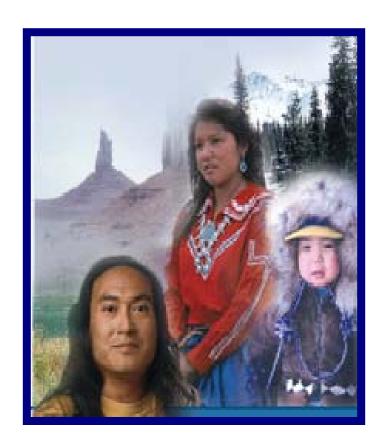


### Department of Health and Human Services Centers for Disease Control and Prevention Agency for Toxic Substances and Disease Registry

## <u>Tribal Consultation</u> Advisory Committee (TCAC) Meeting



November 18–19, 2008 Minutes of the Meeting



Table of Contents	Page
Acronyms	3
Call to Order, Opening Prayer, Welcoming Remarks, Introductions	5
Consideration of July Meeting and Subsequent Conference Call Minutes	6
Area and National Organization Reports	11
Working Lunch: CDC's Healthiest Nation Initiative and Healthy Nations Alliance – An Invitation for American Indian/Alaska Native Tribes to Join	23
Administrative Matters	24
Suggestions and Approaches for CDC Budget Opportunities	27
Updates from CDC in Response to TCAC Recommendations	34
CDC Program Updates	36
Cancer Prevention and Control Update	39
Day 1: Meeting Wrap-Up and Adjournment	44
Site Visit: Tohono O'odham Nation Tour	45

#### **Acronyms**

AIP Arctic Investigations Program
AIR American Indian Recovery

AoA United States Administration on Aging APHA American Public Health Association

ASTHO Association of State and Territorial Health Officials ATSDR Agency for Toxic Substances and Disease Registry

BIA Bureau of Indian Affairs

BRFSS Behavior Risk Factor Surveillance Survey

BSC Board of Scientific Counselors

CDC Centers for Disease Control and Prevention

CCC Comprehensive Cancer Control

CHS Contract Health Services

CMS Centers for Medicare and Medicaid Services

COTPER Coordinating Office for Terrorism Preparedness and Emergency Response

CRIHB California Rural Indian Health Board
DASH Division of Adolescent and School Health
DGMQ Division of Global Migration and Quarantine

DHS Department of Homeland Security

DOD Department of Defense

DSLR Division of State and Local Readiness

EOC Emergency Operations Center EPA Environmental Protection Agency

FEMA Federal Emergency Management Agency
FMO Financial Management Office (CDC)
GPRA Government Performance Results Act
HHS Department of Health and Human Services

HICI Healthy Indian Country Initiative
HIV Human Immunodeficiency Virus
HRAC Health Research Advisory Council

HRSA Health Resources and Services Administration

IGA Office of Intergovernmental Affairs

IHS Indian Health Service
IRB Institutional Review Board
MOU Memorandum of Understanding

NARCH Native American Research Centers for Health

NCHM National Center for Health Marketing NCAI National Congress of American Indians

NCHHSTP National Center for HIV, STD, and TB Prevention

NCI National Cancer Institute

NCIRD National Center for Immunization and Respiratory Diseases

NIHB National Indian Health Board
NIMH National Institute of Mental Health
NIS National Immunization Survey

NPAIHB Northwest Portland Area Indian Health Board
NVDRS National Violent Death Reporting System
OCPHP Office of the Chief of Public Health Practice

OD Office of the Director (CDC)

OEC Office of Enterprise Communication

OMHD Office of Minority Health and Health Disparities

OSH Office of Smoking and Health
PART Program Assessment Rating Tool
PGO Procurement and Grants Office

SAMHSA Substance Abuse and Mental Health Services Administration

SNS Strategic National Stockpile

SPAN Suicide Prevention Action Network
STD Sexually Transmitted Disease
STI Sexually Transmitted Infection

TB Tuberculosis

TCAC Tribal Consultation Advisory Committee
TEMAC Tribal Emergency Mutual Aid Compact

TLBC Tribal Lands Building Credits
TTAG Tribal Technical Advisory Group

US United States

USPHS United States Public Health Service VA Department of Veterans Affairs

VFC Vaccines for Children

# Centers for Disease Control and Prevention (CDC) Agency for Toxic Substances and Disease Registry (ATSDR) Tribal Consultation Advisory Committee (TCAC) Meeting

Minutes of the Meeting November 18–19, 2008

#### November 18, 2008

#### Call to Order, Opening Prayer, Welcoming Remarks, Introductions

Linda Holt, Co-Chair Tribal Consultation Advisory Committee (TCAC)

Chester Antone, Councilman Tohono O'odham Nation

Robert Valencia, Vice Chairman Pascua Yaqui Tribe of Arizona

Chairman Ned Norris Tohono O'odham Nation

On Tuesday, November 18, 2008, the meeting of the Tribal Consultation Advisory Committee (TCAC) was called to order at 8:25 AM by Linda Holt, TCAC Co-Chair. Following an opening prayer and blessing from Chester Antone, Councilman, Tohono O'odham Nation, Ms. Holt welcomed the group to the meeting. She reminded them that their biannual Tribal Consultation was scheduled for November 20<sup>th</sup> and asked any tribal leaders present to prepare their testimony for that session. She noted that the next day, the group would make a site visit to the Tohono O'odham Nation during which they would learn more about border issues that are urgent to this area. Attendees of the meeting then introduced themselves. A participant roster can be found in Appendix A.

Robert Valencia, Vice Chairman, Pascua Yaqui Tribe of Arizona, welcomed those present to Tucson on behalf of the Pascua Yaqui Tribe. He acknowledged efforts in Indian Country to achieve a better healthcare system. Through direct effort, one of the tribes has increased its life expectancy by ten years. He thanked Mr. Antone for keeping the tribe up to date on TCAC's activities and on developments in healthcare. He reminded the group that they were invited to dinner at the Pascua Yaqui reservation, and he hoped for positive results from the TCAC meeting and from the Tribal Consultation.

Chairman Ned Norris, Tohono O'odham Nation welcomed everyone to the Desert Diamond Hotel and Casino, stressing that their visit to the border would illustrate the unique issues that the Nation has dealt with and their impacts on the Nation's people. The issues do not only concern immigrants coming across the Nation's land, but also include the Border Patrol agents who may not be sensitive to the Tohono O'odham Nation's people and land. In addition, he thanked Mr. Moore for representing Indian Country by singing the National Anthem at the Democratic National Convention.

#### **Consideration of July Meeting and Subsequent Conference Call Minutes**

Captain Pelagie (Mike) Snesrud Senior Tribal Liaison for Policy and Evaluation Centers for Disease Control and Prevention (CDC)

Captain Pelagie (Mike) Snesrud, Senior Tribal Liaison for Policy and Evaluation, Centers for Disease Control and Prevention (CDC), extended her personal thanks to Mr. Antone, the Tohono O'odham Nation, and the Local Planning Committee for their hard work in arranging the meeting. She then turned the group's attention to Section Three of their binders, which contained the Action Steps from the July 2008 TCAC meeting. She reminded them that the tapes of the meeting were faulty, so the minutes were reconstructed from their notes.

Ms. Holt then reviewed the agenda for the November 18 - 19, 2008 TCAC meeting. There were no additions or corrections to the agenda.

#### **Motion**

Mr. Robert D. Moore, District Three Council Representative, Rosebud Sioux Tribe, moved to approve the November 18 – 19, 2008 TCAC agenda. Vice Chairwoman Kathy Hughes, Oneida Business Committee, seconded the motion. The motion carried unanimously with no abstentions.

Ms. Holt then reviewed the Action Steps and notes from the July 29 – 30, 2008 TCAC Meeting in Hollywood, Florida.

#### ❖ Action:

With the assistance of TCAC and the National Indian Health Board (NIHB), CDC reached out to tribal leaders nationally for increased involvement and engagement at the November Consultation meeting. TCAC members and the Tohono O'odham Nation provided written advertisement at the annual National Congress of American Indians (NCAI) and NIHB meetings to promote upcoming CDC meetings with tribes.

#### ❖ Action:

CDC shared and distributed the FY 2007 American Indian/Alaska Native Budget Portfolio with TCAC and tribal leaders on February 28, 2008.

#### ❖ Action:

One of TCAC's ongoing projects has been to identify how tribes can expand funding opportunities and access to CDC programs. This activity requires CDC's implementation of its Tribal Consultation Policy to increase tribal access to CDC resources.

#### ❖ Action:

TCAC will "get CDC on board with understanding tribal needs and cultural values." It is crucial to continue to hold TCAC meetings and Tribal Consultations in Indian Country in order to meet with area tribes and determine their needs. CDC must go to Indian Country and experience the needs first-hand.

#### ❖ Action:

Send minutes and recommendations from TCAC meetings to tribes. The Area Health Boards can be helpful in carrying out this action.

#### ❖ Action:

Advise tribes on how far TCAC and NIHB have come in two and one-half years. Capt. Snesrud noted that CDC has been strengthening its partnership with the NIHB and its established infrastructure of Area Health Boards. Information will be posted on the NIHB webpage with direct links to CDC, and CDC will include information on its Office of Minority Health and Health Disparities (OMHD) webpage. She encouraged accessing the web pages because of their ease of navigation and because using the Internet is "green." The minutes and recommendations from this meeting will be sent on a DVD to each TCAC member, to the Area Health Board Directors, and to the Tribal EpiCenter Directors.

#### ❖ Action:

Discuss and clarify how TCAC will be conducting business for the next year. Further, TCAC needs to determine strategic priorities and goals and a roadmap for accountability. These items would be discussed at this meeting.

#### ❖ Action:

NIHB will assist TCAC Co-Chairs in arranging and implementing area ambassador visits by contacting Executive Directors of Area Health Boards to schedule the visits. Ms. Holt noted that she has visited the Albuquerque Area Health Board and the Oklahoma Area Health Board, stressing that the visits had been highly informative and apologizing for missing a visit to Alaska. During these visits, she discusses TCAC, its charter, the Committee's accomplishments, and its goals for the future.

#### **❖** Action:

Develop a briefing book for TCAC members and other tribal leaders regarding CDC. Capt. Snesrud pointed out that the meeting's binder included a number of preparatory documents for this meeting. The CDC/OMHD webpage also includes handouts and notes from each TCAC meeting. CDC plans at least one orientation session per year as part of the Atlanta-based consultation. Further, they are in discussion with CDC's Office of Enterprise Communication (OEC) and National Center for Health Marketing (NCHM) to better utilize the Internet to make CDC resources available to tribal leaders and tribal communities.

#### ❖ Action:

Opportunity to receive information about CDC's Aging Program and Network, and learning how CDC is collaborating with the United States Administration on Aging (AoA) and the Indian Health Service (IHS) to maximize resources and services available to Native Elders and tribal communities. It was noted that representatives from CDC's Aging Network would attend the February 2009 TCAC meeting.

#### ❖ Action:

Update on the CDC Public Health Alert process and how tribal organizations are connected, including information about the Strategic National Stockpile (SNS) and an update from the Coordinating Office on Terrorism Preparedness and Emergency Response (COTPER) about new state plans and their implication for tribes. Capt. Snesrud said that representatives from the Stockpile were present at the meeting, and they would share information. The meeting binder included information from COTPER and the Division of State and Local Readiness (DSLR).

#### ❖ Action:

CDC needs to look at developing a tribal training center and utilize a clearinghouse approach so that the best practices that are being developed in CDC collaborative work with tribes can be mimicked in other new program areas of tribal importance. There is a need for technical assistance in the public health arena so that tribes are able to implement these programs at the local level.

#### **Discussion Points**

- Capt. Snesrud stressed that this issue is important, and that there is a need to share best practices from each of CDC's large program areas, including Injury Prevention, Diabetes, Cancer, the REACH Program, and others.
- Ms. Holt commented that the collaboration with NIHB could be helpful. NIHB can act as a resource gatherer for these implementations and also in bringing tribal programs to the NIHB Annual Consumer Conference to deliver presentations on their programs.
- Mr. Moore commented on concern that the institutionalization of tribes within CDC should be occurring at the same time that CDC, NIHB, or other groups work to help tribes understand the role that CDC can play in their communities. He encouraged CDC to elevate a tribal office to a high level of responsibility within the agency. He was hopeful that CDC was learning to think about tribes in all of the work in which the agency engaged, not "just when it was convenient."
- Ms. Holt felt that some milestones had been reached since March 2008, and that the
  process continued to move forward and grow. CDC's increased access to tribes should
  feed the effort, as should open communication between CDC and tribes. CDC and NIHB
  could collaborate on creating tribal training programs similar to the education received by
  TCAC members.
- Mr. Moore suggested that TCAC recommend that NIHB include CDC as another agency to highlight at its annual meeting. Although the recent Public Health Summit was held, often different folk attend the Annual Consumer Conference, CDC needs to have an entire day at the Consumers Conference.
- Ms. Holt affirmed the need for the Budget Subcommittee to be re-established and become
  active as a critical element in assist tribes to influence and impact CDC's budget planning
  and allocations. The subcommittee should concentrate on giving a strong presentation at
  the next HHS Budget Consultation to CDC that can be used as base information for
  upcoming HHS Regional Consultation and the next CDC Consultation in Atlanta in May or
  June. Tribes should advocate for fewer line-items in the CDC budget.
- Ralph Bryan, M.D., Captain, United States Public Health Service (USPHS), Senior Tribal Liaison for Science and Public Health, OMHD, CDC, asked for clarity regarding the idea of a "tribal training center."
- Ms. Holt replied that the training program could be mobile and used at different conferences, perhaps at NCAI, and could include breakout sessions and training for tribal members.

#### **Motion**

Mr. James Crouch, Executive Director, California Rural Indian Health Board (CRIHB), moved to approve the minutes of the July 2008 meeting. Mr. Chester Antone seconded the motion. The motion carried unanimously with no abstentions.

Ms. Holt then turned to the meeting notes from the conference call held on September 17, 2008. The call included an introduction of Raven Murray as a new staff member of NIHB, as well as information about a change in the TCAC charter to allow for a new contractor to handle all logistics for future TCAC meetings.

#### ❖ Action:

Creation of a TCAC logo: this issue needs attention.

#### Discussion:

- Capt. Snesrud said that a logo should be developed to help people become familiar with the
  work that Indian Country does with CDC. She asked for input on how best to create a logo.
  She suggested that they publicly solicit designs through NIHB and then ask TCAC to choose
  the top three designs by electronic vote. They could then take a face-to-face vote on the top
  three choices during the February 2009 TCAC meeting.
- Ms. Holt asked TCAC members to speak with their local artisans about creating a logo, keeping in mind that TCAC is a national organization representing all areas of Indian Country. Therefore, the logo should have a broad base.
- Bonnie Hillsberg, Senior Program Manager, NIHB, commented that the logo would be a way to brand TCAC and better share its information.

#### ❖ Action:

CDC cooperative agreement evaluator: NIHB will send the scope of work for TCAC.

# ❖ Additional Items from Conference Call: □ There was a Public Health Accreditation Roundtable on September 24<sup>th</sup> at the Consumer Conference. □ CDC's COTPER has established a Board of Scientific Counselors (BSC) to advise CDC on the scientific and strategic direction of COTPER programs. Through board meetings, there will be multiple opportunities to educate other members and CDC about public health preparedness implications to tribes. American Indian/Alaska Native tribes are represented on this board by Bonnie Hillsberg. She will update TCAC and tribes after every meeting of the Board. The next meeting is in April of 2009.

