American Indian Cancer Foundation Vision and Mission

Our vision is a world where cancer is no longer the leading cause of death for American Indian and Alaska Natives. Through hard work, culturally appropriate community-based programs, and policy change that affords Native people access to the best prevention and treatment strategies we see a day where American Indian communities are free of the burdens of cancer.

Our mission is to eliminate the cancer burdens on American Indian families through education, prevention, early detection, treatment and survivor support.

Kris Rhodes, MPH, spent 10 years with the University of Minnesota’s Division of Epidemiology and Community Health conducting community health education, program evaluation and epidemiological and public health research in Native communities in the Northern Plains and Great Lakes areas before taking the leap to follow her dream. She wanted to focus on capacity building in Native communities and community based health improvement initiatives to address the burden of cancer faced by Native people. She takes pride in having recruited a strong, passionate and professional Native team with knowledge, education and expertise in serving the health needs of the Native people. Rhodes, an enrolled member of the Bad River Band of Lake Superior Chippewa was born and raised on the Fond du Lac Reservation in Minnesota. She and her team draw on the rich culture and tradition of their tribal communities to better understand and address the needs of the Native populations. The common values of American Indian and Alaskan Natives are mirrored in the core values of AICAF, they are; community-centered, respectful of tradition, advancing knowledge, native directed and empowering.

THE PUBLIC HEALTH PROBLEM

American Indians and Alaska Natives face alarming inequities in cancer incidence and mortality. Cancer incidence rates vary by tribe, region and gender, but are often much higher than in the Caucasian population.

- Cervical cancer - up to 69% higher
- Lung cancer - up to 83% higher
- Colon cancer - up to 162% higher
- Liver cancer - up to 198% higher
- Stomach cancer - up to 490% higher
- Gallbladder cancer - up to 691% higher

(Cancer, Sept 2008)
According to the Centers for Disease Control, the national percentage of adult American Indians/Alaska Natives who smoke is 21.8% vs the US average of 18.1% (CDC, 2013). The leading cause of death among AI/AN women nationally is now cancer, and lung cancer accounts for most of these cancer deaths (CDC, 2010). In Minnesota a reported 59% of American Indians are smokers (Tribal Tobacco Use Survey, 2013). Cancer is Minnesota’s leading cause of death; and for Indians, their risk of dying from lung cancer is more than two times higher than among non-Hispanic whites. According to the Minnesota Cancer Surveillance System and the Minnesota Department of Health American Indian rates of cervical and larynx cancer are four times higher.

THE PROGRAM

The American Indian Cancer Foundation (AICAF) located in Minneapolis, Minnesota currently offers its programming and services to the 54 tribes and urban Indian centers across the Northern Plains area. The AICAF efforts are expanding nationally with new partnerships and programs with tribes and urban communities in other parts of the country. The organization was established in 2010 as a collaborative effort of Dr. David Perdue, Chicksasaw Nation member and a gastroenterologist at the University of Minnesota and Jackie Dionne, Turtle Mountain Chippewa, with the Minnesota Board on Aging’s American Indian Elder Desk. They recognized the growing cancer rate among American Indians in Minnesota and specifically, colorectal cancer was a major issue in Indian communities and there was little attention being given to the issue. Starting in 2011 with a staff of three and two grants to work on colorectal cancer, the staff quickly expanded to 12 American Indian public health professionals ready to take on the ambitious plans to ensure education, prevention, early detection and treatment, and survivor support across all types of cancers across the spectrum from beginning to end of treatment was carried out in partnership with tribes across the country.

The work of the AICAF falls into three categories: the strategic partnerships and investments for American Indian cancer solutions; training and technical assistance and resource development for American Indian solutions; and a priority area around research, evaluation and evidence based data and solutions for American Indians. Each program area is critical to the success of the foundation and its work. Partnerships are key to delivering community based programs, AICAF with its limited staff would not achieve its objectives without the cooperation and collaboration of partners. The focus on training and technical assistance is to enhance the capacity of tribal groups and service providers to ensure they have the requisite skills and resources to do the job as efficiently as possible.

