

Tribal Advisory Committee (TAC) Meeting March 9-10, 2017 National Institutes of Health (NIH) Building 31C, 6th Floor, Conference Room 10 Bethesda, Maryland

### **Meeting Summary**

### I. Call to Order, Introduction and Meeting Goals

Following a tour of the NIH Clinical Center and the National Library of Medicine, the Tribal Advisory Committee (TAC) meeting began at 11:30 a.m. with a call to order from Co-Chairperson Malia Villegas, Ed.D., of the Native Village of Afognak. Chester Antone of the Tohono O'odham Nation gave the invocation before Dr. Villegas led introductions around the table and around the room. TAC Chairperson Aaron Payment, also chairperson of the Sault Ste. Marie Band of Chippewa Indians, couldn't attend due to a family emergency.

James M. Anderson, M.D., Ph.D., NIH Deputy Director for Program Coordination, Planning, and Strategic Initiatives, next gave brief remarks, noting that NIH continues to seek input from tribal leaders. Dr. Villegas read the Federal Advisory Committee Act meeting requirements and invited TAC members to share their meeting goals and expectations. As the TAC transitions to new leadership, Dr. Villegas sought to identify some formal way to provide feedback and a written record of some of the themes and recommendations committee members have expressed. TAC members should be able to review, document, and archive committee conversations and insight, Dr. Villegas added.

Much of the TAC's work has focused on supporting the development of the Tribal Health Research Office (THRO), and the committee welcomed the arrival of Director David R. Wilson, Ph.D., Dr. Villegas added. The TAC meeting binder included a running list of the committee's top ideas and goals. The TAC used boldface text for a few of the items on that list in an effort to develop themes. However, NIH has requested a more formal set of goals as guidelines. As part of this effort, Dr. Wilson will focus on developing a strategy for the THRO.

Reviewing the meeting's agenda, Dr. Villegas asked if committee members would prefer to use paper ballots for TAC elections on Friday rather than a voice election or show of hands. The committee agreed to use a balloted approach.

### A. Roll Call

1. Tribal Advisory Committee Members

Chester Antone, Tucson Area Delegate Alison Ball, Ph.D., National At-Large Delegate Beverly Cook, Nashville Area Delegate Debra Danforth, National At-Large Delegate Denise Dillard, Ph.D., Alaska Area Delegate Donna Galbreath, M.D., Alaska Area Alternate L. Jace Killsback, Billings Area Delegate Lynn Malerba, National At-Large Delegate



Marcia O'Leary, Great Plains Area Proxy Liana Onnen, National At-Large Delegate Walter Phelps, Navajo Area Delegate Bobby Saunkeah, Oklahoma Area Delegate Joshua Saxon-Whitecrane, California Area Delegate Jeromy Sullivan, Portland Area Delegate Malia Villegas, Ed.D., National At-Large Member Delegate

### 2. Technical Advisors

Deana Around Him, Dr. PH., National At-Large Member Breannon E. Babbel, Ph.D., National At-Large Member Karol Dixon, Portland Area Christy Duke, Nashville Area David Foley, Navajo Area Kori Novak, Ph.D., California Area Michael Peercy, Oklahoma Area Renee Robinson, Pharm.D., Alaska Area Teshia Arambula Solomon, Ph.D., Tucson Area Lisa Rey Thomas, Ph.D., National At-Large Member

### 3. National Institutes of Health

James M. Anderson, M.D., Ph.D., NIH Deputy Director for Program Coordination, Planning, and Strategic Initiatives David R. Wilson, Ph.D., Tribal Health Research Office Director (See attached attendee list for other federal staff in attendance, but not at the table.)

### B. Meeting Agenda

- Highlights of Tribal Activities at NIH and Discussion
- Working Lunch: Native American Heritage Month Challenge Videos
- TAC Charter Discussion
- National Institute on Minority Health and Health Disparities: Plans for the Future and Discussion
- All of Us Research Presentation and Discussion
- Draft NIH Portfolio Analysis on AI/AN Funded Research and Discussion
- Update on Environmental influences on Child Health Outcomes (ECHO) Program and Request for Input
- Election for TAC Chair and Co-Chair
- TAC Priorities Discussion
- TAC Charter Discussion (Resumed)
- Lunch with NIH AI/AN Scholars
- Discussion with NIH
- Cancer Genomics and Research in American Indian and Alaska Native Communities Presentation
  and Discussion



### Action Items

- David Wilson, Ph.D., will continue working to organize the list of TAC priorities. New Chairperson L. Jace Killsback requested a spreadsheet that shows progress made on the TAC's priorities, any new TAC goals, and the Institutes responsible for achieving these goals.
- Malia Villegas, Ed.D., plans to write a co-chairperson's report of the previous year.
- Dr. Villegas encouraged TAC members to share their top committee priority during the next conference call to identify overlapping topics and inform the development of workgroups.
- Dr. Wilson plans to schedule one-on-one conversations to identify each committee member's specific priorities.
- New Co-Chairperson Liana Onnen will summarize the TAC's next steps and topics in an e-mail to the TAC. Committee members should e-mail possible topics and suggestions to Chairwoman Onnen or President Killsback.
- Dr. Villegas and Chairwoman Onnen will work on a post-meeting letter and circulate it to the TAC before sending the letter to James M. Anderson, M.D., Ph.D., and NIH Principal Deputy Director Lawrence A. Tabak, D.D.S., Ph.D.
- Kendra King Bowes will poll TAC members regarding dates for the next in-person meeting in September.
- Ms. King Bowes also will send out the link to the Tribal Health Research Office Website, which has the TAC meeting agenda and the presentation slides. TAC members can forward the link to others.

### 2. Highlights of Tribal Activities at NIH and Discussion David R. Wilson, Ph.D., Director, Tribal Health Research Office (THRO)

Dr. Anderson formally introduced Dr. Wilson, who joined NIH in late January. Dr. Wilson is a member of the Navajo Nation and was a postdoc and then a Senior Research Scientist in the intramural research program in the National Institute on Aging at NIH. Dr. Wilson also has worked for the Indian Health Service (IHS) and the Office of Minority Health (OMH) at the Department of Health and Human Services.

Partnership with NIH presents tremendous opportunities for the TAC and tribal communities, said Dr. Wilson. The new Tribal Health Research Office (THRO) is the NIH focal point for establishing agencywide policies and goals in tribal health research. Dr. Wilson will coordinate research activities across NIH and provide advice and support to NIH staff. The creation of the THRO demonstrates NIH's commitment to supporting and improving Native communities, Dr. Wilson added.

As a first step in building the THRO, each NIH Institute or Center will appoint a representative to serve on the Tribal Health Research Coordinating Committee. The committee will work with the THRO to create and implement a trans-NIH strategic plan. This plan, Dr. Wilson's top priority, will guide NIH's efforts with other agencies and organizations as it reaches out to the American Indian/Alaska Native (AI/AN) community. A portfolio analysis will play a key role in developing the strategic plan. Analyzing reported data from previously funded projects will also help guide the research agenda.