In August 2007, CDC entered into a Cooperative Agreement with the Association of
State and Territorial Health Officials (ASTHO) to develop a document regarding at-risk
populations and pandemic influenza planning guidance for state, territorial, tribal, and
local health.

There was a call to address better separation of an American Indian/Alaska Native and
Hispanic suicide panel. Capt. Snesrud said that a representative from CDC's Injury
Prevention Center would address this topic later that afternoon.

☐ The agenda for the November meeting and Tribal Consultation were discussed.

With no additions or corrections to the September 2008 Conference Call minutes, Ms. Holt called for a motion to approve the minutes.

#### **Motion**

Ms. Kathy Hughes moved to approve the minutes of the September 2008 Conference Call. Mr. Chester Antone seconded the motion. The motion carried unanimously with no abstentions.

Ms. Holt then turned to the October 20, 2008 Conference Call Meeting minutes.

- ☐ Finalizing TCAC meeting dates through May 2009 was discussed.
  - ➤ February 16 18, 2009, is planned for Albuquerque, New Mexico.
  - ➤ May 11 14, 2009 was suggested for a TCAC meeting and tribal consultation session in Atlanta, Georgia.
- ☐ There was discussion regarding the communications flow between CDC, TCAC, and NIHB, including the frequency of TCAC teleconference calls.
  - CAPT Snesrud said that the frequency of the calls was at the pleasure of the TCAC membership.
  - It was suggested, based on attendance, considering not having monthly conference calls, but moving to a structure of less frequent calls with more participation.
- ☐ Re-activation of Budget and Tribal Terrorism Preparedness and Emergency Response Subcommittees.
  - CAPT Snesrud suggested that TCAC consider conducting conference calls every other month and populate the two Subcommittees, perhaps with subject matter or technical experts from their Health Board or EpiCenter. The work of the Subcommittees comes before the whole TCAC.
  - ➤ CAPT Snesrud would distribute the lists generated at the January 2008 meeting in Oklahoma, which included suggested technical experts from tribal areas.
- ☐ The November TCAC meeting and Biannual Consultation were also discussed.

There was a note to edit a typographical error from the October 20, 2008 teleconference meeting notes: Roger Trudell's name was spelled incorrectly.

#### **Motion**

Roger Trudell, Chairman, Santee Sioux Tribe of Nebraska, moved to approve the minutes of the October 20, 2008 Conference Call, with the above noted correction. Lester Secatero, Chairman, Albuquerque Area Indian Health Board, seconded the motion. The motion was carried unanimously with no abstentions.

#### **Area and National Organization Reports**

Aberdeen Area Roger Trudell, Chairman Santee Sioux Tribe of Nebraska

Mr. Trudell reported that the Aberdeen Area recently hired an Area Health Board Director, and offered some updates since the last tribal consultation.

Suicide continues to be an epidemic in the area. Rosebud has taken a strong initiative to bring attention to the problem and is considering ways to address suicide at the local level. His tribe is considering developing a "mental health tech" program to train 10 mental health "techs" to be active "on the ground."

At the Region Seven consultation with the Department of Health and Human Services (HHS), the problem of Hepatitis C was an important topic. Hepatitis C cases are growing on his reservation, largely from sharing needles. Other states in Region Seven agreed that Hepatitis C is on the rise. The treatment program for Hepatitis C is 10 to 11 months long, provided that the individual follows every detail of the treatment plan. Drug use on reservations is prevalent, including methamphetamine.

Gang activity also poses a health issue, and is on the rise on some reservations. Smaller reservations can address these problems, but larger reservations may have trouble controlling gang activity. Alcohol and drug abuse continue to be prevalent in his area. Infant mortality is still an issue. Smoking is also prevalent in the Aberdeen area.

Accidental death still a leading health issue that stems from a number of causes, including poor roads with insufficient signs and driving under the influence of alcohol or drugs. Cancer is also an area of concern. Tribal health facilities are not always able to reach out to outlying districts on larger reservations to provide annual and semi-annual checkups and screenings. There has been discussion of a mobile clinic to reach districts that lie as far as 100 miles from health facilities. Facilities in the districts are often under-staffed and cannot meet the needs of the people. On smaller reservations, there are challenges associated with finding proper medical staff and providing them with housing and other needs.

#### Alaska Area

Tim Gilbert

Alaska Native Tribal Health Consortium (ANTHC)

Noting that the ANTHC has been in transition, Mr. Gilbert introduced Alicia Reft, the new tribal representative from ANTHC.

There are approximately 130,000 Alaska Natives in the Alaska Tribal Health System. Based in Anchorage, they are one of 39 tribal health organizations that serve Alaska Native populations in the state. They manage a tertiary hospital and community and public health programs statewide. Many CDC-funded programs are in his division. They are also home to CDC's Arctic Investigations Program (AIP). He expressed his gratitude for their good working relationship with CDC staff, both locally and elsewhere.

During the last TCAC meeting, five priority issues in Alaska were put forward:

Unintentional injuries: There is a large disparity of unintentional injuries in Alaska due to their subsistence lifestyle. Combined, unintentional and intentional injuries are the leading cause of death in Alaska.
Tobacco use disparities: Alaska has unacceptably high rates of non-traditional tobacco use, which is a risk factor for a host of chronic diseases.
Sexually-transmitted infections (STI): Alaska has had a close relationship in the past with CDC and IHS to identify Chlamydia rates and to begin interventions.
Cancer prevention and control: Cancer is a leading cause of death in Alaska. They receive CDC resources for early detection of colorectal cancer, which is the number-one diagnosed cancer among Alaska Natives.
Obesity prevention and control, especially in pediatric populations: There are a few good diabetes programs in the state, but they do not have good data or a good grasp of the diabetes problem.

Another important area is suicide, particularly among northern populations.

Regarding resource needs, when they toured CDC's facility in Atlanta, representatives from the Alaska Area were impressed by the agency's ability to engage in health messaging, whether via radio, the Internet, Podcasts, or other means. Because many Alaskan populations live at great distances from each other and from resources, Mr. Gilbert felt that they should be creative with their health messaging. They would welcome the opportunity to interact with CDC to learn better means for messaging. They are examining new ways to reach youth, including websites and digital storytelling via a collaboration with the University of Washington.

#### Albuquerque Area Lester Secatero, Chairman Albuquerque Area Indian Health Board

Mr. Secatero represents seven tribes in New Mexico and Southern Colorado. The tribes that the Area Health Board serves are as far as 250 miles from Albuquerque, where the Board is based. The Albuquerque Area was established in 1977 and incorporated in 1980. The United States Census estimates that the Board reaches 162,686 Native Americans. They provide specialized health services, research services, and health promotion and disease prevention programming to the tribes. Some of their programs include substance abuse treatment, diabetes education, domestic violence prevention, cancer awareness, public health capacity building, tobacco awareness, and HIV/AIDS prevention and education.

Advocates from the Board influence healthcare policy decisions at the national, regional, local, and state levels. The Board is also represented on several committees and advisory groups. Their current programs include audiology, HIV/AIDS, a Native American Research Centers for Health (NARCH) 3 Grant, and an epidemiology center.

The Albuquerque area is still experiencing problems with diabetes and alcoholism. At their hospital, they have 27 dialysis chairs, and three shifts are filling those chairs, 24 hours a day. Recently, three tribal members died in one month: one from alcoholism, one from HIV, and one from diabetes. Alcoholism and diabetes are their greatest concerns, while poor quality roads are a problem for them as well.

Three high schools have participated in the Behavior Risk Factor Surveillance Survey (BRFSS). Statistics about smoking, drug abuse, driving without seatbelts, and other risky behaviors are emerging for different communities. Some communities are distant and have kept their native culture and language alive and intact, while others are experiencing problems with methamphetamine. Slowly, they are losing their language and culture.

#### Bemidji Area Kathy Hughes, Vice Chairwoman Oneida Business Committee

Ms. Hughes noted that communication is a challenge in her area. She has one listserv of Health Directors from the Bemidji area, which includes Minnesota, Michigan, and Wisconsin. She has another listserv of elected tribal leaders. She does not always receive notification when there is turnover among Health Directors. When she returns from TCAC meetings, she sends brief reports about the meeting's discussion, and she refers to the website for additional details and presentations. She also attends as many regional Health Directors meetings as possible. It is helpful to have consolidated reports and minutes for her to prepare informative reports to present at these meetings. She hoped for a quarterly report on TCAC activities.

Funding and resource allocations are a significant public health concern for the Bemidji area. It is imperative for CDC to continue to fund at an adequate level all tribes across the United States (US). Funding should be long-term, particularly given that one- or two-year grants do not allow enough time to get programs "off the ground" and to conduct assessments and evaluations. Timing and consistency of funding are fundamental. For instance, the Oneida have received a Preventive Health Grant for the last 11 years, but on an inconsistent basis. The state receives funding through CDC. The Oneida were informed that they would receive funds in July, but they only had three months to spend it, since carry-over is not permitted.

The Bemidji Area has four major health priorities: Diabetes, Obesity, Cardiovascular Disease, and Cancer, particularly prostate cancer since annual testing is not conducted regularly. Early detection is critical for prostate, breast, and cervical cancers.

The CDC needs to work with Native American tribes on other public health initiatives, such as infrastructure development, community capacity, and access to healthcare. Further, health statistics and data collection need to be enhanced and addressed. Many tribes do not have the infrastructure in place to collect valuable data, and data drives funding. Without data, tribes experience difficulty in securing outside funding to address health problems on reservations. Funding for pandemic influenza preparation ended in July 2008, and general funding for preparedness has decreased. Funding for such programs needs to continue at a consistent level. CDC expects more from public health programs, but with less funding. The objectives for this funding source continue to grow, but there is less funding.

The Bemidji Area is prepared for flu season with its flu clinics. In the past, they have been successful in reaching its population with flu shots. Another emerging concern is meningitis. A member of the Oneida tribe fell ill with meningitis, and another gentleman appears to have it as well.

Responding to Capt. Snesrud's comment that the Bemidji Area does not have an Area Health Board, Ms. Hughes replied that not having a Health Board has been a problem, as it is

challenging to disseminate information promptly. She hopes to activate an Area Health Board, and is beginning that work in Wisconsin.

#### California Area

James Crouchm, Executive Director California Rural Indian Health Board (CRIHB)

Mr. Crouch introduced Jackie Caslo, the new Director of the Department of Family and Community Health at CRIHB. He also apologized for missing the meeting in Florida.

CRIHB is engaged in three major efforts:

been excellent collaboration to take this project to the next level, perhaps through research support to implement and evaluate the curriculum.
They are finalizing a publication called "Commercial Tobacco Use: Opinion and Risk Perception among Three California American Indian Tribal Communities."
The CDC-funded collaboration between the EpiCenter in Oklahoma and Portland has yielded important work in injury prevention, including developing a toolkit for dissemination. The EpiCenter at CRIHB does not have a Director. They are advertising for a PhD Director and will be conducting interviews in early December.

☐ CDC-funded tobacco control work, which has been ongoing since 2005, is developing a

The CRIHB held its annual meeting in mid-October. It included discussions regarding emergency preparedness. They held a tabletop exercise in Sonoma County, and some EpiCenter staff met with the state consultant for the Indian community on preparedness. CRIHB has a role in this work.

There are also concerns in the area about accident prevention. A number of reservation-based ATV and bicycle accidents have resulted in the death of adolescents. They have an IHS-funded injury prevention program that recently did a national training session. It also does outreach to the Indian community in Sacramento regarding seatbelt use and child safety seats.

Adolescent obesity is another concern in the California area. CRIHB is finishing a California Endowment-funded pilot project on adolescent obesity. They hope that work with urban and tribal communities will help to identify ways to intervene in adolescent obesity.

Access to data is a continuing concern. There are no IHS hospital facilities or youth regional treatment facilities in California. Therefore, their data are only ambulatory-level. For a more complete picture of the health status of their community, they need access to individual identifiers (e.g., names, addresses, birthdates, Social Security Numbers, et cetera). State datasets are rich in California, and CRIHB is making progress toward being able to use individual identifiers with state hospital discharge data, Medicaid data, and other registries. On September 25, 2008 IHS published a Notice of Rule for their record-keeping system that identified tribal EpiCenters as public health entities for the first time. Further, the notice identified the opportunity for IHS to release data under "business-partner agreements."

They have also had a meeting with national EpiCenter staff in Albuquerque and the California area office, and there will data-sharing for IHS users and registrants in California. Mr. Crouch

added that the publication in the Federal Register will lead to a data-sharing agreement, which will need to be negotiated.

## Nashville Area Michael Cook, Director United South and Eastern Tribes

Mr. Cook greeted the group and explained that the United South and Eastern Tribes organization includes 25 member tribes. The member tribes extend from the tip of Maine to Florida to eastern Texas. They do not have a formal Health Board; however, they do have a Health Committee that meets three times per year. The Health Directors meet on a monthly basis, and information is disseminated through them. The organization has a website, which is being updated.

Their public health issues are not unique, and they report on a macro-level. There concerns include:

Resource allocations: Funding should not go to states, but to tribes. Tribal-state relationships are "hit-and-miss." Further, some tribes are small and do not always meet CDC's criteria for funding opportunities. CDC's Grants and Procurement Office (PGO) should be sensitive to this issue.
Public health preparedness and emergency response: They are leading in peer-to-peer assistance for pandemic flu planning. Other emergency planning efforts include work by the Mohawk tribe on pandemic flu preparation. They have a tribal EpiCenter that provides assistance to tribes in immunization coverage. They have developed a Tribal Emergency Mutual Aid Compact (TEMAC) model that the Federal Emergency Management Agency (FEMA) hopes to replicate across Indian Country. TEMAC formalizes the process of tribes helping tribes.
Government-to-government relationships: Their offices are based in Nashville, Tennessee, and are housed in the same facility as the area office of IHS. They work together in the area of emergency response. IHS has an Emergency Operations Center (EOC) there as well. CDC should recognize IHS's role in the federal emergency management process and should adopt a more participatory approach. Further, the organization includes tribes that border with Canada, and there are health and immigration issues associated with tribes that span the border. State-tribal relationships are important and need attention.
Data access is a priority with their EpiCenter, especially in the area of trending.
Environmental public health: Safe water is a major issue, and sustenance has all but disappeared from many tribes due to contaminants. There is belief that contaminated water and increases in cancer rates are linked, and CDC's assistance is needed to pursue this. Many tribes do not have the necessary resources to assess the full environmental impact on their communities.
Obesity: Of the member tribes' population, 70% are characterized as overweight or obese, of whom over 50% are obese. They are in the process of trending this data.

Mr. Cook stressed that his member tribes want to advance the concept of direct funding to tribes, not funding through the states.

There are also concerns about emergency preparedness work. They recently convened a Health Summit for their member tribes on addressing the psychosocial aspects of dealing with chronic diseases and addictions. They held a medical provider "best practices" and chronic disease management conference in conjunction with the IHS area office. They are developing a model for a national best practices conference. They have developed providers' and community leaders' toolkits as well as one-page information sheets for community members. They work with local universities in the Nashville area. A final major issue is data sharing, and they need help with the process of establishing a mutually agreeable protocol.

#### Navajo Area

Jerry Freddie

#### Navajo Health and Social Services Committee, NIHB

David Filfred, Council Delegate, Navajo Nation HSSC, yielded the floor to Mr. Jerry Freddie for the area presentation. Mr. Freddie introduced himself and thanked all of the tribal leaders for their advocacy to bring dollars to Indian Country.

