

**MEETING SUMMARY  
PRESIDENT'S CANCER PANEL**

**A DIALOGUE BETWEEN THE PRESIDENT'S CANCER PANEL  
AND THE YAKAMA NATION**

July 29–30, 2002  
Toppenish, Washington

**OVERVIEW**

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program and to report to the President on barriers to Program implementation. Throughout 2000 and 2001, the Panel held a series of seven regional meetings exploring issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection/diagnosis, treatment, rehabilitation, and palliative and end-of-life care—to people in the diverse neighborhoods of the nation. Yakama tribal elder Joe Jay Pinkham spoke before the Panel in February 2001 at the regional meeting held in Los Angeles, California. As a result of his experience, Mr. Pinkham invited the Panel to hold a meeting at the Yakama Nation in Toppenish, Washington, to hear about the issues and barriers affecting cancer care for Native Americans in his community.

**MEETING PARTICIPANTS**

**President's Cancer Panel**

Harold P. Freeman, M.D.

**National Cancer Institute**

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel

**Speakers**

Batin Family, Community Representatives, Yakama Nation

Thomas Becker, M.D., Ph.D., Acting Chair, Department of Public Health and Preventive Medicine, Oregon Health and Science University

Louise Billy, Community Representative, Yakama Nation

Rhonda Billy, Community Representative, Yakama Nation

Thomas Boyd, M.D., Medical Oncology and Hematology, Yakima Regional Cancer Care Center

Raymond Colfax, Member, Tribal Council, Yakama Nation

Ruth Jensen, Representative, Northwest Tribal Cancer Control Project, Northwest Portland Area Indian Health Board

Russell Jim, Environmental Waste Management Committee, Yakama Nation

Michael Painter, M.D., J.D., Chief of Medical Staff, Seattle Indian Health Board

Ann Penn-Charles, Representative, Hoh Tribal Center

Joe Jay Pinkham, Secretary, General Council, Yakama Nation

Rex Quaempts, M.D., Physician, Yakama Nation

Dee Robertson, M.D., M.P.H., Special Advisor to the Director, Northwest Tribal Epidemiology Center, Northwest Portland Area Indian Health Board

Catherine Samson, Community Representative, Yakama Nation

Mathew Tomaskin, Chairman, Health, Employment, and Welfare Committee, Yakama Nation

Chris Walsh, B.S.N., R.N., Environmental Public Health Nurse Project Manager  
Contaminated Subsistence Fish Project, IHS  
Anthony Washines, Chairman, General Council, Yakama Nation

**JULY 29, 2002**

**WELCOME AND OPENING CEREMONY—MR. ANTHONY WASHINES**

- Mr. Anthony Washines, Chair, General Council, Yakama Nation, opened the meeting proceedings. He welcomed friends, relatives, and honored Panel guests and, in the manner of his people, sang a song of religious significance, a prayer of his people.

**OPENING REMARKS—DR. HAROLD P. FREEMAN, MEMBER, PRESIDENT’S  
CANCER PANEL**

- Dr. Harold Freeman, Member, President’s Cancer Panel, proceeded with some brief opening remarks. On behalf of the President’s Cancer Panel, he thanked Mr. Washines for welcoming the Panel and its support staff team to the Yakama Nation. He noted that the Panel was honored to be working with Mr. Joe Jay Pinkham of the Yakama Nation and appreciated the opportunity to hear about cancer issues in this region.
- Dr. Freeman emphasized that the purpose of the meeting was to raise questions and hear about the particular issues Native Americans in this region face in receiving cancer care services. He noted that the Panel may not have immediate answers to the questions raised but would work in its role as an advisory panel to the President to bring these issues to the attention of the White House.
- Dr. Freeman encouraged all present to provide testimony, either during the meeting or in writing.
- Dr. Freeman proceeded to give the audience a brief history of the Panel and his role as Member and Chair of the Panel for more than 11 years. He recounted the series of regional meetings held by the Panel in 2000 and 2001 during which the Panel heard testimony from nearly 400 individuals representing all 50 states and territories of America about barriers that prevent people from receiving timely and effective cancer care services. He noted that one of the speakers was Mr. Joe Jay Pinkham of the Yakama Nation and that this meeting was a result of Mr. Pinkham’s testimony and invitation.
- Dr. Freeman stated that he hoped to learn more about obstacles American Indians face in accessing cancer care services and, in particular, the relationship of the Yakama tribe to the Indian Health Service. He also stated that he hoped to hear about success stories in providing for community health care needs.
- It was pointed out that discussions generated in the meeting will form the basis of a report and video summarizing the issues heard and providing recommendations for improving local care and translating findings to other American Indian tribes. The report and findings will be delivered to the President of the United States and to Congress.
- In compliance with Federal statutes and regulations, an official statement was read into the record by Dr. Freeman.
- State and congressional representatives attending the meeting were acknowledged and welcomed by Dr. Freeman, including Richard Krikava, attending on behalf of Senator Gordon H. Smith, Oregon; Carl See, attending on behalf of Senator Maria Cantwell, Washington; and Ramie Haas, attending on behalf of Congressman Doc Hastings, Washington State, Yakima District.
- Ms. Haas provided brief remarks on behalf of Congressman Hastings, commending the efforts of the President’s Cancer Panel and Yakama Nation for organizing the event to better

understand the challenges those with cancer face and facilitating discussions about how to meet those challenges and improve the quality of life for those with cancer and their families.

## **PRESENTATION HIGHLIGHTS**

### **MR. JOE JAY PINKHAM**

- Mr. Joe Jay Pinkham, Secretary, Yakama Nation General Council, provided an overview of the Yakama Nation and Northwest tribes invited to this event. He noted that in his travels throughout the Northwest, people talked about the laws of their state, the laws of their people, and the health of their people, but no one talked about cancer. This prompted him to first speak to the Panel about cancer—including his own diagnosis—at the regional meeting in Los Angeles, California.
- Mr. Pinkham said that he had asked other Northwest tribes, including the Nez Perce, Warm Springs, tribes from Alaska, and others, to speak about cancer at this meeting.
- Mr. Pinkham stated that a big problem on the Yakama reservation is finding out where the “cancer doctor” is. He expressed the hope that one day the Yakama Nation would have a cancer doctor within the Indian Health Service to treat its people rather than have to travel to another town.

### **MR. FRED IKE**

- Mr. Fred Ike, Sr., Vice Chairman, Yakama Nation Tribal Council, provided remarks about his diagnosis of cancer and subsequent treatment. He noted that it was devastating to lose his long hair as a result of chemotherapy, especially since his beliefs and religion require him to have long hair. He also noted his belief in prayers and the positive effect of praying for oneself with other people.

### **MR. MATHEW TOMASKIN**

- Mr. Mathew Tomaskin, Chairman of the Health, Employment, and Welfare Committee, welcomed the Panel and visitors from other Indian nations, both local and from afar.
- Mr. Tomaskin expressed hope that the Panel would learn about the needs that exist in Indian country and take these messages back to the President.

## **DISCUSSION—MR. PINKHAM, MR. IKE, MR. TOMASKIN**

- Tom Lang, a cancer survivor, asked the Panel if it was only listening to testimony or also looking for answers to problems faced by Native tribes from Florida to Alaska. Dr. Freeman responded that the Panel intended to do both.
- Patricia Martin, a member of the Yakama Nation, asked what could be done to address the needs of children and young adults who are getting cancer—specifically, how to educate children about cancer prevention. Dr. Freeman responded that this was an important point and that while most who die from cancer are elderly, things that take place that may lead to cancer occur much earlier in life. Thus, education about cancer should begin when people are very young. He noted that one of the questions he hoped the meeting participants could help the Panel understand was what must be done to educate the young people in American Indian country to know about cancer, to talk about it, to communicate about it, and to prevent it from occurring.
- Mr. Pinkham noted how difficult it had been for him to get people to come to this meeting to talk about cancer and to seek treatment and that many wanted to “tough it out at home” instead.

