



---

**CENTER FOR INDIGENOUS  
CANCER RESEARCH  
AT ROSWELL PARK  
COMPREHENSIVE CANCER CENTER**

---



In pre-colonial America, five Native Nations came together with the goal of living peacefully.

The Haudenosaunee Confederacy united the Mohawks, Oneidas, Onondagas, Cayugas, and the Senecas in a common governance known as the Great Law of Peace, administered by the Haudenosaunee Grand Council. Haudenosaunee communities in the United States and Canada today continue to reflect the tenets of the Great Law. Spirituality is foundational to Haudenosaunee culture, as is consideration for the generations to come.<sup>1</sup>

**Editor's Note:** In this edition of *Oncology Issues*, 2021-2022 Association of Community Cancer Centers President Krista Nelson, MSW, LCSW, OSW-C, FAOSW, announced her President's Theme: "Real-World Lessons from COVID-19: Driving Oncology Care Forward." One of the key lessons learned is that health equity and social justice are critical drivers of quality cancer care delivery. Although cancer incidence and mortality overall are declining in the United States, certain underserved patient populations continue to be disproportionately impacted by certain cancers. To help ensure equitable access and quality cancer care for *all* patients—regardless of race, ethnicity, age, gender identity, income level, sexual orientation, and/or geographic region—the Association of Community Cancer Centers is shining a spotlight on pioneering organizations, like Roswell Park Comprehensive Cancer Center below, that are moving the needle on health equity.

## Development of the Center for Indigenous Cancer Research

Over the course of 2020, the effects of health inequities were made evident by the unequal burden of COVID-19 on racial and ethnic minorities in the United States. The inequities exposed by the virus focused national attention on persistent health disparities, including gaps in care access and health outcomes. Although the oncology community has made progress in reducing disparities for some cancer types, racial and ethnic minority populations continue to bear a disproportionate burden from cancer. Among these are the diverse, heterogeneous, culturally distinct Indigenous peoples of this country, including Native Americans, Alaska Natives, Native Hawaiians, and Pacific Islanders. One important step toward supporting the health of Indigenous Peoples was the opening of the Center for Indigenous Cancer Research (CICR) at Roswell Park Comprehensive Cancer Center in January 2020. Its mission: to reduce the impact of cancer on Indigenous com-

Although the Haudenosaunee culture helped shape the Center for Indigenous Cancer Research and its mission, the center intends to conduct research and education that will benefit Indigenous Peoples from across the United States and around the world.



Center for Indigenous Cancer Research Staff

---

munities regionally, nationally, and internationally. The CICR mission is aligned with a foundational value of the Haudenosaunee, “the duty of preparing for the seventh generation,”<sup>1</sup> and represents the vital role of the local and regional Haudenosaunee communities.

“Roswell Park understood that it is sitting right in the original territories of many of the Native Nations of the Northeast and New York,” said Rodney Haring, PhD, MSW. Dr. Haring, director of the CICR and an enrolled member of the Seneca Nation/Beaver Clan, credits Roswell Park’s Inter-Tribal Community Advisory Board with helping to shape the center’s mission and inform its community-based participatory research model.

In a recent conversation with *Oncology Issues*, Dr. Haring was joined by CICR team members Will Maybee, BS, CSCS, community relations coordinator, member of the Seneca Nation/Turtle Clan, and radiation oncologist David Mattson, MD,

associate professor of Oncology, Department of Radiation Medicine, CICR clinical advisor. A Native Hawaiian, Dr. Mattson advises on Roswell Park’s Inter-Tribal Community Advisory Board.

“Our community advisory board was formed by looking at both our Native American urban population and different tribes in the region,” said Dr. Haring. The center team holds quarterly meetings with the community advisory board. These community members have a voice both in the process and in sharing the results of the center’s work, which focuses on relevant research and education along the continuum of cancer care from education, prevention, and screening, through treatment, survivorship, and palliative care.

“We are taught to look forward seven generations, so what we are creating [at the CICR]—we consider how that will affect our future generations. Education is part of that—for instance,



we are developing opportunities and working with Roswell Park's education team for summer research programming or internships, and we encourage post-docs to look at the opportunities that are available at Roswell Park with a forward look to what impact this will have for clinical care and research," said Dr. Haring.