The Navajo Area has a program called Vision of Health. Its staff has sought technical assistance from the state to elevate this small public health program to the State Department of Health. Navajo have relied on the clinical side of healthcare, and they need a better understanding of the public health arena. The Navajo Nation also intends to address a trauma system, as they do not have a healthcare facility to address that level of care.

Another concern of the Navajo Nation is the need for nursing homes. Many of their elders go off of the reservation for care, since the facilities on the reservation are minimal. Due to the trend of working parents and children, the large population of senior citizens is coming to rely on facilities in border towns for care as they become frail.

Suicide is a also problem for the Navajo Nation. Suicide is devastating for the whole community. More care facilities are needed in this area.

Water and sanitation facilities are a concern. Many areas of the Nation are remote, isolated, and rural. The federal government has put cluster housing in some areas and added some infrastructure, but there are is no fire protection, there are no libraries, and there is no recreation. These omissions add to social vices such as gang activity.

The Navajo Nation has an Emergency Preparedness and Response Plan. Certain regions utilize annual vaccinations as an annual exercise.

The Nation recently held elections of community leaders and school board members. Every two years, there is a change of leadership at local and tribal levels. These new leaders need to be oriented.

The Navajo Nation voted to ban smoking in all public facilities, but language was added to ban smoking in gaming facilities. Opponents of that language caused the resolution to be rescinded. This important legislation will be reintroduced. Already, many community areas are non-smoking, but a policy is needed,

Navajo still rely on traditional practices for self-care and addressing the health, education, and welfare of their people. However, the traditional healers have few apprentices.

Solid waste management is a major problem for the Navajo Nation. Areas are designated for solid waste bins, but regulations can make using them prohibitive, and the Navajo are not utilizing their own equipment and manpower for solid waste management. It is expensive to rely on others. If they do not maintain their solid waste bins, trash is dumped in arroyos. Funding is needed in this area.

There is a large population of wild Navajo horses, and the elders are concerned about their proper management. Many communities are selling the horses, trading them, or giving them away. Slaughterhouses are banned in the United States.

Road maintenance budgets are minimal. There is only funding to surface roads, not to build or insulate them. Seasonal weather is a challenge for access to public facilities.

The Navajo Nation's annual budget formulation is coming up. Their Chairman, Peterson Zod, displays powerful leadership. He is working to entice Indian students to go to college, which is a benefit for Navajo and for other tribal communities.

A young Navajo from Arizona has qualified for the rodeo finals in Las Vegas, Nevada, in December 2008. They are very proud of him and hope that he will serve as a role model for other young Navajo. The sports of rodeo and basketball are very popular in the Nation.

Indian leaders have advocated for IHS and HHS to recognize and establish seven advisory groups. They need feedback about these groups to learn their recommendations and work.

Chairman Norris announced that he was departing, but Vice Chairman Isidro B. Lopez would be there in his place.

#### **Portland Area**

Linda Holt

Council Member of the Suquamish Tribe Chairwoman, Northwest Portland Area Indian Health Board (NPAIHB)

Ms Holt noted that the NPAIHB, which represents 43 tribes in Washington, Oregon, and Idaho, is working on establishing a relationship with the Veterans Administration (VA). Rather than advocating for IHS and the Department of Veteran's Affairs (VA) to join a national Memorandum of Understanding (MOU), they have altered their approach to address the local level. This effort is working well in that several tribes have developed MOUs with local veteran directors. Her tribe, the Suquamish, is in the process of working on an agreement with the local VA to provide home-based service to Native American veterans. The VA would reimburse those expenses, and part of the agreement will include sending veterans that are not eligible for VA for specialty care. This effort will be supported by Contract Health Services (CHS) funds. This approach will be cost-effective and will reduce stress on veterans. They are also working on sharing the VA Community-Based Outpatient Centers. The NPAIHB has been asked by Senator Murray to help develop a health plan for Native American veterans in Washington State.

Long-term care issues are growing, with so many elders living longer. They do not have nursing homes in the Northwest area, so they are working on developing long-term care criteria for the state of Washington, Oregon, and Idaho.

In conjunction with CRIHB, Ms. Holt continued, they are working on American Indian Recovery (AIR), an alcohol recovery program. Alcoholism is still a significant problem in Indian Country, and it is spreading to the young people. Another concern is insufficient facilities to care for those suffering from alcohol and drug addiction, especially for youth. One youth treatment center in Oregon needs to be replaced. Access to recovery is always a problem.

The Northwest Tribal Cancer Navigator Program is helping to track cancer in reservations. Their EpiCenter is working on misclassifications in death records in all three states.

They recently had an exercise of the State of Washington's pandemic flu plan. The site was the Emerald Green Casino in Tacoma, Washington, one of the largest casinos in the state. Joe Finkbonner, is their point of contact, and he was able to work with the Tribal Council in implementing their pandemic influenza plan and to facilitate the process of closing the casino.

Ms. Holt noted that their immunization conference would be held December 3-4, 2008 at the Portland State University Native Center. They have held several conferences on emergency preparedness to assist tribes with their plans.

Several tribes in her area have issues related to the Canadian border. One tribe is experiencing trouble with drugs coming across the border. Most methamphetamine comes from Mexico and goes across the Canadian border. Many people associated with the Mexican drug trade are marrying young women on the reservations, integrating themselves into the tribal communities, and selling drugs out of tribal housing. The Tribal Council passed a no-tolerance drug policy for housing. Their EpiCenter is working on a "Meth Project" supported by the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center is also working on a successful child safety seat project. Project Red Talon, their STD/HIV program, has recently been re-funded, and they are excited about its progress. They are working on rapid HIV testing for the tribes.

#### Tucson Area Chester Antone, Councilman Tohono O'odham Nation

Mr. Antone reported that the creation of the planning committee for this meeting has brought together the Pascua Yacqui and the Tohono O'odham. He announced that Gary Quinn was the acting Director of Health for the Tohono O'odham, as of the week before. The Tucson area has been in transition.

Suicide is an issue in the Tucson area, with alcoholism and drug abuse among the concerns as well. At first glance, the problem of drugs being brought across the border may seem like a law enforcement problem; however, a number of public health issues are also part of the drug problem. These issues include children who need to be raised when their parents are incarcerated. These children may not be given proper immunizations, for instance, if they are being raised by only one parent or by grandparents. The Tucson area continues to work on its STD epidemic. Prostitution is also a public health problem that is affected by drugs.

There is great need for data sharing agreements and collaborations. For instance, they are working on details of data transfers and business agreements. Assessing their public health problems requires research. Other tribes are ahead of those in the Tucson area in that regard. Historically, "research" has been a negative word on his reservation. They need to change that

perception in order to benefit from research. They look to tribal peoples in other parts of the country for help in how to handle this issue. Navajo Nation, for example, has its own Institutional Review Board (IRB), which has guidelines for the destruction of samples.

Their annual Diabetes Fair was well-attended. The San Xavier District Health Department will host its AIDS Awareness Day on December 1<sup>st</sup>. One of the area's major activities was this TCAC meeting and the Tribal Consultation. Their Health Department has also been working with IHS regarding data sharing.

He recommended that they examine the Federal Collaborative, which is specific to research in HHS. The concept of combining expertise from different departments to address problems in Indian Country could be helpful. This idea was raised at the Health Research Advisory Council meeting in Washington, D.C. last year. He hoped that with a new administration, they could move forward by combining the different departments of HHS in research initiatives. In closing, he acknowledged the hard work of his colleagues on the planning committee for the TCAC meeting.

<u>Direct Service Tribes</u>

Robert D. Moore

District 3 Council Representative

Rosebud Sioux Tribe

Mr. Moore reported that the Direct Service Tribes National Meeting was held in August in Spokane, Washington. Their next conference call was scheduled for Monday, November 24, 2008. Their next quarterly meeting was to be held on December 3-4, 2008 in Rockville. All were invited to attend, given that the direct service tribes share many of the same issues as the self-governance tribes. He looked forward to continuing their work with the administration at IHS in recognizing direct service tribes as self-governance tribes. This change should be meaningful and valuable. There are new Advisory Officers for the Direct Service Tribes: George Howell, Chairman, and Andrew Joseph, Vice Chairman.

They are anxious to observe what will happen in the next administration. Mr. Moore was encouraged by the two leading candidates for Secretary of Health and Human Services. Senator Tom Daschle, in particular, is a friend to Indian Country and will likely elevate the importance of the work that the advisory committees do.

## National Congress of American Indians (NCAI) Derek Valdo Southwest Area Vice President, NCAI

Mr. Valdo directed the group's attention to NACI's Legislative Report, which includes details about Indian bills that NCAI is working on. He then described NACI's transition plan, which includes recruiting tribal people to put forward to serve in positions in the new administration. The Obama campaign promised that a tribal person would be included at the Cabinet level in the new administration. They need to find a tribal person with the appropriate skill set and the willingness to move to Washington, D.C. The NCAI website located at <a href="https://www.ncai.org">www.ncai.org</a> includes updates, the Legislative Report, and the transition plan.

National Indian Health Board (NIHB)

Jerry Freddie

Council Delegate, Navajo Nation

Mr. Freddie noted that NIHB has added new staff members and is in the process of moving its office from Denver, Colorado, to Washington, D.C. The new office is at Pennsylvania Avenue and 10<sup>th</sup> Street. NIHB's professional staff are tracking legislation and working with other Indian organizations. Their emphases on public health and enticing young people into public health through the fellowship program have been important. NIHB also coordinates meetings and works on the Tribal Consultations. In the past, the Bureau of Indian Affairs (BIA) and IHS did not communicate well with Indian leaders and did not give them time to provide their input. For that reason, the Tribal Consultation initiative came from their grandparents. The NIHB Board has done strategic planning and updated its plans. He directed them to the website for additional details.

#### Bonnie Hillsberg Senior Program Manager for Public Health Programs, NIHB

Ms. Hillsberg introduced herself and Raven Murray, a new staff member at NIHB. She then offered additional updates from NIHB. NIHB supported the TCAC meeting in Hollywood, Florida on July 28 – 30, 2008. One of the highlights of the meeting was presentations from the six interns of the Morehouse School of Medicine Public Health Fellowship Program, which they hope to replicate. The meeting included a site visit to the tribal health facility of the Seminole Tribe. The NIHB Annual Consumer Conference was held in Temecula, California, in September 2008. The conference theme was "Unite For Health: Advocate Out Loud." Many leaders representing federal public health entities and tribal leaders joined together for workshops and to network.

NIHB has begun a new initiative, the Public Health Accreditation Program. They hired Dr. Yvette Ubito, a Harvard-trained physician, to spearhead this opportunity, which was funded by the Robert Wood Johnson Foundation to explore public health accreditation in Indian Country.

On April 22 and 23 of 2009. NIHB will host a public health summit in Oklahoma City, Oklahoma. That summit's theme will be "Tribal-State Relocations and Foundations for Public Health." Ms. Hillsberg hoped for a good turnout at the summit, and NIHB invites proposals to address topics on any public health issues or programs at the state or local level.

The Healthy Indian Country Initiative (HICI) is a collaboration with the Association of American Indian Physicians (AAIP). HICI was awarded funds to partner with three national organizations: NIHB, the National Indian Council on Aging, and the National Council of Urban Indian Health. This effort will help support preventive health activities with thirteen tribal organizations.

The Centers for Medicare and Medicaid Services (CMS) Tribal Technical Advisory Group (TTAG) held its third quarterly face-to-face meeting at the National Museum of American Indians in Washington, D.C., in early November 2008. Pending Medicare and Medicaid issues pertinent to Indian Country were discussed, and the agenda included a presentation by a professor at West Virginia University who recently completed a long-term care study of Indian country. Ms. Hillsberg noted that the American Indian Museum is a wonderful venue with excellent meeting space.

#### **Discussion Points**

 Mr. Moore emphasized the importance of the next Public Health Summit on State-Tribal Relations. Federal agency representatives should plan to attend this summit. There is a wide range of relationships between states and Indian Country. Direct Service Tribes are concerned because states utilize statistical information within tribal counties and state counties that encompass reservations, but those resources are not being allocated to those areas to meet their needs. CDC should continue to encourage and foster state-tribal relationships.

- Mr. Moore then highlighted the Public Health Accreditation Task Force. The Task Force has
  had two meetings, and when they held an open meeting at the NIHB Annual Consumer
  Conference to share information about their work, they were met with excellent response.
  He encouraged all of the IHS geographical areas to be represented on the Task Force.
  Tribal leaders must engage in the process, and he invited them to speak with him about the
  project.
- Mr. Gilbert asked for additional detail regarding the benefit that voluntary accreditation affords tribes, and whether Alaska is represented on the Task Force.
- Mr. Moore replied that they are interested in additional participation from Alaska. The value of accreditation lies in tribes' ability to determine for themselves the best measures or standards that are appropriate for their public health needs. The National Public Health Accreditation Board is considering developing a set of measures that are broad in their outcomes. Tribes should accredit themselves, given that no one knows the tribes' needs better than the tribes themselves. Accreditation will also allow tribes to improve and build their public health response, and it will also help tribes exercise sovereignty in how public health programs are delivered.
- Ms. Hillsberg added that the issue has been long-standing in Indian Country. The Public Health Accreditation Board was formed through the American Public Health Association (APHA) and other entities to develop accreditation standards in public health, because now there are no standards. This effort is national, but it is important to note that this measurement of best practices will help everyone understand what works internally in Indian Country.
- Dr. Bryan said that this nationally-led effort is based in state and local health departments and APHA. Often, these efforts are ongoing for some time before Indian Country is included as "an afterthought." In this case, however, Indian Country has been engaged at the ground level, and they must act on this opportunity now.

# <u>Tribal Self-Governance Tribes</u> *Jefferson Keel, Chairman Tribal Self-Governance Advisory Committee*

Ms. Holt read the report from the Tribal Self-Governance Tribes. The Advisory Committee met on October 9 and 10, 2008 in Washington, D.C. The Committee received updates from Hankie Ortiz, the Director of the Office of Tribal Self-Governance, Ann Bracken, HHS Office of Inspector General; Fritz Vaughn, White House Intergovernmental Affairs; and Leo Nolen, HHS Inter-Governmental Affairs. Robert McSwain spent the morning of the second day with the Committee discussing issues of concern to the tribes, including the IHS reorganization; how funding will be handled in the continuing resolution; the FAB priority list; the reshaping of IT packages and tribal shares; contract health services funding for the Dorgan Amendment; and the role of the Government Performance Results Act (GPRA) and the Program Assessment

Rating Tool (PART) under the next administration. Mr. McSwain shared the updated vision for the Indian healthcare system and the IHS 2007 Annual Report.

The Self-Governance Strategy Session will be held in Phoenix on November 18-19, 2008 to strategize and focus on transition issues, White House transition, and Congressional staff. Position papers will be developed on specific topics for this purpose. Further, Tribal Self-Governance Advisory Committee meetings are scheduled for February 24-26, 2009 in Washington, D.C., with the July 21-23, 2009 location to be decided. The 2009 Annual Self-Governance Conference will be held May 17-21, 2009 in Orlando, Florida. The 2010 Conference has been scheduled for May 1-6, 2009 in Scottsdale, Arizona.

