

EVENTS RECAP

In April, researchers from the Patient Engaged Research Center traveled to Atlanta, GA for the Health Care System Research Network (HCSRN) Conference. This conference brought together the research departments of some of the nation's best and most innovative health care systems. Collectively, the HCSRN represents more than 1,900 scientists and research staff from a variety of disciplines such as epidemiology, economics, health disparities, outcomes and quality assessment, trials, and genomics. PERC was well-represented in oral presentations, sessions and the poster presentations. Two of PERC's Team members' posters were accepted to be presented at the conference. Andrew Bossick (Project Manager for two of the four PERC research studies) presented a poster on teen's perception of weight loss messaging during well child visits and our Patient Advisor Coordinator, Heather Olden, presented a poster on the Patient Advisor Program, our accomplishments and some challenges we've faced. At the end of the conference, Heather was awarded Poster of the Year! Congratulations to you both for all your hard work!

At the end of June, Andrew Bossick presented "Weight-Related Messages in Well-Child Visits: What do Teens Desire?" at the HealthMeasures Conference in Rosemont, IL.



Heather Olden, MPH, Christine Cole-Johnson, PhD, and Andrew Bossick, MPH



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FEATURE ARTICLE: PATIENTS INSPIRING PATIENTS

For over 9 years, Beth Rubinstein has been the sounding board for hundreds of Henry Ford Patients; and as these patients share their emotionally-charged stories filled with hope, hopelessness, loss, empathy, guilt, pride, despair, compassion, and joy, Beth has been repeatedly amazed by the resilience of the human spirit and the repercussions of hard lessons learned.

Recently, Beth was invited to present her side of these stories to an esteemed group of leaders at the All Leaders Meeting on March 29, 2016, an opportunity she didn't think she would see in a million years.

As the proxy, Beth represented the experience of any and all of her fellow patients, and there is no better person than Beth to represent her fellow patients in sharing such an emotional human experience with a collective group of leaders.

At the age of 38, Beth was diagnosed with PSC, primary sclerosing cholangitis, a chronic disease that slowly damages the bile ducts in the liver. She was given a prognosis of a 3 to 5 year survival. Her mother had passed away with PSC at the age of 49, so Beth knew she was up against the clock and had no choice but to shift gears from living a wonderfully healthy life to instantly becoming a super-patient fighting for her life.

Beth's medical odyssey brought her to the Henry Ford Health System in 2001 through an unlikely vehicle, a chat room associated with a 'Minds of Medicine' television episode about split liver transplant.

She had an appointment within two weeks of seeing the TV show with Dr. Marwan Abouljoud, who kindly told her that she was not a candidate for a split liver transplant and rather than sending her on her way, he introduced her to Dr. Kimberly Brown who helped her manage her PSC and that was the moment she became a Henry Ford patient.



In 2007, the PSC was finally taking its toll and Beth's liver was failing miserably. Beth spent 3 months off and on becoming very good friends with the Henry Ford Hospital medical staff on B2, where they protected her from infection exposure, since they knew she was waiting for a lifesaving transplant. "They listened to me, wiped my tears and made me laugh despite it all. They cheered me on, soothed my soul, reassured my family and sustained me until I was wheeled into the OR and received a lifesaving organ transplant on August 27, 2007," said Beth.

But even after being the recipient of a wonderfully successful transplant, Beth needed to know what she and her family could expect in living a healthy transplant life. "There is no owner's manual for this," Beth proclaimed, and without the self-management tools or lifestyle guidance to go forth confidently, Beth was challenged by her doctor to write the owner's manual herself. And, this was the moment Beth's life changed, as she took the first step in becoming a patient advisor. To no surprise, Beth successfully wrote that owner's manual titled ACES™ with chapters for Attitude, Compliance, Exercise and Support and enlisted the help of other transplant recipients.

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ACES™ was rolled out in 2009 with support from trained and dedicated patient volunteer ambassadors.

This patient-to-patient engagement program addressed the non-medical lifestyle needs of not just transplant recipients but their caregivers and families as well within the medical environment in real time. The patient voice was literally infused into the care continuum from the moment the patient entered into the Transplant Institute. Patient education materials along with tools developed by patients were readily available within the clinic, and ACES lifestyle classes were taught by patients for patients and their families daily. The program empowered patients to become participants and have ownership in their care as teammates with their providers.

The next year, to formalize the partnership the Patient Centered Care Committee was created to foster continued collaborative patient communication, involvement, and partnership in quality improvement projects resulting with improved clinical and over all patient family experiences. Each patient and family is seen as unique and special in their own right, which today gives real meaning to our new Henry Ford promise “All For You”.

The ACES™ model is now used for other chronic diseases at Henry Ford. In addition, the concept of trained patient ambassadors has now found a new home within the Patient Engaged Research Center, PERC, in the form of trained patient advisors assigned to business units and as the foundation of several new Patient Family Advisory Councils.

We are witnessing a renaissance in health care and the doors are opening to the patient/family voice in a very different manner than in the past. We are evolving beyond the patient story and now are truly hearing the patient voices. “I have seen some amazing changes since 2007 and can only thank the health care leaders and staff champions of

Henry Ford who have been insightful enough to trust their gut instinct and give not only me but many other patients the opportunity to make a difference for fellow patients and their families by just giving them a seat at the table,” said Beth.

Beth’s vision to create a patient centered environment was realized when one highly respected surgeon, stopped to listen to an idea developed from a patient’s eye view of hundreds of other patient experiences.

Working with caring professionals who recognize the importance of having patients and families involved in all processes of healthcare and then actually make it happen is what the Henry Ford promise “All for You” is all about, creating world-class, uniquely-tailored patient experiences, one person at a time.

MYCHART HELP US UNDERSTAND YOU BETTER!

