

THE POWER OF PATIENT AND FAMILY ADVISOR VOICES

The Patient Engaged Research Center (PERC) has been in existence for over four years. One of the reasons for our success and growth has been our focus on true collaboration with patients, families and health care providers. PERC also partners with regional and national organizations and stakeholders for both research grants, publications and quality improvement projects.

The group of nearly 400 highly trained and engaged patient and family advisors is unique in the nation. Our collaboration with the Henry Ford Insights Virtual Community of over 4000 members brings together a resource of thousands of meaningful stories and ideas. By acting as a catalyst for linking patients and families with health care providers and researchers, we have been able to broaden the conversation and focus on what matters to the advisors.

For example, A Kaiser Permanente researcher, Dr. Karen J. Coleman, in southern California heard about our work with the Transplant Living Community and Head and Neck Cancer advisory councils, among others, and invited us to share our Flexible Model for Engagement with their Mental Health Research Network which we did successfully in 2018. Now mental health patients and families are involved in conversations about their care and their priorities.

We are also working with the University of Maryland on a project to share our unique model nationwide, including two patient advisors, Steven Wasko and Linda Stetchinson as speakers at a symposium in Maryland in May.

Dementia has also been an area of interest to our advisors, and recently Dr. Andrea Gilmore-Bykovskiy from the University of Wisconsin-Madison asked us to host focus groups here at Henry Ford to ask PERC advisors about their experiences with family members with memory loss and strategies to reduce preventable hospitalizations.

These examples and many more were made possible by our greatest resource, each and every patient advisor voice that you selflessly share in an effort to make health care better for all.



ADVISOR SPOTLIGHT



Deidra Moody is drawing on her own experiences as a breast cancer survivor and using that wisdom to help others on their survivorship journey. She understands the struggle and the needs of cancer patients and her desire to help others is what brought Deidra to the Patient Advisor Program. She has been a valuable member of the Cancer Center Patient & Family Advisory Council

(PFAC) since 2016. The Cancer Center PFAC engages cancer patients and caregivers to provide feedback on all aspects of the new Cancer Center building and support services of the Henry Ford Cancer Institute. Deidra states that her “favorite part of participating in the council is the variety of people in the room and hearing everyone’s different opinions and feedback”. She also enjoys seeing the behind the scenes developmental process of the new facility across from Henry Ford Hospital.

Deidra created The **Remnant Cancer Support Group** because she found the more she talked about her situation the more it

healed her. Her goal is to offer a safe space for others to talk about their own situations in order to heal emotionally. She found that although everyone’s journey may differ, cancer patients usually have common experiences such as surgery, chemotherapy, or radiation treatments. This is why the Remnant group is open to all types of cancer patients and survivors. Deidra finds that her support group members bond over their similar fears and struggles and says that is the beauty of the healing process.

The list of volunteer work does not end there for Deidra. She also serves on the board of the non-profit organization Cancer Awareness and Resource Network (CARN) and is planning the Colors of Cancer Race 4 Resources, a charity run/walk for 2020 as chair for the 2nd year. This run/walk was created to raise money to assist cancer fighters and their families across the State of Michigan.

Deidra’s passion is helping cancer survivors to find a positive light in a difficult time. Her vision and personal goal is to support others on their journey and help create more structure for cancer support groups. Through being a member of the Cancer Center PFAC, facilitating her own support group every month, and helping run a non-profit organization, it is safe to say that Deidra’s wisdom and vision will continue to bring comfort to cancer patients and their families for years to come.

A WORD FROM THE PERC DIRECTOR CHRISTINE JOHNSON, PhD

2019 is quickly coming to an end and it is a great time to reflect on important patient advisor accomplishments. In this issue of the PERC Newsletter you can read about several regional and



national collaborations for engagement and research with our 400+ advisors. In the Patient Advisor Spotlight, **Deidra Moody** a patient advisor and breast cancer survivor shares her passion for volunteer work with PERC and other non-profits. Our Community Partner, The Cancer Awareness and Resource Network (CARN), led by patient advisor

Keith White, talks about his organization’s support for families who have been diagnosed with cancer as a tribute to his late wife Annette. Finally, you can find out more about recent **All of Us Research Program** events with **iHeart Radio** and **Henry Ford Optimeyes**. PERC has 25+ very active patient advisors helping to guide this precision medicine initiative. You can visit allofus@hfhs.org for more information.