#### Discussion:

- CAPT Snesrud thanked the members for their national reports and the richness of their discussion. Anytime an area or national organization is not represented and not sharing their issues, there is a gap. The membership of TCAC includes primary and alternate representatives that are nominated by Area Health Boards. She urged them, if they were not able to attend, to inform her and the meeting contractor so that they could contact alternate representatives to assure full representation: The Area Health Board, the organization, or the local consortia could make the appointments to TCAC and present CDC with important issues.
- This meeting is a transition from NIHB's coordination of meetings to a CDC contractor.
   Capt. Snesrud introduced Natalie Greene of Maximum Technologies Corporation. If TCAC members do not have alternates, then they should nominate them and inform her and the contractor of their names and contact information.
- Ms. Holt asked that they ensure that the list of representatives from each area was up to date.

#### Working Lunch: CDC's Healthiest Nation Initiative and Healthy Nations Alliance

Julia Smith-Easley
Healthy Nations Coordinating Council
National Center for Health Marketing
Centers for Disease Control and Prevention

Ms. Julia Smith-Easley update those present on CDC's Healthiest Nation Initiative, reporting that the US spends more money than any other country on healthcare, but is ranked lower than most developed nations in several areas. While it is imperative to be aware of the possibility of urgent threats and to anticipate those threats, at the same time other urgent realities are major causes of death in the US (e.g., cardiovascular disease, cancer, stroke, diabetes, and preventable injury and violence). The US is not the healthiest nation because it does not get the best value for the money it spends. Health does not occur in the doctors' offices or hospitals. It occurs in homes, schools, workplaces, and communities. The US needs to do a better job of making these places healthy; promoting good health; preventing disease, injury, and disability; and preparing for new health threats. Moreover, health equity makes a difference. Approximately 170,000 lives have been saved by medical advances. However, 900,000 lives could have been saved if the mortality rates between Whites and African Americans had been equalized.

The debate on healthcare is viable, but the focus needs to be changed from a focus on healthcare to a focus on health and wellbeing. Health is not an outcome. Health is a resource that allows people to achieve their dreams and goals. With this in mind, CDC met with ASTHO and NACCHO to create the Alliance for the Healthiest Nation. The Alliance focuses on partnering with leaders from other organizations to create and spark a nationwide movement to create the Healthiest Nation. The Alliance now includes approximately 100 organizations from all sectors of society. They are working toward a committed vision that values health, prioritizes prevention, and protects from emerging threats.

Behavior change is not enough to change health, especially when the social, cultural, and physical environments conspire against that change. It is time, therefore, to think and act differently about health so that the focus is upon being well. The Alliance aims to create and enable physical, social, and economic conditions that will promote health and embrace prevention. The Alliance also wants to make health the default choice for all people and all communities. The organizations in the Alliance work together to create a national commitment to the optimal health of every person. Members and partners include over 100 organizations representing public health, business, health insurance, non-profits, and health care.

The Alliance is a hub to coalesce voices that are already working in these areas. Organizations in the Alliance learn from each other. The Alliance is guided by five basic principles, which are to help the grassroots grow and work with diverse partners; engage in conversation that changes focus from the absence of illness to understanding what will create and maintain health; coalesce voices, convene information, and convene partners to provide the roadmap for the initiative; make it easy to make the right choice—healthy options should be easily available; and measure what matters and to redefine what it means to be healthy.

The Alliance will succeed by engaging all people in the conversation about health. The public's health is bigger than "public health" alone. It takes all parts of society working together. Leaders must be engaged from all sectors of society. Improving health equity is crucial to the effort, because we are only as healthy as the least healthy among us. Further, health must be placed into all policies. Innovations in technology will provide good tools.

The Alliance asks three things of individuals and organizations that choose to join:

Speak Out: Support the need for America to become the Healthiest Nation and improve the value of our health investments
Walk Your Talk: Take at least one specific action to improve health and model positive health behavior in your home, community, organization, school, or jurisdiction
Share Your Successes: Join the Alliance for the Healthiest Nation: <a href="https://www.healthiestnation.org">www.healthiestnation.org</a> ; tell others about your efforts and the impact they have; and encourage others to do the same

Health and healthcare challenges are enormous issues in this country. The solution requires shifting focus from just treating disease to promoting health, being healthy and becoming "well beings." Success is only possible by empowering individuals and organizations through health system transformation, policy, and equity interventions combined with meaningful measures. The time to act is now.

Ms. Smith-Easley requested that the leaders present hold the dates of May 27-28, 2009, for a Leaders-to-Leaders Summit in Washington, D.C. This Summit will assemble a broad spectrum of leaders to link together, leverage assets, and lead to actions to improve the health and longevity of our world and its citizens. Ms. Smith concluded with a brief video created by one of the Alliance partners.

#### **Administrative Matters**

#### **Confirming Dates for Quarterly TCAC Meetings**

Captain Pelagie (Mike) Snesrud
Senior Tribal Liaison for Policy and Evaluation
Centers for Disease Control and Prevention (CDC)

CAPT Snesrud introduced Annabelle Allison, the Tribal Coordinator for the Office of Tribal Affairs. Ms. Allison greeted the group and said that she hoped to incorporate environmental health topics into their discussion. NCEH and ATSDR hope for work more effectively with tribes on these topics. She invited them to share their ideas with her.

CAPT Snesrud clarified the next two TCAC meetings: the next meeting is in Albuquerque, New Mexico, and the proposed dates were February 17 – 19, 2009.

Meetina Minutes

#### **Discussion Points**

- There was discussion about the best dates for TCAC so that the meeting would not conflict with Tribal Lands Bidding Credit (TLBC) or other meetings.
- This meeting will be held simultaneously with an American Indian/Alaska Native pandemic influenza meeting.
- The week of February 10-12, 2009 was suggested, and it was decided that the contractor would check availability at hotels and venues in the Albuquerque area. Native facilities should be given preference.
- CAPT Snesrud commented that the federal agencies and advisory committees should work through the OS/IGA and in communication with the National Indian Health Board, so that there is an informed uniform calendar.

CAPT Snesrud then turned to the May meeting in Atlanta, Georgia. It was proposed that May 11, 2009 would be the travel day for that meeting.

#### **Discussion Points**

- Stacy Ecoffey, Principal Tribal Advisor, OS/HHS/Office of Intergovernmental Affairs, reminded them that because of the transition to a new administration, scheduling would change and shift forward about 45 days. The Budget Consultation will not take place in March as usual, but in April. All regional consultations will be shifted as well. For this reason, she suggested that the TCAC wait until the middle of January to finalize the May dates.
- CAPT Snesrud commented that the meeting would also depend on the availability of the CDC Director. The May dates had been chosen according to Dr. Gerberding's availability. In addition, the CDC National Center Directors and programmatic staff will be available to work with tribes.
- Ms. Holt reiterated that it was important to share information about the dates.
- CAPT Snesrud agreed and added that TCAC members could help by advising Ms. Bohlen
  of their area tribal health board meetings and other national meetings to minimize conflicts.
- Regarding facilitating advisory committees, as many TCAC members sit on multiple
  committees, Ms. Ecoffey said that they have had internal discussions with their ICNAA
  Liaisons regarding better information-sharing. This year, meeting dates were submitted in
  liaison's monthly reports. They hope to have periodic meetings with the chairs of the
  advisory committees so that those leaders are in communication. She commented that
  there are many committees, and they are difficult to coordinate.
- CAPT Snesrud said that they would schedule a conference call for mid-January to receive information from Ms. Ecoffey and solidify dates for the Atlanta meeting in the end of May or early June.

CAPT Snesrud then turned to the next quarterly TCAC meeting and put forward the previously suggestion to hold it in Alaska with a travel date of August 10, 2009, and meeting on August 11 and 12.

#### **Discussion Points**

- There was discussion about the Tribal Health Director's Meeting in Alaska to ensure that they would not conflict. CAPT Snesrud added that if an event was occurring that TCAC leadership might be interested in, then they could "piggyback."
- Mr. Gilbert said that the Alaska Native Health Board meets from August 11 13, and the week prior to that would be preferable for the TCAC meeting.

CAPT Snesrud then noted that they had not set dates for the TCAC meeting and Tribal Consultation in Indian Country for the end of November or early December. Palm Springs, California, had been suggested on December 14-17, 2009.

#### **Discussion Points**

Mr. Crouch agreed that California would be the host area in December 2009. He would provide ideas for an appropriate "host spot." He offered the possibilities of Thunder Valley in Roseville, Rumsey Rancheria in Davis, and the Red Hot Casino in Shingle Springs.

#### Reactivation of the PHEP and Budget Subcommittees

Captain Pelagie (Mike) Snesrud Senior Tribal Liaison for Policy and Evaluation Centers for Disease Control and Prevention (CDC)

CAPT Snesrud indicated that the Subcommittees will be chaired, or co-chaired, by TCAC members. During the January 2008 TCAC meeting, Chester Antone, Jim Roberts, James Crouch, and J.T. Petherick expressed interest (or were nominated by TCAC representatives) for the Budget Subcommittee. Other TCAC members may be interested in joining as well. A senior-level staff person from CDC's Financial Management Office (FMO) will be designated to serve as the point of contact for the Subcommittee. TCAC members can assign themselves to the Subcommittee or return to their areas and designate a technical expert to serve on the Subcommittee. The data will help them prepare for the HHS National Budget Consultation and the CDC Tribal Consultation in Atlanta in the late spring 2009.

The other Subcommittee is the Tribal Preparedness Emergency Response Subcommittee (TPER). The TPER Subcommittee had previously convened several conference calls with participation from Cynthia Manuel, Chester Antone, Allan Harder from the OK Area Health Board, Joe Finkbonner from NWPAIHB, and Lawrence Shorty of NIHB. In the past, the DSLR Al/AN team had also joined the call. CAPT Snesrud would find and share the minutes from those meetings as this group re-establishes itself.

The work of the TCAC will depend on the ability of these Subcommittees to organize and get work done to present back to the TCAC. Ms. Holt suggested that an email go out to TCAC members to ask for names of technical people from their areas to serve on the Subcommittees, as well as TCAC members who might want to volunteer to participate.

#### **Discussion Points**

- Mr. Crouch wondered whether the TCAC Budget Subcommittee would function parallel to the Budget Committee for T-TAG and their preparation of materials for the advisory process.
- Ms. Holt replied that TCAC's Budget Subcommittee would go through CDC's budget and prepare testimony for the HHS budget consultation and two consultation meetings with CDC. The goal is to impact CDC's budget.
- Mr. Antone expressed his continued interest in the Budget Subcommittee.
- Dr. Bryan added that the TCAC Budget Subcommittee would also examine the information that CDC gathers every year regarding the allocation of resources. CDC analyzes the budget in two ways: how the money is allocated via direct grants to tribes, and to which programs the funds are going. The Budget Subcommittee can look at this information and make recommendations regarding how CDC is allocating the funds it does have.
- Mr. Crouch expressed his desire to lead the Budget Subcommittee with Jim Roberts.
- It was decided that the group would move to the next agenda item and move discussion of the revision of the TCAC charter to the "CDC Updates" section of the agenda.

#### **Suggestions and Approaches for CDC Budget Opportunities**

#### Federal Budget Cycle and Process

Michael Franklin
Financial Management Office
Centers for Disease Control and Prevention

Michael Franklin stressed that as Indian tribes are provided with funds and reports along disease lines, it is crucial for the tribes to analyze data about fund allocations, evaluate it, and provide feedback to CDC. The federal budget is operating in a deficit, and CDC has allocations all over the world, so it is important to "get bang for the bucks."

He then explained the federal budget cycle and process. The budgets for FY 09 were begun 18 months to two years ago. To increase visibility, tribes should start working immediately to affect the budget. However, they cannot expect to realize the "fruits of their labor" for 18 months to two years. CDC and HHS can work on four or five years' of budgets at a time. Usually, the planning process at CDC begins in January or February of the calendar year. The nine Coordinating Centers of CDC are also planning. Engagement with partners should start at the beginning of the calendar year, therefore. The Office of Management and Budget (OMB) forwards its guidance to HHS in the spring, and HHS passes it through to CDC. The Coordinating Centers of CDC then respond to the guidance. By the fall, OMB responds, and there is usually a soft agreement from OMB regarding the budget by the end of the year. In the beginning of 2009, they will be considering the 2011 budget. Next, the budget is sent to Congressional Committees. They review all budgets from all agencies. They can add and remove items from the budgets as well as add stipulations for where funds will be spent. This process takes place in January or February. By July, OMB has approved the Congressional

changes. In September, the President should be able to sign the Appropriations Act; however, the signing rarely takes place in September. In this case, the budget goes into a Continuing Resolution in order for the government to keep operating.

It is important for tribes to understand when their partners are planning and when Congress is reviewing budgets. When the Coordinating Centers are planning, tribes should be actively engaged with them and with their partners. CDC has Executive-level committees, including the Executive Leadership Board and the Financial Strategy Committee. Mr. Franklin suggested that tribes work with those groups to present their suggestions about the impact of CDC dollars on tribes. The dollars are getting smaller, and they have to plan better and prioritize their needs for the long-term. Tribes should show CDC where their needs are greatest.

Tribes can also make their wishes known at the Congressional level. There are many other groups competing for dollars, as CDC only has a set amount. Tribes should make as much impact they can at the Congressional level, as Congress has the power to make recommendations regarding the HHS and CDC budgets.

#### **Discussion:**

- Mr. Crouch asked about the organizational chart for CDC and the Coordinating Centers, noting that only six Coordinating Centers appear on the organizational chart.
- Mr. Franklin explained that under the Office of Director, there are Coordinating Centers.
   Under the Coordinating Centers, there are National Centers. The Coordinating Centers are the highest level in the structure, just below the Director, but in some cases, tribes will want to engage with National Centers as well. Any questions could be directed to him. He asked for participants' contact information as well, and indicated that he would email them a document detailing the flow of the federal budget process.
- Mr. Gilbert said that they hoped to develop capacity in early detection for colorectal cancer
  in Alaska. Several tribal organizations have CDC funding for breast and cervical early
  detection, and that model will serve as a base for colorectal cancer screening efforts. He
  clarified that when he speaks with his partners in February of 2009, they are thinking about
  the 2011 budget.
- Mr. Franklin confirmed that timetable. CDC partners are working on the 2011 budget now, and FY 2009 and FY 2010 are complete. There can be some variability in the process. In February 2009, Congress will review the FY 2010 budget. That would be the time to influence members of Congress for 2010. Agencies work 18 months in advance, and Congress works approximately in February for the next fiscal year. He also noted that there is a great deal of overlap in the budget process at the agency level. For instance, even though the FY 2010 budget has already gone to OMB for input, it is still possible to talk to agencies about 2010. This is a "window of opportunity" between when OMB returns the guidance and when Congress approves the budget. Centers usually begin planning between February and May. In earlier months, they are executing the previous budget. He acknowledged that it can take time to make an impact with federal partners, and it is never too early to become engaged and to have conversations about their needs.
- Mr. Gilbert asked whether this timeline also applies to other HHS agencies, or whether there
  is variation among agencies.

 Mr. Franklin answered that the overall timeframes are general to the federal government process. CDC has deadlines for working with HHS, as HHS is CDC's parent agency. This shortens the time that CDC has to respond to HHS so that HHS can turn the response to OMB.

## CDC / ATSDR FY 2008 Resource Allocations: American Indian/Alaska Native Programs Preliminary Report

## Mr. Franklin and Dr. Ralph Bryan Centers for Disease Control and Prevention

Mr. Franklin and Dr. Bryan then presented a preliminary report of the CDC/ATSDR resources committed to programs that benefit American Indian/Alaska Native populations and communities. The fiscal information was summarized according to organizational and disease-specific programs and by defined funding categories.