Although the Haudenosaunee culture helped shape the CICR and its mission, the center intends to conduct research and education that will benefit Indigenous Peoples from across the United States and around the world. As of January 2020, the United States had 574 federally recognized Native tribes in 37 states.<sup>2</sup> About 2.9 million people, or 0.9 percent of the U.S. population, identified as American Indian or Alaska Native alone in the 2010 decennial census.<sup>3</sup> About 5 million people (1.7 percent) identified as American Indian or Alaskan Native alone or in combination with another race.<sup>3</sup> The Indian Health Service (IHS) reports providing services to 2.56 million American Indians and Alaskan Natives.<sup>2</sup> The Native Hawaiian and Pacific Islander population, which includes people with origins in Hawaii, Guam, Samoa, and other Pacific Islands, is an estimated 1.5 million and growing.<sup>4</sup>

The CICR team is made up of professionals from across disciplines who contribute their diverse skill sets to the center's initiatives. "Our current members are clinicians, surgeons, researchers, community health educators, and soon we hope to add navigators," said Will Maybee. "I think we [team members] will be integrated into nearly every aspect of Roswell Park." Drs. Haring and Mattson also sit on Roswell Park's Diversity Action Committee. In addition to Dr. Haring, Dr. Mattson, and Will Maybee, the team includes:

- Whitney Ann Henry, BS, research assistant, enrolled member Tuscarora/Deer Clan
- Josie Raphaelito, MPH, research coordinator, enrolled member Diné/Navajo Nation
- Michelle Huyser, MD, Surgical Oncology Fellow, Department of Surgical Oncology, CICR clinical advisor, enrolled member Diné/Navajo

### Sharing of Knowledge

Collaboration and the sharing of knowledge are integral to the CICR mission. These activities advance the center's goals while fostering bidirectional learning that, in turn, strengthens community engagement. Before the COVID-19 public health emergency curtailed travel, Dr. Haring and team members visited different regions of the country to present on and learn from Indigenous communities about their health concerns and research interests.

In February 2020, the team visited Arizona to conduct a tribal institutional review board training for several tribes in the Arizona and New Mexico region. The team visited nearby Native Nation communities to introduce themselves and the CICR at Roswell Park. Federal treaties and tribal governance policies differ, so there is no one standard process for creating sovereign Nation to Nation agreements, Dr. Haring notes, but such collaborations are a keystone of the center's work. "We are open to collaboration with Native Nations in the mainland U.S. and Alaska, as well as

Indigenous communities in Hawaii. We are always trying to keep the collaborative hat on for both research and team science."

One barrier to care common to many traditional Indigenous communities is geography. In Hawaii, for example, "the majority of the population is on the main island of Oahu, but the population is spread out across six major islands," said Dr. Mattson. "Among the neighbor islands there's a fair proportion of Native Hawaiians, especially in rural areas. The availability of healthcare and access to quality care on those neighbor islands is definitely disproportionately wanting compared to the main island of Oahu." For specialized cancer services, such as specialized surgery and in some instances for radiation therapy, many patients need to travel to Oahu. "So, there is that obstacle of expense that comes with travel and lodging and those costs that are harder to quantitate, like being away from family and not around the social support network they would have on their home island. Financial costs are definitely an obstacle, too, because native Hawaiian incomes are less than many other ethnicities in Hawaii."<sup>5</sup>

The 2010 Census reported that 78 percent of American Indians and Alaskan Natives live outside of tribal statistical areas; 22 percent live on reservations and other trust lands.<sup>6</sup> According to the Office of Minority Health, U.S. Department of Health and Human Services: "Typically, this urban clientele has less accessibility to hospitals, health clinics, or contract health services provided by the IHS and tribal health programs. Studies on urban American Indian and Alaska Native populations have documented a frequency of poor health and limited health care options for this group."<sup>6</sup>

As of 2017, the following states had the largest populations of American Indians and Alaskan Natives: California, Oklahoma, Arizona, Texas, New Mexico, Washington, New York, North Carolina, Florida, and Alaska.<sup>6</sup> Reservations and trust lands are often in geographically remote regions. For specialist care such as medical oncology, surgical oncology, and radiation oncology, long-distance travel is often required. Hazardous weather conditions, cost, and lack of transportation are additional barriers to care. Access to subspecialist care at a major academic medical center may be even more difficult. "We pinpointed all the NCI [National Cancer Institute]-designated cancer centers across the U.S. and overlaid on a map of all the Native Nations," said Dr. Haring. When cross-referenced with the IHS area on the map, Dr. Haring and colleagues found that many tribes in the Great Plains region are at great distances from NCI-designated cancer centers. For example, the nearest NCI-designated cancer center for Native Alaskans living in Alaska is in Seattle, Wash.

