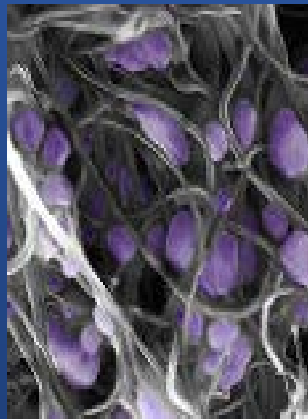
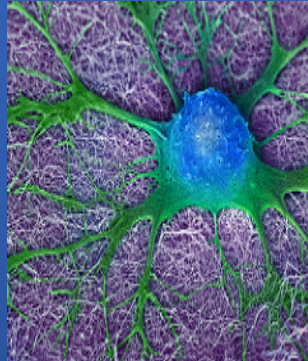
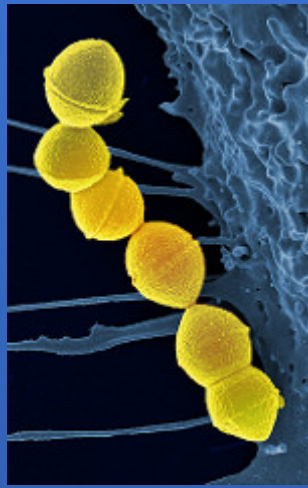




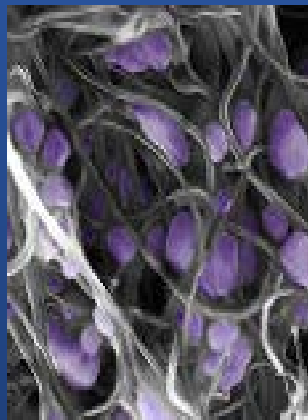
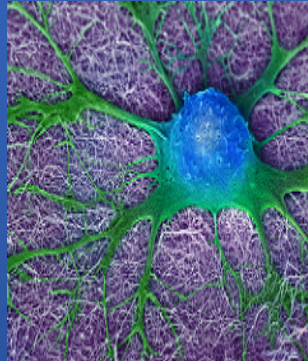
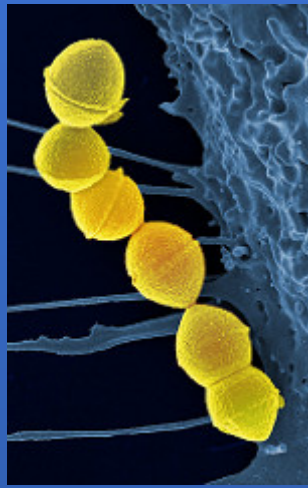
# Tribal Health Research Office Activities

NIH Tribal Advisory Committee Meeting  
September 14-15, 2017



# THRO Activities

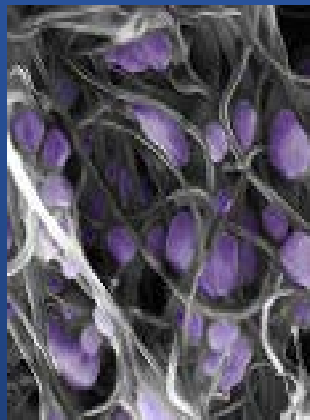
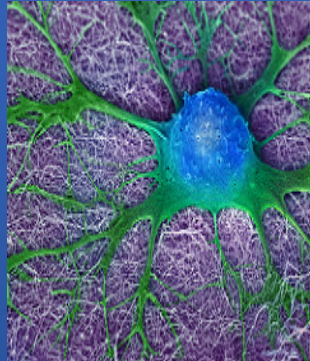
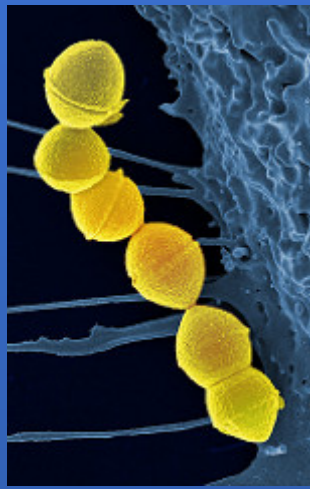
- Meetings
  - External
  - Internal
- Student Engagement
- Tribal Health Research Coordinating Committee (THRCC)
- THRO publication collaborations



# Meetings

THRO has participated in a number of meetings to achieve several goals:

- Who are NIH THRO stakeholders?
- Do they know the office exists?
  - Provide a general description of the office
- What are a communities specific needs?
- Identify areas of collaboration
- What already exists?
- Request input for the strategic plan