Turning the focus to the TAC, Dr. Wilson highlighted delegate vacancies in Albuquerque and Phoenix. Five alternate seats and five at-large positions also remain open. Technical advisor positions are available as well. In addition to committee positions, Dr. Wilson discussed the annual NIH Tribal Consultation on October 9, 2016 and a consultation on human subjects protections conducted February



23, 2017. Data sharing topped the list of future consultation topics, and Dr. Wilson wrapped up his talk with a look at some new initiatives in research and training. The THRO now seeks ideas for the 2017 NIH Tribal Consultation.

Lynn Malerba, chief of the Mohegan Tribe, asked Dr. Wilson to think about how the THRO will provide information back out to tribal communities. Dr. Wilson asked the TAC to recommend specific topics for dissemination as well as communication strategies. Dr. Villegas suggested the assistance of the National Congress of American Indians (NCAI). Dr. Villegas also recommended a timely, useful community brief on interventions research.

Jeromy Sullivan, chair of the Port Gamble S'Klallam Tribe, added that many of the NIH Institutes don't know Indian Country at all. Tribal leaders must also continually educate senators and lawmakers. How will the correct people at NIH get correct information about Native communities? Dr. Wilson highlighted that question as a major goal of the THRO. Responding to a question from Beverly Cook, chief of the Saint Regis Mohawk Tribe, Dr. Wilson said the THRO will still accept comments regarding the human subjects consultation.

Further addressing future consultation topics, Walter Phelps of the Navajo Nation suggested highlighting telehealth. Tribes also request additional research on cancer.

Councilman Antone asked how researching current best practices is part of a new initiative. Dr. Wilson noted that researchers will pull together the best practices from projects that received funding. Those projects vary from community to community so it would be a collection of outcomes and strategies. In the future, the THRO will discuss how to help coordinate those research activities within Al/AN communities. Dr. Villegas reminded Dr. Wilson to keep mentoring on the radar as well. Dr. Wilson expressed a high level of commitment to mentoring students and trainees, and the office will look for ways to develop a formal strategy.

In response to a question from Chief Cook, Dr. Wilson also noted that the THRO director role includes serving as a liaison between TAC and NIH, and other agencies. Dr. Villegas suggested identifying the Institutes that already have working relationships with IHS, the Centers for Disease Control and Prevention (CDC), and the Environmental Protection Agency (EPA), and assessing how those relationships relate to AI/AN issues. Dr. Anderson said that some Institutes already have AI/AN organizations. A more elaborate organizational chart will highlight these organizations and how they communicate and coordinate across NIH and with other agencies. Dr. Wilson is the starting point for any questions, added Dr. Anderson.

Chief Cook raised concerns regarding NIH funding for Tribal Epidemiology Centers (TECs). Dr. Joyce Hunter responded that for many years, the National Institute on Minority Health and Health Disparities (NIMHD) has provided the money that goes to IHS to support TECs.

L. Jace Killsback, president of the Northern Cheyenne Tribe, said the TAC previously heard talk that TEC funding would face elimination, become competitive, or be contracted out. Regionally, tribal Institutional Review Boards (IRBs) continue to struggle with building capacity and attracting qualified professionals to assist tribal efforts to exercise data sovereignty. Will financial support continue or increase to sustain those efforts?



For the support that NIMHD has provided to the TECs, the mechanism used was through the IHS, said Dr. Hunter. NIMHD remains committed to the TECs. Dr. Hunter recommended presenting that question to Eliseo Perez-Stable, M.D., the Director of NIMHD during his presentation in the afternoon.

# 3. Working Lunch: Native American Storytelling Challenge Videos James M. Anderson, M.D., Ph.D.

Dr. Anderson highlighted the winners of the NIH prize competition that commemorated Native American Heritage Month in November. More than 30 participants submitted a brief video for the "Storytelling about Health and Wellness in American Indian and Alaska Native Communities Challenge." Of the entries, 24 were eligible for judging on the basis of the contest rules that called for newly created videos rather than previously shown productions.

Competitors used brief digital stories to communicate how traditions and heritage promote health in AI/AN communities. The THRO hoped that this challenge would showcase the strengths and resilience of these communities, their heritage and traditions, and how their culture promotes their health and well-being. NIH also hoped to draw more attention to the research needs of Indian Country.

The winners were:

First Place	Integrating Culture into Healthcare Southcentral Foundation Anchorage, Alaska
Second Place	Return to Wellness Oneida Nation
Third Place	Ohero:kon Rites of Passage Creating Health and Wellness for Youth in Akwesasne Salmon River Central Native Film Class Fort Covington, New York

### 4. TAC Charter Discussion Malia Villegas, Ed.D. and TAC members

TAC members set aside time to make final changes to the committee's charter. The document in the meeting binder featured additions highlighted in green that the group discussed in September 2016. The items highlighted in yellow and blue were changes that TAC members needed to talk about further.

The group hoped to reach consensus about the language and approve the charter by the end of the twoday meeting.

The committee's name was a large part of the discussion. The most recent suggestion was to change the name to Tribal Consultation and Advisory Committee. However, Chief Malerba and others raised concerns about the word "consultation" in the committee's name, as was noted in a comment in the draft charter. Another suggestion was to move up a sentence at the end of the charter purpose section



that reads, "The TCAC supports but does not supplant other government-to-government consultation activities that NIH undertakes."

Providing some history on the name change, Dr. Villegas said members sought to put the committee on par with the Secretary's Tribal Advisory Committee (STAC) and some of the other tribal advisory groups, and that members chose to include the word consultation intentionally. Members might be at a different point in their thinking and want to consider other options, added Dr. Villegas. Although tribal advisory committees can discuss issues and policies, true consultation is a government-to-government process where tribes exercise their sovereign rights, said Chief Malerba in opening the discussion period. Delegate Joshua Saxon-Whitecrane, council member for the Karuk Tribe, noted that many tribes now develop their own consultation policies, so the committee could develop a policy that conflicts with another tribe.

Chairman Sullivan added that tribes take consultation protocol seriously, and committee members shouldn't speak for other leaders. After further discussion, Dr. Villegas accepted Chief Malerba's motion to change the group's name to the NIH Tribal Advisory Committee (TAC). Councilman Saxon-Whitecrane seconded, and the committee passed the motion. The TAC will still move the sentence regarding "supports but does not supplant" to a more prominent spot in the charter's purpose section.

In the authority section, Dr. Villegas noted text that had been stricken. Prospective new language seemed to be much broader than the executive orders and the Department of Health and Human Services (HHS) policy. The comment in the draft charter suggested the TAC adopt language from the HHS policy.

Chief Malerba, who liked the simplified language, said the TAC may want to keep the broader context because members can't anticipate how the federal government will work in any given administration. Dr. Villegas said the proposed text should include Alaska Natives as well. President Killsback moved to accept the proposed text. Chief Malerba seconded, and the TAC voted to accept the new language.

Next the TAC reviewed the edits in the last bulleted item under Committee Activities. The proposed language said, "Raise pertinent issues to the attention of tribal leaders, provide a forum for timely feedback, and provide information regarding listening sessions, town halls and tribal consultations."