### Prioritizing Needs

Since its inception, the CICR has participated in research to identify disparities, shared research findings with affected communities, and engaged community members on how best to close the gaps. "We recently did an epidemiology-type study<sup>7</sup> looking at what the cancer mortality disparities might be in our region, and we pinpointed some of areas of concern from that data," Dr. Haring said. For both Haudenosaunee and Whites, colorectal and lung cancer were the leading causes of cancer deaths and

rates were similar. However, comparison of liver cancer mortality in the populations revealed significantly higher rates of liver cancer mortality among both Haudenosaunee men and women than in Whites and American Indian/Alaska Natives in the IHS East region.<sup>7</sup> The study also revealed disparities in liver disease, colorectal, and lung cancers. “We brought that data back to our communities and shared [the information], and [we are] creating programs around this for our communities,” Dr. Haring said. In response to the study findings, the CICR developed health promotion intervention education focused on liver disease and has brought that into the community.

---

**As cancer care advances, biomarkers are playing an increasing role in targeted therapies that require companion diagnostics. Understanding of the cultural concerns related to data sovereignty and the use of biological data for testing is important for cancer clinicians caring for Indigenous Peoples.**

---

Other areas of need are emerging. Through NCI grant-funded community-based participatory research, the center is studying the full cancer care continuum among the Haudenosaunee in its region. These communities have expressed the need for an Indigenous patient navigator to help in accessing care along the often-fragmented path from diagnosis through treatment and into survivorship. “It’s a prime example of how we take the concerns and the knowledge directly from the community and apply it to research to address gaps in healthcare,” said Will Maybee.

Another identified gap is a lack of genetic counseling. “We’ve heard this in other studies that we’ve done, too, that there have not been any Indigenous genetic counselors,” said Dr. Haring. “On the clinical side that’s probably a huge gap across cancer centers. Education [of this kind] is always key to what we do.”

### **Increasing Clinical Trial Accrual**

The cascade of events throughout 2020 has focused national attention on the effects of structural and institutional racism—both explicit and implicit. The importance of achieving greater diversity in clinical trials accrual is recognized across the healthcare enterprise.<sup>8,9</sup> The barriers to clinical trial accrual for ethnic and racial minority patients are many. “Across Native culture there are additional layers of challenges,” Dr. Mattson said. “Whether it is in identifying patients who would be eligible [for trial participation] or actually gaining the trust and the understanding of the culture in order [for them] to be comfortable enrolling these clinical trials.” Educating the communities and, especially, younger

community members is essential, added Dr. Haring. “Getting them the information to understand the importance and benefits of clinical trial participation,” agreed Dr. Mattson. “There’s more than one reason for this [lack of accrual]. Some [factors] center around the Native population, others center more around administrative processes that would aid us in identifying candidates for trials who are Indigenous Peoples.”

The CICR is developing culturally appropriate content on clinical trials and will make these materials publicly available. “It is a very polarizing topic,” Will Maybee said. “There is historical distrust of research for many reasons. One of the ways we work directly with the community is to field those concerns and start to cultivate a new narrative about clinical trials.” Even as researchers at Roswell Park, the CICR team members acknowledge, it can be challenging to identify Native Americans who may be eligible for clinical trials among the patient population. The center has already implemented an NCI-funded program, Screen to Save.<sup>10</sup> One objective of this grant is to identify Native American patients at Roswell Park and offer not only an introduction to the CICR but also to clinical trial education. Maybee explains: “This is important because ultimately that may be a conversation that patients have with their physicians or the research teams at Roswell Park. We’ve met people in our communities who were participants in clinical trials, yet prior to being a participant had minimal knowledge of what clinical trials were.”

“We’re taking this model gathered from our communities and starting to offer solutions to address gaps in cancer care, and I think that’s really our most pressing need—filling in those gaps,” Maybee added. “There are clearly some logistical gaps in terms of identifying Native American patients, and we credit that solely to the community to bring those problems into focus because we don’t always know what those problems are.”