Funding allocation categories include intramural, extramural, awardee, or indirect funding. The total American Indian/Alaska Native funding for FY 2008, including Vaccines for Children (VFC) was \$108,080,000. Non-VFC funding was \$43,816,183, or 41%t of the total funding. The \$43 million of non-VFC funding represents an increase from FY 2007. The VFC funding level decreased in this time, given that all of CDC's budget was decreased. Dr. Bryan noted that these figures included all funding categories, including grants, cooperative agreements, resource allocations, and grants to states that benefit tribes. Not including VFC, Chronic Disease Prevention and Health Promotion programs comprised the highest percentage of American Indian/Alaska Native total funds.

Mr. Franklin then detailed the different types of funding allocation categories, which include the following:

Direct Al/AN Awardees: Competitively awarded programs (i.e., grants, cooperative agreements) where the awardees' is a tribe/tribal government, tribal organization, tribal epidemiology, Alaska Native organization, tribal college or university, or urban Indian Health program.
Intramural AI/AN: Intramural programs whose purpose is to primarily or substantially benefit AI/AN. This category would include costs (salary, fringe, travel, et cetera) associated with CDC staff or contractors whose time/effort primarily or substantially (50% or better) benefit AI/AN.
Extramural AI/AN benefit: Competitively awarded programs where the purpose of the award is to primarily or substantially benefit AI/AN.
Federal Al/AN benefit: Federal Intra-Agency Agreements where the purpose of the agreement is to primarily or substantially benefit Al/AN.
Indirect Al/AN: Service programs where funding for Al/ANs can reasonably be estimated from available data on the number of Al/ANs served. This category applies only to the Vaccines for Children program and to NCHS.

Including VFC, most funding to tribes was through indirect means. Without VFC, 52% of the funding allocation was via American Indian/Alaska Native awardees. The funding allocations for FY 07 and FY 08 include the following:

Funding Allocation Categories for	· FY	07 and FY		(with VFC)
Type of Category		FY 2007		FY 2008
AI/AN Awardees	\$	21,948,174.00	\$	22,987,100
Extramural AI/AN	\$	9,500,990	\$	10,423,149
Federal AI/AN	\$	1,963,397	\$	2,166,985
Intramural	\$	6,910,766	\$	6,814,203
Indirect	\$	70,718,481	\$	65,688,647
CDC/ATSDR Grand Total	\$	111,041,808	\$	108,080,084
<b>€</b>	>>>	*()	>> <b>&gt;</b>	CDC

Mr. Franklin noted that American Indian/Alaska Native funding represents 1.2% of the FY 08 budget, which is parallel with FY 2007.

#### Discussion:

- Mr. Crouch asked for clarification about the \$1.4 million that was allocated to tribes, without VFC funds included in the calculation, observing that funding grew in every category.
- Mr. Franklin replied that this category includes services that may service the American Indian/Alaska Native populations.
- Dr. Bryan added that the figure is derived according to population-based estimates sent by the states and generated by the National Center for Health Statistics. He also noted that the FY 07 to FY 08 funding decreased because VFC funds to CDC decreased. Overall, it appeared that the American Indian/Alaska Native allocations increased by 8%. They will generate maps to illustrate the locations of awardees, as well as information about the amount awarded per state, where the funds were spent in each state, and the number of tribal awardees. The amount of funding to tribal awardees appears to have increased by about \$1 million, which is a trend in the right direction.
- CAPT Snesrud apologized for not sharing the information before the meeting. Each year, they collect this information at this time to submit the annual report to the Office of the Secretary of IGA. This report is a work in progress at this time.
- Ms. Holt said that deciphering the budget has been a challenge for TCAC, and she
  appreciated the work that they had done to help simplify the budget. She urged CDC to
  start impacting the budget. She recalled Dr. Gerberding's comments from the February

2008 consultation, when she said that her "hands are tied" to line items in the budget. TCAC should work on breaking those strings that are attached in the line items and give the CDC Director room to move. She reminded them that TCAC looks at CDC's budget as part of the Federal Trust Responsibility that the US government has to each sovereign nation in this country. Every agency within HHS must meet that obligation to provide adequate healthcare for tribal members. If they have to take resources away from a foreign country, then they will advocate for that, as the US government's responsibility is to make its nation whole and well before spreading limited resources throughout the rest of the world. There are Third World conditions across the country, in many different areas. It is time to put focus on those people who have been ignored and neglected, especially the children.

- Mr. Moore returned to the definition of "indirect funding." He suggested that the next step was to find out the numbers of tribal people who were served in the "indirect funding." This issue is significant in the Great Plains states and in other areas in which states have jurisdiction in Indian Country. If resources are going to states based on population estimates that include Al/AN populations, then CDC should be accountable for those resources going to those populations. Tribes also need to be able to advise CDC whether those indirect funds are effectively helping their populations. If not, then they should return to the CDC budget and request 4% of the CDC/ATSDR budget. States do not always include tribal communities and governments in their population estimates. For instance, South Dakota did not include three of the country's poorest counties in its recent unemployment estimates. These three counties include Indian reservations. CDC should especially hold states accountable for distributing resources to populations with large subsets of children.
- Dr. Bryan clarified the "indirect funding" category, indicating that most of the indirect funds are through the VFC program, through which American Indian tribes receive vaccines. Census-based population data are used to allocate funds for VFC. In addition to VFC, CDC sends funds to state- or university-based awardees for programs, some of which benefit tribes. CDC makes sure that awardees can document their work with tribes. He offered the Prevention Health Research Center at the University of New Mexico as an example. They have a number of extramural grants in different categories, and they are accountable for the programs that benefit tribes. There is an accountability issue with states. Some funds received in the extramural category may not directly go to tribes, but can still benefit tribes.
- Mr. Moore reiterated the importance of knowing the number of tribal members served by indirect funding sources. Dr. Bryan said that they would be able to provide that information.
- Mr. Moore said that the United States Census will state that tribal communities are among
  the most under-counted groups in the country. If funds are distributed according to Census
  statistics, then people may be struggling because the numbers of tribal populations are not
  accurate.
- Dr. Bryan said that the Census is only one way that population estimates are reached. They
  also use CDC's National Immunization Survey and information from IHS. VFC can also
  provide information about how many children in a given region are being vaccinated.
- Mr. Moore commented on the Center for Excellence at the University of Colorado at Denver.
  TCAC was not aware that the Center would be awarded to the University of Colorado, and
  two tribal organizations applied for the grant. The choice of a non-Indian institution to
  evaluate work in Indian Country is not acceptable. The \$4.2 million for the Center could

have been divided among three major areas with diabetes problems for those communities to develop their own Centers of Excellence for the delivery of those special diabetes prevention programs. TCAC should always be mindful of what has happened, so it will not happen again. This role is part of the information-sharing process for which TCAC is accountable to its constituency.

- Mr. Trudell recalled when he served on a budget advisory committee. Without fully
  understanding the budget process, they cannot analyze what they are being told by CDC.
  He recommended a series of budget development workshops or seminars, which would
  help everyone involved in the process of advising on the budget to understand how the
  budget is put together. A similar process occurred through IHS, and it was successful.
- Ms. Holt agreed, adding that the education should take place at the ground level with all areas that impact American Indians and Alaska Natives.
- CAPT Snesrud said that although CDC and IHS budget process are fundamentally similar, they are quite different in that all of IHS's budget is allocated to benefit AI/AN tribes. CDC's budget only includes a few categorical areas with set-asides for tribes as CDC allocates its resources to benefit all people and communities. Only about 15% of CDC's total budget is not earmarked by Congress (discretionary). Tribes have a great deal of power to influence CDC's budget planning process. CDC's budget last year was \$8.8 billion, tribes can play a role in making more of these funds available to tribes. CDC is attempting to be transparent regarding the budget process and budget figures, tribal leaders who know their priorities and issues to can choose to make their voices be heard to HHS and congressional leaders.
- Mr. Trudell said that it would be helpful to learn what drives the budget and where tribes can fit in, other than as tribes. Tribal communities share common problems with other populations, and they could eliminate themselves from participation if they hold out as strictly tribal entities. Treaties are the force behind their requests, but they still need to fit into the rest of the country and the funds available for the rest of the country. They may not have their own earmarks, but they could find resources from other directions.
- Larry Alonson, Division of Diabetes Translation, offered an example of how extramural dollars are spent to benefit tribes. There an ongoing effort on behalf of states for a diabetes prevention and control grant. This grant would affect all populations in the state, and American Indians are part of that "big picture." Now is the time for tribes to work with states to ensure that they are part of the discussion. The technical assistance document for the grant includes the requirement that states engage tribes in consultation. Tribes can, therefore, influence the dollars that are granted to states to impact diabetes.
- Ms. Holt said that states are not held accountable for funds awarded to them on behalf of AI/ANs. States often do not share with AI/AN tribes, and they are falsifying statements and reports that go back to granting authorities. Some states have good relationships with tribes, but other states are not negotiating or meeting with tribes. Tribes try to work with states, but she noted that she would continue to advocate for block grants for tribes. Tribal communities should not have to go through states for money that is specifically for Indian tribes. It should be allocated directly to Indian tribes.
- Mr. Antone wondered whether the statewide application for funding for diabetes prevention
  will have the same process as the preparedness grants, for which states had to engage
  tribes.

- Dr. Bryan said that CDC hopes to emulate the Public Health Emergency Preparedness Funds model across the agency. Tribes are not eligible for some funding opportunities, but for others, CDC's funding guidance states that in order for states to apply for and receive dollars from CDC, states must engage tribes in the process from the beginning. The model that started with preparedness has spread to immunization funds and STD funds, as well as diabetes funds. Language is just the first step, while accountability is the next step. CDC must work with its programs to ensure that the engagement is meaningful and that resources are being shared. The process will be slow and variable. They are training their project officers to be sensitive and attentive to these issues. If these processes are not going well in a state, then the applicable project officer will work through the problem.
- Mr. Antone asked for clarification on which funds that are not flexible. Tribal nations can then lobby to change those laws. When CDC requires states to provide estimates of American Indian/Alaska Native populations to be served, the state should include the signature of the Chief Officer of the tribe. Direct funding to tribes will be important, and tribes will need to make plans to affect legislation. Funding to states translates to employment, and it will be a tough fight to take part of the total state funding and turn it directly to tribes.
- Dr. Bryan added that funding language is not always clear. CDC then has to interpret
  whether "state and local," for instance, is meant to include tribes. He encouraged those
  present to inform those writing the laws that tribes should be specifically included, and the
  intent of laws should be clear regarding tribes.
- Ms. Holt recalled that emergency preparedness money must have accountability as well. In a recent hurricane in Louisiana, tribes were not helped by FEMA. When an emergency happens, CDC should demand that the state clarify how reservations within the disaster area are being helped. State reports to CDC regarding how monies are spent should include a signature from tribes regarding where the money has gone.
- Mr. Gilbert hoped that the rest of the TCAC understood the budget process well enough to know when to bring information to the committee. Further, he wondered whether TCAC had made a broad recommendation to CDC regarding doubling the percent of CDC's budget that goes to tribes. He stressed that leadership in any agency must be a champion for their causes, observing that SAMHSA allocations to Al/AN projects have increased because of the change in leadership there. Now might be a good time for TCAC to make a strong recommendation regarding increasing the budget, given that new CDC leadership is likely.
- Ms. Holt said that TCAC testified at the HHS budget consultation in 2008. She and
  Jefferson Keel testified for an increase in the CDC budget for Al/AN issues. They plan on
  being very visible with the new leadership, since getting CDC senior leadership engaged
  with TCAC has been difficult. The process has been educational on both sides, both with
  CDC learning about tribes, and tribes learning about CDC.
- Dr. Bryan said that the leaders of an agency make a difference regarding how much progress is made on a number of fronts, including AI/AN issues. Some leaders may not be engaged in the process, while others can actively put up barriers and roadblocks. He felt that CDC has made good progress, but he hoped for more engagement from leadership while ensuring that they keep working as they have done.

- Mr. Trudell addressed emergency preparedness in a big snowstorm at Rosebud. There was
  no ongoing dialogue between the state and tribes. There is individual communication,
  however. The IHS Region Seven Director called him personally when he heard about heavy
  snow in the area.
- CAPT Snesrud said that the area of public health emergency preparedness, including
  bioterrorism and pandemic flu, created the opportunity for putting the first strong, authorizing
  language in their funding guidance was based on input from TCAC going back to January
  2007. Relationships and partnerships need to be built in times when there is not an
  emergency, so that when a situation occurs, those relationships are in place. There have
  been changes in leadership in COTPER, which is a critically important office. TCAC needs
  to re-educate and re-integrate leadership from this critically important office.

#### **Updates from CDC in Response to TCAC Recommendations**

Captain Pelagie (Mike) Snesrud
Senior Tribal Liaison for Policy and Evaluation
Centers for Disease Control and Prevention (CDC)

CAPT Snesrud and Dr. Bryan offered feedback on the following TCAC recommendations:

The most important overarching TCAC recommendation was to continue to fully implement procedures of the consultation policy. This policy was put into place to increase tribal access to CDC resources and programs. All other actions flow from this policy.
CDC included stronger language in all cooperative agreements with the states regarding Public Health Emergency Preparedness dollars with the Division of State and Local Readiness (DSLR). There are many advocates for tribal issues within CDC. Standardized language within the DSLR was mimicked in the Immunization Program. The National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) Program staff have also responded and are committed to using this language. Recently, senior staff from NCHHSTP made site visits to Indian Country and requested that PGO include this language in all of the Center's new funding opportunities. These three programs are forming a precedent across CDC to engage more programs. The language is specific and direct regarding tribal eligibility.
With regard to the TCAC recommendation concerning the timeframe for response from CDC, there is a flowchart to improve response time.
With respect to training for project officers assigned to AI/AN communities, CAPT Snesrud has reached out across the agency to meet with project officers in different programs to inform them about their roles in working with AI/AN tribes and communities throughout Indian Country.
Regarding competitive applications, CDC programs are working diligently to ensure that

when funding opportunity announcements target tribal communities and tribal applicants,

the best objective review panel possible is assembled. In situations when funding announcements are more broad, the objective review panels should still include

members who are savvy and knowledgeable about Indian Country. The federal granting process is peer-reviewed, and all agencies work to provide an objective and fair process. In some cases, it is difficult to find knowledgeable reviewers.
In terms of monitoring and tracking where tribal recommendations have influenced CDC priorities to enhance tribal access to CDC resources, CDC is working to be transparent about where dollars are going in Indian Country. Sharing this information with TCAC helps the committee return to CDC with advice.
There a continued discussions with FMO about guidelines to allow tribal stakeholders to provide input into the CDC budget formulation process.
Pertaining to increasing tribal stakeholders' knowledge of CDC funding opportunities and how to obtain technical assistance in the application process, CDC is working with NIHB and other partners to disseminate this information as broadly as possible. PGO staff members are available to provide technical assistance and are trying to institutionalize these processes.
While a CDC-wide AI/AN strategic plan has not yet been created, Dr. Stephanie Bailey strongly supports the concept of a plan. This plan will be re-visited after the administration transition.
Formal orientation has been delivered to tribal leaders once, and it went well. This will be planned and offered again at each Atlanta based consultation session.
Concerning the assurance of adequate staff and resources within the Office of the CDC Director (OD), funds are short across the federal government, and the infrastructure at the Office of the Director is taxed as efforts are underway to shrink the office, not to grow it. Following the transition, TCAC should be prepared to make strong recommendations. Dr. Bailey has voiced support for establishing an Office of Tribal Affairs within the OD. There is also a need for a succession plan, as both Dr. Bryan and CAPT Snesrud are of retirement age, as is their boss, Dr. Williams. Their positions must be institutionalized, and that will take active planning and foresight on the part of TCAC.
Regarding conscious awareness of HIV/STD infections among AI/ANs resulting in maintaining level based funding, NCHHSTP is invested in Indian Country and is hosting an External Consultation to address Social Determinants. Outcomes will be used to guide policy, programmatic, and research efforts.
The Division of Adolescent and School Health (DASH) is strengthening its relationship with Indian Country and addressing issues facing Native youth. Tribes are now funded under Comprehensive School Health. DASH provides technical assistance to BIE and Navajo Nation to conduct YRBS in addition to funding states and large urban areas, and is partnering with NCIPC and the Adolescent Goal Action Team to address suicide prevention in AI/AN youth.
TCAC will remain engaged in the Goal Management Process, as long as that process continues. There has been an agency-wide response to TCAC's recommendations. They are making headway, but they are not where they want to be.