Alison Ball, Ph.D., of the Confederated Tribes of the Colville Reservation, said the language remained unclear. For instance, where and how would the TAC provide a forum for timely feedback? Members discussed ways to maintain a feedback loop that brings information in from community organizations and represented areas, and sends details back out. After further discussion from Councilman Antone and Liana Onnen, chair of the Prairie Band Potawatomi, Dr. Villegas read this suggestion to the committee: "Raise pertinent issues to the attention of tribal leaders. This information can be shared/disseminated in various national/regional/area tribal forums to facilitate timely feedback and to share information regarding listening sessions, town halls and tribal consultations." Chief Malerba seconded, and the committee approved the language.

Chairman Sullivan asked about the second bullet under Committee Activities, which read, "Serve as a forum for tribes and NIH to discuss proposals for changes to NIH policies, regulations and procedures." Based on a suggestion from Technical Advisor Karol Dixon, Chairman Sullivan suggested adding



"including research priorities" to the end of the original sentence. Councilman Saxon-Whitecrane seconded the proposed change. The TAC passed the motion.

The TAC next addressed charter language the committee members discussed during the September 2016 meeting. The committee made no additional changes. Under the Removal section of the charter, Councilman Phelps discussed the difficulty of participating in TAC conference calls. Dr. Villegas noted that the TAC alternate can participate in the calls in place of the delegate. After further discussion, Councilman Phelps suggested changing the language to "does not participate in a meeting or teleconference on four successive occasions, the Executive Secretary will notify Indian Tribes in the respective area and ask them to nominate a replacement." President Killsback asked if teleconference should be included in the language at all. Chief Malerba suggested clarifying the language to note conference calls that TAC members consider official meetings. The committee approved that language.

Denise Dillard, Ph.D., of the King Island Native Corporation in Alaska, asked for a quicker written summary. Because NIH has an approval process for the official minutes, perhaps the technical advisors could assist with sharing information about the meeting. Dr. Villegas tabled the rest of the charter discussion until the TAC Priorities Discussion on Friday.

# 5. National Institute on Minority Health and Health Disparities (NIMHD) – Plans for the Future and Discussion

Eliseo Perez-Stable, M.D.

Dr. Perez-Stable highlighted the history and mission of the NIMHD and addressed data on issues around AI/AN health. NIMHD began as an office in 1990 and transitioned to a Center in 2000 through legislation. As part of the Affordable Care Act (ACA) in 2010, the Center was elevated to an Institute. Dr. Perez-Stable became the head of the Institute in September 2015. The FY 2016 budget was \$280 million.

Dr. Perez-Stable noted that inclusion of diverse participants in clinical research is a mandate. Further, workforce diversity remains an urgent issue. Less than 1 percent of medical graduates in 2014 were American Indian.

Compared to Whites, Blacks, and Latinos in 2014, life expectancy for AI/ANs and Native Hawaiians is significant lower: 68 years old for men and 74.3 years old for women, said Dr. Perez-Stable.

Further, rural residence is now a health disparity. Nonmetropolitan areas, compared with metropolitan areas, have higher age-adjusted death rates and greater percentages of potentially excess deaths (potentially preventable deaths) from heart disease, cancer, stroke, accidents, and chronic lung disease. Dr. Perez-Stable noted that a significant proportion of the American Indian population lives in rural areas.

Statistics also show increased deaths in whites and AI/AN from accidental overdoses, chronic liver disease/cirrhosis and suicide, from 1999-2014. However, diabetes-related end-stage renal disease has dramatically decreased for AI/ANs from 1996-2013, according to the CDC.

Addressing AI/AN research in FY2015, NIMHD spent close to \$19 million to fund 78 projects and subprojects. NIH-wide, Dr. Perez-Stable identified about 422 AI/AN research projects/subprojects at a



cost of about \$180 million. NIMHD also has launched a series of initiatives, including research with TECs that the Institute will publish soon.

Councilman Saxon-Whitecrane, who also sits on an advisory committee to the president of Humboldt State University, noted that applications to the university from Indian students with Hispanic heritage will only be counted as Hispanic. The census has created the multiracial category, but most people identify with one group, and that is what they check, said Dr. Perez-Stable. Capturing more detailed information will require a secondary question to get people to identify all aspects of their heritage.

Chief Malerba questioned the role of health economics. Al/ANs experience true budget inequality in terms of funding, an issue that requires deeper examination. Further, issues such as transportation to school or health care play a role in social determinants of health.

Chief Cook readdressed the relationship with the TECs and NIH's funding relationship with IHS. Will cooperative agreements continue? Dr. Perez-Stable said NIMHD will propose funding research projects that must use TECs. The TECs will go out and get a partner, and the grants will come in as a partnership as some of the TECs don't have the research infrastructure to do some of the work. NIMHD's commitment to providing modest support for the basic infrastructure of the TECs will continue, and perhaps funding can go to the TECs directly with bureaucratic approval. The grants program will provide competitive funding, and Dr. Perez-Stable hopes other Institutes will participate.

Chief Cook spoke of the federal government's obligation to tribal health. Grants force tribes to compete for money they should receive anyway due the federal government's trust responsibility. That obligation shouldn't get lost in the process, said Chief Cook. Dr. Perez-Stable said the commitment to the TECs won't change. The grants are in addition to that commitment.

Jennifer Alvidrez, Ph.D., and Dorothy Castille, Ph.D., addressed the issue further in a presentation titled Proposed Research Initiative: Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers. TECs, which help address significant gaps in knowledge regarding the health of AI/AN populations, receive funding as five-year cooperative agreements by the IHS along with additional funding through the CDC, NIMHD, and the OMH. Twelve TECs operate nationwide under the umbrella of an Indian health board or tribal health consortium.

Dr. Alvidrez provided details on a trans-NIH initiative to support collaborative research between TECs and external investigators, with a particular emphasis on areas where there are significant gaps in data and knowledge for AI/AN populations. These projects would help TECs build capacity by giving them the opportunity to gain experience preparing NIH grant applications and conducting NIH-funded research. Further, the TECs would engage community stakeholders in research and generate baseline data for future studies. The NIMHD Advisory Council approved the concept in February.

Delegate Bobby Saunkeah, manager of the Chickasaw Nation Department of Health, asked if NIMHD received input from tribes on the new initiative. Oklahoma tribes often find themselves competing with TECs for grant funding. The project seemed like another mechanism to take away direct research funding for tribes, said Mr. Saunkeah. Further, external researchers working directly with TECs can bypass tribal IRBs.



Councilman Phelps yielded time to Technical Advisor David Foley, who works for the Navajo Epidemiology Center. Mr. Foley said the amount of money offered in these grants often isn't worth the time to go through the application process and fund a complete project. Mr. Foley also wondered about the length of the grants and collaboration with area universities before yielding the seat back to Councilman Phelps.

Regarding IRB issues, Dr. Alvidrez said NIMHD didn't want to impose numerous restrictions knowing that the TECs have different arrangements. As the TECs will use existing data, Dr. Alvidrez doesn't foresee \$500,000 a year R01 grants; however, the initiative will likely provide a flexible range because some TECs can't undertake large-scale projects.

Dr. Villegas proposed drafting a letter at the end of the TAC meeting that would include further committee input on this issue.

# 6. *All of Us* Research Program Presentation and Discussion Eric Dishman, Director

Mr. Dishman brings experience as a patient and a patient advocate to this research project, which will reflect America's diversity, earn trust through engagement and transparency, and provide data to empower research.

