

**American Indian/Alaska Native Health Research Advisory Council (HRAC)
Quarterly Conference Call
January 18, 2011**

HRAC Tribal Delegates and Alternates

- Jay Butler, Alaska Area Alternate
- Kathy Hughes, Bemidji Area Delegate
- Phyllis Davis, Bemidji Area Alternate
- Reno Franklin, California Area Delegate
- Elizabeth Neptune, Nashville Area Delegate
- Madan Poudel, Navajo Area Delegate
- Cara Cowan Watts, Oklahoma Area Delegate
- Stephen Kutz, Portland Area Delegate
- Chester Antone, Tucson Area Delegate
- Jefferson Keel, National At-Large Member Delegate
- Christina Daulton, National At-Large Member Alternate

HRAC Federal Partners

- Wendy Perry, Agency for Healthcare Research and Quality
- Sue Clain, Office of the Assistant Secretary for Planning and Evaluation
- Bud Nicola, Centers for Disease Control and Prevention
- Wilbur Woodis, Office of Minority Health

Other Attendees

- Kristal Chichlowska, California Rural Indian Health Board
- Victoria Warren-Mears, Northwest Portland Area Indian Health Board
- Jill Mattia, National Institutes of Health, National Institute on Minority Health and Health Disparities
- Lisa Kaeser, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Jessica Kaposy, Indian Health Service Office of Tribal Self-Governance
- Steven Hirschfield, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Annie Huntington-Kriska, Gana-A'Yoo Services Corporation
- Ric Bothwell, Native American Management Services, Inc.
- Pat Parker, Native American Management Services, Inc.

Meeting Minutes

- A quorum was reached on the call.

Call to Order and Introductions

- Introductions and facilitation: Cara Cowan Watts, Co-Chair

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1. HRAC Updates

- Cara Cowan Watts provided an update on the HRAC Research Roundtable held in October 2010. Cara asked the HRAC to review the notes as they would provide a better overview of what was discussed during that meeting.
- Kathy Hughes discussed the NIH meeting that was held on November 8 with Dr. Francis Collins, NIH Director, and Dr. John Ruffin, Director of the National Institute on Minority Health and Health Disparities. Topics that were discussed were the National Children's Study, Tribal Consultation, and the University of New Mexico's (UNM) Native Health Database (NHD) need for funding. Kathy felt Dr. John Ruffin was a closer contact for the HRAC.
- Cara discussed the upcoming meeting with Dr. Ruffin. This meeting is to follow-up on the UNM NHD's request for funding. The tentative date has been set for February 2nd from 2-3PM. NAMS will send out an email to the HRAC to see if anyone is able to attend this meeting along with Cara. (Note: This was cancelled due to inclement weather and will be rescheduled.)
- Wilbur Woodis discussed the status of the HRAC Charter. The charter was revised in December and sent back to the Office of General Counsel (OGC) for review. Some of the language from the Secretary's Tribal Advisory Committee (STAC) was used for the national organizations as OGC suggested. The national organizations are now referred to as National At-Large Members (NALMs).
 - Wendy Perry wanted to clarify that the primary person must be an elected or appointed Tribal official.
 - Wilbur said that is one item that still needs to be answered and once he receives feedback from the OGC, he will send out the revised charter for HRAC to review.
 - Jefferson Keel thinks there is a misrepresentation of FACA. He has had attorney's from different organizations to take a look at what "tribal official" means. He defined it as elected or duly appointed officials of Indian Tribal governments or authorized intertribal organizations. He also mentioned Executive Order 13175 which also defines it as stated above.
 - Cara asked if Jefferson Keel could send her briefs or position papers so the HRAC can discuss with the OGC.
 - Pat Parker, from NAMS, recommended setting up a separate conference call with OGC to discuss FACA.
 - Wilbur will work with OGC to get the revised charter and arrange a teleconference call between the HRAC and OGC.
 - Jefferson Keel suggested providing legal analysis from other groups.
- Wilbur then provided an explanation on the HRAC budget.
 - 2011 HRAC Budget Requested (not funded as of 1/14/11)
 - Administrative Overhead (contract with NAMS): \$140,000
(printing, rental of meeting facilities, supplies, transcript/facilitator, writer, mailing, other direct labor, etc)
 - HRAC member costs: \$80,000
(travel, per diem, etc)
 - Public Health Advisor/Project Officer Travel Budget \$20,000

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- Wilbur then discussed the HRAC invitation letters that were created for HRSA and SAMHSA. Informational packets are currently being reviewed and will be sent to the above mentioned agencies. Since the HRAC is an HHS advisory body, it is recommended that the HRAC engage EPA via presentations, etc. Wendy Perry suggested inviting CMS.
- The next HRAC face-to-face meeting is tentatively scheduled for Wednesday, April 27, 2011 pending travel funds.