- Mr. Washines remarked that one of the barriers that exist in the American Indian community is a cultural gap. Many of the impacted populations are reluctant to discuss or come forward and talk about issues they have to deal with, particularly cancer. There is also a reliance on holistic health and healing that, when misunderstood, creates another barrier. He asked, “How do we cross the cultural gap and how do we approach holistic methodologies in the Native American community?” He supported the concept of education as one way to bridge gaps so that people will know and understand that they can prevent cancer rather than try to address it only after it has been discovered.
- Mr. Washines asked that veterans’ issues be addressed during the meeting, noting that there were a number of Vietnam veterans among tribal members who had been subjected to chemicals such as Agent Orange.
- Stella Washines expressed appreciation to the Panel and the Yakama Nation leadership for facilitating this meeting. She pointed out that coming to the meeting was a very big step for a lot of her people, since it is not within their cultural realm to talk about these kinds of issues.
- Ms. Washines mentioned that there are difficulties with collecting data on Native Americans; thus, data suggesting that they have the lowest incidence of cancer may not be accurate. Dr. Freeman acknowledged this point, noting that one of the recommendations from this meeting could be to look at how data on the Native American population are collected and reported.

#### **OVERVIEW OF CANCER CONCERNS—DR. REX QUAEMPTS**

- Dr. Quaempts expressed his honor at being asked by Mr. Pinkham and the General Council to voice his concerns regarding cancer care and noted that he is a member of the Yakama Nation and a board-certified family physician employed by the Indian Health Service.
- A significant barrier to cancer care, and care in general, is access to the local clinic in Yakima. Budget restraints have frozen hiring of new physicians and nurses. The staff at the Yakima clinic cares for approximately 22,000 people: 6,500 Yakama, 7,000 from other tribes, and 7,000 descendants. Only four of five physicians take appointments, leaving approximately 5,000 patients per physician.
- Physicians cannot prevent cancer when they cannot keep up with the number of patients who need primary care—or when people delay diagnosis and treatment because they must wait 2 months for an appointment. If Native Americans have a higher mortality rate from cancer, it is most likely because they are not screened and diagnosed early enough.
- Budget issues and lack of physicians have created barriers to screening. Flexible sigmoidoscopy to screen for colon cancer has been discontinued due to lack of staffing. According to year 2000 data, for approximately 5,000 women who should have received Pap smears, only 1,100 Pap smears were performed. Colposcopy is no longer provided, because staff are not available to perform the procedure, and mammogram services were recently halted for 10 months due to lack of Contract Care funds.
- One request to the Panel is to increase health care funding for Native Americans.
- Treatment of patients diagnosed with cancer is very difficult as well. Often, patients are diagnosed and then referred outside the reservation with no primary care physician to help them navigate the medical system. They are left to face overwhelming issues and often do not receive appropriate follow-up care.

- It is important for the Yakama people to participate in research in order to learn more about cancer and better treat and cure this disease. The chairmen and other leaders of the Northwest tribes were urged to open dialogues with universities and the Panel to learn more about this disease in the Native American community.

#### **ACCESS ISSUES SPECIFIC TO NATIVE AMERICANS—DR. THOMAS BOYD**

- One issue is that accurate figures on incidence of cancer for the Yakama Nation are not available. There is likely underreporting based on inaccurate identification of Native Americans.
- System problems in providing care apply to primary as well as specialty care.
- In comparing the incidence of cancer across the United States for the year 2001, with local data derived from the tumor registry for both Memorial and Providence Hospitals, it appears that local cancer incidence levels are consistent with those of the rest of the population. However, there seems to be a higher-than-expected incidence of breast cancer compared with the general population. However, the local data set is small, making it difficult to reach any conclusions.
- Challenges to cancer care for the Yakama Nation include a rural health care system, physician undersupply, problems with Medicare and Medicaid payments to physicians working in rural areas, geography, social and cultural issues, and poverty.
- Physicians in rural areas face unique problems whether or not the area is a designated tribal area. For example, for every \$2 Medicare spends for physician health care services, \$1.05 is spent in larger, urban communities, and approximately 92 cents goes to rural communities. Thus, there is a significant economic disincentive for individual physicians to practice in rural settings. This has been an ongoing issue with Medicare and other payers.
- Geography is a considerable issue. The Yakama Indian Nation covers a large area. Some clinics are up to 60 miles away, so transportation, especially in winter, becomes a significant hurdle to receiving appropriate care.
- Adequate access to primary care is critical. Without adequate primary care, a patient cannot move on through any of the other health care systems in Yakima or other communities.
- The costs of providing specialty care are high. When the expenses of specialty practice are higher than the potential reimbursement the private physician can receive, there is a disincentive to provide care for certain groups of patients. This creates another barrier in terms of access to specialty care. In the state of Washington, for example, Medicare and Medicaid patients have been “abandoned” in some communities because the cost of providing certain kinds of care exceeds physician reimbursement.
- Access to clinical trials is critical. Advances are not possible without research trials, and research trials conducted with others may or may not apply to the Yakama Nation and other Indian people. There are a variety of clinical trials ongoing at the Yakima Regional Cancer Care Center, including those sponsored through the Southwest Oncology Group and NSABP, as well as the STAR study and sponsored (pharmaceutical) trials.
- The STAR study is a breast cancer prevention trial involving 200 sites, and the Cancer Care Center is one of 5 private practices around the country selected to participate. So far, locally, 45 women have been placed on medication through the STAR study; 4 (close to 10 percent) of these are Native American. Nationally, only 48 Native American women have been placed on the study—one-twelfth from the Yakama tribe. There may be as many as 50 to 100

women eligible for this study among the Yakama Nation. More needs to be done to get Native Americans to participate so that information from this study used to make decisions for future generations is appropriately representative of the Yakama people.

- Physician undersupply is another barrier to access. Rural areas across the country face this problem for a variety of reasons, some of them purely economic. Other reasons include quality of life, or lack thereof, due to heavy patient load, physician burnout, and lack of access to other specialists needed to provide quality care.
- There are also reimbursement issues unique to rural areas relating not just to reimbursement of physician costs, but also to how states are reimbursed. Medicare allocates certain funding on a per capita basis: based on the number of people in a particular region. Differences can be striking. More populous states in the East and Southeast receive the most in terms of amount spent per patient. Near the bottom of the list are states that could be associated with large Native American populations—i.e., New Mexico, Oregon, and Washington. Challenges faced in rural areas are amplified because fewer dollars are allocated for patient services.
- One point regarding social and cultural barriers to access is that trust has to be established no matter who the provider is, and this can take time; however, cancer does not always allow the time to develop that trust. Having a system integrated with cancer care specialists could provide an advantage in terms of establishing trust as quickly as possible so appropriate interventions can be made.
- Individuals also perceive their risks very differently, even when presented with the same information under identical circumstances. Unless it is understood how people perceive their risks or individual social circumstances, it can be very difficult to explain appropriate treatment options.
- Recommendations to the Panel include recognizing the increased costs of rural health care; encouraging the local and private medical communities to participate in areas of rural health care; having adequate access to primary care; providing specialty care contracts consistent with the real cost of providing that care; doing a better job of coordinating care—for example, working harder to encourage women to participate in efforts like the STAR study; continuing to encourage participation in research; and trying to obtain accurate information on the costs of cancer care as well as the incidence of cancer.

## **DISCUSSION—DRS. BOYD AND QUAEMPTS**

- In response to a question regarding enrollment in clinical trials, Dr. Boyd encouraged audience members to contact Dr. Quaempts.
- Dr. Boyd was asked if it is possible for those living in remote areas to participate in clinical research. In response, he agreed that this was a challenge. Clinical research has been performed in Yakima for 12 to 13 years, jointly between two hospitals. However, similar resources are often not available in remote areas, requiring creativity on the part of individual health care providers and tribes. Access to clinical trials in this setting is an important issue.
- Mr. Russell Jim pointed out that the Yakama Nation is proximate to the oldest and largest nuclear facility in the United States—Hanford—and the Yakama people wonder how chronic radioisotope exposure may have affected their gene pool. He asked for a better understanding of why indigenous people such as the Yakama are more susceptible to cancer and what the Panel intended to do regarding these issues. In response, Dr. Freeman clarified that the Panel is an advisory committee that holds hearings and collects testimony, but it does not have the



power to implement its recommendations. However, recommendations of the Panel will be communicated to the President and Congress.

- Ms. Julia Davis Wheeler, of the Nez Perce Tribe in Idaho, supported Dr. Quaempts' point that tribal councils need to endorse tribal participation in research that addresses leading causes of disease among Native American people. The importance of prevention and education was also noted; research must be done, but in concert with outreach efforts. For example, Ms. Wheeler said she was unaware that there was a familial connection with breast cancer until a friend was diagnosed, or that one could be tested for genetic predisposition to breast cancer. As a member of a fishing tribe, she reiterated her concern over contaminants in the Columbia River. While a study by the Columbia River Inter-Tribal Fish Commission reported minimal amounts of dioxins in salmon, concern and fear over contamination persist.