Seeking one million participants, this research project will accelerate scientific discovery and breakthroughs in precision medicine. Consented and engaged participants will provide clinical, environmental, lifestyle, and genetic data on an ongoing, longitudinal basis of 60+ years. Researchers hope the TAC will help NIH learn how to approach AI/ANs regarding tribal involvement in this project.

Describing the project as partly exciting and partly terrifying, Dr. Dillard asked if NIH had fully examined all the project's potential risks. Researchers could use the data to reinforce stereotypes or pathologize people. Further, some people don't participate in research because they don't see the benefits coming back to their communities. NIH also must include tribal review. Involving AI/ANs is a worthy goal, but the project raises complicated issues, said Dr. Dillard.

Chief Malerba asked Mr. Dishman to consult broadly with tribes regarding who owns the information and how researchers and others will generalize it. Briefly recounting the history of the Mohegans, Chief Malerba said tribes wonder if researchers will use the information with care and sensitivity. Further, if a Mohegan participates, will researchers generalize the data to say all Mohegan genetic material must look just like this? Last, small tribal communities are identifiable. Other questions include: How will the data get published, will tribes have any control and what will be the outcome from the pharmaceutical industry?

Mr. Dishman agreed that deidentification is an issue for small, rural communities. NIH will need a risk deidentification filter that calls for credentialing and controls the use of data. Great Plains Area Proxy Marcia O'Leary asked how NIH would handle urban tribal members. To whom would those tribal members answer? Mr. Dishman said the first principle would be participant choice. Some tribal members may come to the project through a relationship with a community partner. Others may hear about the project through health insurance available through an employer. In all cases, researchers want to make participation an easy experience.



Noting the importance of free will, Ms. O'Leary said tribes have a different dynamic, and researchers often try to circumvent tribal authority. Mr. Dishman said NIH needs the TAC's assistance thinking through all those issues and maintaining a trusting relationship. NIH expects to update its protocols with additional survey modules or future biosample collections due to participants' comments and the results of nationwide scientific workshops that include patient advocacy groups, industry, academics and others. Researchers also could recruit participants for follow-up clinical trials, but that would lead to the risks TAC members previously discussed, added Mr. Dishman.

Councilman Antone asked about researchers' access to data and if there are restrictions for researchers. Certain kinds of data, such as summaries of what people answer on surveys, will be deidentified and safe to share with the general population. A working group continues to develop tiered levels of data access. Access to deidentified information from a participant's clinical record presents a certain level of identification risk. Access to genetic information, a really complicated issue, would be an extra tier. Users must adopt privacy and security principles as well as research principles that govern how researchers will and won't use information.

Most important, researchers must be willing to give back. NIH will commit to returning raw data if a participant requests it. Further, as technology improves, participants will have access to information that shows how their voluntarism moved science forward. Information also can go back to a participant's doctor, said Mr. Dishman.

Councilman Antone asked if researchers can study whatever they choose with the data or will NIH exclude race studies. In general, NIH seeks to protect participants' identities without restricting researchers. However, NIH must put in place a set of policies and a review committee, said Mr. Dishman. All the researchers' tools will not be available until the project gets further along and the infrastructure has been built.

An *All of Us* Tribal Forum will take place in Arizona, added Councilman Antone, who then yielded time to Technical Advisor Teshia Solomon, Ph.D. Dr. Solomon asked numerous questions, including these:

- How will populations that already have problems getting imprecise health care access get precision medicine?
- How will NIH ensure benefits to the participating population?
- What about data security? Tribes have a negative history from many angles, so security is imperative.
- Is there a benefit to individuals as well as communities? If industries make money in the future from various therapies, what benefit will come back to all of the individuals who contributed to that scientific process?
- In dealing with issues of mixed heritage, NIH might find more value in examining place, socioeconomic status, and other crossover issues that create health problems.

Dr. Solomon also invited TAC members to attend the May 2017 *All of Us* forum in Phoenix before yielding the floor back to Councilman Antone.

Mr. Dishman noted that NIH remains connected to other countries that are working on large cohorts,



defined as 250,000 people or more. The agency also partners closely with the Veterans Affairs' (VA) Million Veterans Program. Dr. Anderson encouraged Mr. Dishman to continue reaching out to the TAC for guidance on connecting with tribal communities.

# 7. Draft NIH Portfolio Analysis on AI/AN Funded Research and Discussion James M. Anderson, M.D., Ph.D.

Dr. Anderson presented an overview of NIH's draft quantitative analysis of the AI/AN portfolio. This is the first time such an analysis has been completed. This work in progress will give NIH some direction regarding its AI/AN research. Among other things, the analysis examines the focus of NIH's investment in AI/AN research, where the research is performed and by whom and how the investment aligns with the burden of disease (mortality) among AI/AN populations.

The analysis showed that in FY2015, of the number of projects assigned to AI/AN health research, most of it addresses disease prevention or treatment, said Dr. Anderson. Workforce development was about 14 percent of the projects. Infrastructure and community outreach 10 percent of the projects. Further analysis showed, among other things,

- Which NIH Institutes conduct the research
- The geographic distribution of AI/AN research projects, and
- The distribution of FY2015 research dollars and projects by institution type.

Going forward, analysis should place the dollar amounts in the context of the overall available funding within an Institute to benchmark the information, said Dr. Dillard. Dr. Dillard also requested funding amounts for mental health, as well as information on rejected funding applications that might be missed opportunities.

Dr. Anderson noted that the Center for Scientific Review (CSR) attempts to bring junior or unfunded investigators into study sections to explain the process with their early career reviewer program. Perhaps the TAC can provide to CSR a list of early investigators or post-doctoral participants who could sit in on those sections, said Dr. Anderson. Further, applicants who didn't receive funding perhaps could benefit from additional training, added Dr. Wilson. Taking a look at those who haven't succeeded could play a role in building research capacity, said Dr. Dillard.

Chief Cook expressed a concern about the presentation's geographic distribution map of AI/AN research projects. New York State showed a large tribal population although some Native communities don't participate in the U.S. census. Looking at the population totals for Texas, Chairwoman Onnen reminded the TAC that census data is self-identified.

What's more, researchers don't seem to take AI/AN deaths from accidents seriously, said Chief Cook. Those researching historical trauma and substance abuse also should consider accidental deaths as a symptom of a deeper issue.

Turning the focus to research findings would help tribal communities start to build on a body of research, said Dr. Ball. Adding on to Chief Cook's point, Dr. Ball said accidental deaths do have something in common with suicide; however, researchers have never been able to look at the relationship between historical trauma, accidents, suicide and the larger picture. Looking at the findings



these projects have revealed can help tribal communities get a broader view of an issue. Dr. Anderson said the findings are publicly available on NIH Reporter.

Given the high number of AI/AN deaths from diseases of the heart, Councilman Saxon-Whitecrane asked about NIH's plan for putting more funding into that research area. Dr. Anderson said that a lot of research dollars go toward that issue, and in general researchers can apply the findings to tribal communities. The reduction in end-stage renal disease due to diabetes among Native Americans, for example, came from decades of NIH-funded basic and clinical research findings that led to treatment guidelines that the IHS implemented in their clinics.