### **Cultural Humility, Traditional Values, and Clinical Advances**

Though beliefs, customs, and cultures are distinct among Indigenous populations, a holistic (mind-body-spirit) model for well-being is found in many traditions. This holistic approach finds alignment in the 2008 Institute of Medicine consensus report, *Cancer Care for the Whole Patient*, which recognized the need to address the psychosocial effects of living with cancer.<sup>11</sup>

For example, in the Haudenosaunee tradition both male and female healers cared for the sick and fostered wellness in the community. Healing is in equal measures a spiritual process and a natural process complemented by traditional medicines and practices.<sup>1</sup> In a similarly holistic approach, traditional concepts of health for Native Hawaiians place emphasis on *lokahi*, or balance.<sup>12</sup> Wellness occurs when the physical, mental, and spiritual are united in balance.<sup>12</sup>

As cancer care advances, biomarkers are playing an increasing role in targeted therapies that require companion diagnostics. Understanding of the cultural concerns related to data sovereignty and the use of biological data for testing is important for cancer clinicians caring for Indigenous Peoples. Challenges may arise along the continuum of care: in cancer diagnosis, in shared deci-

sion making, in determining clinical trial eligibility, in conversations on palliative care, end-of-life care, and more. “In the research context, this means working with the tribal nations on what they feel is best for the community,” said Dr. Haring. “Do they need more information? What does this mean in terms of partnership from Nation to cancer center?”

### **Growth Through Understanding**

To conclude the conversation, Dr. Haring, Will Maybee, and Dr. Mattson were each invited to share a key takeaway about the CICR with *Oncology Issues*’ readers.

### **Seven Generations—A Legacy of Sustainable Change**

**Dr. Haring.** “For me it’s always the seven generations philosophy. We are honored and thankful that Roswell Park has supported our efforts, that we’ve showcased that these are some of the needs in our communities, and really put a team science approach to it at Roswell Park. We are working across disciplines and across team members not only on our campus but with our partners that are on reservations, in the cities, and across borders. Our Indigenous team is building strength on campus; however, our success is only through the collaborative efforts of our other team members at Roswell Park. In this way, we are creating this platform to be sustainable not just for my generation as a Roswell Park employee, my generation as a cancer scientist, or my generation of oncologists—we are really looking forward seven generations so our children’s children’s children have a place and a voice at the table to continue that change for wellness.”

“The Center for Indigenous Cancer Research at Roswell Park has a cancer-specific MOU [memorandum of understanding] in place with the federal Indian Health Service office. The MOU is a blueprint of sorts, and having that partnership in cancer with the Indian Health Service is important to us. It can also be important to cancer centers across the U.S. that they know what IHS clinic is in their service or catchment area and that they really connect with them.”

### **Indigenous Models of Wellness—Caring for the Whole Person**

**Will Maybee.** “The Indigenous model of wellness that encompasses everything holistically was traditionally used to complete the individual—which in turn completed the entire community. I believe those values have a direct impact on both the research as well as the value structure of our community. As it turns out, food, physical movement, mindfulness, emotional well-being, spirituality—these are of tremendous value in many different biological systems. We know that to be inherently true now. These are all values deeply embedded in most—if not all—Indigenous cultures and values. It’s important for our voices to be heard, to have a seat at the table because our traditional values can directly impact the amount of suffering that all communities endure from cancer. What I know from our communities is that these [traditional] activities, this knowledge, is still very, very strong. My belief is that ancestral knowledge combined with modern medicine holds the key to the best outcomes as it relates to the cancer burden in our communities. I believe there is a lot of untapped potential there.”



Dr. Rodney Haring




Will Maybee



Dr. David Mattson



## A New Perspective on Research Endpoints

**Dr. Mattson.** “With a holistic perspective, there are a lot of important endpoints that Western remedies do not address. Some of these endpoints aren’t things that we normally measure in Western medicine. For example, with cancer care, we measure local control of disease and survival with cancer, but there is also the quality-of-life component, the spiritual well-being. These are things that traditional remedies can address that chemotherapy or radiation therapy or surgery would not. So, it’s that holistic approach that is important, and the endpoint—striving for more holistic well-being and spiritual healing in addition to the physical healing—that is something that is important.” 