### **CANCER ISSUES FACING NATIVE AMERICAN COMMUNITIES: AN EPIDEMIOLOGICAL PERSPECTIVE—DRS. DEE ROBERTSON AND THOMAS BECKER**

- Dr. Robertson stated that he works for the Northwest Portland Area Indian Health Board (NPAIHB) and, specifically, for a project entitled the Northwest Tribal Epidemiology Center (referred to as the "EpiCenter"). His co-presenter, Dr. Becker, is a consulting medical epidemiologist for this project.
- Background information was provided on the Health Board. It is a regional organization, tribally operated, and has been in existence for 28 years. Its goal is to improve the health and quality of life of the federally recognized tribes in the Northwest. It does this by providing advocacy, technical assistance, and other member support services. The NPAIHB has allowed the Northwest tribes to speak with a unified voice.
- There are multiple ongoing projects performed by the EpiCenter. Examples include tracking clinical performance measures among tribes; collecting standardized health information data; training people on the Resource and Patient Management System (RPMS), which collects data from Indian Health Service programs nationally and from most Indian health care programs in the Portland area; operating the Western Tribal Diabetes Project; operating the Northwest Tribal Behavioral Risk Factor Survey Surveillance System (BRFSS) project; maintaining the IHS-sponsored Indian Community Health Profile; managing the Northwest Tribal Health Research Center, an NIH-funded Native American Research Center for Health; and others.
- The Portland Area Institutional Review Board (IRB) is also coordinated through NPAIHB. The IRB includes members from IHS, the Federal sector, and NPAIHB; all cancer research among the Northwest Tribes that has Federal involvement must be approved by this IRB. The IRB reviews proposed research and is diligent in approving only research that is both scientifically sound and culturally sensitive.
- The core operating budget (excluding funded projects) for staff and operations at the NPAIHB is approximately \$78,000 per year.
- The Northwest Tribal Registry Project was described in detail. This is an effort to identify and eliminate health disparities among Native Americans. It addresses the need to: (1) determine who the Indian people are; (2) accurately measure their health; and (3) measure health in a manner that will provide useful data to inform effective programs and interventions.

- There is much existing data on Northwest Indian people: the RPMS, state vital statistics records, Health Care Financing Administration payment system, disease-specific registries, state cancer registries, HMO data sets, and private practices, to name a few. However, most data sets do not have racial identifiers, and those that do are frequently inaccurate. The exception is the RPMS, which is local and identifies Indians and non-Indians.
- Tribes understand the need for accurate data to inform their programs but do not have access. The Northwest Tribal Registry, a tribal system containing demographic information only—name, date of birth, and Social Security number—is linked to state cancer registries in Washington, Oregon, and Idaho. The Registry has been a unique collaboration among tribes, the tribal organization that operates it, the regional Indian Health Service, and its funding source, the National Cancer Institute. The goal is to improve cancer rate information as a result of the linkage.
- Dr. Becker introduced himself and provided an example of data linkages that can be performed using the Tribal Registry Project. In terms of cancer incidence in Northwestern American Indian and Alaskan Native people, rates nearly doubled after data linkage.
- Critical messages include: (1) data linkage is an efficient and effective way to improve the accuracy of cancer rate estimates for American Indians and Alaska Natives; (2) cancer incidence rates increase substantially following data linkage through the Tribal Registry Project; and (3) similar annual linkages will allow the EpiCenter to follow trends in cancer occurrence, helping to measure the effectiveness of ongoing programs and interventions as well as design more effective interventions.
- Specific methods used to perform data linkages were presented to the Panel and examples provided of how data are matched and compared. The software used can process millions of data matches within seconds and is very accurate and powerful.
- There are nearly 140,000 American Indian/Alaska Native (AI/AN) people in the Tribal Registry. Before performing data linkage, participating state cancer registries identified 739 AI/AN cases. Following data linkage, 895 cases were identified. Of the original 739 cases, only 472 would have appeared in both the state cancer registry and the Northwest Tribal roster; 266 were not included in the Northwest Tribal roster but appeared in state registries. Thus, for analytical purposes, the number of cancer cases in this population that would otherwise have been identified nearly doubled.
- The rates for preventable cancers also show substantial room for improvement, highlighting the need for improved screening and early detection.
- Limitations of the current project are the availability of only 4 years' worth of data and that the Tribal Registry does not include all AI/ANs in the Northwest; only those using IHS or Indian Health Clinics are included, excluding urban Indians and those using private practitioners.

## **DISCUSSION—DRS. ROBERTSON AND BECKER**

- Denise Brennan, an outreach coordinator for the Port Angeles, Washington, Breast and Cervical Health Program, emphasized the need not just for research, but to provide needed services in underserved Native American communities. She related her experiences as an outreach coordinator and the difficulty in obtaining funding to provide clinical services, such as annual exams and screenings.

- Dr. Robertson commended Ms. Brennan’s advocacy and noted that representatives from the Indian Health Board and Northwest Tribal Epidemiology Center have visited the communities she referred to and understand the issues she has raised. He stated that provision of direct services is a separate issue from research, however, and he believes much progress has been made by the IHS and other programs in improving cancer screening and immunization rates.
- Dr. Freeman cautioned against putting research funding in a contest with the health delivery system. Health delivery, he noted, costs more than a trillion dollars a year, and the issue is one of distribution—how to allocate and spend that money on services that benefit all people—not one of reducing funding to research programs.

#### **NORTHWEST TRIBAL CANCER CONTROL PROJECT—MS. RUTH JENSEN**

- The Northwest Tribal Cancer Control Project began in December 1998 as a Cooperative Agreement with the Centers for Disease Control and Prevention under its Comprehensive Cancer Control Program. Its immediate goal is to reduce cancer incidence, morbidity, and mortality for AI/ANs in Northwest tribal communities by taking an integrated and coordinated approach to cancer control. A 20-year comprehensive cancer control plan has been developed to achieve this goal.
- The Project, in looking towards the future, recognizes that the next generation of cancer researchers must be trained. A partnership with the Fred Hutchinson Cancer Research Center has enabled AI/AN high school students to access the Hutchinson laboratory.
- Many challenges face AI/AN communities, and there are barriers to optimal screening, diagnosis, and treatment. Tribal communities are collaborating with cancer control partners to institute change.
- Specific issues being addressed include racial misclassification, patterns of care, lack of knowledge about the sovereignty of Indian nations, and the myth of total health care coverage for all AI/ANs.
- Undercounting due to racial misclassification is an issue because it impacts how resources are allocated; this, in turn, affects the level of health resources available to tribes. A recommendation to the Panel was to advocate for policy change to collect and provide accurate data.
- Patterns of care may be different for Indian people. For example, because of the long-distance travel required to receive specialty care, specialists might offer not lumpectomy but, rather, mastectomy for a breast cancer diagnosis. Ms. Jensen asked that the Panel help support efforts to overcome the barriers of economics and distance and ensure that all communities receive the highest standard of cancer care.
- Lack of understanding about the sovereignty of Indian nations has implications in terms of allocation of resources. There is also a perception that all AI/AN health care needs are already provided for; this is not true. When contract health service funding, budgeted by IHS, is exhausted, people diagnosed with cancer cannot get needed referrals, medications, or treatment. So, an important need is for the Panel to support the DHHS budget for contract health service funding as allocated through the IHS.

