

**American Indian/Alaska Native Health Research Advisory Council (HRAC)  
November 2009 Face to Face Meeting  
Tulsa, Oklahoma  
November 12, 2009**

**HRAC Tribal Delegates and Alternates**

- Donald Warne, Aberdeen Area Alternate
- Tim Gilbert, Alaska Area Alternate
- Norman Coeoyate, Albuquerque Area Delegate
- Kathy Hughes, Bemidji Area Delegate
- Jim Crouch, California Area Alternate
- Darrell Flyingman, Direct Service Tribes Advisory Committee Delegate
- Sarah Hicks, National Congress of American Indians Alternate
- Madan Poudel, Navajo Area Delegate
- Cara Cowan Watts, Oklahoma Area Delegate
- Violet Mitchell-Enos, Phoenix Area Alternate
- Stephen Kutz, Portland Area Delegate
- Chester Antone, Tucson Area Delegate

**HRAC Federal Partners**

- Wendy Perry, Agency for Healthcare Research and Quality
- Ralph Bryan, Centers for Disease Control and Prevention
- Wilbur Woodis, Office of Minority Health

**Meeting Minutes**

- A quorum was reached, thus results from meeting are considered official.

**Opening Session**

- Invocation by Governor Norman Coeoyate
- Opening Remarks by HRAC Co-Chairs Cara Cowan Watts and Kathy Hughes and OMH Special Assistant on Native American Affairs, Wilbur Woodis

**Cherokee Nation**

**1. Presentations**

- Melissa Gower, Gloria Grim, and Sohail Khan provided a history and overview of the Cherokee Nation and discussed research activities including their Institutional Review Board (IRB). The IRB meets once a month and provides feedback immediately. Rarely do proposals get approved on the first time. They typically get 15-20 proposals a year, so they can be much more thorough than large IRBs. It was also mentioned that they have participated in two clinical trials, TODAY for diabetes and STAR for breast cancer.

**Tribal Epidemiology Centers**

**1. Presentations**

- Diddy Nelson, Oklahoma Inter-Tribal EpiCenter, presented on current projects including: Community Health Profiles; methamphetamine; suicide prevention; Tribal needs assessment survey; and data sharing agreements. Ms. Nelson suggested

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creating a National Data Sharing Agreement since data ownership is always an issue when collaborating with funders, researchers, and Tribal communities.

- Kristin Hill, Great Lakes Inter-Tribal Epidemiology Center, reported that they are currently on a growth curve having a tremendous number of requests for research projects and new emerging partnerships. They produce a Three State Profile Annual Report and Tribal Profile Reports every two years.
- Dr. Donald Warne, Northern Plains Tribal Epidemiology Center, announced that the Centers for Disease Control and Prevention funded a five-year capacity-building grant for HIV/AIDS and they were the only Native grantee. The EpiCenter is currently working on a Meth Initiative and will be creating a Regional Behavioral Health Center of Excellence. They also are doing domestic violence prevention.
- Madan Poudel, Navajo Nation Epidemiology Center, said he also has difficulty getting access to health data. They work with both 638 and direct service providers and cover three states. They have capacity issues with only two staff members and 3-4 years of experience with the EpiCenter. Public health data is missing and needs work. The National Data Warehouse at IHS should be a central clearinghouse, but not all the data makes it there. Also, not all Tribes have an RPM system.
- James Crouch, California Rural Tribal Epidemiology Center, said that CMS funded data collection in a recent national study of Medicare in AI/AN populations. They would like to hold a symposium to take a closer look at the CMS data collected.
- Tim Gilbert, Alaska Native Tribal EpiCenter, said they recently developed an Alaska Native Health Status Report that is available online at the Alaska Native Tribal Health Consortium (ANTHC) EpiCenter website. Also, during the recent Alaska Federation of Natives meeting they used social marketing sites (Facebook and Utube), radio PSA's, and mini bottles of anti-bacterial gel to communicate prevention information for the flu and H1N1 flu.

## **2. Discussion**

- Dr. Donald Warne commented on how difficult it is to coordinate data with states, especially in regards to cancer. Ms. Hill said they have an excellent relationship with their three states. However, they are involved in a pilot project as they've found that local, state, and IHS cancer numbers are all different.

## **3. Next Steps**

- HRAC could make a recommendation on how data has to be channeled.
- Post a link on the HRAC website to ANTHC's report and also the Utube video.

## **Recent Events**

### **1. Updates**

- The Native Health Research Conference was held on August 3-6 in Portland, Oregon. The next conference will be held in Rapid City, SD in July 2010. The HRAC needs to build strong coalitions so we can present and introduce HRAC at these conferences. HRAC should also consider holding its second meeting of 2010 in conjunction with this conference.
- The National Indian Health Board Conference was held on September 14-18 in Washington, DC. According to Dr. Warne, the number of federal officials in

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attendance was exciting, which included Senator Lisa Murkowski from Alaska and HHS Secretary Kathleen Sebelius.