*Amanda Patton, MA, is a freelance healthcare writer. She worked as a senior writer and editor for the Association of Community Cancer Centers for more than 15 years.*

## References

1. Haudenosaunee Confederacy. About the Haudenosaunee Confederacy. Available online at: [haudenosauneeconfederacy.com](http://haudenosauneeconfederacy.com). Last accessed December 9, 2020.
2. U.S. Department of Interior, Indian Health Service. Indian Health Service fact sheet. Available online at: [ihs.gov/newsroom/factsheets/ihsprofile](http://ihs.gov/newsroom/factsheets/ihsprofile). Last accessed December 9, 2020.
3. National Congress of American Indians. Demographics. Indian Country demographics. Available online at: [ncai.org/about-tribes/demographics](http://ncai.org/about-tribes/demographics). Last accessed December 9, 2020.
4. American Cancer Society. Cancer facts & figures 2016. Special section: Cancer in Asian Americans, Native Hawaiians, and Pacific Islanders. Available online at: [cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2016/special-section-cancer-in-asian-americans-native-hawaiians-and-pacific-islanders](http://cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2016/special-section-cancer-in-asian-americans-native-hawaiians-and-pacific-islanders). Last accessed December 28, 2020.
5. U.S. Department of Health and Human Services, Office of Minority Health. Profile: Native Hawaiians/Pacific Islanders. Available online at: [minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=65](http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=65). Last accessed December 28, 2021.
6. U.S. Department of Health and Human Services, Office of Minority Health. Profile: American Indians/Native Alaskans. Available online at: [minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62](http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62). Last accessed December 28, 2021.
7. Haring RC, Jim MA, Erwin D, Kaur J, et al. Mortality disparities: a comparison with the Haudenosaunee in New York State. *Cancer Health Disparities*. 2018;2. Available online at: [pubmed.ncbi.nlm.nih.gov/31777774](https://pubmed.ncbi.nlm.nih.gov/31777774). Last accessed December 29, 2020.
8. Bierer BE, White SA, Meloney LG, Ahmed HR, et al. Achieving Diversity, Inclusion, and Equity in Clinical Research. Version 1.0. Cambridge, MA: Multi-Regional Clinical Trials Center of Brigham and Women’s Hospital and Harvard (MRCT Center); 2020. Available online at: [mrctcenter.org/diversity-in-clinical-research](http://mrctcenter.org/diversity-in-clinical-research). Last accessed April 3, 2021.
9. American Association for Cancer Research. Cancer Disparities Progress Report 2020. Available online at: [cancerprogressreport.aacr.org/disparities](http://cancerprogressreport.aacr.org/disparities). Last accessed December 29, 2020.
10. U.S. Department of Health and Human Services, National Cancer Institute. Connect with Screen to Save. Available online at: [cancer.gov/about-nci/organization/crchd/inp/screen-to-save/connect](http://cancer.gov/about-nci/organization/crchd/inp/screen-to-save/connect). Last accessed December 9, 2020.
11. Adler NE, Page AEK, eds. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press; 2008. Available online at: [nap.edu/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs](http://nap.edu/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs). Last accessed December 9, 2020.
12. Stanford School of Medicine. Ethnogeriatrics. Traditional health beliefs: Native Hawaiian values. Available online at: [geriatrics.stanford.edu/ethnomed/hawaiian\\_pacific\\_islander/fund/health\\_beliefs.html](http://geriatrics.stanford.edu/ethnomed/hawaiian_pacific_islander/fund/health_beliefs.html). Last accessed December 9, 2020.

## How Can Your Cancer Program Participate?

Suggestions from the Center for Indigenous Cancer Research Team:

**Step 1. Connect with the population of Indigenous Peoples in the communities you serve.** If no partnership exists with Native Nations, Dr. Haring suggests reaching out to the Office of the Tribal Chair or the president or chief’s office as a starting place.

**Step 2. Sign up for the Center for Indigenous Cancer Research newsletter and webinars and follow the center on social media.** The center has Indigenous-specific podcasts; Indigenous-specific, relevant virtual grand rounds; and a quarterly newsletter.

**Step 3. Share information about the Center for Indigenous Cancer Research and its outreach and education programs with your providers and patients.** “We want to make sure that our communities are aware that we have information to share,” said Dr. Haring.

**Step 4. Visit the Center for Indigenous Cancer Research website at <https://www.roswellpark.org/research/center-indigenous-cancer-research>.** Education content developed by the CICR will be available through the Native CIRCLE initiative, which is currently in progress. “Our goal is to not only share content from across our Native Nations but also to provide our audience with all the research and content that we’re creating,” Will Maybee said.