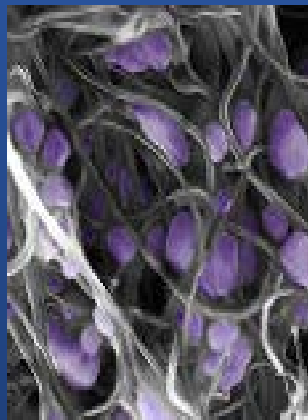
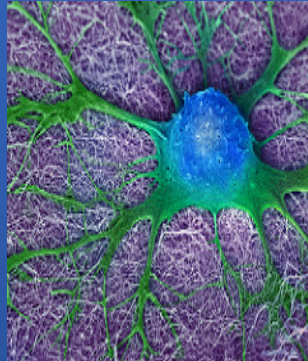
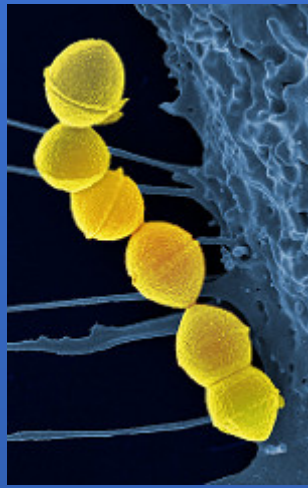




# Meetings

## External Meetings:

- Annual Tribal Epicenter Directors meeting, March 22
- HHS Annual Budget Consultation, March 29
- NIDA Medication Assisted Treatment for Opioid Use Disorder meeting, May 4
- All of Us Research Program, May 23
- NCI IRINAH, May 30
- National Indian Health Board – Public Health Summit, June 6
- AIHEC Behavioral Health Institute, June 18
- 14<sup>th</sup> Biennial Joint Board of Directors Meeting, NPAIHB & CRIHB, July 19
- Meeting with Navajo Nation (ECHO), August 7
- Tribal Data Sharing and Genetics workshop, August 30



# Meetings

## Internal Meetings:

IC Directors and/or Senior staff:

NIMHD

NIGMS

NIDA

NIMH

NLM

NIDCR

NINR

NHGRI

## Programs:

ECHO

All of Us

NARCH

SEPA

Strong Heart Study

## Offices:

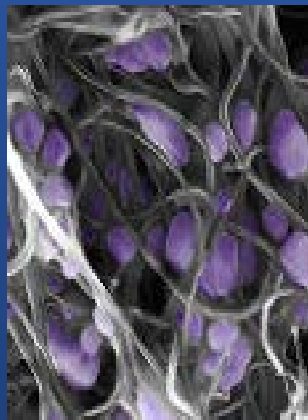
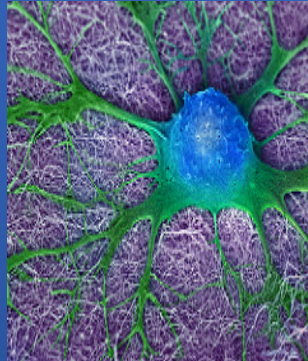
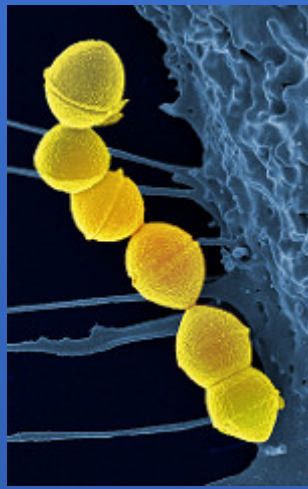
Intramural Training and Education