- The American Indian/Alaska Native Health Policy Conference was held in Albuquerque, NM on October 22-23. Cara Cowan Watts presented at the breakout session for Tribal Health Codes and Research Policies. She shared Cherokee Nation's experiences and ended with a discussion on national issues. She was surprised that attendees were not familiar with the Federal Coordinating Council for Comparative Effectiveness Research and National Children's Study issues. This is an annual meeting and there are many opportunities for HRAC to participate.
- The SAMHSA/IHS/CDC Youth Suicide Prevention meeting was held in September in Rockville, MD. The meeting was diverse representing African Americans, Latinos, and Tribes. There are many shared issues within these communities. There was concern that the National Institutes of Health was not involved since they have the most funding for research.

## **2. Discussion and Next Steps on Suicide Prevention**

- The HRAC discussed the need for more collaboration between agencies and the need for a written commitment. The HRAC should consider writing a letter to the HHS Secretary addressing the suicide problems plaguing Indian Country.
- NCAI has a Youth Suicide Task Force and perhaps the HRAC can work with them to show collaboration and unity.
- Consider asking Jami Bartgis at National Council of Urban Indian Health to pull all interested groups together.
- Chester Antone and Sarah Hicks will take the lead on efforts of work products for suicide prevention and then bring to HRAC for review and approval.

## **Federal Partners Research Activities**

### **1. Presentation**

- Dr. Kathy Etz, National Institute on Drug Abuse (NIDA) American Indian/Alaska Native Coordinating Committee said NIDA is planning to hold a three-day meeting focusing on epidemiology, treatment, and prevention. They also have a conference on April 22-23 in Albuquerque, New Mexico that will bring together health care providers to collaborate on health issues with an AI/AN track. Dr. Etz said they have a Mentoring Program for Junior Investigators and an NIH Intramural Internship Program for students, which HRAC could assist by disseminating this information.

## **NCAI and White House Tribal Nations Conference**

### **1. Presentation**

- Sarah Hicks reported about the recent First Annual White House Tribal Nations Conference where President Obama signed a directive to establish and strengthen all federal agencies' Tribal consultation policies. The President gave 90 days to provide him with a detailed plan. NCAI is in the process of developing a meeting summary and they will also create a matrix of what commitments were made.

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## **Federal Advisory Committee Act (FACA) Issues**

### **1. Update**

- Cara Cowan Watts said she met with Stacey Ecoffey of IGA and other tribal advisory committee chairs during the recent NCAI meeting to discuss concerns about being FACA compliant. Under the Obama Administration, the Office of General Counsel is reviewing this issue closer to make sure HHS complies with consultation policies, so this is coming with good intentions. No decisions have been made as to how this should be handled, but it is in the works.

### **2. Next Steps**

- It is very important for HRAC to: (1) Verify from the Tribe that the person nominated is an elected official. (2) For Alternates, there must be a clear paper trail appointing the Alternate. (3) If the Delegate and Alternate cannot attend, then a proxy letter is needed for the replacement. (4) Eventually, amendments to the Charter will have to be made.

## **Federal Partners Research Activities, Continued**

### **1. Presentation**

- Dr. Ralph Bryan, CDC, talked about current projects, health concerns, and CDC structure. The CDC publication, *Advancing the Nation's Health: A Guide to Public Health Research Needs, 2006–2015* (also referred to as the *Research Guide* and available at: <http://www.cdc.gov/od/science/PHResearch/cdcra/>) will serve as a critical resource for research areas that should be addressed during the next decade. He also reported that the focus of AI/AN-related research at CDC has been broad and includes infectious diseases and immunizations; cancer; diabetes; injury prevention; violence/suicide; environmental health; maternal and child health; health disparities; and public health policy research.
- Dr. Garth Graham, Office of Minority Health, joined the HRAC via a conference call to discuss updates on the Federal Coordinating Council for Comparative Effectiveness Research (FCC CER). The Agency for Healthcare Research and Quality (AHRQ) currently has funding available under the Recovery Act for comparative effectiveness research products and grants. Initially the FCC CER developed a draft of definitions and the strategic framework, and then the Council developed an Annual Report to the President and Congress on CER.
- Wendy Perry, AHRQ, presented on her agency's current research activities involving Tribes. She reported that Carolyn Clancy, M.D. was reappointed as AHRQ's Director. Also, she suggested that HRAC members apply and sign up for grant notifications at <http://grants.gov>. Another good resource to find grants and track federal spending is <http://recovery.gov>. AHRQ provides technical assistance for grants, so call Wendy Perry or the program person identified on funding announcement.

