Introduction to SOE Special Issue

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This issue of the *Journal of Cancer Education* (JCE) features 15 articles that summarize presentations from the Eighth National Changing Patterns of Cancer in Native Communities conference that was held in Seattle Washington on September 11–14, 2010. Over 300 cancer survivors, community members, health care providers, researchers, and students gathered under the conference theme of “Strength through Tradition and Science.” The conference provided an opportunity to celebrate great progress that has been made in addressing cancer in American Indians and Alaska Natives (AIAN), utilizing both indigenous knowledge and wisdom and scientific understanding of cancer prevention, treatment, and research. While many challenges remain, looking back over the years since the first conference was held in Tucson in 1989, we can see the tremendous

change in efforts and attitudes towards addressing cancer in native communities. The goals of this conference were:

1. To provide a forum for researchers, clinicians, and providers to present and discuss critical cancer issues for native people;
2. To present updates on the unique problems of natives in the prevention, early detection, treatment, clinical trial participation, and cancer control;
3. To review ongoing cancer research activities focusing on cancer in Natives, as well as to determine future research priorities for these populations;
4. To explore common cultural and socioeconomic barriers to access or utilization of prevention programs and/or services for early detection; and
5. To publish selected papers presented at the conference so that this information can reach a wider audience.

Mayo Clinic’s “Spirit of E.A.G.L.E.S.” (SoE), a national Community Networks Program (CNP) funded by the National Cancer Institute, sponsored this triennial conference. SoE is the only CNP with a national program for outreach, research, and training specifically for American Indian and Alaska Native populations. The segment of SoE name, “E. A.G.L.E.S.,” also reflects the major goals of the network: education, advocacy, grants, leadership, elders, survivors, and scholarship.

The past decade has seen a remarkable growth in the availability of cancer surveillance data for Native Americans. The Annual Report to the Nation for 2007—a collaborative effort among the National Cancer Institute, the Centers for Disease Control and Prevention, the American Cancer Society, and the North American Association of Central Cancer Registries—featured nationwide and regional cancer surveillance statistics for American Indians and Alaskan Natives [1].

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One year later (2008), a comprehensive overview of cancer in Indian Country was published in a series of articles contained a supplement to the journal *Cancer* [2]. In this issue of JCE, Megan Hoopes and her colleagues document their ongoing activities of the Northwest Portland Area Indian Health Board to provide useful and accurate cancer statistics to native communities in the Pacific Northwest. Dr. Anne Lanier reports on the Alaska component of the Education and Research Towards Health study and documents the prevalence of numerous cancer-related risk factors in the Alaska Native study population.

Four articles offer unique perspectives on health care in Indian Country. Dr. James Hampton—the first Native American oncologist—chronicles challenges in measuring the burden of cancer in native populations. Dr. Hampton also discusses cancer advocacy that was conducted through the Network for Cancer Control Research in American Indian and Alaska Natives, work that now continues through the Spirit of Eagles Steering Committee. This conference provided the first gathering of Hampton Faculty Fellows, named in his honor. Four postdoctoral fellows are engaged with CBPR projects with AIANs across the country.

Dr. David Baines describes encounters with native healers who both inspired and influenced his practice of medicine, and reflects on the strength and wisdom he gained from those encounters. Dr. Judith Salmon Kaur—the second Native American to become an oncologist—discussed the promises and limitations of personalized medicine in the context of Indian Country. Dr. Donald Warne and colleagues review historical patterns of AIAN health care and the challenges of providing the complex care needed from prevention through end of life care specific to cancer. For many years, palliative care and hospice were not addressed in AIAN communities. The first gathering of allied health professionals seeking such training occurred as a result of our 2001 conference at Gila River, AZ. Now there is a cadre of trained specialists improving care for those individuals for whom cure is not possible.

The majority of cancers occur among older adults, and many result from risks that accrue from a lifetime of unhealthy behaviors. For this reason, it is important to reach individuals throughout their lives with clear messages about the benefits of healthy lifestyle, including proper diet and exercise, while discouraging nonceremonial use of tobacco and alcohol abuse. It is imperative that such messages be communicated to young people in a culturally acceptable way. Tobacco issues can and must be addressed within tribal communities. Michelle Montgomery and her colleagues summarize their creative use of comic books to engage young people.

Community-based participatory research (CBPR) holds promise for fostering collaboration between native communities and academic researchers to address issues of cancer control in Indian Country. Dr. Linda Burhansstipanov and her colleagues review “lessons learned” from their CBPR-based project that involved patient navigators in five native communities. In a separate article, Dr. Burhansstipanov and colleagues discuss the importance of evaluating cancer programs and present results from an online evaluation tool that was developed for this purpose.

Breast cancer is the most common cancer among women and routine mammographic screening has proven efficacious in reducing morbidity and mortality from this disease. Dr. Marilyn Roubidoux summarizes the burden of breast cancer among native populations, including low rates of screening and a disproportionate proportion of cases diagnosed with late-stage disease. Dr. Roubidoux also reviews strategies for addressing these disparities in Indian Country. Using a CBPR approach, Dr. Christine Makosky Daley and her colleagues employed focus groups to better understand the barriers to mammography and to identify opportunities for improving screening rates.

In some regions, including Alaska, California, and the Northern Plains, AIAN lung cancer incidence rates are among the highest in the USA. In these areas, tobacco control is arguably the greatest priority for cancer control. Dr. Christi Patten and her colleagues describe their CBPR-based program to foster tobacco cessation among pregnant women and children in native communities. Dr. Delight Satter examined data from the California Health Information Survey and other sources to provide an overview of the adverse consequences of tobacco abuse in California tribal communities. They also offer suggestions for cancer control to addressing this health problem.

A number of conference sessions focused on cancer survivors and issues related to quality of life. One of the outstanding changes in addressing cancer on the community level with AIAN populations has been the visibility and strength of native cancer survivors. A report by Dr. Linda Burhansstipanov and her colleagues compares quality of life outcomes between AIAN and nonnative cancer survivors. Elizabeth Warson reported results from a pilot study among AIAN cancer survivors and the benefits of art on healing, coping, and recovery. These efforts reinforced a Native American concept of wellness based on mind, body, and spirit. Conference presentations and discussions demonstrated the strength, vitality, and commitment of the many individuals and groups that are addressing cancer in native communities, giving us all hope.

Finally, while not presented as a paper in this supplement, the conference included an honoring of the life of former principle chief of the Cherokee Nation of

Oklahoma, Wilma Mankiller. Chief Mankiller succumbed to pancreatic cancer after surviving other prior cancers. She had been the keynote speaker at the triennial conference in 2001 and always spoke passionately about community empowerment and the need for AIAN patients to have access to the latest and best treatments including research clinical trials. Her family members joined us to honor that ongoing commitment to work towards better health for all of our communities.

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Conflict of Interest The authors declare that they have no conflict of interest.

References

1. Espey DK, Wu X-C, Swan J, Wiggins C, Jim M, Ward E, Wingo PA, Howe PA, Ries BA, Jemal A, Ahmed F, Cobb N, Kaur JS, Edwards BK (2007) Annual report to the nation on the status of cancer, 1975–2004, featuring cancer in American Indians and Alaska Natives. *Cancer* 110:2119–2152
2. Cobb N, Wingo PA, Edwards BK (2008) Introduction to the supplement on cancer in the American Indian and Alaska Native populations in the United States. *Cancer* 113(5 supp):1113–1116