SGMRO

Office of Portfolio Analysis

Office of Science Policy

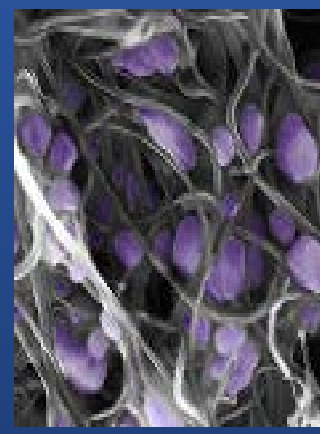
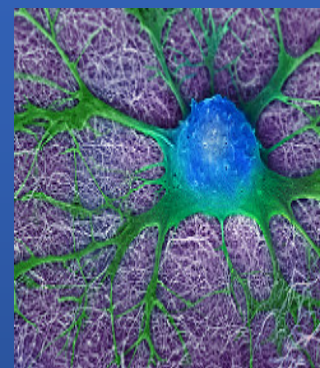
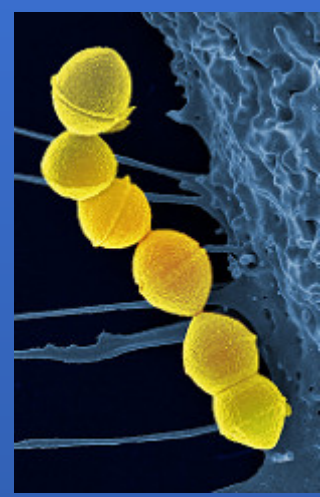
Equity, Diversity & Inclusion







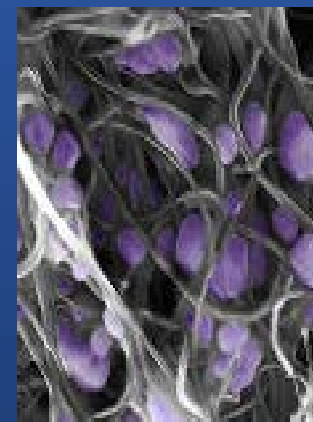
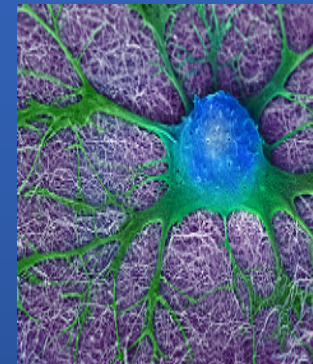
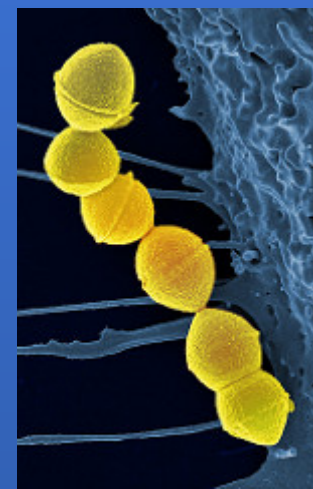
Tribal Data Sharing and  
Genetics workshop at  
University of New  
Mexico's Comprehensive  
Cancer Center







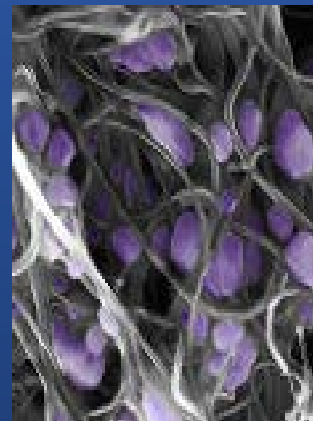
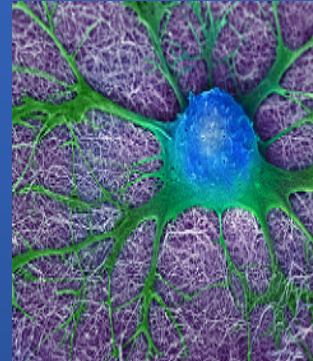
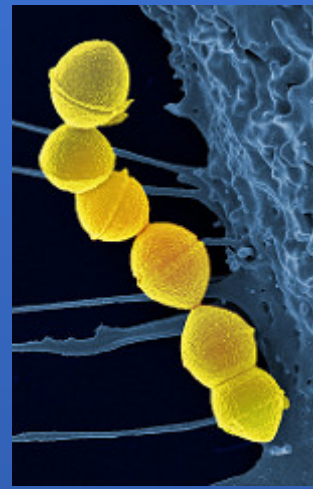
## Meetings with Navajo Nation Leaders