## **REPRESENTATIVES OF YAKAMA SURVIVOR SUPPORT GROUP—MS. RHONDA AND MS. LOUISE BILLY, THE BATIN FAMILY, MS. CATHERINE SAMSON**

- Ms. Rhonda Billy related her experience as a cancer patient and survivor, having twice been diagnosed with a brain tumor. She related that she is a 54-year-old, college-educated grandmother and worked as a counselor for the tribal court system before her diagnosis. At the time she was diagnosed, physicians stated that her tumor was 2 years old and the size of a softball. It has since recurred as more than one tumor. She feels the most difficult part is the impact on her family and spouse. They do not seem to want to hear about her illness or discuss planning a funeral. She also noted that she misses working and has tried to apply for jobs but receives no phone calls in return. Her biggest prayer is to see a change in her community, to have guidance, and to receive help.
- Ms. Elana Batin spoke on behalf of her family, which is part of the local cancer support group within the Yakama Nation. Although not a cancer survivor herself, her older and younger sisters are breast cancer survivors, and her 21-year-old daughter has trophoblastic disease, a rare cancer. Her recommendation to patients is to seek a second opinion if that seems reasonable—she had encouraged her sisters to seek second opinions about appropriate treatment for their breast cancers.
- Ms. Batin expressed concern that screening guidelines recommend mammograms after 40. Her sisters were diagnosed in their thirties, and she wondered, had they had mammograms, would their cancers have been detected earlier. Her family was recommended for genetic testing for breast cancer, but the cost was prohibitive. Other financial issues have created challenges. While they get basic medical care on the reservation through IHS, they must be referred elsewhere for more extensive care. Her sisters had to drive to Yakima every week for radiation, but no reimbursement for gas was available. Her daughter had to enroll in a clinical trial in Seattle.
- A recommendation is that those affected by cancer participate in support groups. Cancer is a private issue and difficult to speak about, particularly with those who do not have cancer.
- Ms. Catherine Samson, a breast cancer survivor, spoke about her cancer. She discovered a breast lump and was diagnosed with infiltrating ductal carcinoma. She had a radical mastectomy. Her initial reaction was that she had done something wrong. She had had regular physical exams and kept track of her health. She noted that she had many questions but did not ask her surgeon in Yakima. The medical terms used by the surgeon were very technical, and she did not understand them. Her gynecologist answered many of her questions following her surgery and explained the treatment process. She was told that the probable cause of her cancer was use of Premarin following a hysterectomy.
- Ms. Samson related to the Panel that one of her daughters has been diagnosed with breast cancer, and her 15-year-old granddaughter has had a precancerous tumor removed from her cervix. This has made her wonder which of her family members will be next and whether they will have to go through what she has gone through.
- During her illness, she spoke little of her cancer and kept her feelings to herself, even though she experienced fear and pain. At the invitation of her daughter, she attended a conference in Scottsdale, Arizona, coordinated on behalf of Native American cancer survivors; this was the first time she spoke of her deepest feelings: her lack of knowledge about the disease and fear whether she would die or survive. It was the first time she said she was a cancer survivor. The meeting gave her strength.

- There is a need for Native American people to have a counselor or an oncology nurse—someone who can meet with newly diagnosed patients and explain the procedures and treatments.
- Ms. Samson relayed what she has been told by those who study human behavior—that there are three elements that build human personality: heredity, environment, and personal response. She remarked that she cannot do much about heredity, and she is not going to move from her environment, leaving her with personal response. Her personal response, she said, is that people with knowledge and ability need to work with Native Americans to detect cancer early. The high cost of medication, surgery, and hospitals is a hardship for her people.
- Ms. Samson left the Panel with words from a traditional healer that have helped her: “The Creator gives us everything, good and bad. Sometimes we question why and do not understand why, but we must treasure this gift, take care of it, and take special care of the gift of your body that the Creator has given you.”

#### **DISCUSSION—YAKAMA SURVIVOR SUPPORT GROUP**

- Contact information was provided by Ms. Brennan for the Susan G. Komen Foundation, which is a good source of information on breast cancer prevention.
- Dr. Freeman thanked the participants for sharing their stories and opened the floor to other audience members who had a story to share with the Panel.
- Ms. Ann Penn-Charles introduced herself as a community health representative for the Hoh River tribe. Her grandmother and mother-in-law both had cancer. Issues they faced were the distance to treatment and lack of education about their disease and treatment options. Advocates and community health representatives are needed to assist and educate people. Ms. Penn-Charles recommended more caregiver workshops and support groups. Those caring for loved ones with cancer are often deeply affected.
- System barriers exist. Ms. Penn-Charles mentioned that if a tribal member is living in a different service area, he or she can receive only direct care through IHS and cannot receive a treatment referral. More funding for services is needed; many people wait on referral lists. It may also take 6 months to apply for and receive Medicaid, during which time cancer continues to spread. Ms. Penn-Charles asked the Panel to take these messages to tribal leaders, politicians, and President Bush.

#### **STORIES FROM TRIBAL REPRESENTATIVES**

- Dorothy George, a member of the Warm Springs tribe, spoke about her diagnosis of ovarian cancer. She was in remission for 2 years, but her cancer returned. She believes that alcohol use caused her cancer. She must travel 60 miles for treatment. Money is always an issue. She is trying to create a “cancer house” near the treatment facility for patients to use while in treatment, rather than have to travel back and forth. She is holding fundraisers for this purpose.
- Tina Kalama-Aguilar also spoke from the Warm Springs Tribe. Her father died of a brain tumor. She is a best friend to “Pebbles” (Ms. George), who was repeatedly told her cancer symptoms were a virus or constipation and was repeatedly sent home. Only as a result of her persistence was she diagnosed with stomach cancer. Physicians need to treat people as individuals and not make assumptions about people because they are Native American. People know when their bodies hurt and something is wrong.

- Geneva Charley spoke next from the Warm Springs. She is a community health information specialist, charter member of the Women's Health Promotion Coalition, and involved with the Northwest Cancer Control Project. Ms. Charley raised the issue of access. Warm Springs is 60 miles from the nearest specialized health care delivery system. Transportation is difficult and can be expensive.
- Screening and early detection is another important issue. Ms. Charley believes the reason Native American incidence rates are low, but mortality rates are high is that people are not catching their cancers early enough. People need to understand that cancer must be caught early, and the best way to do that is to increase awareness and provide education. There are good models for doing this.
- Lack of accurate data is another problem. The only data Warm Springs has come from ambulatory patient care records. These are raw data and not shared consistently with tribal counterparts by the Indian Health Service unit. The tribe used to issue a yearly health status report, but this was discontinued in the 1990s. In order to have an informed community, however, it is imperative to know about health trends. Better data are needed to produce good leaders, good decision makers, good advocates, good educators, and good consumers.
- Ms. Charley recommended increasing emphasis in Native American communities on health promotion, disease prevention, and prevention education, because it is important for people to learn that lifestyles and environmental issues play a role in the causes of disease and death.
- Janice Clements, Chair of the Warm Springs Health and Welfare Committee, spoke about her husband's diagnosis of prostate cancer. She said that hearing the word *cancer* was like a death sentence for him. They traveled 60 miles each day to receive specialized cancer treatment. He is doing well now but does not have the same energy. She has tried to support him, and members from the tribe have called to speak with him about his cancer, but it is not something he will talk about. Ms. Clements emphasized the need to address not just women's health issues, but men's health issues as well.
- Ms. Clements also pointed out that Indian Health Service budgets are cut each year, and the tribes are told to get alternate insurance and Medicaid and/or Medicare. She noted they did not sign a treaty for Medicaid or Medicare or alternate resources.
- Patricia Ike, a member of the Yakama tribe, spoke about her diagnosis of breast cancer. Transportation was a big challenge. She needed radiation 5 days a week for 6 weeks; there was no reimbursement for these costs. She used all of her insurance coverage and was told to apply for welfare; this was very difficult. She has also suffered secondary medical problems and wonders if they are a result of her radiation and chemotherapy treatments.
- Ms. Ike closed with the point that people in her community need to change their lifestyles: modify their diets, and stop drinking, smoking, and using drugs.
- Ms. Anita Pimm Swan spoke on behalf of her husband, Tom Swan, who was first diagnosed with bladder cancer at the age of 43; she described his treatment. He has been cancer-free for more than 4 years. Tom's mother died of lung cancer, even though she was a nonsmoker. Ms. Swan said that she herself was diagnosed in January 2000 with breast cancer and had a total mastectomy. During this time, she and her husband had to take care of each other while continuing as caretakers for other family members.
- Ms. Swan pointed out that she and her husband have private insurance but that no one advocated for them or explained what they were going to go through. It is vitally important, she recommended, for someone to explain to newly diagnosed patients exactly what kind of

cancer they have, what they will be going through, what the treatment will be like, and what the costs will be, including transportation. She received no counseling, no psychological support, and no assistance for transportation. One year following her surgery, a “mentor” from the Yakima Wellness House called her with information that she should have been provided a year earlier. Somehow, she feels, when Yakima’s non-Indian community provides services, Native Americans fall through the cracks.

**CLOSING REMARKS—DR. HAROLD P. FREEMAN**

- Dr. Freeman thanked all community representatives and speakers for their moving testimony.
- He reiterated that the problems outlined in the meeting would not be solved instantly, but that every journey begins with a step. The Panel is listening seriously to the testimony provided, and he assured participants that he would take their story to the White House, the President, and policy makers and be persistent in telling their story.

**CLOSING CEREMONY—MR. JOE JAY PINKHAM**

- Mr. Pinkham concluded the day’s events with a ceremony in the native Yakama language.

