Henry Ford Health System

PERC News

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HOW HENRY FORD IS GETTING TO KNOW "ALL OF US"

All of Us

THE FUTURE OF HEALTH BEGINS WITH YOU

At Henry Ford we know that the future of health begins with you, and that is why we are a proud leader and Healthcare Provider Organization primary site in the research program called *All of Us*.

All of Us, formerly known as the Precision Medicine Cohort Program, is part of a National Institutes of Health (NIH) led effort to build a national, large-scale research enterprise with one million or more volunteers to extend the understanding of medicine to all diseases. *All of Us* is a participant-engaged, data-driven enterprise supporting research at the intersection of lifestyle, environment, and genetics to produce new knowledge, with the goal of developing more effective ways to prolong health and treat disease. To reflect the diversity of the U.S. population, the program will enroll participants from diverse social, racial/ethnic, ancestral, geographic, and economic backgrounds, from all age groups and health statuses. Information from the program will create a broad, powerful resource for researchers working on a variety of important health questions. Importantly, the program will focus not just on disease, but also on ways to increase an individual's chances of remaining healthy throughout life.

Randee Bloom, RN, MBA, PhD, volunteers on Henry Ford Hospital's Patient Advisory team and also on a national level for *All of Us*. Dr. Bloom, along with many others who work nationally across the program, are working to ensure that all volunteer participants receive information about their personal, medical, and health results in an informative and useful manner.

By working together, every person involved in this study will see how their contribution benefits personal health and medical treatment as it pertains to not only themselves but to their community, families, and society as a whole, including future generations.

Dr. Bloom emphasizes the importance of volunteers in *All of Us*. "Volunteers help medical professionals hone in on individuals, not diseases, allowing each volunteer to have a better understanding of their own health and the information and resources they need to improve their own quality of life."

Two guiding principles of *All of Us* are to "focus not just on disease, but also on ways to increase an individual's chances of remaining healthy throughout life" and "to empower study participants with data and information to improve their own health."

Dr. Bloom, who has dedicated much of her career to volunteer services, says she is "honored to be able to contribute to the global scope of this project through the recruitment of diverse participants." What many people don't recognize is that in this study, "volunteers have an equal opportunity to learn about and improve their own health so that they can live their best possible lives."

All of Us is for Everyone

Anyone in the United States will be able to enroll voluntarily in *All of Us* either directly through its website or through a participating healthcare provider organization such as Henry Ford Hospital, both of which will begin recruiting in the summer of 2017. Participants will volunteer to share data including their health records, and health survey information including information on their lifestyle, habits and environmental exposures.

Volunteers may also be asked to complete a standard exam that will check their vital signs and provide a blood sample. Participants will have access to their results,

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including a summary of the data collected from across the research program. All of the data will be stored in alignment with NIH privacy and security safeguards in place.

All of Us is a progressive and interactive research model, where participants function as the primary partners in the development and implementation of the program with proper governance and oversight by researchers and other healthcare providers. Through this approach, all participants will gain the knowledge needed to advance patient care in terms of approaches and treatments as it applies specifically to any disease or individuals.

Partners in this program come from all backgrounds including scientific, medical, health, societal, and public and private sectors. Henry Ford Hospital is one of eight regional medical centers awarded and is leading the Trans-American Consortium for the Health Care Systems Research Network (TACH) which is comprised of Henry Ford Health System (Detroit, MI), Baylor Scott and White Research Institute (Dallas, TX), Essentia Institute for Rural Health (Duluth, MN), Spectrum Health (Grand Rapids, MI) and the University of Massachusetts Medical School (Worcester, MA).

"I applaud Henry Ford Hospital in being selected to lead this project", states Bloom. "It is a prestigious award and more so a tremendous achievement to have the vision, capacity, resources, and dedication required to carry out such an organized and impactful project that truly integrates the health and wellness of millions of individuals across the country."

"Within the next year, our consortium will recruit 8,000 participants, making this a very ambitious project" states Cathy Peltz-Rauchman, PhD, the TACH Operational Director for *All of Us* as well as an Epidemiologist in the Department of Public Health Department at Henry Ford Hospital.

By enrolling in All for Us, you help ensure that your community is included in the studies that lead to improved health for future generations. If you are interested in helping the future and learning more about yourself, look for communication announcements by signing up for email updates at http://joinallofus.org/ and clicking "learn more."

All of Us℠ Research Program

WHAT IS IT?

