

## What is Patient-Engagement?

Patient-engagement is at the core of the Patient Engaged Research Center (PERC). This means that PERC team members are genuinely interested in what matters to you and your family when it comes to your health. Our commitment to learning and doing what is best for you and your family, is what drives the success of this new health-care initiative.

Whether you participate through focus groups (in person or online), in-depth interviews, or as a patient and family advisor, at PERC, we believe that together, we can discover what matters to you and implement those ideas into healthcare practice to help improve your care.

Currently, the PERC team has four types of Patient and Family Advisors all of whom are interested in and available to discuss the many ways in which we can better understand your lifestyle, home, health, healthcare and community needs.

- Henry Ford Health System Advisors
- Research Advisors
- Focus Group Advisors
- E-Advisors (Henry Ford Insights Virtual Community)

Patients like you are our number one priority, which is why PERC has extensive collaboration with local community stakeholders and organizations. These strong collaborations are aligned with the same goal - to serve you and your family, and your community. PERC utilizes surveys, workshops, and interviews, to help us to understand your needs. Currently, we have four ongoing research projects utilizing advisors in the area of obesity, asthma, hysterectomy and head and neck cancer.

Several Patient and Family Advisory Councils are being formed now on the following topics including:

- Patient Service Experience
- Hysterectomy Care
- Hepatitis C Quality of Life
- Patient-Engagement Advisor
- Physician-Patient Communication (Caring Conversations)
- Hospital Discharge Care Plans

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## COMMUNITY ORGANIZATIONS

Circles of Care is an educational program offered by The Interfaith Health & Hope Coalition, a collaboration of organizations committed to the holistic well-being of the Southeast Michigan Community. Circles of Care was created to engage faith-based congregations, health systems, social service agencies and others to help develop and expand small networks that serve as partnerships in health education and wellness.



*Circle of Care luncheon meeting.*

Within a Circle of Care, organizations serve as trusted and effective forums and network opportunities for educating, counseling and encouraging the community regarding health issues. By working together, these faith-based communities in collaboration with others, can share best practices in health ministry, while at the same time promoting a more effective linkage with existing social, human and health services in faith centers, schools, clinics and primary care providers.

The Circles of Care currently partners with:

- Trinity-Health (St. Mary Mercy in Livonia),
- Oakwood Healthcare System (Western Wayne, Downriver, SW Detroit/Dearborn, Downtown Detroit (Central United Methodist; St. Aloysius, Fort St/Presbyterian, Second Baptist in Greektown and Griswold Pharmacy
- Henry Ford Health System & Tabernacle Missionary Baptist Church.

Together, these partnerships provide surveys that assess the current health and social needs of a community, give presentations on chronic disease awareness and workshops on special topics such as mental health, Medicaid/MiChild, Medicare Part D Prescription Coverage, Veterans Services and Hearing Services.

A Circle of Care is generally located in a defined geographic area with an approximate radius of three-to five miles. Pilot sites could have up to 20 inter-denominational faith-based organizations, working in close proximity with public and private health centers, as well as local human service agencies.

The American Hospital Association has highlighted the need for nonprofit hospitals and health systems to have open and honest discussions with community members regarding their needs- above and beyond the provision of medical care. That is why the Interfaith Health & Hope Coalition convened in March 2011 in collaboration with the Henry Ford Health System, Institute on Multicultural Health, to link leaders of the faith communities to representatives of health systems, community, and social and human service agencies.

*Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity. - World Health Organization*



## COMMUNITY ORGANIZATIONS (CONT.)

The partnership, called New Center/Michigan Center of Care (NCMCOC), is ideal to address unmet needs of an underserved population around Henry Ford Hospital. Beginning primarily as a group focused on information-sharing, the NCMCOC evolved into a process of strategic envisioning for a healthier neighborhood. Through a series of discussions regarding social determinants of health, including a shared viewing of the PBS documentary, “Unnatural Causes,” participants completed a strategic plan and began working on several action items, including mapping New Center/

Midtown “place” boundaries; accessing more in-depth needs assessment information for the area; and asset mapping.

If you are interested in participating in a Circle of Care or wish to establish one in your community, please contact Ron Beford, Executive Director, Interfaith Health & Hope Coalition at [rbeford@yahoo.com](mailto:rbeford@yahoo.com) or by calling 810-923-6940. If you are interested in the Circle of Care at Henry Ford Health System and Tabernacle Missionary Baptist Church, please contact Monica White 313-874-6993 or [mwhite11@hfhs.org](mailto:mwhite11@hfhs.org).