**JULY 30, 2002**

**INVOCATION—MR. FRED IKE**

- Mr. Ike welcomed guests from Washington, DC, and others attending the meeting. He sang a prayer song and spoke a few words in his native tongue before turning the meeting over to Mr. Anthony Washines, Chair and General Counsel, Yakama Nation.

**WELCOME AND OPENING CEREMONY—MR. ANTHONY WASHINES**

- Mr. Washines spoke a few words in his native tongue and welcomed meeting participants, including those visiting from other tribes. He expressed enthusiasm for the opportunity to discuss an epidemic that has touched the Yakama reservation and develop ideas that can be incorporated into a national strategic plan.
- As on the first day, Mr. Washines stated, participants would hear firsthand stories describing issues such as access to care, funding problems, cultural differences, and other barriers that face the populations of rural areas. Economic issues prevent rural areas from investing in technology that big cities take for granted.
- When members of the Yakama community need an MRI or another screening procedure, they must travel to the city of Yakima. There they are often confronted with bureaucratic barriers. Many are uncomfortable seeing doctors they do not know and who may not understand their culture. Training more Native Americans in the medical field is important.
- Mr. Washines encouraged the Panel to continue to push for ways to provide better access to care for rural communities. He expressed his gratitude to the Panel for visiting his community.

**SUMMARY OF DAY 1—DR. HAROLD FREEMAN**

- Dr. Freeman thanked Mr. Washines, Mr. Ike, and Mr. Joe Jay Pinkham for their hospitality. He reviewed the meeting's first day, focusing on his impressions of the remarks made by the various speakers.
- What the Panel will take away from this meeting, Dr. Freeman said, is not scientific discoveries but the information received from the hearts and memories of the people.
- Many asked what the Panel planned to do with the information gathered during this meeting. Dr. Freeman explained that this meeting takes place in the context of other activities focused on learning about health disparities. He noted that in his 12 years on the Panel, a number of reports have been produced, and he believes that they have had some influence in creating change. While he could not promise results, he promised that testimony from this meeting would get a serious hearing at the highest level of Government.

**PRESENTATION HIGHLIGHTS**

**SOCIAL BARRIERS TO CANCER CARE—MS. KAY MAPLES**

- Ms. Maples is a social worker at the North Star Cancer Center in Yakima. In her previous position as a field director for the American Cancer Society, she traveled through the region and met many people with cancer.
- Ms. Maples explained that her perspective on barriers to cancer care is local, not global. The barriers she has seen are educational, cultural, financial, and psychological, in addition to other issues. Psychological barriers include stigmatization and the fear that one caused one's



own cancer. Access issues include lack of transportation, shortages of basic resources, inadequate insurance coverage, and language barriers. Family support issues include fear of the unknown, anxiety caused by facing health care challenges on top of other complications of life, and problems of family members faced with the responsibility of being caregivers.

- Members of the community are consumers and have choices they may not be aware of. Service providers sometimes assume that when information has been provided, consumers will use it.
- Lack of access to health care affects not only individuals, but also families and the community at large. Without access to care, people suffer with chronic or deadly diseases, become disabled, and become burdens on their spouses, partners, families, employers, and society in general. Early detection can help prevent undue physical, psychological, and financial hardships.
- Long waits for appointments increase distrust in physicians, and delay encourages denial about disease. When people retreat into isolation, problems become worse, and recovery becomes less likely.
- Many Native American veterans feel disenfranchised. They return from service with post-traumatic stress disorder, drug and alcohol dependence, and service-related illness or injury. They find after discharge that access to care is fragmented and the system is insensitive to their distress.
- Local cancer prevention, education, and screening efforts are uneven. Collaborative efforts to provide services are increasing, but they are infrequently scheduled and poorly attended.
- System barriers include the wait to see a primary care physician, the search for specialists, and a longer wait for insurance coverage. Sometimes patients sign agreements to pay for their own treatment, even when they know they will not be able to pay. This contributes to a sense of powerlessness and stigmatization.
- In her social work practice, Ms. Maples spends 75 percent of her time trying to find money and resources for clients and helping them fight for access to state-of-the-art cancer care. However, many people are not aware of available social services that can guide them through the system.
- Positive developments in the community include a rural transportation project to bring patients to clinics; volunteer chore services to do things like building ramps for disabled people; and services provided by case managers and community health nurses.

#### **URBAN INDIAN ISSUES: AN OVERVIEW FROM THE SEATTLE INDIAN HEALTH BOARD—DR. MICHAEL PAINTER**

- Dr. Painter, a physician at the Seattle Indian Health Board, stated that according to some estimates, 50 to 60 percent of the American Indian population lives in urban settings, but they are often excluded from registries and studies focusing on Indian populations. Some urban American Indians live in cities, while others travel back and forth between cities and reservations.
- Historical factors that have influenced urbanization of the population include the end of mandatory reservation living, acquisition of U.S. citizenship, reservation economic issues, specific Federal relocation policies, and the Civil Rights movement.
- Many people believe that diseases such as HIV and AIDS are not a problem in American Indian communities because the numbers are small, but the numbers reported may

misrepresent the problem. A number of studies focusing on urban Indians have shown that this population is doing badly in almost every disease category, including cancer.

- The Seattle Urban Indian Health Program is a network that includes a number of urban Indian clinics. The Program has also established the Urban Indian Health Institute, which conducts research on urban Indians. The Program functions as a community health center that serves everyone and relies on patients to self-identify as American Indians, rather than rely on blood quantum or paperwork to determine eligibility.
- The Program's mission differs from that of a tribal or IHS clinic because it addresses the needs of a diverse group of AI/AN people who come from many different communities and cultures. Resources include outpatient medical, dental, mental health, and substance abuse treatment services, as well as inpatient alcohol and substance abuse treatment. As a Breast and Cervical Health Program (BCHP) participant, the Program provides onsite mammography. A BCHP nurse helps locate women and get them to the clinic for screening. The Program relies on Medicare and Medicaid for specialty referrals. Social workers help patients find funds to pay for services provided outside the clinic.
- Statistics presented show that the cancer burden among American Indian and Alaska Native (AI/AN) populations in the state of Washington is higher than the national average; the disparity is probably even greater, since the figures for AI/AN populations are likely underestimated. This includes higher incidence rates, higher death rates, and lower survival rates. American Indian women who have breast cancer are diagnosed later than other women in the United States.
- Compared with other populations in King County, Washington, more AI/ANs live below the poverty level. They have greater unmet insurance and financial needs than other populations, are at higher risk for chronic disease, and have a lower life expectancy, higher mortality rates, and lower utilization of screening.
- No difference has been found in health disparities between urban and rural Indian populations. Urban Indians, like their rural counterparts, tend to prefer traditional to Western medicine.
- Some published data indicate that even if screening were increased and smoking reduced in the Indian population, disparities would not be eliminated. Policies and interventions that focus on individual risk behaviors have limited potential to reduce disparities.
- Disconnection of urban Indians from their traditional culture and relationships is a possible explanation for loss of optimism and heightened levels of anger and stress.
- Policy makers at all levels tend to rely on national databases that have significant limitations, such as racial misclassification, undercounting, coding errors, and inability to reach conclusions on some questions because of the small numbers of individuals in certain geographic areas.
- Dr. Painter wondered why the urban American Indian population is not represented in the Northwest Tribal Registry.

## **DISCUSSION**

- Ms. Amber Flammig, a 14-year-old who lived in Seattle for several years and recently moved back to the Yakima Valley, addressed the Panel. She described her emotions on hearing the stories of cancer patients, survivors, and family members during Day 1 of the meeting. and expressed her respect for the elders of the Yakama Nation.