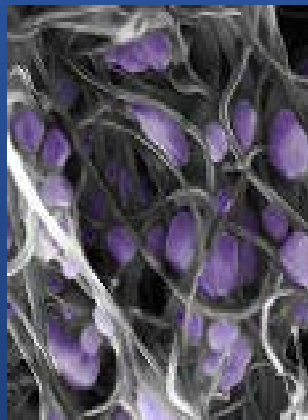
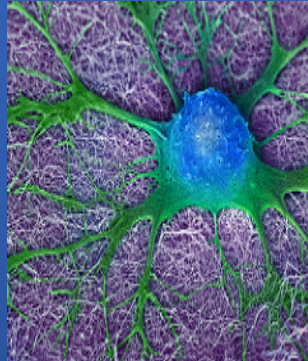
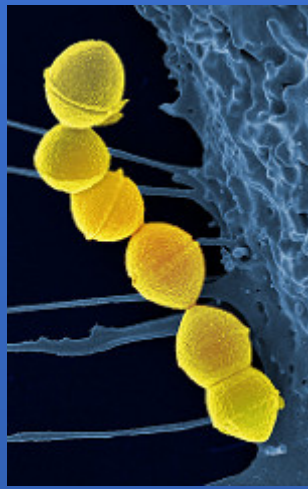
# Student Engagement

- NIH summer interns
- NIHB policy fellows
- NCAI fellows
- AAIP Students





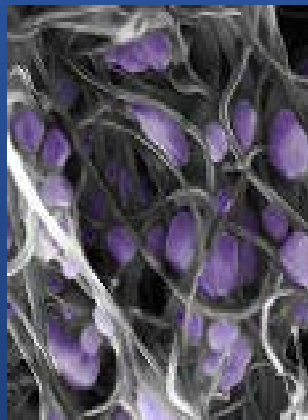
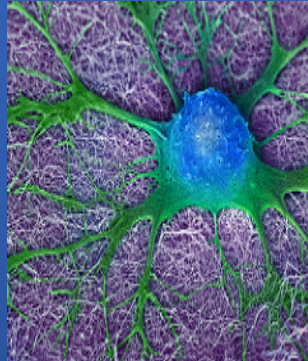
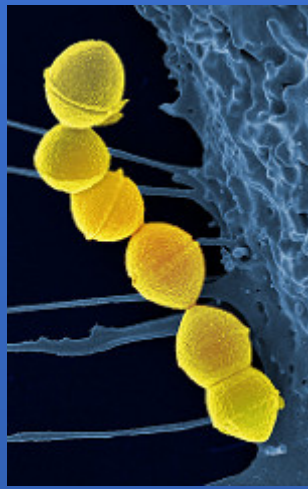
# Trans-NIH Tribal Health Research Coordinating Committee (THRCC)