Precision medicine is a groundbreaking approach to disease prevention and treatment based on people's individual differences in environment, genes and lifestyle.

The *All of Us* Research Program will lay the foundation for using this approach in **clinical practice.**

WHAT ARE THE GOALS?

Engage a group of **1 million or more U.S. research participants** who will share biological samples, genetic data and diet/lifestyle information, all linked to their electronic health records. This data will allow researchers to develop more precise treatments for **many diseases and conditions**.

Pioneer a new model of research that emphasizes **engaged research participants, responsible data sharing and privacy protection.**

Research based on the cohort data will:

- Lay **scientific foundation** for precision medicine
- Help identify new ways to **treat and prevent disease**
- Test whether **mobile devices**, such as phones and tablets, can encourage healthy behaviors
- Help develop the **right drug** for the **right person** at the **right dose**

WHY NOW?

The **time is right** because:

We have a greater understanding of human genes

People are more engaged in healthcare and research

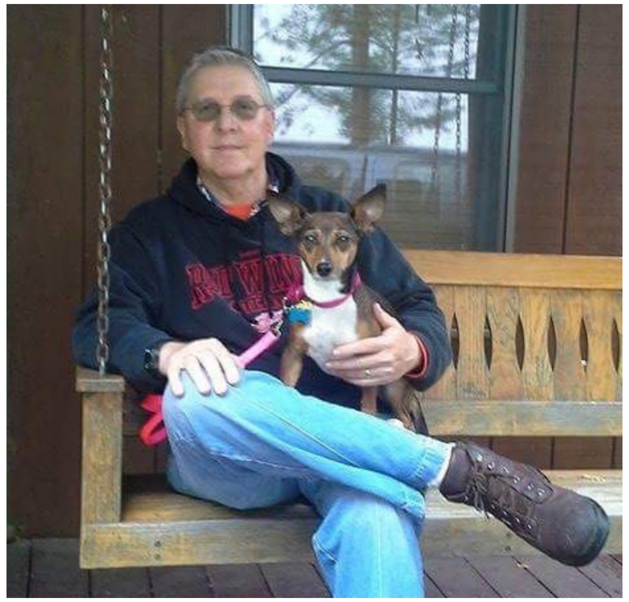
We have the tools to track health information and use large databases

Research technologies have improved

Follow the Program's progress and be one of the first to join this landmark effort.

www.nih.gov/AllofUs-Research-Program

ADVISOR SPOTLIGHT – AN INTERVIEW WITH JIM PUJDOWSKI



Jim Pujdowski, PERC Patient Advisor with his dog, Penny.

At PERC, our Patient Advisors are essential to improving patient care policies, processes, communication materials, quality improvement activities, and safety efforts. As a result, our Patient Advisors, such as Jim Pujdowski, provide invaluable feedback that has a direct impact on other patients' healthcare experiences.

Jim became an Advisor after he underwent a total knee replacement about a year ago. He decided that becoming an Advisor would help other patients understand that a total knee replacement is a feasible, and "very doable surgery". Previously, Jim had undergone several other surgeries and he wants to share this story "as a way to encourage other patients to get knee surgery, and not to hesitate, out of fear or uncertainty," as the surgery can really reduce pain, increase mobility, and improve the quality of life for many.

As a member of the Macomb PFAC Advisory Council, Jim assists in overseeing much of the literature that Henry Ford Macomb publishes for patients and the public, including the pamphlets and brochures that patients receive prior to their surgery, as well as the literature they are given to take home during recovery.

In this role, Jim has learned that there is a plethora of publications HFHS produces and he plays a vital role in pointing out instances when the literature contains verbiage and terminology that can be confusing to or easily misunderstood by patients. Jim says he "is learning to become a better editor and concentrate on every word as it relates to the topic of the brochure;" this ensures clarity and consistency when trying to communicate with patients of all different backgrounds.

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Jim's favorite part of being an Advisor is the connections he's made with the other members on the council. "Our shared experiences cover a wide range of medical issues," said Jim. Recently, Jim attended the Patient Advisor Retreat, which brought together many of the other members of the different councils from around Detroit. "This event was more engaging than I expected. The retreat presenters respected everyone's opinion and we had a great session about how to remain positive," said Jim.

Jim looks forward to becoming an even more engaged Advisor in 2017 by contributing to more meetings, participating in brainstorming sessions, and learning getting to know new members and learning about their ideas.