## SPOTLIGHTED INVESTIGATOR



Andrea Cassidy-Bushrow, Ph.D., MPH, is an Assistant Scientist of Epidemiology in the Department of Public Health Sciences. Her research interests include cardiovascular epidemiology and the developmental origins of cardiovascular health and disease. Dr. Cassidy-Bushrow is the Principal Investigator of the PERC project that focuses on improving how weight and weight-related (e.g. blood pressure, lipids) messages are conveyed during well-child visits.

## EVENTS RECAP

PERC’s Executive Director, Karen Kippen, along with Stephanie Ryan, Ganesa Wegienka, Ph.D., and Nancy Combs were invited to present PERC’s Innovations at Academy Health’s Annual Research Meeting (ARM) on June 15th. The interactive presentation covered the new partnerships developed in the virtual Henry Ford Insights Community ([HenryFord.com/Insights](http://HenryFord.com/Insights)), the neighborhood based partnerships, and how public health researchers are visiting patients and their families where they receive care with a program called REAL Rounding. For more than 30 years, Academy Health’s ARM has been the premier forum for health services research, where more than 2,400 attendees gather to discuss health policy implications, sharpen research methods, and network with colleagues from around the world.



## PROJECT UPDATES

***Developing Patient-Centered Approaches to Asthma Management and Weight Control*** (Christine L.M. Joseph, Ph.D., Principal Investigator)

Currently seeking Patient Advisors. If you are the parent of a child between the ages of 13-18 that has persistent asthma, is experiencing an unhealthy weight and are interested in providing feedback, please contact Heather Olden at 313-874-6031 or [holden5@hfhs.org](mailto:holden5@hfhs.org).

***Pediatric Preventative Health Screenings - Obesity and Family-Centered Outcomes*** (Andrea Cassidy-Bushrow, Ph.D., Principal Investigator)

Currently seeking Patient Advisors. If you are the parent of a child between the ages of 2-18 that is experiencing an unhealthy weight, high blood pressure, and/ or high cholesterol, and are interested in being engaged through research process from start-to-finish, please contact Andrew Bossick at 313-874-6232 or [abossic1@hfhs.org](mailto:abossic1@hfhs.org).

***Hysterectomy Surgical Approach Guidelines for Obese Women*** (Ganesa Wegienka, Ph.D., Principal Investigator)

Currently seeking Patient Advisors that have recently undergone a hysterectomy. For more information, please contact Andrew Bossick at 313-874-6232 or [abossic1@hfhs.org](mailto:abossic1@hfhs.org).

***Hepatitis C*** (Stuart Gordon, MD, Principal Investigator)

The Henry Ford Medical Group, the Department of Public Health Sciences, Henry Ford Hospital and three other nationwide health system sites are applying for a research grant to study how to improve the care of patients with chronic hepatitis C. The goal of this study

is to thoroughly understand what outcomes are most important to patients and their family members living with hepatitis C. The PERC team is inviting individuals who have personal experience with hepatitis C to become patient advisors for the proposed study.

At this point, we are still in the process of applying for the grant and are not certain whether we will receive funding to conduct the research. However, we would like to begin building our patient advisory council so that we can be prepared to begin the study, if funding is received in 2015.

To get involved or to learn more, please visit [www.henryford.com/patientadvisor](http://www.henryford.com/patientadvisor).

***Head and Neck Cancer*** (Steven Chang, MD, Principal Investigator)

PERC received its first PCORI (Patient-Centered Outcomes Research Institute) funding for a collaborative project to focus on SCOOP, which stands for Squamous cell carcinoma of the oropharynx. SCOOP is a rapidly increasing cancer. In 2012, 52,000 adults were diagnosed with head and neck cancers, comprising 3 % of all US cancers with the majority being squamous cell carcinomas. SCOOP is predicted to represent a major public health burden for decades to come. PERC's goal in this project is to create a patient advisory council of head and neck cancer survivors/caregivers to learn about patient preferences in choosing a cancer treatment (surgery vs. radiation) and whether quality of life and survivorship preferences affect the outcomes of treatment. This project will be important to understanding the short term and long term sequelae of treatment and the patient outcomes that are most critical to the patient and their families related to the survivorship experience.

## SQUAMOUS CELL CARCINOMA OF THE OROPHARYNX (SCOOP)

PERC is currently looking for SCOOP patients and their family members to participate in this newly-funded program by becoming a patient-advisors. To learn more or to become a patient advisor visit [www.henryford.com/patientadvisor](http://www.henryford.com/patientadvisor).