The third area focuses on the development of an evidence base to support American Indian solutions. The need to demonstrate American Indian cancer burden inequities is through the effective use of data. Research and evaluation develop the evidence based data which supports proposal applications to address the inequities and demonstrates effectiveness.

Part of strategic partnerships includes community engagement, AICAF works with the community to organize the Annual Powwow for Hope. Community involvement and active participation is a way to engage communities in coping with the cancer burden. Teams of community members begin fundraising efforts in advance and raised over $25,000 annually in donations, sometimes one dollar at a time. “This really engages so many people in being a real part of the solution” says Rhodes. The Powwow continues to grow
each year and it’s a way for the community to have an active role in both raising needed funds and in prioritizing and direct the funds to community needs. AICAF is working on the development of a toolkit to be made available nationally so that other communities can host their own Powwow for Hope.

Another facet of the work involves developing supports for clinical systems to enable the innovations and improvements that help ensure that all cancer related issues are addressed in an efficient and systematic way. This involves moving the emphasis from urgent care needs to one of prevention and wellness. For example in the Northern Plains where more than half of the adult population are smokers; clinics need an efficient system to not only ask about smoking but have a way to follow up and offer effective quit smoking support.

**RAISON D’ETRE**

The AICAF is a 501(c)3 non-profit organization established to address the growing cancer burden in American Indian communities and the lack of resources to address cancer and the cancer inequties faced by American Indian and Alaska Native communities. AICAF’s board members and employees are American Indian, with an array of experience serving the health needs of American Indians and Alaska Natives in the Northern Plains area.

**PROGRAM CHALLENGES**

Funding for the organization is a constant challenge but never as critical as in the first couple of years before funding started to come in. Rhodes questioned the wisdom and her ability to continue operating without funding. Relying on her personal commitment, determination, persistence, an equally committed staff and on a line-of-credit, AICAF was able to continue operations through the financially challenging times. “We were able to make it through and are in a much better place today. There are resources out there and we’re asking funders to invest in our communities and strengthen the health of our communities” says Rhodes. She sees it as an economic issue and asks businesses that have been financially successful in Indian Country to re-invest in the health of these communities.

One of the biggest challenges relates to the lack of resources beyond those specifically designated for programmatic activities. It is challenging to operate a business with little to no discretionary funds for administrative, fund raising and strategic planning expenses. To this point this obstacle has been managed by staff working harder, longer and more off-hours.

The other major challenge has been the broad mission of wanting to address all cancer needs for all tribes across the country. The organization has been successful in its programming with its focus on the Northern Plains area but expanding the reach and making the resources available to other tribes around the country is the next challenge. AICAF is in the process of addressing the issue and has recently engaged a national partnership manager in these efforts.

**ACCOMPLISHMENTS AND IMPACT**

“Wouldn’t it be great if all Indian children had as much access to fresh food as they do to cigarettes?” Too often the stores in our community sell cigarettes but not fresh fruit and vegetables. Cigarette advertising is still everywhere. Where are the ads for our indigenous foods, the foods that will heal us? AICAF is working with partners to make these changes.

Garden greens are cancer prevention. Eat up!
The number one risk factor for cancer is commercial tobacco, usually in the form of cigarettes. The AICAF is clear about this fact; tobacco is a challenging topic to address in American Indian communities. Tobacco has a huge effect on just about everything in tribal communities that make it politically charged and brings unique complexities when discussing the impacts within any given tribal community. “Tobacco has economic impacts, health impacts, and is central to our spirituality and every ceremony that we conduct. We must discuss the true impacts of tobacco on us as Native people and separate out the traditional uses from the destructive uses” says Rhodes. In this work, AICAF consults with American Indian elders and youth to guide the tobacco control work. The AICAF supports many tribal programs to develop and implement tobacco control programs and policies that are based on tribal teachings, sovereignty and self-determination. “This is how we find the solutions to the challenges faced by our communities; we reach back into the community and highlight the wisdom that is within. This is how we establish our evidence-base, what works in Indian Country is what has worked for time immemorial. The strategies that have been implemented within tribal communities by mainstream haven’t worked so well, we need to find our own solutions” states Rhodes.