ANNOUNCING A NEW PATIENT & FAMILY ADVISOR COUNCIL (PFAC) AT HENRY FORD MACOMB

Henry Ford Macomb Hospital in Clinton Township

At all of Henry Ford's hospitals and medical centers, it's our pledge to treat patients as unique individuals. We promise to help and support you on your unique journey to better health by enhancing the Henry Ford care experience, rooted in compassion and empathy.

It is with this mission in mind that we are proud and excited to announce the start of Henry Ford Macomb's very own Patient and Family Advisory Council (PFAC).

"Many people including patients and community members have long-supported the initiatives at Henry Ford Macomb by attending events and making generous contributions, and now it is time that Henry Ford Macomb give back to the individuals that make up such a special community. By creating a PFAC, our patients will have the distinct opportunity to voice their opinions, express their feelings, and share their experiences with healthcare. "The main goal of starting a PFAC at Henry Ford Macomb is we, as health care providers, having a better understanding of your diverse needs for you and your family" said Debi Schroeder, the Director of Care Experience and Volunteer Services at Henry Ford Macomb, "we want to know how we can help you."

The PFAC at Macomb followed in the footsteps of the PFAC at Henry Ford Wyandotte, which has demonstrated a growing and proven track record in patient-centered care since it launched several years ago.

The Macomb PFAC team is actively taking suggestions, recording feedback, and honing in on improvements. They just hosted their third meeting and plan to meet quarterly to welcome new members and continue bringing the voice of the patient to the Hospital.

If you would like to learn more about being a Patient Advisor for the Henry Ford Macomb team, please visit the Henry Ford PERC website at: www.henryford.com/visitors/perc

FEATURED COMMUNITY GROUP: THE COVENANT HOUSE

Opening Doors for Homeless Youth

Founded in 1972, the Covenant House's mission is to help homeless kids to escape the streets. Today, it is the largest privately funded charity in the Americas providing loving care and vital services to homeless, abandoned, abused, trafficked, and exploited youth.

Each year in the U.S. alone, as many as 2 million youth experience a period of homelessness, and every year more than 5,000 of these young people lose their lives to the streets. Their hope and promise are lost forever unless they find someone – like Covenant House – to love and care for them.

The Covenant House provides homeless youth with daily necessities such as hot meals, a warm shower, and a clean bed, and also works with the kids to overcome the psychological, physical, and economic reasons for homelessness. By offering three core services known as the Continuum of Care, the Covenant House focuses on the Street Outreach, Crisis Care, and Rights of Passage. These core services are comprised of a wide array of in-house training programs, including healthcare, educational support, GED preparation, job readiness and skills training, drug abuse treatment and prevention, legal services, mental health services, the Mother/Child program, life skills training, and aftercare. These programs are designed to provide these kids with a holistic approach to leaving the streets and achieving independence.

Last year, Covenant House Street Outreach Teams and Residential and Community Service Center programs cared for over 56,000 at-risk and homeless kids in 30 cities in the United States, Canada, and Central America.

The Covenant House Michigan located in Detroit at 2959 Martin Luther King, Jr. Blvd. serves as a sanctuary for young people who have nowhere else to go. Most of these children are victims of abuse and neglect. Each year, the Detroit location Covenant House helps more than 6,000 youth who often were abandoned by their own families.

Covenant House Michigan sits on a 5.3 acre campus that houses two residential programs, a dining and recreation center, and job development center. They provide shelter and support programs to help homeless kids overcome the hurdles of unemployment, inadequate education, violence, drugs, and gangs.

Covenant House

Opening Doors for Homeless Youth

In 2005, Detroit Public Schools (DPS) authorized Covenant House Michigan to open three charter schools in order to better serve the needs of homeless and other at-risk youth who lack a high school diploma. The three schools located on the east and southwest sides of Detroit serve youth aged 16-22 and are named Covenant House Academies. They can be reached at (313) 463-2000.

In addition to its various locations, the Covenant House also operates a toll-free crisis hotline (1-800-RUNAWAY) which is available 24 hours a day, seven days week, 365 days a year, for homeless youth who don't have access to one of the sites. Every year, the crisis hotline promptly responds to tens of thousands of crisis calls from frightened youth – and many of the caring adults in their lives.

Covenant House is a leading advocate on behalf of homeless youth – those who can't speak up for themselves at local, state, national, and international levels of government. If you would like to learn more about the Covenant House or would like to make a donation to help homeless youth, please visit www.covenanthouse.org.