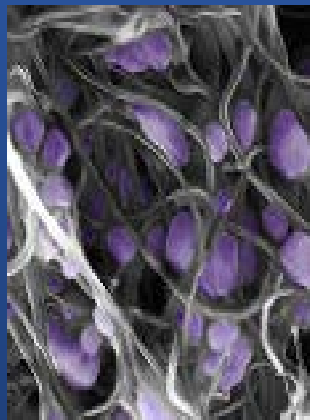
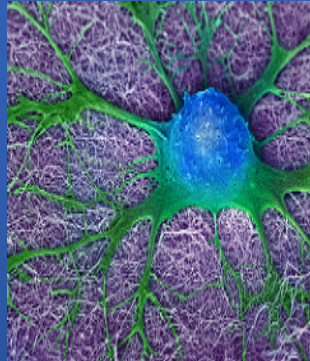
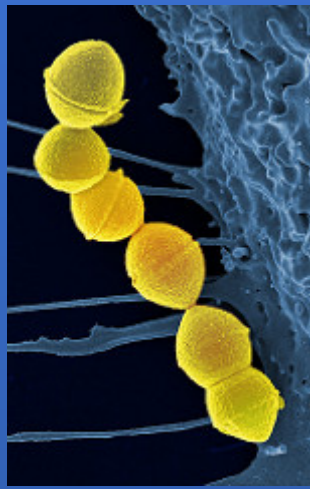
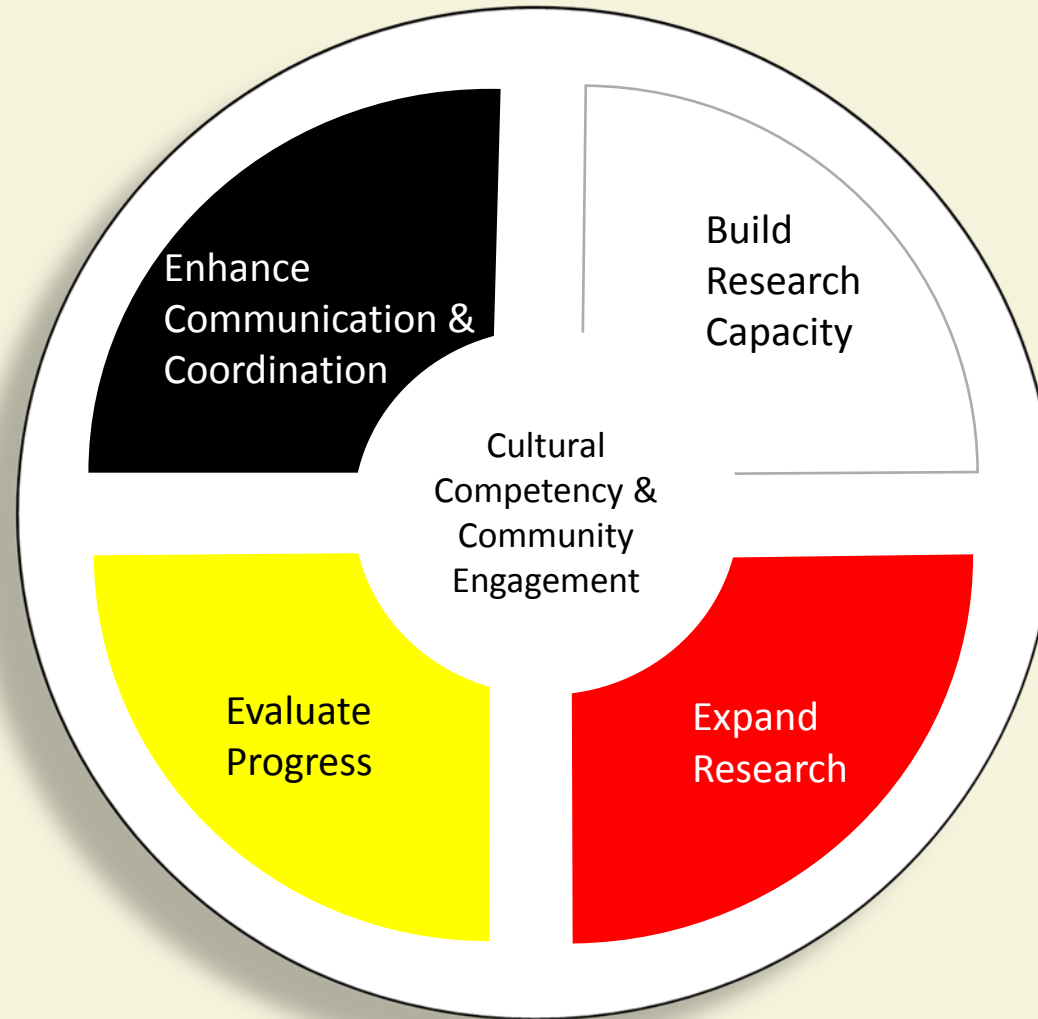
# Trans-NIH Tribal Health Research Coordinating Committee (THRCC)

- Drafting the first AI/AN portfolio Analysis and Strategic Plan for THRO
- ICs and THRO collaborations
  - NHGRI-Genomics initiative
  - NIMH attended the 1<sup>st</sup> Tribal Leaders Behavioral Health Summit; Tulsa, OK
  - NIMHD and TECs
  - Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (R01) [PAR-17-484](#)
  - Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (R21) [PAR-17-483](#)
  - NIGMS-NARCH
- Student Training and Development
  - Trans-NIH effort

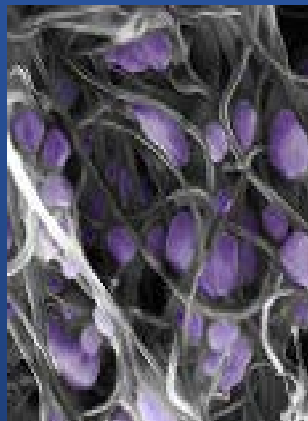
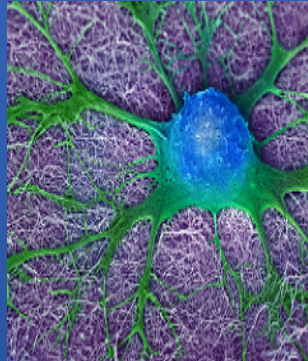
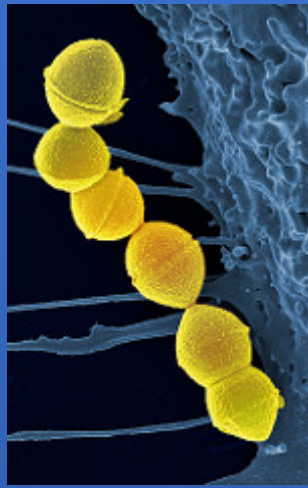