- Mr. Bob Brisbois, a cancer survivor from the Spokane tribe in northeastern Washington, made a statement about environmental health. The Spokane tribe is bordered by the Spokane River, which is contaminated with PCBs, lead, and other substances, and the Columbia River, which is contaminated with dioxins and other substances.
- There are two uranium mines on the Spokane reservation: the Midnite Mine, an Environmental Protection Agency (EPA) Superfund site that is contaminating a 1,500-acre basin that feeds into the Spokane River, and the Sherwood Mill, which has been closed and reclaimed as close to pristine as possible—which is not very close. The reservation also has a history of being a “downwinder” tribe, eating fish, animals, and plants affected by contaminants originating at the Hanford nuclear facility.
- The Spokane used to be a fishing tribe like the Nez Perce and Yakama. After the Grand Coulee Dam was built, there was no access to salmon fishing. The only salmon, other than those raised in tribal hatcheries, are excess salmon distributed by the state of Washington. The tribes, Mr. Brisbois noted, appear at the end of the list of recipients, after landfills and dumps.
- The tribe recently met with EPA officials and learned that it will now be treated the same as the rest of the state in terms of water quality. Previously, the state of Idaho and the city of Spokane did not recognize the tribe as having an interest in environmental cleanup, stating instead that contamination stopped before it reached the reservation. This was a political answer, not a scientific one. Tribal members who have advanced scientific degrees have said that contaminants that flow into the Spokane and Columbia Rivers are affecting all of the tribes in the Northwest.
- An EPA scientist told the tribe that anyone who eats 100 pounds of fish from the Columbia River is at risk of a shortened lifespan. This kind of information, Mr. Brisbois argued, has gone unpublished to conceal the fact that the Government’s responsibility to the Indian people has been neglected. The Spokane tribe has high rates of leukemia, lupus, thyroid disease, and other conditions associated with the contaminants to which they are exposed.
- The Spokane tribe, he continued, is funded at about 35 percent of its needs in health care. Nationally, the budget for Indian health is about \$2 billion, compared with an estimated needs-based budget of \$18 billion.
- The 185,000-acre Spokane reservation was created in 1881. The tribe is still fighting with its trustees to keep some of that land clean for the future of the tribe’s children. Tribal members, as well as the plants and animals the tribe depends on, live in contaminated basins along the contaminated Spokane and Columbia Rivers and among the contaminated streams that feed into them.
- The tribe has conducted many studies, Mr. Brisbois said, and knows a lot about the origins of contaminants on the reservation. He suggested that the Spokane tribe is a good potential population for further research.
- Another problem of the Spokane tribe is related to urban health care. The tribe serves an urban population in the city of Spokane; there are as many as 10,000 Indians in Spokane, and about 2,000 use the tribe’s clinic. Patients whose problems are not life-threatening are put on waiting lists.
- Ms. Jeannie Bailey, a cancer survivor, said she first heard of the President’s Cancer Panel 3 weeks before the meeting. Since the Panel has existed for 30 years, she asked what it had done for people with cancer and what the outcome of this meeting would be.

- Dr. Freeman responded by placing the work of the Panel into the larger context of the National Cancer Program. The first aspect of that program extends from basic research to clinical trials to cancer control research and research that helps translate knowledge to benefit patients and communities. The second aspect of the National Cancer Program involves delivery of care.
- The Panel has written a report about the disconnect between the research and service delivery aspects of the National Cancer Program. Research discoveries have not been applied to all American people, irrespective of who they are—race, tribe, or economic status. The Panel tries to speak to this entire spectrum of issues, whereas the research community addresses only research issues. The Panel has tried to show the nation that there is a need to bridge the gap between discovery and delivery. The problems causing the disconnect between the \$5 billion research capacity and the trillion-dollar health care system, Dr. Freeman suggested, exist primarily on the delivery side.
- The Panel is an advisory group and does not have funding to implement programs, but it can point out problems that exist.

### **COLUMBIA RIVER RESEARCH PROJECT—MS. CHRISTINE WALSH**

- Ms. Walsh reported that she started out as an R.N. at the Yakama Clinic and now works as a public health nurse and environmental health nurse.
- It is difficult for outsiders to understand the relationship between fish and the tribes along the Columbia River. Many religious and cultural practices are centered on salmon. In addition, good scientific management of fishing resources by the Yakama, Nez Perce, Umatilla, and Warm Springs tribes has benefited non-Indian fishermen. A 1955 treaty guaranteed the right to take fish at “all usual and accustomed places.”
- An EPA study in 1989 found that the fish in the Columbia River were contaminated with dioxins. However, the samples taken by the EPA were too small, and samples were not collected at traditional fishing sites. Therefore, the EPA study did not produce the kind of data needed to determine the health risks associated with this contamination.
- The Columbia River Inter-Tribal Fish Commission developed a fish consumption survey. It was learned that adult tribal members consumed an average of 62.3 grams per day, which is 10 times the average for the general population. For many, fish is the sole source of protein.
- A fish contamination survey was conducted by the Commission and the EPA at the sites at which Yakama tribal members collected fish, and the results were made available to the tribes about 2 years ago. Contamination was found to be widespread throughout the Columbia River system, at levels similar to those at other sites at which remedial actions are already being taken. The sources of contamination are local, regional, and global, and restoration and protection of fisheries will not be easy to accomplish.
- No uncontaminated fish were found. Contaminants of concern included polychlorinated biphenyls, aeroclor, dioxins, furans, and various pesticides (including DDT, which was banned 20 years ago).
- The total cancer risk for all chemicals combined was estimated by the EPA to be about 1 in 1,000. The risk level is much higher for tribal members than for the general population—including sport fishermen who visit the area—because of their much greater consumption of fish. Regulatory action has often been taken in other areas when the risk exceeded 1 in 1 million.

- Noncancer risks, such as neurobehavioral problems, reproductive health issues, and organ damage, were also elevated among tribal members.
- Recently, the fisheries program received a grant from the National Institute of Environmental Health Sciences (NIEHS) to develop risk communication methods. Three videos have been produced to educate health care providers at the IHS clinic and their patients about contamination issues.
- The Yakama Nation hopes to establish an environmental health advisory committee and an institutional review board (IRB) to ensure that research conducted in the area is designed to benefit the tribe. The tribe also seeks to strengthen its relationships with university researchers and is already working with the Oregon Health and Science University (OHSU).
- Ms. Walsh has received an NCI training grant to collect baseline data on cancer in the Yakama Nation through chart reviews at the clinic. Her work will also provide quality assurance in monitoring the accuracy of cancer diagnosis at the clinic. Linkages will be established with cancer registries in Washington, Oregon, and Idaho.
- Ms. Walsh pointed out that due to lack of resources, the clinic is providing only urgent care. This means that chronic illnesses such as cancer are not adequately managed. The clinic needs an oncologist, a radiologist, and mammography equipment.

#### **ENVIRONMENTAL WASTE MANAGEMENT ISSUES—MR. RUSSELL JIM**

- Mr. Jim stressed that the effort to prevent cancer is as important as the effort to discover a cure. Cancer can be thought of as a symptom of modern times rather than an unavoidable disease.
- For untold generations, indigenous peoples have sustained themselves using natural foods and medicines while respecting the importance of even the smallest environmental factors that affect their lives.
- In his work as a board member of the Center for World Indigenous Studies, Mr. Jim reported, he has learned that indigenous people around the world are beginning to relearn the importance of natural foods and medicines. It is important that these natural resources are not contaminated.
- The dominant Euro-American culture has radically transformed the natural world through its agricultural, forestry, and mining practices; the negative effects of these activities include production of toxic waste, global climate change, species extinction, and disease epidemics.
- Mr. Jim expressed concern that the current administration appears to view global warming and species extinction as inevitable events that the world should adapt to rather than prevent. The EPA, which recently lowered the limits for arsenic in drinking water only in response to public pressure, has not done enough to regulate environmental chemicals.
- The 1 in 50 risk of developing cancer among Indian people who eat fish according to their dietary needs would not be accepted in other parts of the country. The EPA has stated that risk can be reduced by reducing the amount of fish consumed, but this is not a viable option for Indian people, who need fish to sustain their culture and health. They should not be required to assimilate into mainstream culture to avoid this risk.
- Mr. Jim asked the Panel to convey the message that the Federal Government has a trust responsibility to protect tribal natural resources. The right of the Yakama people to fish, hunt, and gather food is protected by treaty.

- A problem that may be even greater than toxic chemicals is radioactive waste produced by the Hanford nuclear site on the Columbia River. Over almost half a century, this facility produced 74 tons of plutonium 239, one of the most hazardous materials in existence, with a half-life of 24,000 years. One microscopic speck can cause cancer if inhaled.
- Hanford has the country's greatest inventory of high-level radioactive waste, with more than 53 million gallons stored in leaking tanks; more than a million gallons have escaped into the soil and groundwater.
- In 1996, a number of people, including several Yakama members, filed a lawsuit against Hanford's contractors for harm to their health from the facility's operations. A Federal judge dismissed the case, which was returned to the same court by the Ninth Circuit Court of Appeals. The tribe hopes that scientific evidence overlooked by the original judge may now be heard. Although the nuclear industry tends to minimize the dangers associated with radiation, the Ninth Circuit Court of Appeals has ruled that there is no safe threshold for ionizing radiation.
- Mr. Jim expressed concern that millions of dollars have been spent on what he described as questionable studies (e.g., the Hanford Environmental Dose Reconstruction Project) that appear to be intended to limit Government responsibility for health effects caused by the Hanford facility.
- Soon, the Department of Energy (DOE) will release its new strategy for restoring the damaged environment at Hanford. To save the cost of removing radioactive waste, the plan involves creating a "sacrifice zone" of Yakama Nation-ceded land near the Columbia River to permanently dispose of the waste. Since environmental laws do not allow disposal of long-lived radioactive waste near the surface, the DOE is relabeling the materials at Hanford as "incidental waste." The Yakama Nation has filed suit to block this strategy. The DOE has also sought to nullify Yakama rights by citing "compelling interest" to restrict access to ancestral land.
- Environmental justice, Mr. Jim stressed, requires restoration of the environment so that the Yakama people are exposed to risks no greater than those of any other citizens.
- Mr. Jim asked that the President communicate one-on-one with the leader of the Yakama Nation to address these issues.