Dr. Bryan then distributed a document from COTPER regarding awareness in Indian Country for accessing and utilizing the Strategic National Stockpile. He asked for their feedback on the document.

CAPT Snesrud turned the group's attention to the TCAC Charter. In mid June, PGO instructed OMHD that it was inappropriate to direct funds through the NIHB Cooperative Agreement to do CDC's work. Since the TCAC is CDC's Advisory Committee and convening this committee is CDC's responsibility, funds for this should go through a contractor already working to do this task for other CDC advisory committees. This necessitated changes in the TCAC Charter and in NIHB's responsibilities. The suggestion changes were discussed by Dr. Williams, OMHD Director, and Stacy Bohlen, Executive Director of NIHB, and are reflected in the new Charter.

Ms. Holt offered a point of order, noting that the outside contractor has been retained without the approval of a revised charter. TCAC should have handled the revision of the Charter on a conference call.

#### **Motion**

Mr. Moore moved that TCAC request the new administration to establish an American Indian/Alaska Native-specific OD office within CDC. Mr. Trudell seconded the motion.

#### **Discussion Points**

- Mr. Crouch felt that it was appropriate for TCAC to give advice to CDC. Institutionalizing the American Indian/Alaska Native-focused leadership in CDC is important. The position should be "as high as possible" within CDC's organizational structure.
- Mr. Moore suggested that NIHB also submit this recommendation to NCAI in their transition activities. He further suggested that they identify tribal persons who can transition into the positions held by Dr. Bryan and Capt. Snesrud.
- Ms. Holt said that an Al/AN Internship program with long term funding would also be a beneficial and critically needed element.

#### **Motion**

Mr. Moore amended his motion to include the recommendation that tribal persons should be identified who can move into positions currently held by Dr. Ralph Bryan and CAPT Mike Snesrud. Mr. Trudell seconded the motion. The amended motion carried unanimously with no abstentions.

#### **CDC Program Updates**

<u>CDC's Division of Violence Prevention's Activities on Suicidal</u>
Behavior Prevention Among American Indians and Alaska Natives

#### **Alex Crosby**

National Center for Injury Prevention and Control / Division of Violence Prevention

Dr. Crosby addressed the group via telephone, thanking them for the invitation to speak to them about the Division of Violence Prevention's (DVPs) activities regarding suicidal behavior prevention. The Injury Center is involved with a number of other activities as well (e.g., motor vehicle injuries, intentional injuries, drowning, recreational injuries, intimate partner violence, et cetera). He explained the public health approach to prevention, regardless of the problem being considered. They begin with a foundation of assessment: Who, What, When, and Where is the problem? After they describe the problem, they move to identifying the causes of the problem and learning about risk and protective factors. If they do a good job of identifying the problem and its influences, such as the roles of depression in suicidal behavior, then they should be able to address the problem. The next step is to develop and evaluate programs and policies to address the problem, followed by implementation and dissemination of successful programs and policies.

Dr. Crosby reviewed selected CDC activities in suicidal behavior prevention among Native Americans. In the area of problem description and surveillance, they are using the National Violent Death Reporting System (NVDRS). Data on death certificates are often limited, and certificates frequently do not include a great deal of information on factors that play a role in suicide. The NVDRS combines death certificate data with data from law enforcement; from the medical examiner or coroner; and from toxicology lab or crime lab. Law enforcement can provide details regarding where a firearm came from, for instance, and who its last owner was. Toxicology reports shed light on the state of the person prior to death. The medical examiner or coroner data can include information about the person's past medical history, including psychiatric history. Interviews with police can reveal personal details, such as financial problems or family history. This rich information is not available on the death certificate alone. The NVDRS is operational in 17 states, including several in the Western United States.

In the area of evaluating programs, the Division of Violence Prevention has developed a partnership with the Substance Abuse and Mental Health Services Administration (SAMHSA). The G.L. (Garrett Lee) Smith Memorial Act provides funding for a number of tribal suicide prevention activities. The majority of funds from this Act go to programs and not to evaluation. It is important with youth suicide to find out which programs work better in which circumstances. An agreement with SAMHSA allows for this crucial evaluation. The work focuses on the promotion of protective factors, connecting them with the cultural history of tribes. The G. L. Smith Memorial Act-funded suicide prevention program took place in three waves. The first wave of projects is assembling information about its evaluation. The results appear to be positive.

Another important collaboration is with the Tribal Epidemiology Centers, which are funded by IHS. The Centers are regionally located and provide scientific epidemiological support to tribes in their areas. Technical assistance is available for assessment, research, programming, applying for grants, and in other areas. The Division routinely conducts conference calls with the Tribal Epidemiology Centers and IHS to provide technical assistance on injury-related issues and to facilitate communication between the Centers about their activities.

The Division has collaborated with IHS and a tribal reservation in the Midwestern United States in response to a cluster of adolescent suicide. They engaged in conversations with the tribal president, local community groups, IHS, and others. A team from CDC went to the reservation to conduct epidemiological studies on the cluster. They held focus groups and examined emergency department data, emergency medical system data, coroner data, and other sources to characterize the factors that play a role in suicide in this area. The team is conducting its final analysis.

Suicidal behavior in certain populations is tied to health disparities, and the division intends to address those disparities. The Division is working with several programs at CDC and in other federal agencies two look at two specific populations and suicidal behavior among adolescents: the American Indian/Alaska Native population and the Latino population. They will bring together an expert panel to examine some of the problems related to adolescent suicidal behavior and to identify recommendations for where federal agencies and local communities can take action. Expert panels will meet separately, but at the same time, and they will come together to discuss common aspects that their populations share. These panels will convene in the Spring of 2009.

# **Discussion Points**

- Mr. Valdo asked about the division's work with the Suicide Prevention Alliance Network (SPAN), which is working along parallel lines.
- Dr. Crosby replied that they are connected with SPAN. In particular, they have worked with SPAN regarding survivors who have lost a friend or loved one to suicide. SPAN will be asked to provide suggestions for expert panel members. A working group of federal partners that work in the area of suicide prevention is active. The group includes representatives from the National Institute of Mental Health (NIMH), SAHMSA, IHS, AoA, VA, DOD, and other groups that address national strategies for suicide prevention. They may move forward with an Action Alliance, an oversight group over a national suicide strategy that includes both public and private organizations and entities.
- Dr. Linda Frizzell described a workgroup with IHS and Health Canada that has been active. She strongly urged Dr. Crosby and the Division to include a youth on the expert panel, noting that in her experience, youth have provided great insights on issues that field professionals have been unaware of.
- Dr. Crosby appreciated the recommendation to include a youth on the expert panel. CDC has worked with Health Canada in the past. The IHS has been the lead in that relationship and First Nations issues.
- Mr. Gilbert offered to forward Dr. Crosby suggestions for expert panel members from Alaska, where they have a great deal of activity in suicide prevention.
- Dr. Crosby welcomed suggestions, noting that they are limited to approximately eight to ten people per panel. He asked that names be sent to Capt. Snesrud or Dr. Bryan to be forwarded to him.

# **Quarantine Regulations**

Dr. Bryan introduced the update on quarantine regulations. Tribal consultations in 2005 and
2006 were held on this issue around the country. The new proposed regulations are still in the
review and approval mill with HHS and OMB. Representatives from the Division of Global
Migration and Quarantine (DGMQ) were present on the telephone:

Stacy Howard, Senior Policy Analyst
Ashley Malone, Legal Analyst
David Gatham, Associate Director for Policy
Steve Waterman, medical epidemiologist

Dr. Malone thanked the group for the opportunity to present to them and apologized for not being there in person.

The Public Health Service Act passed by Congress granted the Secretary of HHS the authority to quarantine individuals. Within that authority is the ability to apprehend, detain, and conditionally release individuals. The purpose of this authority is to prevent the introduction, transmission, and spread of communicable diseases within the United States. The Secretary of HHS delegated that authority to CDC, and the Director of CDC passed the authority to the DGMQ.

Part of the Division's responsibility includes the quarantine regulations, which were last updated over twenty years ago. Science, technology, and travel have come a long way since then. The purpose of updating the regulations is not only to bring the current regulations in line with modern technology, but also to codify current procedures. Over 500 comments were received when the updated regulations were published in the Federal Register. For the past three years, the division has worked with state, local, and tribal health authorities and conducted tribal consultations. They have come a long way in clarifying their roles and responsibilities as well as their authorities and practices. They cannot create new authority, but they have worked to clarify the regulations for the general public.

The Division submitted a draft of the revisions a few months ago, and it is now at the level of the Department of HHS. She expressed her appreciation for comments presented by tribal communities during the process.

Dr. Bryan described activities since the tribal consultations in 2005. A letter to tribal leaders explained the pertinent changes and updates to the Federal Quarantine Regulations. The proposed changes clarify a number of jurisdictional issues in Indian Country, where the current regulations make no mention of Indian Country. Feedback was received from individuals as well as from representatives of tribes and tribal governments. The majority of those comments were treated positively and incorporated into the document. The transition of governments will likely delay the publication of the Final Rule, but when the date of release is known, CDC will send tribal leaders a letter advising them of the imminent publication of the regulations in the Federal Register. Ongoing questions and technical assistance around quarantine and isolation can be addressed at that time.

# Office of Smoking and Health (OSH) Video Presentation

"Nathan's Story -The Impact of Secondhand Smoke on an American Indian Tribal Casino Worker" Produced by CRIHB Tribal Support Center

CAPT Snesrud directed the group's attention to the handouts in Tab Seven of their binders, noting that a number of CDC programs wanted an opportunity to share their programs with and for Indian Country. The Office of Smoking and Health (OSH) presented to TCAC at the July 2008 meeting, and they sent a staff person and a video to share.

# **Cancer Prevention and Control Update**

<u>Comprehensive Cancer Control National</u>
Partnership: *Collaborating to Conquer Cancer* 

# Dr. Gary Gurian Senior Program Officer for C-Change Active member of the National Cancer Partnership

CAPT Snesrud introduced Dr. Gurian, reminding the group that a point of consideration in the April 2008 TCAC meeting was the topic of CDC's Division of Center Prevention and Control and CDC's role with national cancer partners. As a result, Tom Keen of C-Change was invited to address TCAC at this meeting. Dr. Keen was not able to attend, and he extended his desire to get to know TCAC and to bring cancer partners to TCAC.

Dr. Gurian presented information about the National Partnership for Comprehensive Cancer Control (CCC), stressing that C-Change is not a government organization. The National Partnership for Comprehensive Cancer Control is a collection of government and non-profit and professional organizations whose primary interest is to advance comprehensive cancer control. C-Change is a national cancer collaborative that was founded in 1998 as the "National Dialogue on Cancer." Former President George Bush founded the organization and now serves as its honorary chair. Its membership is non-partisan and includes 130 leaders representing 150 private, public, and nonprofit organizations. This organization represents one of the first times that leaders from the three sectors have joined together to address policy and practice areas. A number of federal organizations are engaged in C-Change, including CDC, National Cancer Institute (NCI), and HRSA. The nonprofit organizations in C-Change include the American Cancer Society, the Lance Armstrong Foundation, the American College of Surgeons, and more. Private sector organizations in C-Change include pharmaceutical companies, insurance companies, and professional organizations.

C-Change's mission is "to leverage the expertise and resources of its members to eliminate cancer as a public health problem at the earliest possible time." They address policy and practice issues, working collectively to address those issues. The strategic focus areas of C-Change are to accelerate cancer research; improve access to the full continuum of cancer care services; and support state, tribe/tribal organization, territory, and Pacific Island Jurisdiction comprehensive cancer control efforts. C-Change has integrated its efforts into the National Partnership for CCC. C-Change has used some of its resources to assist in the funding and management of leadership institutes and policy and practice summits convened in conjunction with the national partnership. C-Change has assisted in the ongoing development of a 2008-2012 strategic for the partnership and provided annual awards to exemplary state, tribe/tribal organizations, and Pacific Island Jurisdiction CCC programs. This year, they provided an award to an American Indian/Alaska Native program: the Cherokee Nation.

The National Partnership's mission is to advance CCC. Similar to C-Change, the partnership works to leverage member organizations' resources and coordinate expertise to support CCC efforts. The partnership also strives to build capacity of cancer control systems that ultimately results in reduced cancer risk, early detection of cancer, better treatment of cancer, and increased quality of life for those diagnosed with, and treated for, cancer. The national partnership represents a unique collaboration among twelve national cancer organizations.

In addition to the national organizations in the partnership, there are liaisons and designated representatives from the Pacific Island Jurisdiction CCC Coalitions and Programs and from the American Indian/Alaska Native Advisory Workgroup. This workgroup was established in conjunction with CDC in February 2006 at the request of a group that planned a 2005 American Indian/Alaska Native CCC leadership meeting in Tucson, Arizona, that brought together tribe and tribal organizations with CCC programs to address issues and to help advance their respective efforts. This workgroup advises and guides the national partnership in its efforts to

advance CCC in Indian Country. They are looking to expand the membership to include representatives from key American Indian/Alaska Native organizations and to include all Al/AN CCC program directors.

The initiatives are funded through CDC and also through the organizations that make up the national partnership. They have conducted planning assistance team visits to help cancer control coalitions. With the NCI, they created Cancer Control P.L.A.N.E.T. (plan, link, network with evidence-based tools) which provides evidence-based tools to develop programs and assist in implementation efforts. The partnership also created cancerplan.org, an online resource for cancer control programs and coalitions. In addition, the partnership implemented a series of Webinars to encourage more local involvement in cancer control efforts. In May 2008, they convened a State Comprehensive Cancer Control Policy and Practice Summit, which was an opportunity for CCC coalition leaders and national partners to discuss and identify key issues and policy solutions. Over several years, the partnership has implemented a series of cancer control leadership institutes to share success stories and to provide guidance in planning and implementation efforts. The Institutes were convened in 2005 and 2006, and the 2006 meeting in Seattle, Washington, included tribes to create synergy and interaction between states and tribes.

The CCC national partnership recently fostered the development and implementation of CCC plans in all states and in a growing number of tribes, territories, and Pacific Island Jurisdictions. The partnership's efforts have resulted in success in the development and implementation of these plans. The national partnership has developed a Strategic Plan for 2008-2012. The plan includes strategies to help advance American Indian/Alaska Native CCC coalitions, programs, and efforts. The first goal of the plan is to provide technical assistance and training to coalitions on implementing their plan priority strategies. The second goal is to increase resources for the implementation of CCC plans. Thirdly, they intend to establish communication mechanisms on CCC National Partnership initiatives. They will also facilitate the exchange of information between CCC coalitions; summarize and report on the progress made through the CCC movement; and sustain the National Partnership, which is a unique model of collaboration.