- ***Would you like to share your ideas on healthcare change?***
- ***Would you like to have a voice in patient-centered healthcare programs?***
- ***Do you want the opportunity to improve healthcare for the next patient?***

If you answered YES, to 1 or more of these questions, we invite you to become a

HENRY FORD PATIENT/FAMILY ADVISOR!

At Henry Ford's Patient-Engaged Research Center (PERC) patients can volunteer to serve as advisors on new programs and enhance how we deliver care. Based on your areas of interest, we have the right role for you!

OPPORTUNITIES INCLUDE:

- **Henry Ford Health System Advisor** – Serve as a representative on a hospital council or committee. You will attend meetings focused on designer or improving a new or current program, service, policy or process. *(Meeting times vary from once every 3 months to once a month)*
- **Research Advisor** – Share ideas and give feedback on projects, including patient reading materials and strategies to enroll people into studies. *(Meeting once a month to once every two months)*
- **E-Advisors through Henry Ford Insights** – Share feedback in short online surveys. Topics may include patient care experiences, communications, new services and improvement ideas, and better ways to partner with patients. *(Time commitment: about 1-2 surveys per month)*
- **Focus Group Patient Advisor** – Participate in a focus group and provide feedback on your own personal health care experience. *(One-time commitment of 1.5-2 hours per focus group)*

To learn about Henry Ford's efforts to EMPOWER their patients and how to become a patient/family advisor visit www.HenryFord.com/PatientAdvisor

Henry Ford
HEALTH SYSTEM

WHAT IS IT LIKE TO BE AN ADVISOR?

HFHS ADVISOR

As an HFHS Advisor, your voice and experience as a patient will influence the changes that are made across Henry Ford Health System to benefit other patients. As an active partner on these councils, you represent the patient voice and experience and will attend meetings with other members of the team. Telling your patient story and providing feedback on hot topics around the system are just two of the many duties of HFHS Advisors. For example, you may be placed on a Service Excellence Patient Advisory Council, focused on customer service, or serve as an Advisor to help create an After Visit Summary that is easier for the patient and their caregivers to navigate.

RESEARCH ADVISOR

As a Research Advisor, you will be asked to share your experience as a patient and share feedback on how things could be improved for the next patient. Depending on the project, you will help create surveys used in research projects or review those already created to evaluate if they make sense, are too long, or need rewording. You also may be asked to review letters sent to participants as well as give your feedback on how we can recruit more participants. The study team may ask you, how much do you think is an appropriate amount to pay someone to fill out a survey, or you may be asked to complete the survey to see how long it takes. These are just a few of the many key types of input you as a Research Advisor may be asked to provide.

E-ADVISOR (INSIGHTS COMMUNITY)

As an E-Advisor, you will be sent surveys anywhere from once a month to once every three months. At the beginning of each survey, there are pre-qualifying questions to make sure you are eligible to continue. With each eligibility survey you take, you will be entered into a sweepstakes drawing. The surveys can vary widely in content and will vary in length. For example, a survey was sent to the members of Insights Community that focused on teens and their parents and how they work together to achieve a healthy lifestyle. Teens and parents, meeting certain eligibility requirements, were asked to take 20-30 minutes to answer questions about how often they exercise together, eat dinner together and the types of lunches the teens take to school every day.

FOCUS GROUP ADVISOR

As a Focus Group Advisor, you will be a part of a group of Advisors with many different experiences and backgrounds. Whenever there is a focus group request, we will reach out to the pool to see if you are eligible to participate. For example, we just finished focus groups on how Henry Ford Hospital might be able to improve customer service, if needed, and making sure the healthcare you receive is the best it can be. Being a Focus Group Advisor is a one-time commitment although you may qualify and can participate in more than one group.

To learn about Henry Ford's efforts to EMPOWER their patients and how to become a patient/family advisor visit www.HenryFord.com/PatientAdvisor