Low levels of funding in community-specific research, however, could lead to a discussion with a particular Institute to mention investments are relatively low and could they consider funding more community-specific opportunities, said Dr. Anderson. Ms. O'Leary said the fight continues for more research dollars for the 30-year Strong Heart program, the only American Indian cohort study on Native American cardiovascular disease. The portfolio analysis should encourage TAC members to ask if funding levels are commiserate with the level of burden on a community.

Dr. Anderson noted that the projects captured in the analysis looked at community-specific research. Those reviewing the analysis should consider why the funding seems somewhat low and ask if there is an opportunity to apply research among a particular population. In its critical role, the TAC can provide insight and recommendations that lead to better health outcomes in Native communities, said Dr. Villegas.

The TAC adjourned at 4:39 p.m. for tribal caucus, to resume at 8:30 a.m. on Friday, March 10.

### 8. Welcome, Introductions, and Meeting Recap

Following the opening blessing and introductions from new participants, Dr. Villegas shared items for follow-up as the TAC prepared for its conversation with Lawrence Tabak, D.D.S., Ph.D., principal deputy director for NIH:

- Provide input to NIMHD about its priorities
- Clarify NIH's financial support of TECs
- Understand interagency coordination -- determine what is already happening and discover ways to improve CDC/IHS/FDA collaboration
- Promote community engagement within the All of Us effort
- Identify the connection between research and health-care service delivery
- Offer guidance on improving the consultation process
- Consider issues regarding data security/infrastructure/sharing as priority areas for future consultation

### 9. Update on Environmental Influences on Child Health Outcomes (ECHO) Program and Request for Input Matthew Gillman, M.D., Director

ECHO is a nationwide program that aims to enhance the health of children for generations to come. Its overall scientific goal is to answer crucial questions about the effects of a broad range of early



environmental exposures on child health and development. The program remains committed to tribal consultation and collaboration with the TAC and AI/AN partners, said Dr. Gillman.

ECHO wants to attend to cultural and historical issues that Native communities bring to the table and conduct research that serves AI/AN communities directly and enhances consortia-wide research. ECHO especially wants to focus on sharing data and biospecimens. ECHO investigators also have questions about genetics, said Dr. Gillman.

Dr. Ball's community found high levels of arsenic in the well water four years ago. No one has studied the health consequences, said Dr. Ball. What's more, river water affected by a Canadian mine upstream flows along the border of the Colville reservation. These issues would be worthy of an ECHO study, said Dr. Ball. Any tribe that decided to work with ECHO would decide on its own data-sharing agreement, Dr. Ball added.

Dr. Gillman said the ECHO-wide cohort may address many of the issues Dr. Ball raised. ECHO staff are willing to visit tribes to make presentations on its work.

Regarding data sharing, Dr. Dillard noted that the King Island community would want to have oversight of scientific publications that come out of a research effort. Residents also would want to know how ECHO investigators would return information to the community as well as health providers. These efforts help build trust and transparency and show the benefits of research, said Dr. Dillard.

Dr. Gillman addressed two aspects of returning results: returning aggregate results, the results of research, and returning individual results. If someone contributes a lab test that comes back at an abnormal level, investigators will report that information if it is clinically actionable. Regarding aggregate data, communications specialists report results to internal audiences and external stakeholders. Participants might be the number one stakeholders in ECHO research, said Dr. Gillman. Researchers also must report their findings in an accessible way, taking time to explain what the research means.

For the past 30 years, the Saint Regis Mohawk Tribe has maintained a research relationship with the State University of New York at Albany (SUNY Albany) School of Public Health, Department of Health Disparities, said Chief Cook. Researchers have learned how to navigate the community, and reporting comes to the community first. Publications list the tribe's environmental department or individuals as co-investigators. Researchers also must return information and specimens at the study's completion, said Chief Cook. Findings also should translate into solutions for the tribe.

The Saint Regis Mohawk Tribe has faced environmental issues stemming from General Motors, Alcoa and other adjacent corporations. Community size shouldn't disqualify a tribe from being an important indicator of how environmental issues affect residents, said Chief Cook. Dr. Gillman agreed that trust takes time. Researchers often must balance taking time to build trust with producing early research results. Suggestions from TAC members can help ECHO investigators include tribes in the early stages of a research project to develop a valuable partnership, said Dr. Gillman.

Dr. Gillman also requested tribal leader input on using genetic data with the AI/AN cohort and managing biospecimens. ECHO hopes to create a genetics core that will measure some element of genetics on mothers and children. TAC can help ECHO determine when and how the program should collaborate with AI/AN communities.



Councilman Phelps asked if ECHO's Navajo Birth Cohort Study would help the tribe secure more funding from IHS and the EPA as the community seeks to mitigate the effects of uranium mines. The Navajo Nation has planned water infrastructure projects that will cost millions in tribal and federal money, said Councilman Phelps. If the cohort study shows a connection and a need, that message must go to Congress immediately, particularly in light of President Trump's trillion dollar infrastructure projects. Other issues affecting the Navajo Nation include emerging environmental issues, such as the effects of a Colorado mine spill, and access to healthy foods.

ECHO's job is to provide scientific information that policymakers can use to take action, said Dr. Gillman. Rather than just asking interesting questions, researchers want to address issues that will affect policy. Investigators trained in research methods also can learn from tribes the importance of linking research with meaningful cultural traditions.

### 10. Election for TAC Chair and Co-Chair

As the next order of business, Dr. Villegas began the election process for TAC chairperson and cochairperson.

According to the charter, the TAC chairperson and co-chairperson will be an elected or appointed tribal leader, not a designee, said Dr. Villegas. After brief discussion, TAC members agreed to keep that charter language as stated. Villegas, who plans to write a co-chair's report to reflect on the previous year, reminded the TAC to finalize the charter.

Dr. Villegas passed out paper ballots and opened nominations for chairperson, noting a nomination from Dr. Ball for President Killsback. Chief Malerba seconded. Councilman Antone nominated Dr. Villegas, who respectfully declined. After a show of hands, the TAC elected President Killsback as chairperson.

Opening nominations for co-chairperson, Dr. Villegas noted a nomination for Chairwoman Onnen. The motion was seconded, and Dr. Villegas called for a vote. After a show of hands, the TAC elected Chairwoman Onnen as co-chairperson. President Killsback and Chairwoman Onnen took over the meeting after the elections. President Killsback thanked former Chairperson Aaron Payment and former Co-chairperson Dr. Villegas for setting a strong foundation for the TAC.

### **11. TAC Priorities Discussion**

Leading the discussion, Dr. Wilson reviewed the list of over 40 priority needs and asks to strengthen research investments and outcomes in Indian Country. The TAC must identify some short-and long-term objectives to reach together to increase awareness and achieve the priorities relevant to all the tribes represented on the TAC.

Dr. Ball asked if Dr. Wilson's internal committee could begin working on some of the priorities while the TAC turns the big-ticket items into its agenda. Dr. Wilson agreed that experts within the agencies can comment on what is achievable. Chief Malerba asked how the TAC would engage other tribes as the priorities move forward. NCAI, STAC and other tribal advisory groups could assist in that role, said Dr. Villegas. For other priorities, such as "invest in interagency coordination on research policy and development," the TAC must understand what is already in place at NIH, said Dr. Villegas. As the TAC



identifies priorities, Dr. Wilson will gather background information. Further, other agencies will have ongoing engagement. The TAC can leverage those efforts to take steps forward, said Dr. Wilson.