The Partnership plans to convene an American Indian/Alaska Native CCC Policy and Practice Summit in the Summer of 2009. This Summit will be modeled after the State CCC Policy and Practice Summit in May 2008. It is designed for American Indian/Alaska Native CCC coalitions and programs to tell national partners what policy and practice issues need to be addressed to help advance CCC. The Summit is also designed for American Indian/Alaska Native coalitions to identify areas and issues that they need to collectively address to advance CCC within their jurisdiction. The Summit planning committee has met, and it includes a range of representatives from the Partnership.

The Partnership's strategic plan includes a 2010 "Mega CCC Leadership Institute." State, territories, tribes/tribal organizations, and Pacific Island Jurisdictions will all be invited to this Institute. The CCC National Partnership will continue to leverage its financial and staff resources and coordinate cancer expertise to collectively support CCC. The Partnership will continue to utilize its strengths to change the trajectory of the cancer burden in the United States.

# **Discussion Points**

 Mr. Crouch asked about the structure of the American Indian/Alaska Native Summit and what its goals will be.

- Dr. Gurian replied that they began the Policy Practice Summit by asking states to name their top three policy issues for discussion. The states identified access to care; colorectal cancer screening; and funding of plans to advance CCC. The Partnership plans to use the same survey of the seven American Indian/Alaska Native cancer control programs. They do not want to enter into the Summit with preconceived ideas. The state Summit was a broad discussion of the three policy issues, and the result of the Summit was a number of suggestions for how national partners and the states, collectively, can do to advance CCC. The states at the Summit were also introduced to a number of products from national partners that can help them with the implementation of their programs.
- Mr. Gilbert asked whether the Partnership talks about reimbursement for cancer care.
- Dr. Gurian said that they do discuss this issue, and it is an example of a policy issue that, if it is important to the American Indian/Alaska Native community, should be discussed at the Summit. At the Summit, they will discuss strategies for addressing reimbursement. The issue is timely, as President-elect Obama has made healthcare reform a priority. C-Change is working with its member organizations to address the issue as well, he noted. They need more specifics about how to address the issue and how to collectively address it through the National Partnership, through C-Change, and through Indian Country.

## **CDC's Division of Cancer Prevention and Control**

Ena Wanliss, MS
Associate Director
Office of Program and Policy Information
Division of Comprehensive Cancer Control

Ms. Wanliss expressed her appreciation for the opportunity to present and offered greetings from Dr. Barbara Bowman, the Acting Director of the Division of Cancer Control. Ms. Wanliss reported that over the past several years, the Division of Cancer Prevention and Control (DCPC) has worked with a number of tribes and tribal organizations as partners in the national breast and cervical cancer early detection program, as well as the CCC program.

The DCPC is one of ten divisions in the National Center for Chronic Disease and Health Promotion. DCPC is the lead authority for all cancer matters and provides national leadership in developing and implementing a comprehensive public health approach to cancer control, from primary prevention, to prevention along the cancer continuum, to the end of life and palliative care. DCPC initiative are centered on risk reduction, early detection, cancer survivorship, and reducing or eliminating health disparities. The division works with a variety of partners, including state, tribal, and territorial health agencies; voluntary and professional organizations; academia; other federal agencies; and the private sector to conduct a wide range of activities to develop, implement, and promote effective programs and practices for cancer prevention and control.

The National Breast and Cervical Cancer Program (NBCCP) provides free or low-cost breast and cervical cancer screening and diagnostic services to low-income, uninsured, or underinsured women in all fifty states, the District of Columbia, four United States territories, and twelve American Indian/Alaska Native tribes or tribal organizations. Their tribal partners include eight tribes and tribal organizations in the lower 48 states.

# The tribal program locations include:

		Cheyenne River Sioux Tribe in South Dakota,		
	]	Poarch Band of Creek Indians in Alabama,		
	1	Kaw Nation and Cherokee Nation in Oklahoma,		
	1	The Navajo Nation and Hopi Tribe in Arizona,		
	1	The Native American Rehabilitation Association in Oregon, and		
		South Puget Intertribal Planning Agency in Washington state.		
Four Alaska Native groups are included:				
	<b>_</b>	Arctic Slop Native Association,		
		South East Alaska Regional Health Consortium,		
	]	South Central Foundation, and		
	ב	Yukon-Kuskokwim Health Corporation.		

Since the program's inception, approximately 52% of women screened through the program were of racial or ethnic minority groups, and 5% were American Indian/Alaska Native women. In Fiscal Years 2003 – 2007, Native American and Alaska Native organizations provided 84,606 Pap tests and 44,786 mammograms to 52,582 unique women. A total of 241 breast cancers were detected; 13 invasive cervical cancer cases were detected; and 468 high-grade, precancerous cervical lesions were detected.

The program makes significant contributions beyond providing screening. For example, the program focuses on health education. CDC has worked with the National Indian Women's Health Resource Center to produce a set of breast and cervical cancer early detection health guides for native women. One of the requirements of the program, which funds states, is that the state must coordinate its activities with the tribes located within its boundaries. Arizona is an example of such a collaboration. The Arizona State Health Department has sponsored a collaboration with a number of tribal organizations, the American Cancer Society, and the IHS. They focus on enhancing and expanding the use of American Cancer Society Programs; share best practices; enhance existing collaborations; provide case management, training, and skills development; assist in meeting CDC data quality measures; and plan for education and training.

Another example is Women's Education and Awareness: A Vision for Increasing and Nurturing Good Health (WEAVING). This program is conducted by the Urban Indian Health Institute and is designed to build collaborative relationships and partnerships between Urban Indian Health Organizations and state breast and cervical cancer programs to provide services to Native women living in urban areas. Approximately 60% of American Indian women live in urban areas. In addition to providing screening services, the program aims to improve access to quality diagnosis and treatment services that are timely and culturally appropriate. They also aim to establish culturally respectful partners and to provide a framework to encourage culturally appropriate collaboration. The initiative focuses on all 34 Urban Indian Health Organizations in 18 states.

The Comprehensive Cancer Control (CCC) Program was established by CDC in 1998. It provides seed money, structure, and support for developing and implementing CCC plans. CCC is a collaborative process through which a community pools resources to reduce the burden of cancer that results in risk reduction; early detection; better treatment; and enhanced survivorship. The program promotes healthy lifestyles and recommendations for cancer care and quality of life. The CCC program assists states, tribes, and tribal organizations in

developing, implementing, maintaining, and integrating the evaluation of cancer control programs. The program is administered by the DCPC's Comprehensive Control Branch. Seven tribal organizations are currently funded under the CCC program. The CC program is unique because each CCC program is unique. Each plan addresses the unique challenges facing each state, tribe, or territory and leverages the area's unique assets.

The Tohono O'Odham began the planning phase of their CCC program in July 2007. Because of their participation in the Arizona Department of Health Services CCC Planning Process in 2005, the Nation had experience with the planning process. The assessments of partners and stakeholders are the foundation of their comprehensive plan. Multiple partners were part of the planning committee. The first meeting was held in January 2008. The completed plan will be used to reduce the cancer burden for tribal members and to enhance the quality of life for individuals who have cancer and their families through coordination, prevention, early detection, diagnosis and treatment, end of life, and survivorship.

The inter-agency agreement with IHS facilitates and enhances collaborative relationships and partnerships between states with American Indian/Alaska Native populations that conduct comprehensive screenings. This effort increases attention to comprehensive approaches to cancer control. They monitor the progress of all states in developing plans to specifically address to American Indian/Alaska Native women for breast and cervical cancer screening. DCPC maintains these agreements with IHS to support ongoing program activities. Three staff members are essential to these efforts. The Public Health Advisor in Phoenix serves as a tribal liaison and provides technical assistance to the breast and cervical cancer and CCC programs.

CDC will continue to leverage its partnerships to increase access and resources, helping to facilitate and assist program work with tribes and Native communities. CDC will assist with the implementation of Tribal Consultation policies and support workgroup activities around comprehensive cancer control and provide technical assistance to expand tribal linkages to the breast and cervical program and the CCC program. CDC publishes documents and registries with information about cancer epidemiology and prevalence.

# Day 1: Meeting Wrap Up and Adjournment

## Jerry Freddie

#### Navaio Health and Social Services Committee, NIHB

Mr. Freddie offered closing comments from the perspective of a tribal leader, stressing the excellent quality of the information shared during the first day of the meeting.

He has observed changes in the Navajo Nation over the years, especially in the area of health. He has noticed that the Navajo people are not presenting for healthcare until their health problems have escalated to a tertiary level, which is a concern. The ability of tribal health institutions to diagnose chronic diseases is limited. Many people are required to take numerous medications per day just to silence their pain. TCAC should demand better equipment in tribal facilities if they are going to address cancer. Further, the healthcare facilities are antiquated. Updated, larger facilities and trained staff are needed to address the levels of diagnosis and treatment. Training of healthcare professionals is a concern. In medical schools, students are trained with state-of-the-art tools. There are problems with retention and recruitment of healthcare professionals on Indian reservations because of the state of their healthcare facilities.

Mr. Freddie described tribal members and relatives who are in hospice care who waited too long to seek treatment. Insurance coverage is basic, and the only coverage that Indians receive is through Medicare and Medicaid. Those with private insurance can go to larger centers, but most have limited resources. Tribal leaders are given preference on the reservation, but are often ignored in larger facilities. Children are obese and diabetic. A recent meeting in Washington, D.C., addressed the epidemic of diabetes. There is new medication available to treat diabetes, but there is no money in Indian Country to purchase the new medications. TCAC should find collaborators to see that new research and new medications are available in Indian Country. IHS has limited resources, and surgery is costly. Many Indians with cancer could be cured by surgery, but without resources and with outdated healthcare facilities on the reservation, surgery is often not possible. Further, many Indian people seek help for their health problems when it is too late, or they are too sick or too old for surgery.

Mr. Freddy wondered what happened to research findings. He shares information with his tribes, but the messages are not analyzed and translated for the people. Who among their young will be able to take healthcare information and bring it to the people, so that prevention, primary care, secondary care, tertiary care, and hospice can be recognized by Nations? Indian people are not looking at the "big picture" of the life stages. When research is conducted with American Indian people, the results should be shared back with them to make it useful. Tribal communities need help understanding prevention, primary care, and other health ideas, but in their own language and terminology.

Mr. Freddie remarked on another meeting in progress in the next room, Native Nation Building, in which participants were discussing many of the same subjects. Perhaps they should collaborate and communicate with these Native groups and others, such as School Boards. TCAC might recommend that information from national conferences could be shared at "miniconferences" in TCAC members' regions. There is concern about how to entice their children to become professionals and about the meaning of education. He thanked the group for their attendance and CDC for sharing information.

With no further business raised or discussion posed, Ms. Holt adjourned the meeting for the day.

## November 19, 2008

## Site Visit: Tohono O'odham Nation Tour

# International Border Visit: San Miguel Community Building

At 10:00 AM, Verlon Jose, Chairman of the Tohono O'odham Legislative Council, welcomed the group to the Tohono O'odham Nation. He then introduced Chukut Kuk District Chairwoman, Marla Kay Henry.

Chairwoman Henry added her welcome and noted that the Chukut Kuk District is one of the two Border Districts. They have the majority of the border between Mexico and the United States. The Tohono O'odham Nation and the Chukut Kuk District are sensitive to "border issues," both negative and positive. One of their leaders resides in a community south of the border in Mexico. The "international border" is walking distance for some of their members, and many of

those residing the United States have family members residing in Mexico. Many children come to the gate to go to school. She indicated that as a local government and as a tribal government, they support the vehicle barrier that is being built. The district includes ten communities. The eastern part of the district has infrastructure, including roads, water, and housing. The western part of the district is more rural. Cattle ranching is important to the district, and the border barrier is important to how they keep their cattle and how they communicate with ranchers in Mexico.

Mr. Jose explained that he and Ethel Garcia represent the Chukut Kuk District on the Tohono O'ohdam Legislative Council. He echoed Chairwoman Henry's comment about their sensitivity about "border issues," adding that they still maintain their responsibilities for caring for the land that was given to them by their Creator. Every day, they interact with the Border Patrol, which transports illegal immigrants out of the area. The Tohono O'odham Nation now comprises about 2.8 million acres, but that is a small part of their aboriginal land. The Chukut Kuk District is about 285,000 acres, and Chairwoman Henry is responsible for them. She walks the border and works with the Border Patrol in their construction projects to ensure that the land is protected.

He then introduced Councilman Tom Joaquin, who offered a presentation on the Tohono O'odham Nation, "Desert People." Councilman Joaquin welcomed the group to the Nation and said he looked forward to the opportunity to share the Nation's issues with them. He recognized his colleagues from the Council who were present, and thanked the Planning Committee for their help in organizing the visit.

The Tohono O'odham Nation is comprised of 2.8 million acres of land. It includes 75 miles of international border between the United States and Mexico. Currently, the Border Control is building a vehicle barrier and fencing on the border. Ancestral lands of the Nation extend across the border into Mexico, and the Nation includes nine communities with over 1500 members in Mexico. Those members come across the border to receive services such as healthcare, financial assistance, education assistance, and other aid.

The Nation provides transportation for those members who reside in Mexico to cross the border. These members have tribal identification cards that help them get across. When the vehicle barriers were constructed, the Nation advocated for three traditional crossing points that are specific to tribal members. The Tribal identification cards allow them to cross the border at those points. There are occasions in which tribal members on the United States side cross into Mexico to provide services, such as enrollment into services or accounting. There is the potential for spread of infectious diseases when Tohono O'odham Nation members cross into the United States for services. Further, Mexico has "relaxed" environmental regulations.

The Nation has traditional sites in Mexico, such as a salt mine. Members cross to this site to gather salt to use in ceremonies and in everyday life. Every year, a pilgrimage is made to Magdalena de Kino, Mexico, for the Feast of Saint Francis. Close to 5000 members make this pilgrimage for the Feast. Because of the increase in violence from drug cartels in Mexico, they have been forced to halt some of the pilgrimages. This year in particular, violence has increased along the border, so the Nation sent vehicles to Mexico to bring its members who were on a pilgrimage back because of concern for their safety.

All along the border, signs facing south remind illegal immigrants of the dangers facing them if they cross the border, whether they cross in the winter or in the summer. Other organizations come and provide assistance, such as water stations, to illegals. When the illegals have health-

related issues such as dehydration, local Indian health services incur costs for providing services. According to IHS, the Nation helped 751 illegal immigrants from May 2005 to May 2007 at a cost of over \$400,000 in unpaid medical bills. The Border Patrol apprehended about 317,000 illegal immigrants in Fiscal Year 2008 on the Tohono O'odham Nation alone, they have done about 573 rescues on the Nation in FY 2008. In 2007, IHS reported about 83 illegal immigrant deaths on the Nation.