Just like tobacco, the choices we make about the food we eat can make a difference in future cancer diagnoses or even cancer survival. Access to good healthy food is difficult for many American Indian people. The AICAF is committed to working with partners to better understand how this happens and how we can again use tribal teachings, sovereignty and self-determination to make sure that American Indian people have access to our own indigenous foods.

AICAF initially targeted the 54 Indian Health Service, tribal and urban Indian health clinics within the seven states of the Northern Plains area. In the first two years, 2011-2013, AICAF staff, Anne Walaszek, White Earth Ojibwe, led the efforts to conduct on-site visits with the clinical staff of 40 of the 54 sovereign nations. One of the major accomplishments according to Rhodes is “being able to support overworked and underfunded health systems with tools and education on cancer prevention and early detection to make them more effective at their jobs.”

Colorectal screening presents unique challenges for health care providers who work with American Indian patients. In a two year period, AICAF engaged the Twin Cities American Indian community to encourage and promote colorectal screening. With a small pilot grant, the AICAF Colon Cancer Screening Navigator, Joy Rivera, Haudenosaunee, convinced 200+ Native people to complete a colonoscopy. A clinician shared stories of her attempts to get her patients in for colonoscopies for several years, “then all of a sudden they’re showing up requesting colonoscopy appointments. What are you doing to get them to come in?” It was the direct result of a trusted community member talking about the ways in which colon cancer can be prevented. A colonoscopy can actually prevent colon cancer by finding polyps in the earliest stages and removing them before they cause any problems.

As an organization, AICAF has taken the position that it will not compete with tribes for limited grant funding. In funding applications AICAF either applies for funding in partnership with tribes and when seeking funds independently, AICAF will request that if tribes have an application in, AICAF will remove its application from the competition. They don’t want to take the limited resources away from tribes. “We want to be a resource to tribes and work in partnership with tribes not in competition. It’s a matter of ethics and doing the right thing “says Rhodes.
Finally, some of the biggest successes have resulted from working with community leaders to do things differently. “Tribal communities are so much more self-determined and stronger than they have ever been, and we see tribal leaders who are using sovereignty to protect the health and strength of our communities. I think it’s amazing to see our people leading in new ways” says Rhodes. She sites her staff as having a positive impact on the issue of cancer in Indian country and as contributing to this new way of thinking. “My team is an incredible bunch of people that are working really hard on behalf of Indian Country to make things better.” Rhodes takes pride in having recruited a team of native health professionals with strong science and cultural competency skills, which facilitates the rapid dissemination of evidence based programs. Cultural competency is an important facet of the AICAF approach. By focusing heavily on training and technical assistance to tribal communities, community capacity to do the job is enhanced and communities are able to sustain the programs.

Rhodes says five things that make the organization work:

• Partnerships are key to how we get things done. We don’t do anything alone; everything we do is in partnership.
• Diversity in partnerships including tribes, federal agencies, state governments, other non-profit organizations, health care institutions, and academic researchers.
• Listening to communities and understanding and valuing the wisdom that exists within communities.
• A hardworking, committed and passionate staff who truly understand American Indian communities inside and out.
• The size and infrastructure of the organization enables AICAF to be innovative, flexible and responsive to tribal needs.

CONCLUSIONS/LESSONS LEARNED

• Trust that the solutions to the challenges faced by communities are within the communities.
• Be ambitious in your goals but stay focused on what matters.

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