### **2. Discussion and Next Steps**

- Send out June 30<sup>th</sup> FCC CER Report to HRAC again.

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- Dr. Graham was asked about HRAC's request for someone from IHS to serve on the Council. He replied that IHS was at the table during the overall process as equal as any other agency. As HRAC requested, he will send a list of who participated from IHS and what subcommittees they were involved in.

## **National Children's Study**

### **1. Presentation**

- Dr. Donald Warne updated the HRAC on the National Children's Study and the proposed Great Plains/Alaska Native Children's Study. Due to the fact that these key areas are missing from the study and they have the highest infant mortality rates, it has been discussed that a separate study should be funded. However, funding would need to come from Congress. Is a high enough priority on a national level to have HRAC advocate for funding at the Congressional level?

### **2. Discussion**

- Tim Gilbert said that in Alaska they would talk to the Association of Tribal Health Directors to confirm their interest rather than getting Tribal resolutions. Their legislative staff needs to know where this study is on their list of priorities before approaching the Congressional delegation. If it is lower, is there another approach?
- Kathy Hughes asked that a formal resolution be sent out to HRAC for review as it should rank very high as we are talking about our youth, our future.
- Cara Cowan Watts said funding must come from the American Recovery and Reinvestment Act or other federal funds, but not from existing programs or IHS.

### **3. Next Steps**

- HRAC to draft a letter in support of the study. Use Ralph Bryan's language about the study missing key geographic locations that have big disparities.

## **NCAI Research Priorities**

### **1. Presentation**

- Sarah Hicks reported that the NCAI Policy Research Center is conducting an Introduction to Research Training for Tribal leaders. They sent out a copy of the first module to all Tribes, organizations and colleges.
- NCAI's Mid-Year session will be held in June and they hold the Tribal Leader Scholar Forum during this meeting where researchers impacting Tribal communities present their projects.
- Sarah provided a copy of the Human Resources Research Agenda, but stressed that this does not take the place of local priorities. The intent of the "Research Agenda" is to put all of the national research priorities in one place. They are going to begin discussions with the Native Research Network to see about potential collaboration, but they realize that NCAI has a tribally-driven research agenda.

## **Dr. David Boyd - IHS**

### **1. Visitor/Presentation**

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- Dr. David Boyd, head of the Trauma and Prevention Program at IHS, visited the HRAC meeting briefly as he was attending the National Native EMS Association meeting at the hotel. They are trying to put a system together to get better trauma centers. A CT is needed in each hospital, as most are very behind on technology.
- They are currently conducting the SW Research Project – What is the Impact of CT and What is the Economical and Clinical Outcome?

### **Public and HRAC Comments**

- Kristin Hill mentioned an Evaluation Conference in Indian Country that was held during August in Polson, MT and sponsored by the SAMHSA Native Center for Excellence. She suggested that HRAC review the notes and recommendations that are produced.
- Kathy Hughes recommended that HRAC send a letter to Secretary Sebelius to allow for access to data with all HHS Agencies as IHS has been a problem.
- Cara Cowan Watts said that we need to coordinate what EpiCenters are doing, so there will be a standing item on the HRAC agenda for EpiCenters. The Data Workgroup will give feedback and suggest how we can interact better.
- Jim Crouch said that Tribes and Tribal organizations need to have appropriate access to HIPAA data for American Indians and Alaska Natives. A letter might be sent to Secretary Sebelius regarding this issue.

### **Committees**

- Access to Data/EpiCenter Coordination: Steve Kutz and Tim Gilbert (End work product should be a brief or recommendations to full HRAC group.) Sarah Hicks from NCAI offered support.
- National Children's Study: Donald Warne and Tim Gilbert

### **Action Items**

- Tribal Consultation Policy and NIH – NCAI could assist or recommend task force to develop consultation policy.
- IHS research dollars – include in next HRAC testimony at Tribal Budget Consultation Session.
- FCC CER – Dr. Graham will provide list of IHS committee members.
- FCC CER – Jim Crouch will follow up regarding data infrastructure.
- Secretary Meeting – Cara Cowan Watts and Kathy Hughes will make request for a meeting in late February/early March
- Suicide Prevention – Sarah Hicks and Chester Antone to keep this moving. Did HHS respond to testimony? Chester thought the recent meeting was a response, but he will follow up to find out.
- Superfund Sites – Tracey “Ching” King with assistance from Cara Cowan Watts
- HRAC/NRN Partnerships – Dr. Warne and Steve Kutz
- Research Priorities – HRAC will rely more on Sarah and the NCAI Agenda
- Next quarterly conference call to be held on Wednesday, February 3<sup>rd</sup> at 1pm Central Time.