

# The Talking Circle

## News and Updates

OCTOBER 2020



CENTER FOR INDIGENOUS  
CANCER RESEARCH

Cultivating Indigenous Cancer Knowledge



## CICR Director Joins COVID-19 Vaccine Expert Panel with NIH



**Rodney Haring, PhD, MSW**, CICR Director, has been named to the Native Expert Panel to support the COVID-19 Prevention Network (CoVPN) established by the National Institute of Allergy and Infectious Diseases at the National Institutes of Health. This network brings together leading research experts to help support safe and effective vaccine practices to help end the global pandemic and save lives. Specifically, the CoVPN is a new clinical trial network heading the recruitment of volunteers to sign up for trials of COVID-19 investigational vaccines. CoVPN's Native Expert Panel, comprised of a dozen Indigenous researchers, will ensure that diversity and education are part of the review of clinical trials, and that Tribal Nation to Federal Government relationships are understood and respected when discussing research ethics and pharmaceutical collaborations.

"All too often, Indigenous populations are left out of trials, so inclusion is of utmost importance. We need to learn whether the science will work in diversified communities," says Dr. Haring regarding his participation on the Native Expert Panel. To read more,

Sign up for **FREE** **EARN A \$15 GIFT CARD**  
**LOVE** Virtual Classes!

The Center for Indigenous Cancer Research  
is now offering 2 FREE Virtual Classes!



### 1. Colorectal Cancer Screening

This class includes the benefits of colorectal cancer screening, how to get screened safely, text message cancer screening reminders, and navigation to free cancer services if uninsured.

### 2. Clinical Trial Education

This class will help you to understand the basics of clinical trials and research, how to participate in clinical trials and the risks and benefits involved.

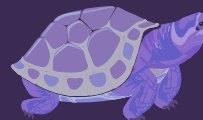
CICR's grant from the National Cancer Institute, referred to as Screen to Save, focuses on building awareness, providing resources and educating Native American and rural communities in regard to two critical topics – colorectal cancer and clinical trials. These communities experience disproportionate rates of colorectal cancer and have limited opportunities to participate in clinical trials, the only way to access the very latest cancer treatments. CICR works closely with Native communities, individual community members, families and rural partners to provide education and resources regarding cancer and the importance of clinical trials. Classes on colorectal cancer and clinical trials are now offered virtually!

Contact **Will Maybee** to set up  
an individual or group session.

TEXT OR CALL 716-225-3418

Email [William.Maybee@RoswellPark.org](mailto:William.Maybee@RoswellPark.org)





## Enhancing CICR's Community Engagement

The CICR team is collaborating with Indigenous Knowledge leaders, scholars and Roswell Park colleagues to create two new community engagement efforts – the Public Virtual Grand Round Series and the CICR Talking Circle Podcast Series.

**The Talking Circle**  
**Webinar Series**  
COMMUNITY OUTREACH ONLINE



The Public Virtual Grand Round Series is designed to inform and educate CICR's networks on CICR-related work – cancer prevention, cancer care continuum, cancer screening and more.

The first webinar on Aug. 26 featured Dean Seneca, MPH, who discussed "Health Disparities: COVID-19 and Exercising Public Health Authority." Future webinars will feature various experts who will share information and resources important to Indigenous communities.

The CICR Talking Circle Podcast Series involves brief conversations (30-minute episodes) with CICR partners and local community leaders about prevention, health and wellness that might be helpful to Indigenous community members. Topics will include discussions on mental, emotional, physical and spiritual health and wellness as they relate to seasonal changes; resource and partner highlights; and messages from emerging Indigenous leaders in the science, technology, engineering, art and mathematics (STEAM) fields. The first episode features Dr. Rodney Haring and Whitney Ann Henry introducing listeners to our work at the CICR.

Follow CICR on Facebook to receive updates and details about the Public Virtual Grand Round and Talking Circle Podcast series. To access previous webinars and podcast episodes

## September was **CHILDHOOD** Cancer Awareness Month!



**In the U.S., more than 15,00 children ages 0 to 19 are diagnosed with cancer each year.**

While there are many types of childhood cancer, the most common are leukemias and brain and spinal cord tumors. Treatments include chemotherapy/infusion, radiation therapy, surgery, bone marrow transplant, as well as experimental treatments and therapies. Due to advances in research and treatment efforts, survival has improved significantly over the last decades, and today, **more than 80% of children diagnosed with cancer in the U.S. will be cancer-free after five years.**

In Buffalo and Western New York, young cancer patients and their families benefit from the Roswell Park Oishei Children's Cancer and Blood Disorders Program, a collaboration of Roswell Park Comprehensive Cancer Center and John R. Oishei Children's Hospital. This joint effort is designed to improve medical and supportive care for children and adolescents with cancer and hematologic disorders in the Western New York region and beyond.