President Killsback requested a spreadsheet that shows progress made on the TAC's priorities. The spreadsheet also should include any new priorities. Further, the priorities should identify the Institutes responsible for achieving these goals, said President Killsback. Chairwoman Onnen asked Dr. Wilson to categorize the priorities into themes. Those themes or buckets will be part of the strategic plan, said Dr. Wilson. The coordinating committee will identify which Institutes and Centers will serve as lead experts.

TAC members can focus on the priority list and the committee's expected outcomes during the monthly conference calls, suggested Chief Malerba. Dr. Villegas agreed, noting that the bolded sections of the priority list are an attempt to categorize the topics. Dr. Villegas encouraged the committee members to share their top priority during the next conference call to identify overlapping topics and inform the development of workgroups. Dr. Wilson also plans to schedule one-on-one conversations to identify each committee member's specific priorities. An annual report of activities and accomplishments might also be useful.

President Killsback encouraged the committee to focus on sustaining its priorities throughout NIH so work can go forward even as TAC leadership changes. The committee took a brief recess before returning to complete changes to the TAC charter.

### 12. Charter Discussion (Resumed)

Opening the discussion, Dr. Villegas made a motion to approve the charter. The motion was seconded, and after a show of hands, the committee approved the motion.

Dr. Ball asked to return to the question of reporting on TAC outcomes. Councilman Saxon-Whitecrane noted feedback received from the Northern California Tribal Chairmen's Association prior to the TAC. Historical trauma was a main theme, and Councilman Saxon-Whitecrane will complete the feedback loop by reporting the TAC's work back to the association. Those members can disseminate information out to organizations, tribal membership and councils/leadership.

Dr. Ball also noted the partners and individuals who have assisted Native communities. Dr. Wilson might consider those partners for the THR Coordinating Committee. Dr. Villegas added that those partners can help the TAC navigate the internal NIH landscape and its role in consultations, workforce development, and training. TAC members also can get feedback from regional leaders and testify in appropriations hearings. Dr. Villegas encouraged committee members to think about possible audiences with whom they want to communicate.

Whereupon, the TAC called a recess to go into Tribal Caucus until 11:45 a.m.

### 13. Lunch with NIH AI/AN Scholars

TAC members met with two AI/AN scholars during the afternoon session. Loretta Grey Cloud is a postbaccalaureate fellow at the National Institute for Dental and Craniofacial Research (NIDCR). Alec Calac is post-baccalaureate fellow at the National Institute of Neurological Disorders and Stroke (NINDS). Ms.



Grey Cloud and Mr. Calac shared details about their studies and background before answering TAC members' questions about their challenges as AI/AN students.

Councilman Saxon-Whitecrane asked for the scholars' bios to share with other tribal students and education departments so Native youth know this level of study and success is possible. TAC members can get a copy of the NIH Native Scholars Handbook featuring past and current scholars, said Ms. Grey Cloud.

The TAC also can reach out to the scholars for youth mentoring opportunities, said Mr. Calac, who encourages students and younger relatives to pursue their passions and keep that fire lit. Ms. Grey Cloud highlighted the importance of writing skills when developing personal statements. Tribal youth need to see older Native students doing cool, exciting work in STEM fields. Tribal leaders should begin developing that STEM pipeline as early as kindergarten, said Ms. Grey Cloud.

Program Coordinator Rita Devine, Ph.D., encouraged TAC members to e-mail or stay in touch with the scholars to keep them encouraged. Dr. Devine also reported that NIH will develop a neuroscience curriculum for Salish Kootenai College (SKC). Principal investigators at NIH will teach SKC students online. The investigators also will go out to SKC to teach the professors and students how to do some neuroscience techniques. Dr. Devine asked the TAC to assist in developing a plan for post-bac students who want to go back to their communities after studying at NIH.

### 14. Discussion with NIH

Lawrence A. Tabak, D.D.S, Ph.D., Principal Deputy Director James M. Anderson, M.D., Ph.D.

Departing from PowerPoint slides and prepared remarks, Dr. Tabak met with the TAC to listen and have a conversation. Dr. Tabak briefly discussed the AI/AN scholars, then took questions from committee members.

To begin, Dr. Dillard commented on the *All of Us* presentation to the TAC. The project carries real risk for Native communities. Tribes remain concerned about data sharing and have put limitations in place. Further, tribal leaders question how researchers will describe the data. Last is the concern about results going back to Al/AN communities with a benefit to those who participate.

Chief Malerba added that tribal leaders struggle with advancing research and science to help community members while protecting tribal members from harmful research practices. Dr. Tabak said NIH must be sensitive to tribal nations, but one answer will not fit all communities. The TAC will play an essential role in helping NIH move forward with *All of Us*, which remains a work in progress.

Adding to the discussion, Dr. Ball highlighted a document from Canada on Indigenous research ethics. Perhaps NIH could consider developing or endorsing an Indigenous research ethics document that would encompass data sharing, genetics and other topics, said Dr. Ball. Dr. Villegas will circulate the Canadian document to TAC members. The committee also has discussed inviting tribes with successful research programs to the next TAC meeting.

Chairwoman Onnen recommended starter grants to assist tribes with research capacity building. Dr. Villegas yielded the floor to Technical Advisor Deana Around Him, Ph.D., who encouraged NIH to think



critically about funding needs to oversee research at the tribal level, build policies around data, store returned data and information and increasing researcher capacity. Dr. Ball gave a plug for Native American Research Centers for Health (NARCH) grants, which have a building-capacity component. Building processes for tribal research also require time for training and gaining perspective, Dr. Ball added. Dr. Tabak encouraged the TAC to consider a systematic review of lessons learned of the major research programs or program types.

Tribes actually have been doing research for thousands of years, said Ms. O'Leary, just in a different way. Research applications should acknowledge that tribal knowledge. Further, NARCH funds often go to institutions and don't circulate back to build community capacity, said Ms. O'Leary. Dr. Ball noted that research outside the western cultural lens often requires more explaining and description. Researchers also must find the balance between studying Indigenous approaches and exploitation, said Dr. Tabak.

A focus on process remains critical, said Dr. Villegas. TAC and NIH must explore the what and the how. Solutions-oriented research that has policy implications explains the why of research: to improve communities. Visits to Indian Country would enhance these efforts, added Dr. Tabak. Councilman Antone encouraged Dr. Tabak to attend the *All of Us* panel on cultural traditions in Phoenix or to send Dr. Wilson. Finding the balance between cultural and scientific knowledge teaches Native youth to embrace rather than fear science. Councilman Phelps wrapped up the session by requesting help from NIH to protect the Indian Health Care Improvement Act.

### **15.** Cancer Genomics and Research in American Indian/Alaska Native Communities L. Michelle Bennett, Ph.D., Director, Center for Research Strategy National Cancer Institute

TAC members continue to express great interest and concern about the rates of cancer in Native communities. Dr. Bennett's presentation served as a follow-up to the September 2016 TAC presentation by Bob Croyle, Ph.D., on cancer control in AI/AN populations. Reviewing statistics on the incidence in mortality for cancer in different populations, Dr. Bennett said the AI/AN population isn't benefiting from advances in cancer research in the same ways as other populations. Incidence and mortality of some cancers, such as liver cancer, are increasing in the AI/AN and other populations. Kidney cancer also is increasing in AI/AN populations. Although mortality is flat, Dr. Bennett noted a gap between AI/AN and other populations.