2. Agency or Other Updates

- Chester Antone provided an update on the Secretary's Tribal Advisory Committee (STAC). The HHS Tribal Consultation Policy was revised and signed and is now located on the IGA website.
- Bud Nicola from CDC provided an update:
 - There is a Public Health Advisor for Tribal Relations position that will be posted in a few weeks and he will send it out. Melanie Duckworth is currently in this position.
 - The CDC now has a Tribal website, under the OSTLTS section of the website with CDC's consultation policy, biannual session information, new cooperative agreements, funding for grantees, etc.
 - TCAC is expected to have a meeting February 1-3.
 - Kim Cantrell is a new staff person taking over the TCAC.
 - The Public Health Apprentice Program recruitment is underway. Tribal universities will be getting the announcement.

4. HHS Blue Print and National Plan for Action – Pat Parker

- Pat Parker, OMH Contractor, provided a quick update on the status of the National Plan for Action to End Health Disparities (NPA) and how she would like to involve the HRAC.
 - The National Plan for Action is now called the National Stakeholders Strategy for Achieving Health Equity (NSS).
 - An American Indian and Alaska Native (AI/AN) report that parallels the NSS is being drafted that sets out the historical information about eliminating health disparities that includes statistics and data specifically for the AI/AN population and communities.
 - Regional Blue Prints are the Action Plan and will address the question: What can we do to eliminate health disparities? An AI/AN Blue Print will be developed.
 - Regional Health Equity Teams will emerge from the implementation of the Regional Blueprints and an AI/AN Health Equity Team will also be created. There will be tribal representatives on the Regional Health Equity Teams.
 - To insure the AI/AN community collaboration, the OMH would like the HRAC to be a part of the creation and oversight of the AI/AN Stakeholders Strategy for Achieving Health Equity Report and the AI/AN Health Equity Team.

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- The AI/AN Health Equity Team will consist of Tribal, Urban and national organizations, etc. It is anticipated that the tribal representatives that are members of the Regional Health Equity Teams will also be members of the AI/AN Health Equity Team. Once this team is formed they will provide the guidance for the finalization and implementation of the AI/AN Blue Print.
- None of this will transpire until the Secretary makes an announcement about this Initiative.
- Chester Antone asked if the HRAC could have a separate conference call dedicated to this issue alone. Pat will send draft report to review before the conference call.

3. National Children's Study Update – Dr. Steven Hirschfield

- Dr. Steven Hirschfield from NICHD joined the call to discuss the current approach to the NCS.
 - The Children's Health Act of 2000 has a section that focuses on the National Children's Study with the purpose to examine a multitude of genetic and environmental factors that influence the health and development of children.
 - US Congress funds this study and there is an Interagency Coordinating Committee that oversees the study. There is also a Federal Advisory Committee that meets quarterly.
 - The NCS follows a model that is data-driven, evidence-based, and community and participant informed.
 - In January 2009 the study went into the field with the Vanguard Study to evaluate the design approach and recruitment strategies.
 - The study started off with 7 locations that were selected based on infrastructure, so the locations were logistically prepared to set up the study.
 - People enrolled in the study reflected the demographics in the Area they came from without meaning to. 1% self identified as Native American.
 - The Study started moving into 30 new areas in November 2010.
 - By the end of 2011, the NCS will have data to help inform NIH. They will then decide what adjustments need to be made.
 - He read the paper provided by Dr. Warne and the factors discussed such as prematurity, exposures, and health outcomes. He posed the question – will the study answer for everyone? The answer is No. We will wait to see evidence, but the study should capture populations that will have families and communities with these health conditions.
- Cara asked if there were any updates or changes.
- Ric Bothwell, from NAMS, raised his concern.
 - When you limit the selection to these locations, they are very unrepresentative of the AI/AN sample.
 - He is concerned that the area where the highest infant mortality exists, will not be included in the sampling.
- Steve Kutz raised concern about the Tribes not being notified in the planning phases of the NCS. He suggested that they reach out to Native populations.

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- Dr. Hirschfeld said that there are Community Advisory Boards located in the areas and you could find information on the NCS website. The Outreach Coordinator is also listed and can provide information.