• Sources: American Cancer Society; American Childhood Cancer Organization; John R. Oishei Children's Hospital; Roswell Park Comprehensive Cancer Center



## How Families Cope with Pediatric Cancer



Roswell Park Comprehensive Cancer Center provides cutting-edge treatment to children with cancer and conducts ground-breaking research on pediatric cancer. An important ongoing study examines how families cope when a child in the family has cancer. This research, called the CARE Study, is led by Elizabeth Gage-Bouchard, PhD, Associate Director for Community Outreach and Engagement at Roswell Park and Associate Professor in the Department of Cancer Prevention and Control.

Having a child with cancer can be extremely stressful for families and parents must quickly adapt to the new demands of caring for a seriously ill child. Support from others can be critical for these families as they manage their child's illness and treatment. With funding from a five-year grant from the National Cancer Institute, Dr. Bouchard and her research team, Paula Vincent, PhD, Project Manager, and Hital Patel, Research Associate, are examining which types of support (emotional support, information/advice or practical help with household tasks) are most helpful to these families, and who do they turn to for this support? Parents (or primary caregivers) are asked to complete online surveys every four months for a one-year period to report on their social support, psychological health, and experiences as a cancer caregiver. Parents also participate in a study of their daily lives by completing a brief survey at the end of the day for 14 days.

The CARE Study currently has about 100 participating families and data collection will continue through 2022. Families with a child (age newborn to 18) who has been diagnosed with cancer in the past 18 months and undergoing treatment are eligible to participate.

Recruitment takes place at Roswell Park and John R. Oishei Children's Hospital in Buffalo, NY, and Golisano Children's Hospital in Rochester, NY. The CARE Study team monitors the racial/ethnic representation of participants through data collection and revisits participant recruitment and retention strategies regularly to ensure representation is maintained in the study sample. Currently, the race/ethnic breakdown of the sample largely

reflects the population of families of children undergoing treatment for cancer in Western New York, suggesting study findings should generalize to this special population.

The CARE Study staff use a variety of strategies to recruit, enroll and retain a diverse sample of participants. For example, study procedures are designed to address potential technological barriers to participation, such as a lack of a personal computer or tablet, or internet service. Staff can provide equipment (iPads/laptops) for participants to borrow or conduct the surveys by phone interviews. The surveys have also been formatted for easy use on smartphones. Study procedures remain flexible in order to facilitate participant involvement and reduce the burden of participation for these already-overburdened families. CARE Study staff work to establish and maintain rapport with families by having the same staff member interact with them over time, sending holiday cards and personalized thank you letters to the families, and maintaining a website for the study.

This research will help us understand how pediatric cancer impacts families, including parents' paid work outside the home, family finances, and parental health and well-being. Findings will help us learn which kinds of support parents and caregivers need most. We will use these findings to design programs that connect families to these supports and resources. Above all, we are so grateful to the participants who have so generously shared their experiences to help other families impacted by childhood cancer.



Elizabeth Gage-Bouchard, PhD

Please contact Project Manager **Paula Vincent** at [Paula.Vincent@RoswellPark.org](mailto:Paula.Vincent@RoswellPark.org) with any questions regarding the CARE Study.

# Dr. Michelle Huyser, Diné,

Fellow – Surgical Oncology



**Michelle Huyser, MD**, is an enrolled citizen of the Navajo Nation. She grew up in Window Rock, Arizona, the political capital of Navajo. She attended Calvin University in Grand Rapids, Michigan for her undergraduate degree in Biology. After college she worked with the Centers for American Indian and Alaska Native Health at the University of Colorado Denver as a research assistant. While working there she was involved in program evaluation of substance abuse and education programs in Alaska as well as data processing of Diabetes and Healthy Heart projects throughout the United States. She eventually moved on to the University of Minnesota in Duluth and Minneapolis to obtain her medical degree. Initially hoping to become a primary care provider for Indigenous peoples, she found her talents and interests were more in line with surgery, so then completed general surgery residency in Oakland, California, at the University of California San Francisco East Bay. While in surgery training, she completed a year of research with the Phoenix Indian Medical Center (PIMC) in Phoenix, Arizona. Her research focus included benign breast disease, breast cancer and colorectal cancer in the Arizona American Indian population. Through her cancer research work at PIMC, she became interested in cancer care within surgery and cancer disparities, specifically regarding American Indians. Thus, she decided to pursue a fellowship in surgical oncology and is now a first-year fellow, in a two-year program, at Roswell Park Comprehensive Cancer Center in surgical oncology. She is excited to continue her work in cancer disparities and cancer care with the Center for Indigenous Cancer Research at Roswell Park.