Reviewing the basic biology and genetics of cancer, Dr. Bennett noted that cancer remains very complex. The genomics revolution and advances in biomedical technology have helped but cancer research must continue. Increasing evidence shows obesity is a risk factor for various cancers, including liver, kidney and colorectal. Aflatoxin, secreted by a mold that grows commonly on corn and peanuts, present a less-obvious cancer exposure through food.

The Cancer Genome Atlas (TGCA) project began more than a decade ago as a collaboration between the National Cancer Institute and the National Human Genome Research Institute. The TGCA uses convenient samples and doesn't include several demographic groups, including the AI/AN population.

An aspect of the Early Onset Malignancies Initiative will work with minority-serving National Community Oncology Research Programs sites across the nation. Through this project, researchers will collect samples from individuals who are diagnosed with cancer at an early age. The samples come from



different population groups, and researchers will characterize the samples at the molecular level and collect information from the individuals about their clinical background and exposures. This project also will develop a tissue bank for future study. Native American populations will participate in this effort.

Biospecimens will be critical for advancing cancer research in AI/AN populations. This will include collecting tissue/blood samples from individuals diagnosed with cancer (informed consent) and information about the individuals (clinical data, exposure data, family history, and so on). Researchers will securely store all data, share it with the cancer research community and integrate it with other data types and use it in future studies.

A national meeting on precision medicine and cancer in the AI/AN communities took place in Oklahoma in November 2016. During that well-attended meeting, TAC member Dr. Dillard shared details on a Tamoxifen study in Alaska that involved years of community investment and capacity building. Another presenter shared details on a study of ancestry and relapse of childhood acute lymphoblastic leukemia in Hispanic and American Indian children. The findings showed how ancestry and associated genetic background can play an important role in treatment decisions, said Dr. Bennett.

A rural cancer control meeting will occur May 4-5, 2017, at the University of Memphis. Dr. Bennett posed a final question to the TAC: Are AI/AN communities willing to participate in efforts to increase our genomic understanding of cancer?

Dr. Villegas opened the discussion session by asking how certain cancers became priorities. Although researchers are looking at prostate cancer, ovarian cancer remains an under researched area, particularly for Native women, perhaps due to the effects of stress on the body or the effects of historical trauma. In addition, conversations about co-occurring conditions have had some traction among TEC staff looking at the intersection of cancer and diabetes or cancer and mental health/depression. Last, tribes have concerns about the role of industry in terms of who funds research, who benefits, and the risks to Al/AN communities.

Councilman Phelps asked if the research on AI/AN communities is part of the Cancer Moonshot Initiative championed by former Vice President Biden, which included a \$1 billion investment into NCI. Congress authorized the \$1.8 billion commitment to cancer research over 7 years, so for FY17, NCI got \$300 million. Congress has to appropriate the funding each year, said Dr. Bennett. Components of cancer genomics research fall under the Moonshot project. Warren Kibbe, Ph.D., head of biomedical informatics and computing at NCI, said a focal point of the next few years will be managing the data NCI wants people to contribute.

Councilman Phelps expressed a willingness to help NCI lobby for funding if the research includes representation in tribal communities. Tribes would want assurances that this work would trickle over into Indian Country, Councilman Phelps added. Dr. Kibbe noted that lobbying would be the tribe's decision. NCI can't discuss lobbying efforts. Further, NCI wants better interactions with Native populations and other underserved minorities.

Given that Dr. Bennett's presentation listed arsenic as a cancer risk factor, Dr. Ball shared her community's struggle with high levels of arsenic in well water. The tribe seems to experience high rates of cancer diagnoses. Tribal members might be willing to participate in studies after seeing Dr. Bennett's presentation, said Dr. Ball. NCI can explore the cancer registry of the Northwest Portland Indian Health



Board and get back to Dr. Ball with any thoughts. NCI also can provide larger graphs to aid in articulating information to tribal leaders, said Dr. Bennett.

Mr. Saunkeah took several meanings from NCI's question about tribes' willingness to participate in efforts to increase the genomic understanding of cancer. Tribes want to learn more about genomic research but tribes in the Oklahoma area generally aren't willing to commit to donating samples. Tribes want more knowledge and clarity on the issues. Some Native communities in Oklahoma have engaged in genomic research, whereas others have said no. NCI must continue educating Indian Country on genomic research and the project, said Mr. Saunkeah.

Ms. O'Leary agreed that tribes want to listen and work toward solutions for better health. Most tribes have research processes, and other tribes are adopting them. Councilman Saxon-Whitecrane asked about the definition of "our." Does "our" mean NCI and tribes? Will tribal communities gain information and have the option of sharing it with NIH? Those and other concerns hinder participation. Dr. Villegas added that previous AI/AN participation in cancer research can inform future efforts.

Dr. Dillard added that the Southcentral Foundation agreed to certain stipulations as part of the Tamoxifen study. The data and the specimens remain under the control of Southcentral Foundation.

Further, if the research required contributions to the genomic data warehouse, the foundation wouldn't participate to maintain control over the specimens and the resulting publications.

NCI stressed its commitment to working jointly with various communities to understand and reduce the burden of cancer across the country and around the globe. The Institute seeks to generate scientific evidence that can lead to policies and interventions that benefit everyone, said Dr. Kibbe.

### 16. Wrap Up/Next Steps

Pleased with the two-day meeting, Chairwoman Onnen said the TAC continues to move forward. Chairwoman Onnen also thanked NIH for serving as host. Chairwoman Onnen will summarize next steps and topics in an e-mail to the TAC. Committee members should e-mail possible topics and suggestions to Chairwoman Onnen or President Killsback.

The next in-person meeting will occur in September, possibly September 21-22 during the same week as the STAC meeting. Chairwoman Onnen suggested polling the TAC. Dr. Villegas and Chairwoman Onnen also will work on a post-meeting letter and circulate it to the TAC before sending the letter to Dr. Anderson and Dr. Tabak.

Councilman Saxon-Whitecrane asked for electronic copies of the presentations to share with California tribal leaders and health professionals. Kendra King Bowes noted that all the slides are on the THRO Website. Ms. King Bowes will send out the website link, which TAC members can forward to others.

Possible agenda items for the next in-person meeting included:

- Indigenous research ethics
- More time to talk about genetics
- Lessons learned/case studies



• Tribal IRB presentations

The THR Coordinating Committee will get details from the individual NIH Institutes and Centers about AI/AN offices or programs and also any lessons learned. Dr. Anderson also suggested inviting one or two Institutes to an in-person meeting for an institute-specific overview.

TAC members appreciated the portfolio analysis and asked if Dr. Wilson could share the analysis with Institutes to generate input. Working with the Institutes on the analysis will be an ongoing effort as the coordinating committee seeks more detail on programs that weren't in the initial analysis, said Dr. Wilson. Continued work on the portfolio will provide a comprehensive view of the tribal programs and research occurring at NIH. Dr. Wilson also hoped to talk to the TAC during the regularly scheduled conference call on March 14, 2017, to plan the next NIH tribal consultation.