## DISCUSSION

- Ms. Denise Brennan stated that she works for a women's health clinic in Port Angeles, Washington. The clinic operates a breast and cervical cancer screening program that serves many low-income women. She reviewed barriers that women in northwest Washington experience.
- Distance is an important barrier to access to care; related issues include lack of childcare, telephone service, and electricity.
- Another problem is discrimination against Native American people at hospitals. Health care providers lack knowledge of the traditions of local tribes and the barriers they face. Cultural proficiency training should be made part of the accreditation process for clinics and hospitals. Systems should be created so that the community can monitor cultural proficiency.
- Pesticide spraying creates risks for the tribes in the region. Chemicals sprayed along roads contaminate buildings in which Native American people work.

- There is evidence of pollution from ITT Rainier; dumpsites leak into lakes in which Native American people fish.
- Native American women are reluctant to talk about their bodies, and this creates a barrier to screening.
- Problems occur when state agencies have employees playing dual roles. For example, in one town, a women serves as both a social worker and a nurse practitioner. Many Native American women who had dealt with her in her role as social worker did not want to deal with her in an exam room.
- Much of the educational outreach conducted in the region fails to take literacy levels into account.
- Researchers planning projects involving Native American people should visit the target community well in advance of beginning each project to build trust, which could make the population more receptive to research efforts.
- Tribes need technical assistance in writing grant applications and establishing nonprofit clinics.
- Dr. Freeman asked Mr. Jim whether any measures of the effects of radioactive contamination on people in his community are available. Mr. Jim cited evidence of large amounts of radioactive contamination recorded in documents released by the DOE in the 1980s. This led to the Hanford Environmental Dose Reconstruction Project, which has been identified as a flawed study. Since then, no efforts have been made to determine the effects of this contamination. No true radiological survey has been conducted in the Hanford area; only chemicals have been studied.
- In preparation for the 1996 court case previously mentioned, nine people representing a cross-section of the Yakama population were tested and found to have DNA damage. This evidence was not admitted by the court.
- The Columbia River Comprehensive Impact Assessment (CRCIA), conducted about 5 years ago, could have provided recommendations for solving some of the problems associated with the Hanford facility, but the DOE did not accept the findings of the CRCIA.
- Ms. Janice Andrews Mesplee, a member of the Yakama Nation, noted that Ms. Walsh spoke of “my grant” rather than a grant for the people. She asked where the grant will be coming from, what the money will be spent on, how the grant will benefit the people, and how confidentiality will be protected when Ms. Walsh reviews clinic files.
- Ms. Walsh explained that she had described a small training grant that will enable her to perform a chart review of RPMS cancer diagnoses at the clinic. She said the resulting data would be released to the clinic and to the Yakama Nation. No confidential information will be taken from the charts. The purpose is to obtain baseline data on what types of cancers are being diagnosed and how many cases there are. The study is important to the health of the Yakama people because baseline data are needed to learn about the impact of cancer on the community.
- Ms. Michelle Sconawah asked how people could learn the outcome of the dialogue between the President’s Cancer Panel and the Yakama Nation, including what recommendations are conveyed to the President and the President’s response. Dr. Freeman replied that a public report would be produced and made available to anyone who is interested. The President is required to make a response to the Panel’s recommendations, but this may take some time.

## STORIES FROM TRIBAL REPRESENTATIVES

- Dr. Freeman invited audience members to come forward and speak. He also acknowledged the presence in the audience of Mr. Clark Mather, Central Washington Director for Senator Maria Cantwell.
- Ms. Elsie Dick spoke to the Panel through an interpreter. She thanked Mr. Pinkham for giving her recognition to speak and thanked the Panel for traveling to the Yakama Nation to hear their stories, because all families have the same concerns about illnesses that affect them.
- Ms. Dick lost two sisters to cancer, and her son has the disease. In her opinion, the contamination of natural resources—salmon, berries, and roots—is a cause of cancer. She noted that when the Creator first created mankind, everything was clean; there was no sickness. Native Americans were one with the land, and the land took care of them. But today, there are many illnesses, and it is making her people die before their time. The non-Indian, she noted, uses chemicals to grow food and raise cattle, and she believes this has brought illnesses.
- Ms. Dick spoke of the contamination of Native American salmon resources. Today, there are chemicals in the water, and dams have damaged natural spawning areas. There are hatcheries that take the eggs out of the salmon and put them into buckets. She doubted whether a day would come when her people could eat clean food grown by the non-Indian, adding that if the non-Indian would stay within God’s law and keep the chemicals away, there would not be so much illness.
- Ms. Dick asked why people with cancer receive radiation, when she thought radiation caused their cancers. She also asked why the Panel was there and what they intended to do for the Yakama people.
- Ms. Dick expressed concern that the new casinos will generate so much money that the non-Indian will remove treaty protection, believing Native Americans will be able to take care of themselves. She said that this is not true, and many remain without homes. She implored those in positions of authority within the tribe to be careful in the decisions being made on behalf of their land and people.
- Ms. Dick’s niece/interpreter, Ms. Lavina Washines, then spoke. Her mother died at age 42 from breast cancer. She does not appreciate those who come upon Native Americans’ land and tell them that the salmon are causing their cancers; chemicals in the water have poisoned the salmon. Hatcheries have removed most of the wild salmon from the Columbia River. Ms. Dick’s niece wondered if they would next be told that their Indian berries and roots are causing their cancers. She noted that under God’s rule and law, Indian food represents wisdom through work and life as they are received; they cannot allow another race to convince them that their Indian foods are wrong. She asked for results from the Panel: feedback from their findings and someone to take responsibility for the contamination of food sources.
- Dr. Freeman first responded to the question of why the Panel was in Toppenish, stating that, truthfully, it was because Mr. Pinkham had invited the Panel to come. He noted, however, that the Panel has been hearing from populations around the country that are not doing as well as other Americans. These populations are defined in various ways. For example, poor people, irrespective of race, do not fare as well as others when they are diagnosed with cancer, and being of a minority race, such as African American or Native American, complicates this further. Dr. Freeman emphasized that the Panel was in Toppenish to



understand the Yakama people's words and circumstances, reflect these in a report, and make recommendations to the White House. He said the particular disparities involving the Indian people go back more than 500 years and are built into the social and historical fabric of what has happened to the Native American people; thus, theirs is a very deep and complex set of circumstances. While he cannot assure Ms. Dick and others of any specific action resulting from this meeting, he can assure them the Panel will try to carry their story forward.