Q How have your Indigenous values inspired you to pursue a career in medicine?

A It has been an interesting process in the sense that the standard mindset for many aspiring Indigenous physicians is to enter primary care medicine because it most readily encompasses Indigenous values. Being a primary care physician allows you to form a relationship with the patient and provide care for the whole person by nurturing the individual's spiritual, emotional, environmental and physical needs. For me, I enjoy surgery because of the technical and mental aspects of it. What specifically drew me to surgical oncology is that you do get to form long term relationships with your patients and experience whole person treatment that align with Indigenous beliefs. You must treat the entire person as well as the community that plays a role in their individual well-being. I not only understand the disease process and how to treat it surgically, but also how it impacts all aspects of their lives. I feel that falls in line with how my mother and elders have taught me about Indigenous health and well-being.

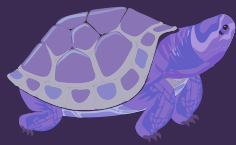


**Q** How do you balance life as a surgical oncology fellow and life outside of work?

**A** I think that is a tricky question because I am still a surgeon-in-training. I feel surgical training, in general, is all encompassing in terms of time obligations. The work schedule is very demanding, and it is difficult to get around how demanding it can be at times. I am finding out, in the month I have been in fellowship, that residency was more demanding than fellowship in terms of physical hours at the hospital. I learned most of the technical aspects of doing surgery during residency and can now focus on how to navigate very complex oncological questions and procedure planning. It has been an interesting shift and a mental challenge. But overall, time ends up being the most precious commodity that we in health professions have and that's where you learn what is important to you. For one, I have always been someone who enjoys being outdoors because I feel that it grounds me as a person. I hike when I have time off and it reminds me that no matter how big things in my profession seem, it is actually a really small part of what is happening in the world. I also maintain regular communication with my family because they too act as a grounding mechanism for me. Those would be the two main ways I spend my time and it helps to remind me that my profession is just a small part of who I am as a person and my role in the world.

**Q** How do you feel your work as a surgical oncologist will address health disparities among Native Americans?

**A** I think it is huge and something really lacking in the research literature. Cancer oncology regarding Native Americans is not well studied or even part of the discussion, especially regarding surgery. After researching at the Phoenix Indian Medical Center, I realized the databases we use to capture Native American experiences and outcomes are flawed. First, these databases often only collect information from a subset of patients, mostly in rural environments, even though most Natives now live in urban areas, so they do not demonstrate a representative sample. Second, as Indigenous peoples, we all know each Tribal Nation can be much different than others, yet we often group all Native people across the United States together as one entity. We are spread out across the country and depending on your region, each region often presents its own unique cancer challenges. In terms of surgical oncology, Native Americans do not have a clearly defined place and in many ways are non-existent. Even at Roswell Park we know there is a large Native American patient base, but it appears we never see them. This may be because we are not tracking them appropriately, we are not sure. Ultimately, my goal is to raise awareness for Native American cancer issues and for all Native Americans to receive the high quality surgical oncology care that they deserve.



# The Talking Circle

Cultivating Indigenous Cancer Knowledge



## Our Mission

The Center for Indigenous Cancer Research aims to honor the values of Indigenous Knowledge, sovereignty, and respect for the environment through community-driven partnerships, collaborative research and education to reduce the impact of cancer on Indigenous communities regionally, nationally and internationally.

## Need to Talk to Someone?

- ✓ Talk to family, friends, spiritual leaders or Indigenous medicine people. Simply expressing your fears can greatly alleviate anxiety and uncertainty.
- ✓ Reach out to your Indian Health Services Behavioral Health Team.
- ✓ Tribal and Indian Gaming Employee Assistance Programs (EAPs) by way of human resources, is a free service that can provide virtual counseling for employees and family members that reside in the same household.
- ✓ Call the Substance Abuse and Mental Health Services Administration (SAMHSA) Disaster Distress Helpline: **1-800-985-5990** or text TalkWithUs to **66746 (TTY 1-800-846-8517)**.

*Pictured from left to right: **Rodney Haring, PhD, MSW**, CICR Director; **Josie Raphaelito, MPH**, Research Project; Coordinator; **Will Maybee BS, CSCS**, Community Relations Coordinator; **Whitney Ann Henry, BS**, Research Assistant. Not pictured: **David Mattson, Jr., MD**, Director of Radiation Oncology Residency Program; **Shannon MacCallum, MBA, PhD**, Student*



Elm and Carlton Streets | Buffalo, New York 14263

**(716) 845-4541 | [CICRinfo@RoswellPark.org](mailto:CICRinfo@RoswellPark.org) | [RoswellPark.org](http://RoswellPark.org)**