Happy Reading!

Christine Cole Johnson



YOU COULD PLAY A PART IN THE NEXT BIG RESEARCH BREAKTHROUGH

The *All of Us* Research Program is bringing together one million or more people across the United States to improve precision medicine and accelerate health and research breakthroughs.

Henry Ford and the *All of Us* Research Program

Henry Ford Health System is a proud enrollment partner in the *All of Us* Research Program. This means that individuals who complete all the required steps can visit a participating Henry Ford clinic to become a full participant. This involves creating an online account, completing consent forms, taking online surveys, and

scheduling a visit for physical measurements and blood and urine collection. After completion of your visit, you'll receive a \$25 gift card.

In the fall of 2019, All of Us continued to make it easy to be a part of the program. Henry, the All of Us mobile unit headed to local businesses and events across Southeast Michigan in partnership with **iHeart Media Group, Henry Ford OptiEyes** and **Entercom Radio Stations**. Onsite enrollment took place as well as activities to learn about the program.

For more information about the program, or events near you, please visit HenryFord.com/JoinAllofUs or call **1-844-893-3908 (Option 1)**.

CANCER AWARENESS AND RESOURCE NETWORK: BUILDING PURPOSE THROUGH PAIN

In 2014, Annette White was diagnosed with Stage 3 ovarian cancer and with their 30th wedding anniversary approaching and armed with faith and patience, Annette and Keith White began their cancer fighting journey. Later in the year when Annette was two weeks post-surgery, she and Keith met a young woman recently diagnosed with cancer whose husband, after hearing the diagnosis, left her with 3 kids to raise alone. Annette, still healing from her surgery, was determined to help, and what started as an effort to raise money for a young family around the holidays, blossomed into the Cancer Awareness and Resource Network (CARN).

CARN is a 501(c)(3) not for profit organization that provides financial, emotional, spiritual, and nutritional resources for fighters, survivors, and caregivers of all cancer types. CARN's mission is to improve the health and wellbeing of communities with a concentration on families who've been diagnosed with cancer through awareness, services, and empowerment. An organization born out of helping people, in 2016 CARN hosted its first fundraising event, a "6K Race 4 Resources", and in the same year, hosted a golf outing, "Chipping Away at Cancer," and have hosted this successful fundraiser every year since. In 2016 they also hosted a "Colors of Cancer" fashion show where cancer survivors told their stories and strutted the catwalk along with cancer fighters and caregivers, donning the many colors associated with various types of cancers. CARN will host another "Colors of Cancer" fashion show in Spring 2020. After being

introduced at the inaugural fashion show, Patient Advisor Deidre Moody introduced Keith to the Patient Advisor Program. As a caregiver for his wife, Keith was interested in becoming a Patient Advisor because it enabled him to truly advocate for Annette during her care. "Everyone sees their experience differently, that doesn't make anyone else's [experience] right or wrong, just different," Keith says. As an active member of the Cancer Center Patient and Family Advisory Council, Keith credits the Patient Advisor Program for providing another level of support for him and providing a therapeutic environment.

On August 31, 2018, Keith's wife and CARN's beacon of faith, courage, and perseverance, Annette White, passed away. She leaves an immense legacy of hope and compassion for future diagnosed cancer patients. While it is difficult for Keith to talk about the passing of his wife, it's a healing process for him. "I share my story because you never know how your story can not only heal yourself, but others as well....I love what I do, but hate why I do it, because I had to lose my girl in the process." Continuing the legacy, CARN plans to continue to host fundraising events like the 6K race, golf outing and fashion show every year as they grow more in support and finances. "We raise money to give it away," Keith says with pride. December 1st, CARN will kick off it's "CAPITAL CAMPIAGN", to raise \$300,000.00 to establish "Annette's Boutique". This boutique will be an upscale store with all the latest fashions for men and women, however, "if you are a current cancer fighter, all of your clothing will be free." Keith says, reflecting on how Annette felt when she put on clothes that fit her. "There is a direct connection on how you feel based on how you look. **To learn more about CARN, visit www.carn.co .**