Henry Ford MyChart, an online resource and app, allows patients and families to take an even more hands-on approach to their health care. Not only can patients control their appointment scheduling, view test results and health data, communicate with doctors, and pay bills, they now have the ability to create a demographics profile. As pointed out by one of our Patient Advisors, patients are asked to provide their race, ethnicity, ethnic background, and language preferences when arriving for an appointment. To save you time, enhance your privacy we have now added the option to change and update your demographics details, under the “MyChart News for You” on the home page. We created this page so that patients like you can enter their personal information including race, ethnicity, and racial background on a home computer or mobile device. By updating this information before an appointment, patients will save time and can rest assured that their personal data is stored privately and securely within MyChart. By updating your demographics, Henry Ford Health Professionals are able to understand you better. When you provide your demographics, we listen, and are better able to provide you with the resources and tools you need to have a uniquely-tailored patient experience. We encourage you to share with us, so together, we can increase cultural competencies and health equity for all.

To fill out your demographics, please visit: www.henryford.com/mychart and click the “Preferences” tab.

Speak with a TLC Ambassador
for details at TLC@hfhs.org

Play Your “ACES”!™

Attitude
Maintain a fighting spirit and positive outlook.

Compliance
Follow doctor’s orders and take medications as prescribed.

Exercise
Walk to stay healthy as part of your regular routine.

Support Team
Develop a team of family, friends, and community.

The Transplant Living Community does not engage in the practice of medicine and under no circumstances, recommends particular treatments for specific individuals. In all cases the “TLC” recommends that patients consult their physician before pursuing any course of treatment or action concerning personal medical care.

TRANSPLANT LIVING COMMUNITY



In my current work as a coordinator and volunteer with the Transplant Living Community (TLC), I feel it is very important to bring the patient perspective to the conversation and provide ideas and input on ways to improve healthcare delivery for myself, my family, and other patients and their families. Becoming a Patient Advisor with PERC allows me to share my story as a way to give feedback that can influence the decisions that are made concerning the quality of care patients receive in the Transplant Institute, the Henry Ford Health System, and beyond. It also enables me to provide input and feedback on projects and policies that improve the care, service, and partnership for patients and families of Henry Ford. As a former patient who had a Stem Cell Transplant at Henry Ford in 2006, I have a unique perspective that I want to use to help the next patient and their caregiver.

LETTER FROM DR. JOHNSON



Christine Johnson, PhD

This spring has been full of activity at the Patient-Engaged Research Center (PERC)! One of the exciting events you can read about in this issue of the PERC Newsletter is the presentation by Beth Rubinstein of her patient story at the Henry Ford Health System All Leader Meeting. We truly value the insights and ideas of every patient and caregiver. A great patient advisor idea, from our featured Patient Advisor Chris Sims, about being able to share personal demographic information privately instead of at the medical clinic desk led to the article on how to enter your race, ethnicity and language information through MyChart. This edition's Community Organization Spotlight is on New Center Community Mental Health Services which enables patients and families to function at their fullest potential in their communities. Finally, I want to congratulate two of our young researchers, Andrew Bossick and Heather Olden, on their accomplishments at the Health Care Systems Research Network Meeting in Atlanta in April. You can read more about their work in the events recap section.

Enjoy the beautiful Michigan summer and be sure to visit our website www.henryford.com/perc for updates.

Happy Reading!

Christine Cole Johnson



NEW CENTER COMMUNITY SERVICES

Incorporated in 1979, New Center Community Services is a private, nonprofit, community mental health agency with five locations in Detroit and Highland Park, MI. These communities have a high concentration of poverty, trauma and vulnerability - all of which impact the prevalence of mental illness. Our mission is to provide and promote quality behavioral health services in a caring and safe environment. Our interdisciplinary staff including psychiatrists, social workers, nurses, psychologists, therapists and educators provides a wide range of comprehensive mental health services to over 5,500 clients annually.

New Center professionals also work with residents, businesses and community agencies to improve and enrich neighborhood life and provide informational programs to increase awareness of mental health issues. In each of its locations, New Center plays a positive role in neighborhood revitalization and works to improve the quality of community life.

Across Detroit, Highland Park, Wayne County and most recently Oakland County, New Center Community Services can help with:

- Adults with serious mental illness (SMI)
- Children and adolescents who are seriously emotionally disturbed (SED)
- Persons with co-occurring disorders
- Anyone who is experiencing a crisis that disrupts their daily lives, including stress, substance abuse, marital conflict, anxiety and depression.

New Center's staff of professionals is trained to provide group and individual therapy, counseling, and other therapeutic services. Our services are designed to enable individuals and families to function at their fullest potential in the community and to prevent recurring crises and psychiatric hospitalizations. We have a full range of comprehensive services, from the highly complex services of our Partial Hospitalization Program

and our Assertive Community Treatment to our least complex support and socialization programs such as our Supported Employment, Supported Housing and Clubhouse (Phoenix Friendship House).

Under the governance of an expert, 16-member, community-minded Board of Directors, New Center endeavors toward its vision to be the premiere behavioral health organization for consumers, staff, and the community. We strive for continuous quality improvement through efficient, effective processes and measurable performance outcomes for all consumers. We accomplish this through teamwork and collaboration while empowering consumers, staff, and the community, through our commitment to our core values of dignity, excellence, innovation, and quality. New Center Community Mental Services asks you to join us in STANDING UP FOR MENTAL HEALTH! Doing so helps reduce the stigma associated with mental illness and helps more individuals receive comprehensive treatment.

To learn more, please visit www.newcentercmhs.org/. On social media, "like" our Facebook page, www.facebook.com/newcentercmhs/ and follow us on Twitter: @NewCenterCMHS.





- *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 designing 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



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.

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