There is a great deal of illegal human cargo and drug trafficking across the border. Along the border, there are "staging areas" where illegal immigrants wait to be picked up and brought into the United States. When they are picked up, they are asked to leave everything behind, so the "staging areas" are littered with their cargo, such as water bottles, backpacks, clothing, and other items. In 2004, the Nation received close to \$300,000 to implement a cleanup project on the Nation. They located 134 sites that needed to be cleaned up. They removed the trash to try to restore the vegetation and land. The cleanup project yielded 8,200 bags of trash. The trash also includes vehicles and bicycles. Because continuous funding was not received for cleanup, the Nation dedicated \$100,000 this year to continue the cleanup efforts. They are extremely concerned about the vegetation and the land. They do not have reports on the contamination of underground water tables due to abandoned vehicles on Nation lands. There are oil and gasoline spills. Many vehicles that were stolen from Tucson or Phoenix are left on the land. Every year, there is a monsoon season, and the Nation looks for assistance from federal agencies for flooding. An infectious substance has been found in the water after flooding. The substance is not regulated in Mexico, and it is infectious to humans and animals. Many environmental issues affect Nation members on both sides of the border.

Another concern is Mexico military incursions. Nation members cannot be sure whether the armed men are Mexican military guarding the border, Mexican drug cartels disguised as military, or Mexican military working with the drug cartels. They can search vehicles, and encounters with them can be frightening.

Because of the increase of drug activity in Tijuana, Nogales, and Sonora and along the 75 miles of international border on Nation land, there is increased stress amongst people living along the border. The stress leads to behavioral health issues associated with living in fear. Nation members fear being attacked, held hostage, and held at gunpoint. Anxiety not only affects Nation members living along the border, but also those living in the northern districts feel the effects of unrest on the border.

They have a relationship with the Border Patrol and are thankful for their local law enforcement, which works with the Border Patrol to assist with the ongoing violence problems. The Nation's law enforcement assists Border Patrol efforts in the federal checkpoints on the Nation. Drug busts occur with tribal members and non-tribal members who come onto the Nation to assist drug cartels and in moving human cargo. In FY 2008, the Tucson Sector of the United States Border Patrol seized 812,142 pounds of marijuana and cocaine. They are seeing an increase in methamphetamine trafficking, and this methamphetamine finds its way to other tribal communities, towns, and areas all over the country. The Nation does its best to assist the Department of Homeland Security (DHS) in the name of saving its people. Unfortunately, tribal members participate in illegal activities.

The border construction includes a vehicle barrier and three types of fencing. The first type restricts vehicle traffic. The Nation will never agree to a wall-type fence because of the relationship that they have with their members and aboriginal lands on the Mexican side of the border. The Nation helps the Border Patrol with their 24-hour-a-day presence and other

measures to keep the lands safe. The Nation wants assistance at the border, but they are also sensitive to vegetation and animal migration in the area. They work closely with the Border Patrol in these areas.

Water issues are a concern on the Nation. The United States Environmental Protection Agency (EPA) provided close to \$150,000 for a well project for a Tohono O'odham community in Mexico. The United States government is allocating funds to be spent across the border to assist Nation members in Mexico. Water is an environmental issue and it also affects people's health and well-being. A natural spring in Kitowa is the site of traditional ceremonies, and some members live there. A toxic waste facility was proposed by the Mexican government to be built 12 miles north of this community. Region Nine was helpful in halting this project because of environmental worries, including the groundwater tables and the air. Nation leaders focus on how they can best help their people in their everyday living. They all face health issues every day, including the water and the environment. The Nation is working with the federal government to assist each other in many areas. They are working together in Indian Country.

Mr. Jose expanded on the idea of living in fear. Nation members have encounters with the military every day. There are military incursions into the United States, which are probably in violation of international treaties. He stressed that Nation members have no way of knowing whether the military-looking personnel are actually military, or drug cartel members dressed as the military. In a nearby community, masked men came to a Nation member's house. The woman in the house said that they could not enter the house without a warrant, and the men said that they did not need a warrant because they were federal agents. The family had no way to know whether this was true. The children are frightening, and their emotional distress leads to health issues. Not long ago, children on the school bus witnessed the Border Patrol doing a major drug bust, with guns drawn. They must maintain a professional relationship with the Border Patrol.

Geneva S. Ramon, Chairwoman of the Gu Vo District then welcomed the group on behalf of the Gu Vo District, which also includes the United States-Mexico border. She noted a few issues of concern for her District. Vehicle entry across the border has been closed due to drug trafficking. There is concern about the District Recreation Center. She was also concerned about trash on the lands as a result of drug trafficking and other illegal activities. The people of the District and Nation depend on cattle for their feasting and other purposes, and the trash on the land presents a danger to the cattle. Her community is 85 miles wide, and transportation for people to receive health services is another concern. In particular, some dialysis patients have to be picked up at 4:00 AM and driven to Sells, Arizona for treatment. They do not arrive home until late in the evening after a long day of dialysis. In addition, the long distances in the District mean that response to emergencies takes a long time. Some people in the community do not have telephones to call for help.

In response to Ms. Holt inquiry about whether the Nation police force is cross-deputized with federal powers, Mr. Jose replied the force is regulated under the Bureau of Indian Affairs, and some of their law enforcement officers are state-certified.

Regarding Mr. Alonson's question about who responds to medical emergencies on the Nation, Chairwoman Ramon replied that the Border Patrol are the first to respond, as their agents are all over the reservation. She added that they often run over vegetation or cultural areas.

Stanley Cruz, Chairman, Pisinemo District described where his district is located, which is about twelve miles from the United States-Mexico border. He pointed out some of the issues that affect his District. Even though they are twelve miles from the border, his district still sees many of the issues described by Councilman Joaquin. His district is isolated, and he has a chance to see the desert scenery as it used to be for the Tohono O'odham people. The Tohono O'odham people are so named because they come from the desert.

Issues on the border affect them not only mentally, but physically. He recalled when he used to go out into the desert to connect with the land. He still participates in hunting ceremonies. Now, though, when he goes into the desert he "takes extra bullets" or "a bigger gun." One of their ceremonies, and annual celebration called the *Deer Dance*, takes place on the desert in a ceremonial hunt. They must now inform the Border Patrol that they will be conducting their ceremony in the desert. The ceremony is important for the people, and they have had instances in which the Border Patrol has interrupted their ceremonies. These intrusions hurt them as a people, because when they cannot perform their ceremonies, they cannot come together as a community.

With the vehicle barrier's construction, foot traffic has increased. One of the drug smugglers' hideouts is located next to one of their communities. The drug smugglers used materials to conceal the hideout from above. The drug smugglers will stay in that hideout and work with some members of the community to plan how to move drugs across the District and Nation.

A new Health Center was opened in the western part of the Pisinemo District. It was built to address problems such as the distances that must be traveled for tribal members to obtain healthcare. The Center is located more than twenty miles from the border, but even there, they are seeing illegal immigrants who stop there for help. There is a housing complex there, too, and the illegal immigrants stop to ask for water and food as well as medical care. Their Health Center is affected, and the hospital in Sells is also affected when illegal immigrants go there for emergency services. The Nation is not reimbursed for these services. His district does not have a police force. Nation police must come from Sells to his District to respond to problems. They do have a Border Patrol presence, but not always where the District wants them to be! In conclusion, Chairman Cruz agreed with previous comments regarding trash on the desert.

Mr. Jose reinforced the importance of ceremonies to the Tohono O'odham. Every year, they hold a ceremony across the United States-Mexico border. This ceremony is not just for the Nation, but for the world. The ceremony was taught to them in order to right the world and to assure a good harvest, and they have not been permitted to conduct the ceremony. The ways of the ceremonies are not written down. Ceremonies are performed for the community, and if they are not done, then the community's health suffers, and members turn to healthcare facilities. All of the issues being described "spill over" into other areas and affect the entire health of the people. He emphasized that they do not intend to "bash the government," but to help them understand these issues. The Nation is on the front lines.

Elder and Spiritual Leader Felix Anton, who lives across the United States-Mexico border, walked across the border to join the participants. Mr. Anton wished the group a good morning. He had only recently learned about this meeting, and it takes time to put his thoughts together. He said it feels good to live on the desert, and every person and animal can enjoy the good weather. There are problems on the border and in the Nation, but there are good people in Mexico and in the United States. Everyone is not like the people who are written up in the newspaper or described on the radio. He stressed that the most important way to support the

O'odham land and the people was to realize that people need each other, "We need each other. We need support to support each other any way we can."

Looking at what is happening everywhere, not only in Arizona but all over the world, one must ask: Who will stop this? Many laws have been passed, but are they doing any good? Are laws the only way they can work out solutions? The people must come together to determine what they can do for their children. Maybe they can help their children understand that O'odham land was not always like it is today. The children go to school and receive higher education, but who will teach them about the land? In his seventy-plus years, Mr. Anton has had many memories and seen many happy endings. At the same time, he and the elders have prophesied that these times would come. They must think of a remedy.

The burdens are getting heavier and heavier, and they need each other. They need each other, and they need support: not from a few people or from one race, but from everybody. People must come together strongly and communicate. The only way to stay together is to stay together spiritually. He said, "We are all one under the Creator's law. We were all created, as was the land, the animals, the air, and the water." Mr. Anton gave his blessing that they came, and his blessing that the Creator understands.

Mr. Jose noted that Mr. Anton is one of his mentors. He described a Unity Run, which has gone on for more than thirteen years. This Run began as a result of discussions about how to promote spiritual wellness. It started as a handful of people running from a point near Mr. Anton's home in Mexico all the way to Red Mound on the Salt River reservation. Young people make this run in a traditional relay of several hundred miles over a five-day period, carrying a sacred staff. The group has grown to 150 youth and it part of their effort to promote spiritual and physical wellness.

# **Discussion:**

- Mr. Antone noted that when a tribal elder speaks, it is important to listen with a different set
  of skills. He also asked about the meaning of the Tohono O'odham tribal symbol.
- Mr. Jose said that they would explain the "Man in the Maze" symbol at the Museum.
- Dr. Jamila Rashid, COTPER, echoed the importance of collaboration and coming together
  to solve problems. She asked about the collaborations that they have had with other groups
  and agencies. Events and forces that affect native lands affect everyone, and she asked
  how they can help more and provide more opportunities for collaboration to address issues
  on the Nation.
- Mr. Jose replied that he hoped that after this day and these presentations, they would go
  back to their workplaces with an understanding of what is happening on the Tohono
  O'odham Nation. They are making progress, building better healthcare facilities. There is a
  misconception that because Natives have casinos and casino money, they are rich. On the
  contrary, they are "barely catching up," and they have to add their own dollars to the federal
  government's responsibility to address healthcare, education, and roads.
- Councilman Joaquin said that for many years, he has worked with a committee from the
  Nation to work with federal agencies and Congress. They have seen several appropriations
  come from House and Senate committees, and members of Congress have made site visits
  to the Nation's law enforcement center and to address environmental issues. Secretary
  Michael Chertoff visited the Nation to hear these issues. They have made their needs

known to federal agencies regarding roads, environment, health, and other issues. Collaborations are in place, and when it is time to seek resources, the federal agencies come into play.

- Helen Pootoogooluk spoke from her perspective living in Alaska. They have a border with Russia, and she noted that the issues presented were an "eye-opener" for her. Their villages that lie near the Russian border have some common issues, but they are not as dire as those faced by the O'odham. She thanked her Health Board for sending her to this meeting and she hoped that more collaborations could emerge as a result. Border issues affect all tribes and all people, and they can work together to network and solve problems.
- Mr. Jose agreed, adding that the collaborative effort can be as simple as a Prayer for the People. They understand effects on other peoples, because they have heard about and seen the shift in Mother Nature. They have professional responsibilities as well for Indian Country, the First Peoples.
- Dr. Rashid said that the presentations and speakers impacted her as an individual, not just as a federal employee. She has connections that she can exercise as a citizen. Collaboration extends beyond the professional.
- Mr. Jose appreciated the comments and closed by noting that they had all lost their titles—they were all just common people. Chairwoman Henry noted that because CDC is a health entity as well as a federal organization, they are easier to work with.
- With that, the group boarded vans for a tour of the International Border.

# **Tohono O'odham Museum and Cultural Center**

The group arrived at the Museum at 12:40 PM, when Bernard Siquieros, Administrator of the Tohono O'odham Museum and Cultural Center, welcomed them. The Museum, built of concrete and steel, has the vision of being a repository for all of the Tohono O'odham Nation treasures for preservation and education. There are O'odham treasures located all over the world, and the Museum will be their home.

The Museum and Cultural Center includes a library and archives for research into Nation history and culture. It houses documents as well as photographs and recordings. There is an Exhibit Hall, museum, and an Elders Room for use by the community. The Center is 38,000 square feet and covers 32 acres of land; however, only six and one-half acres of land were disturbed to build the facility. The site was chosen for its view and because of the variety of vegetation on the land surrounding it. A nature path with signage to identify the desert vegetation is planned. Visitors from all over the world have come to the Center.

Mr. Jose introduced Mr. Felix Anton. who described a variation of the story of the Tohono O'odham tribal symbol, "The Man in the Maze." The symbol is one of the most sacred aspects of the O'odham way of life. The Maze is how the O'odham were created, and the Man in the Maze is the Elder Brother who created the O'odham. All O'odham people believe in the same Creator and in the Maze. These stories have no end, he said. It takes a lifetime to understand this kind of story and this kind of storytelling. He compared these stories to a cookbook, or even to the Holy Bible—many symbols can mean many things, and each person understands them in his or her own way. The small Man in the Maze carries a staff, and power comes from this staff.

Mr. Jose said, "We can never achieve the power of the Creator or of the Elder Brother, because we are Children of the Creator. The Elder Brother is addressed as such because we are all one heart. Before we are born, we are given a Gift. We begin outside the Maze, and as we travel, our Gift emerges. The Gift could be music, pottery, or singing. Our life is the Maze, and the trail leads to the Man in the Maze. The Maze is what we do on Mother Earth throughout our lifetimes. We discover our own treasure as we travel the maze. We learn how we should be on Mother Earth and how Mother Earth should be respected." The Tohono O'odham people come together strongly, respecting all they have left of Mother Earth and their way of life. There are sacred places where they conduct ceremonies, and sacred fires are kept burning in these respected places. The Creator gave the O'odham this image to respect and treasure. They all must work hard and come together strong to help children see that it takes a lifetime to understand and to feel it. Sharing this image is like sharing friendship, water, and a way of life.

The group enjoyed lunch prepared by the Ramone Family on the patio of the Museum and Cultural Center. Following lunch, a group of traditional dancers from the local school entertained the participants with traditional dance and song. All present joined in the "Friendship Dance." Then, Jaleen Wood, Miss Tohono O'odham Nation, offered remarks to the assembly.

Ms. Wood is 18 years old and is from the Santa Rosa Village in the San Lucie District. She attends the community college in Sells. Health issues are a large concern for the O'odham people, especially diabetes among elders and youth. She observed that her people are not keeping active, and they are not eating right. In the past, O'odham were farmers. They worked for their food, and they were healthy. Now, with technology and television, many people "just sit there" and eat food that is not good for them. She described a Diabetes Health Fair held recently, which included information booths on eating, exercise, and diabetes control. She also described the Healthy O'odham Promotion Project, which provides exercise equipment, classes, and education on how to eat right. She then sang three traditional songs for the group, including one about the sacrifice described in the story of the Children Train.

Mr. Jose thanked Ms. Wood and stressed that children are very important, and that their health is crucial to the Nation. He said that if the people were healthy, they would not need so many healthcare facilities. They lack the simple things, like going to the desert to gather food. Instead, they go to the store to buy food, or buy it from a truck that comes to their homes. He thanked the Local Planning Committee for their efforts in arranging the events of the day.

At the conclusion of the tour, the second day of the meeting was adjourned with the group departing to return to the Desert Diamond Hotel and Casino in Tucson, Arizona.