Serving on the TAC was an honor, said Dr. Villegas as committee members gave closing remarks. Dr. Anderson thanked the committee as well, giving special appreciation to Dr. Villegas. After the closing prayer, the meeting adjourned at 3:04 p.m.

# NIH Tribal Consultation Advisory Committee Meeting March 9-10, 2017

## **List of Attendees**

### NIH Tribal Consultation Advisory Committee Members and Technical Advisors

### **Chester Antone**

Delegate Tucson Area Tohono O'odham Nation chester.antone@tonation-nsn.gov

### **Deana Around Him**

Technical Advisor National At-Large Member National Congress of American Indians daroundhim@ncai.org

### **Alison Ball**

Alternate National At-Large Member Confederated Tribes of the Colville Reservation alison.ball@colvilletribes.com

### **Breannon Babbel**

Technical Advisor National At-Large Member National Indian Health Board bbabbel@nihb.org

### **Beverly Cook**

Delegate Nashville Area Saint Regis Mohawk Tribe beverly.cook@srmt-nsn.gov

### **Debra Danforth**

Delegate National At-Large Member Oneida Nation ddanforth@oneidanation.org Denise Dillard Delegate Alaska Area King Island Native Corporation dadillard@scf.cc

Karol Dixon Technical Advisor Portland Area Port Gamble S'Klallam Tribe Health Services karold@pgst.nsn.us

### **Christy Duke**

Technical Advisor Nashville Area United South and Eastern Tribes cduke@usetinc.org

### **David Foley**

Technical Advisor Navajo Area Navajo Department of Health david.foley@nndoh.org

### Donna Galbreath

Alternate Alaska Area Mentasta Traditional Council dgalbreath@SouthcentralFoundation.com

### L. Jace Killsback

Delegate Billings Area Northern Cheyenne Tribe voaxaa@hotmail.com Lynn Malerba Delegate National At-Large Member Mohegan Tribe Imalerba@moheganmail.com

Kori Novak

Technical Advisor California Area Karuk Tribe knovak@karuk.us

Marcia O'Leary Proxy Great Plains Area Missouri Breaks Industries Research Inc. marcia.oleary@mbiri.com

Liana Onnen Delegate National At-Large Member Prairie Band Potawatomi LianaOnnen@pbpnation.org

Michael Peercy Technical Advisor Oklahoma Area Chickasaw Nation Department of Health Michael.Peercy@chickasaw.net

Walter Phelps Delegate Navajo Area Navajo Nation nakaidinee@yahoo.com

Renee Robinson Technical Advisor Alaska Area Southcentral Foundation rrobinson@scf.cc Bobby Saunkeah Delegate Oklahoma Area Chickasaw Nation Department of Health Bobby.Saunkeah@chickasaw.net

Joshua Saxon-Whitecrane

Delegate California Area Karuk Tribe jsaxon@karuk.us

**Teshia G. Arambula Solomon** Technical Advisor Tucson Area University of Arizona solomont@email.arizona.edu

# Jeromy Sullivan

Delegate Portland Area Port Gamble S'Klallam jeromys@pgst.nsn.us

#### **Lisa Rey Thomas**

Technical Advisor National At-Large Member University of Washington lisarey51@gmail.com

Malia Villegas Delegate National At-Large Member Native Village of Afognak malia.m.villegas@gmail.com

## **National Institutes of Health Attendees**

#### Lynn Adams

NIH/National Institute of Nursing Research lynn.adams@nih.gov

Margo Adesanya

NIH/National Institute of Dental and Craniofacial Research margo.adesanya@nih.gov James Anderson NIH/NIH/Office of the Director/Division of Program Coordination, Planning, and Strategic Initiatives james.anderson2@nih.gov

Jennifer Alvidrez NIH/National Institute on Minority Health and Health Disparities jennifer.alvidrez@nih.gov

Judith Arroyo NIH/National Institute on Alcohol Abuse and Alcoholism jarroyo@mail.nih.gov

Laura Bartlett NIH/ National Library of Medicine bartlettl@mail.nih.gov

L. Michelle Bennett NIH/National Cancer Institute I.bennett@nih.gov

Juliana Blome NIH/OD/ECHO Program blomeju@od.nih.gov

Vence Bonham NIH/National Human Genome Research Institute bonhamv@mail.nih.gov

Sheila Caldwell NIH/National Institute of General Medical Sciences caldwells@mail.nih.gov

**Dorothy Castille** NIH/National Institute on Minority Health and Health Disparities dorothy.castille@nih.gov

**Rita Devine** NIH/National Institute of Neurological Disorders and Stroke rita.devine@nih.gov **Eric Dishman** NIH/OD/*All of Us* Research Program Office eric.dishman@nih.gov

Jessica Escobedo NIH/National Institute on Minority Health and Health Disparities jessica.escobedo@nih.gov

Kathy Etz NIH/National Institute on Drug Abuse ketz@nih.gov

Matthew Gillman NIH/OD/ECHO Program matthew.gillman@nih.gov

Michael Hahn NIH/National Human Genome Research Institute michael.hahn@nih.gov

Sara Hull NIH/National Human Genome Research Institute shull@mail.nih.gov

Joyce Hunter NIH/ National Institute on Minority Health and Health Disparities joyce.hunter@nih.gov

Daozhong Jin NIH/OD/All of Us daozhong.jin@nih.gov

**Robin Kawazoe** NIH/Office of the Director/Division of Program Coordination, Planning, and Strategic Initiatives kawazoer@mail.nih.gov

Liam O'Fallon NIH/National Institute of Environmental Health Sciences liam.o'fallon@nih.gov Jef Palframan NIH/National Human Genome Research Institute Jef.Palframan@nih.gov

Eliseo Perez-Stable NIH/National Institute on Minority Health and Health Disparities eliseo.perez-stable@nih.gov

Shobha Srinivasan NIH/National Cancer Institute shobha.srinivasan@nih.gov

Lauren Stern NIH/National Institute of Allergy and Infectious Diseases Iauren.stern@nih.gov

Karyl Swartz NIH/Center for Scientific Review karyl.swartz@nih.gov Lawrence A. Tabak NIH/Office of the Director

**Emmanuel Taylor** NIH/National Cancer Institute taylorem@mail.nih.gov

Rachael Tracy NIH/National Heart Lung and Blood Institute tracyr@mail.nih.gov

**Della Brown White** NIH/*Eunice Kennedy Shriver* National Institute of Child Health and Human Development whitede@mail.nih.gov

David Wilson NIH/Office of the Director/Division of Program Coordination, Planning, and Strategic Initiatives Dave.Wilson2@nih.gov

## National Institutes of Health AI/AN Scholars

Alec Calac NIH/National Institute of Neurological Disorders and Stroke alec.calac@nih.gov **Loretta Grey Cloud** 

NIH/National Institute of Dental and Craniofacial Research loretta.greycloud@nih.gov

### Guests

Akosua Asantewa Gyekye-Kusi HHS/Indian Health Service

akosua.gyekye-kusi@ihs.gov