- Mr. Pinkham told the story about his meeting Dr. Freeman at the Panel's regional hearing in Los Angeles and inviting him to visit the Yakama Nation. He spoke about cancer in the Yakama community. He pointed out that the Panel could communicate their messages to others, who can, hopefully, help the Yakama people.
- Mr. Wilbur Slockish, Jr., representing Columbia River Education and Economic Development, made a few comments. He believes that products his people use daily cause cancer because of the chemicals they are made with. The medical waste incinerator burns waste and releases dioxins into the air. Crops are sprayed with chemicals, and this contaminates the watershed. He asked the regulatory agencies to understand the impact of this pollution and set standards acceptable to the Indian people.
- Mr. Slockish mentioned the Human Genome Project as an example of the free enterprise system that profits at the expense of Native Americans' health. He feels the Project will study the Indian gene pool, patent it, and sell it without providing any benefit to the Indian community. He also asked that modern scientists recognize the tribal science of his people.
- Mr. George Yahyowan introduced himself. He is a Vietnam veteran who believes he is dying from cancer as a result of exposure to defoliants and pesticides used in Vietnam, as well as those sprayed near his home for more than 17 years. He stated that nothing is accomplished by degrading each other's cultures and races and that economic issues will always exist. He recommended that the Tribal Council reach out to the Government and ask for monetary assistance. He also asked that enrolled members of the casino mandate their leaders to purchase life insurance and hospitalization and medication coverage for tribal members because, as a nonprofit organization, the casino should be taking care of the people.
- Mr. Tom Lang spoke as a representative of the Tsimshian tribe of Alaska. He is considered a tribal elder and was asked to attend and represent his people at this meeting. He has been diagnosed with both colon cancer (in 2000) and throat cancer (in 2002). He believes he is alive today because when he retired as a commercial fisherman, he received Social Security, Alaska retirement benefits, and a Medicare/Medicaid card.
- Mr. Lang spoke of people in his tribe who have died of cancer. He implored the Panel to hear the cries of his people as yet another plague has descended upon them. He stated that his message to the Panel was one of early detection. Without adequate funding, facilities, personnel, and access to ordinary medical care, his people cannot be survivors but, rather, are victims.
- Mr. Lang believes that there are three issues common to the more than 500 tribes of America: the operation of existing health facilities on reservations, changing systems that divide tribes, and the trust responsibility of the Federal Government to the American Indian.
- One of the main issues with local tribal medical facilities is lack of attention to cancer; it has not been an important issue. People are treated for common Indian diseases such as heart disease, alcoholism, and diabetes; when cancer is finally detected, it is usually too late. The best chance of surviving cancer is early detection and immediate treatment, neither of which is now available to the American Indian. Mr. Lang said he is alive today because he had a

card (Medicaid/Medicare) that got him into a medical system other than IHS. He recommended that all American Indians be covered under an insurance program and given a card that provides them the right to access all available facilities and doctors throughout America—a card just like Medicaid/Medicare.

- While there is great diversity among the more than 500 Indian tribes, one thing they all have in common is cancer. Tribes must unite and make sure that every Indian person is treated the same no matter where he or she is from. Currently, if a woman moves to another reservation as a result of marriage, she cannot use its medical facilities. She must go home to her own reservation. Urban Indians must go back to their reservations to be eligible for tribal services. A majority of these cases are detected too late by the time these system issues are addressed. There are also some tribes completely without health facilities. Mr. Lang recommended that Indian health facilities be unified under a single principle of health care to correct this problem.
- Mr. Lang's third issue regarded the trust responsibility of the Federal Government. Almost every presenter at the meeting mentioned lack of funding as a major barrier to adequate IHS care. Mr. Lang suggested that American Indians demand that the Government live up to its trust responsibility to take care of their health and welfare. Only 60 percent of what is needed by IHS is currently funded; Native Americans should petition Congress and the President to raise this percentage.
- Ms. Geneva Charley, from the Warm Springs tribe, spoke. She said cancer has been with them for some time. Her mother had cancer. She urged her Native brothers and sisters to remember who they are and why they are here and to be true to their customs and practices, as this benefits them. She said to be thankful and ask for guidance, and this will help in life. Ms. Charley concluded by thanking the Panel for inviting the Northwest Indians to speak and for listening to the needs of her people, who are no longer reaching old age.
- A participant with the Indian name Iatel, who comes from a small reservation covering Tacoma, Fife, Puyallup, Port of Tacoma, Fife Heights, Commencement Bay, and Port Defiance, Washington, addressed the Panel. She noted that her people had had no needs prior to "civilization" arriving. They were wealthy in that they had deer, elk, salmon, seafood, berries, roots, and permanent housing. There were many sacred foods and medicines, some still used today. But when civilization arrived, many changes occurred. As a former comanager of the Puyallup Tribal Fisheries Department, she was proud to say that the Puyallup had initiated the Bolt decision; she stated that much of the information the Panel is looking for is in that decision. Tribal elders brought many of the changes that had occurred with the onset of civilization to the attention of the United States. These included timber practices and how they affected the environment and, ultimately, the salmon, as well as chemical contamination and how it affected the environment and survival of the salmon. The salmon are not normal now; the ones bred in hatcheries are called "retarded" salmon because they are often deformed and are not as strong, big, or smart as natural salmon. She further noted that her people have survived many catastrophes and genocides.
- Iatel related how cancer has affected her immediate family. Her grandmother had cancer, although she died from pneumonia; this raised the point that statistics are not very accurate, because many deaths occur from causes secondary to cancer. Her mother and niece also had cancer. At 50, she said, she was diagnosed with breast and, subsequently, stomach cancer. Thus, her family has experienced four generations of cancer.

- She expressed sadness that many of her people are not practicing their tribal ways and spirituality. When her elders cared for her before she was first diagnosed with cancer, there was a balance of Western and traditional medicines. She believes that a cure for cancer will come, and she prays for that. She also learned through her time of healing that food is her people's medicine; it must be respected in a certain way in order for it to help. She prayed that their children will have a better life and that all of the things that now make them weak and sick can also make them stronger. She closed by saying that the Creator put her Indian sisters and brothers here with instructions for what to do, and they are not leaving; Mother Earth has existed for billions of years, and Native Americans are patient people.

#### **CLOSING REMARKS—DR. HAROLD P. FREEMAN**

- Dr. Freeman expressed his sincere honor at being invited to the Yakama Nation and described the experience as very moving. He thanked the community representatives and speakers for their testimony.
- Dr. Freeman reviewed some of the points made during the day by those who testified. The importance of economics was a recurring theme. Economics have driven historical events and some of the environmental changes mentioned.
- Limitations of data were discussed. Questions were raised as to whether there really is a lower incidence of cancer in the Indian community. There are problems related to misclassification and collection of data that limit the ability to report accurate statistics. Further, perhaps half of Native Americans live in urban settings, and their unique needs are not often discussed.
- Dr. Freeman noted that even if behavior change occurs (e.g., diet, smoking), disparities will still exist. Recent information suggests that this is partly due to how people are treated once they are diagnosed with cancer, and race seems to matter, regardless of insurance or economic status.
- A representative of the Spokane tribe indicated that tribal health data are collected, but tribal members are not willing to share them because they do not know how these data will be used.
- The relationship between the Native American people and salmon and other animals was brought up repeatedly; it was said that the salmon and people are inseparable. Yet, the environment has been contaminated as well as the salmon.
- Dr. Freeman cited the importance of Mr. Jim's presentation. He had spoken of environmental injustice and went into depth about these issues and Native Americans' disappointment with Government adherence to treaty agreements. It was also stated that the current administration, particularly the EPA, was not as concerned about the extinction of species as about maintaining economic status. Radiation was also mentioned as a critical issue.
- Dr. Freeman said that the issues that affect Northwest Native Americans have been clearly stated and that the Panel will transmit this information to certain authorities in hopes of showing them what the real problems are and providing recommendations for improvement.
- Dr. Freeman said that he believes he heard a story during the 2 days of the meeting that is more than the present story. What he heard was that Native Americans' story began thousands of years ago, when the land and water were clean, and that this is no longer so. Native American history is also interrelated with everything that has happened to them, and cancer is only one indicator of what has happened.

- Dr. Freeman then presented Certificates of Appreciation and awards to members of the Yakama Nation. Mr. Pinkham spoke of the pleasure of meeting Dr. Freeman again and thanked him for listening to his people.

#### **CLOSING CEREMONY—MR. ANTHONY WASHINES**

- Mr. Washines expressed his appreciation on behalf of the tribe, the people, and the land and the water.
- He expressed hope that Dr. Freeman would be able to take their words back to the “Great White Father from where the sun comes up.”
- He said the Panel has been a witness to the words and lives of his people and to a better understanding that, in this part of the earth, they are gifted with a certain food, a certain animal to take care of them and blessed with a certain language, and this is within the lineage and legacy left them by their elders. Together, they have participated in a dialogue, and Mr. Washines stated that he was very grateful for this.
- Mr. Washines concluded in the same manner in which they started “this great discussion”: with a song left by the elders that takes care of tribal members from day to day. He thanked the Panel again and stated he would sing, and all would once again raise their hands when the bell rang for the final time and turn and depart in a good way.
- Mr. Washines then sang a song in his native language, and the proceedings were concluded.

I certify that this summary of the President's Cancer Panel meeting, *A Dialogue Between the Yakama Nation and the President's Cancer Panel*, held July 29–30, 2002, is accurate and complete.

Certified by: *Harold P. Freeman*

Date:

3/7/03

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Harold P. Freeman, M.D.  
Member  
President's Cancer Panel

3/7/03

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LaSalle D. Leffall, Jr., M.D.  
Chair  
President's Cancer Panel