

Statements from the President's Cancer Panel

A Dialogue Between the Yakama Nation and the President's Cancer Panel July 29-30, 2002

"When the Creator made land, everything was clean and there was no sickness. Now, we have much illness and it is making our people leave this world."

*Elsie Dick, Tribal Elder,
Yakama Nation*

On July 29-30, 2002, the Yakama Indian Nation and other American Indian Tribes of the Pacific Northwest voiced their cancer care concerns to Dr. Harold Freeman (representing the President's Cancer Panel) and called upon President Bush himself to meet with their tribal leaders one-on-one to discuss the cancer and health care needs of their people. For 2 days, health care providers, tribal members, and Indian Health Service (IHS) representatives provided testimony about cancer care issues that impact American Indians in this region. Among the tribes who spoke were the Yakama, Nez Perce, Warm Springs, Spokane, and Puyallup.

American Indians in the Pacific Northwest face barriers similar to those of other underserved populations in accessing quality cancer care. These include lack of community-based cancer care facilities and equipment, shortage of primary and specialty care providers, cultural insensitivity, inadequate education regarding early detection and screening, and geographic isolation and transportation issues. Other issues raised include the disjointed nature of the cancer care delivery system, underfunding of services, and lack of data that clearly reflect the cancer burden for American Indians in this region.

Personal health for Pacific Northwest tribes is inextricably linked to the health of the environment. The Panel heard repeatedly that the Indian people view themselves as one with the land and rely heavily on subsistence foods derived from the land-e.g., fish, roots, and berries. Salmon are deemed sacred. Information was presented that salmon and other fish are consumed by American Indians at 10 times the rate of the general population. Many believe that chemical and radioactive waste on or near reservations have contaminated traditional food sources in this region. Tribal members fear this contamination has harmed their gene pool and is the cause of their cancers. Lifestyle change recommendations are not well received: *"You cannot tell a population that depends on fish and has lived with them for eternity that they cannot eat fish. It is not an acceptable cultural solution."*

Funding and access to services through the IHS health care system is another issue unique to American Indians. One participant observed: *"There is an assumption that the IHS covers all needed care, but it doesn't."* Care is received through a combination of IHS clinic services and funds for contract services, Medicare/Medicaid, and private sources. The Panel heard that if annual appropriated funding for IHS contract health services is exhausted, patients cannot receive referrals, treatment, or medicines. As tribal budgets are depleted, services are provided only on an urgent-care basis. Compounding this problem, information was presented that those states with high concentrations of American Indians appear to have the lowest Medicare reimbursement rates.

A perceived disjointed and overburdened system of care creates other challenges. Adequate access to primary care is critical, as this is the entry point into the health care system and where, hopefully, cancer is detected early. However Dr. Quaempts, a Yakama Nation physician, testified that he currently serves 5,000 patients and that many wait 2 months or more for an appointment. A diagnosis of cancer usually requires a referral out of the IHS system for specialized care. The nearest facilities may be many miles away, and transportation costs are an issue. Rules for tribal access to care create other barriers. For instance, when tribal members migrate to urban settings or live in other tribes' areas they may lose eligibility for IHS services. The extent to which they can access other services or become eligible for private insurance was not discussed.

Outreach and education are lacking, particularly concerning prevention and early detection. In general, American Indians appear to have a low incidence of cancer but high mortality rates. Many feel it is because cancer is diagnosed too late. Joe Jay Pinkham, Secretary, Yakama General Council and cancer survivor, noted that *"going to the doctor only when feeling bad"* is not enough. *"With cancer, you want to come in before you feel bad."*

The cultural gap between the American Indian community and the community at large creates other barriers. The Indian community is not as comfortable discussing bodies, organs, or diseases such as cancer; women are particularly private. Traditional medicines, holistic treatment, and prayer are indispensable to Native people. Trust takes time to build, particularly with "outside" caregivers. However, a diagnosis of cancer may not allow time to build such trust. Also, side effects of cancer treatment may conflict with cultural norms. For example, hair loss as an effect of radiation and chemotherapy: *"This is very devastating when you have a belief or religion that requires you to have hair."* Anthony Washines, leader of the Yakama Nation, asked, *"How do we bridge the cultural gap? How do we approach holistic methods in Native American communities? How do we educate people so that we can prevent cancer before it is discovered at late stages?"*

The lack of data on cancer incidence and outcomes is a significant issue for Northwest Indian tribes. Data are scattered among state vital statistics records, HCFA records, disease-specific registries, HMO records, and private medical

practices-many of which are prone to misclassification. No available data are tribe-specific, and many tribes are distrustful of sharing data, even if they collect it. While the expansion of SEER will help provide new data for some tribal groups, it was emphasized that other methods for measuring the cancer burden are needed. One such model was presented: a "data linkage" collaboration among the Northwest Tribes, Northwest Portland Area Indian Health Board (NPAIHB), IHS, and NCI. Findings from preliminary data linkage indicate that incidence rates among American Indians/Alaska Natives may be more than double current estimates for all cancer sites combined.

Closely connected with data issues is participation in research and clinical trials. Several doctors urged Yakama tribal leaders to reconsider collaborations with universities and researchers, noting that advances are not possible without research and may not apply to the Yakama if the research is on other people.

Responding to concerns about what would come of this dialogue, Dr. Harold Freeman, member and immediate past Chair of the Panel, stated that in every journey, there is a first step. This meeting is that step. He promised to deliver the messages of the Pacific Northwest tribes, *"I can assure you we will take your story to the White House . and be persistent in telling your story."*

The President's Cancer Panel, an advisory group established by Congress to monitor the Nation's efforts to reduce the burden of cancer, reports directly to the President on delays or blockages in that effort. For more information, visit the Panel's web site at <http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp.htm>, call 301-451-9399, or e-mail to pcp-r@mail.nih.gov.