIGHBORHOOD NETWORK IS A WINN-WIN FOR DETROIT

Despite excellent, nationally ranked health care in the Detroit region, infant mortality in the metropolitan area rivals that of developing countries. Noticing stark racial health disparities and appalling death rates of infants, the Detroit Regional Infant Mortality Reduction Task Force, chaired by Henry Ford Health System's Kimberlydawn Wisdom, M.D, took action in 2008 when the CEOs of Detroit's four major health systems joined forces in 2008 and formed the Women-Inspired Neighborhood (WIN) Network: Detroit, an initiative dedicated to finding effective, long-term solutions to reduce infant mortality and decrease racial disparities in birth outcomes throughout Detroit.

The WIN Network: Detroit formed exceptional and diverse public-private partnerships with Detroit's major health systems, public health department, schools, and community organizations, creating a comprehensive community resource network or "safety net" for some of Detroit's most vulnerable residents.

"The key component to achieving better outcomes is the relationship-based model of incorporating CHWs in helping vulnerable women address infant mortality-related issues," says Kimberlydawn Wisdom, MD, MS, Senior Vice President of Community Health & Equity and Chief Wellness and Diversity Officer at Henry Ford Health System.

In April 2016, the WIN Network working with Henry Ford Certified Nurse Midwives began bringing together



pregnant women at the same stage of their pregnancy for group prenatal care – an enhanced model of care that combines prenatal education, social support, and clinical care. This model of care is effective and groundbreaking, explains Dr. Wisdom. "WIN Network: Detroit is unique because we are the first in the country to engage Community Health Workers working side-by-side with Certified Nurse Midwives to co-facilitate group prenatal care."

Although the fight against racial disparities and infant mortality is far from over, WIN Network has been changing and saving lives for nearly a decade. "WIN Network: Detroit is not just about saving babies," says Dr. Wisdom, "it's about understanding how multiple sectors in our community must come together to support our families and reduce these disparities."

If you are interested in learning more or getting involved, please contact WIN Network by calling (313) 874-4581 or email info@winnetworkdetroit.org.