Together, we can discover what matters to you

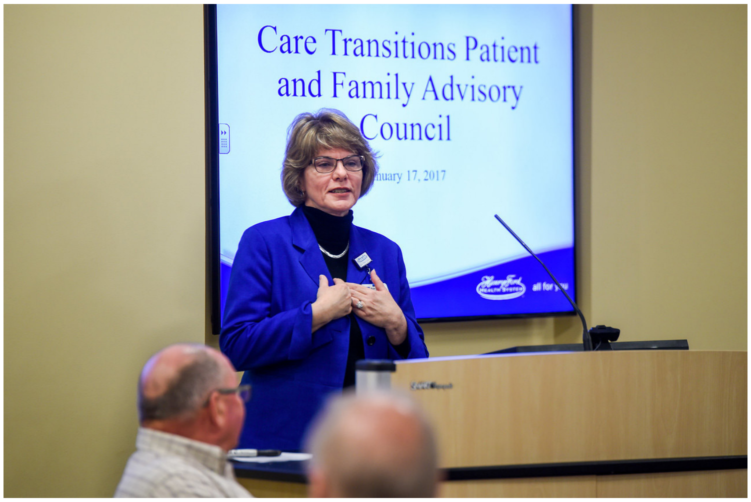
RECAP: THE 1ST ANNUAL PATIENT ADVISOR RETREAT

On January 17, 2017, the PERC team hosted its first annual Patient Advisor Retreat.

The event was attended by over 75 people, including advisors, leaders, and administrators. The event was dedicated to celebrating over 300 Patient Advisors who, over the past several years, passionately dedicated their time, ideas, and stories to helping the PERC team make positive changes in research and healthcare across HFHS.

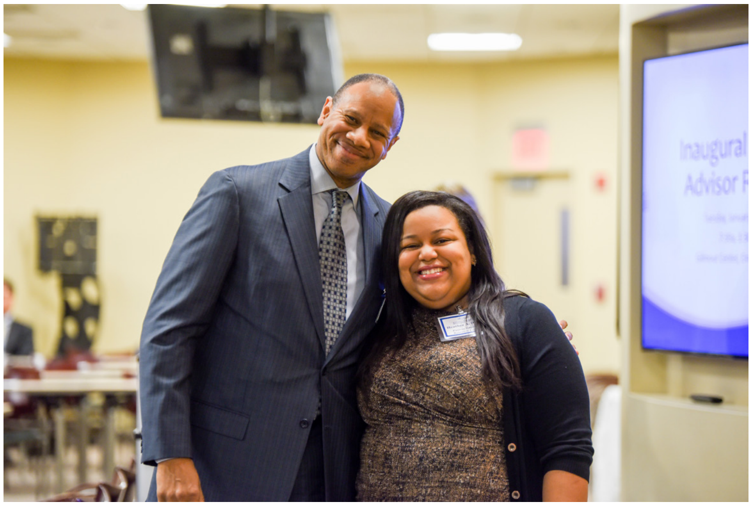
In addition to thanking and honoring all of the Advisors, the Advisor Retreat gave everyone an opportunity to join together in sharing what we have all learned – including our successes and challenges - and provide opportunities to network with other Patient Advisors. The event included skill building exercises and team building learning sessions throughout the day, with various keynote speakers, raffles, and giveaways.

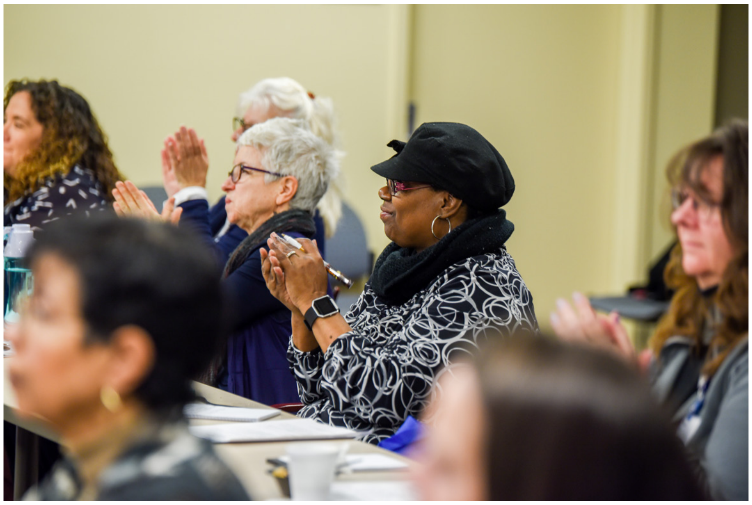
Again, we would like to sincerely thank all who attended the Advisor Retreat and those who took the time to complete the post-survey. Your opinions, ideas, and honest and candid feedback help us to improve and learn what we can do better for next year.



Karen Kippen, the Executive Director of the Patient-Engagement Research Center, speaking at the first annual Patient Advisor Retreat.

> **"I feel that it was a good retreat and I can't think of anything that would have made it better."**





Wright Lassiter III, CEO, Heather Olden (above) and Patient Advisors (right) at the 1st Annual Patient Advisor Retreat at One Ford Place.