# Strategic planning for THRO



# Publications





AutoSave ON

THRO Brochure2b - Saved to P: Drive

Wilson, Dave (NIH/OD) [E]

Share

FileHomeInsertDesignTransitionsAnimationsSlide ShowReviewViewACROBAT

Tell me what you want to do

New Slide

Table

Pictures

Online Pictures

Screenshot

Photo Album

Shapes

Icons

SmartArt

Chart

Store

My Add-ins

Zoom

Link

Action

Comment

Text Box

Header & Footer

WordArt

Date & Time

Slide Number

Object

Equation

Symbol

Video


Audio

Screen Recording


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SlidesTablesImagesIllustrationsAdd-insLinksCommentsTextSymbolsMediaFlash

1



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### Tribal Advisory Committee, NIH

The Tribal Advisory Committee (TAC) is advisory to the NIH, and provides a forum for meetings between elected Tribal officials (or their designated representatives) and NIH officials to exchange views, share information, and seek advice concerning intergovernmental responsibilities related to the implementation and administration of NIH programs. It was established to help ensure that Tribes and AI/AN people have meaningful and timely input in the development of NIH policies, programs, and priorities. The NIH TAC seeks to ensure that NIH policies or activities that affect AI/AN communities are brought to the attention of Tribal leaders.

The NIH TAC charter calls for representation from each of the 12 geographic areas served by the Indian Health Service (IHS) including Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson. In addition, the NIH TAC charter calls for one representative (and a designated alternate) for each of five National at-large Tribal member positions.

### NIH Tribal Health Research Coordinating Committee

The NIH Tribal Health Research Coordinating Committee (THRCC) serves as a catalyst for developing research, research training, and career development initiatives focused on American Indians and Alaska Natives (AI/AN). It provides a forum for discussing the diverse health issues and challenges facing AI/AN communities, and how NIH research can help address those needs. The committee meets monthly and THRCC members are representatives from the NIH ICOs and the Division of Coordination, Planning, and Strategic Initiatives offices.

THRCC members are tasked to:

- Participate in the development of an AI/AN Research Strategic Plan and developing and recommending strategies to track and monitor NIH research initiatives and progress
- Provide feedback to refine the initial AI/AN research portfolio analysis
- Facilitate and coordinate collaborations and other activities related to AI/AN health research across the NIH Institutes, Centers, and Offices (ICOs) as well as with other federal agencies
- Develop potential research and research training activities for NIH and ICO leadership to consider
- Contribute to reports on AI/AN research activities to HHS and in response to other requests

### NIH Guidance on Implementation of HHS Tribal Consultation Policy

In 2013, the NIH issued its Guidance on the Implementation of the HHS Tribal Consultation Policy that describes how the agency will consult with and share information with the Indian tribes about planned and current NIH programs relevant to American Indian/Alaska Native (AI/AN) health research. The purpose of the NIH guidance is to facilitate the implementation of the HHS Tribal Consultation Policy. Following the issue of the Tribal Consultation Policy, the Tribal Consultation Advisory Committee (TCAC) was established in September, 2015. The NIH convened its first consultation session on September 21, 2015.

### Department of Health and Human Services (HHS) Tribal Consultation Policy


In 2004 and updated in 2010, the United States Department of Health and Human Services (HHS) Tribal Consultation Policy was issued. The policy directs HHS divisions to establish a process to ensure accountable, meaningful, and timely input by Tribal officials in the development of policies that have Tribal implications. The policy is applicable to all HHS staff and divisions, including the NIH, and supports President Obama's national efforts on Tribal Consultation.

Note:

This brochure is designed to be printed. You should test print on regular paper to ensure proper positioning before printing on card stock.

You may need to uncheck Scale to Fit Paper in the Print dialog (in the Full Page Slides dropdown).

Check your printer instructions to print double-sided pages.

To change images on this slide, select a picture and delete it. Then click the Insert Picture icon  in the placeholder to insert your own image.

To change the logo to your own, right-click the picture "replace with LOGO" and choose Change Picture.

Slide 2 of 2

Notes

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# Policy Issues

*This is an Accepted Manuscript of a forthcoming article to be published by Taylor & Francis in The American Journal of Bioethics, available online: <http://www.tandfonline.com/UAJB>.*

## **Beyond Belmont: Ensuring Respect for AI/AN Communities through Tribal IRBs, Laws, and Policies**

*AJOB Open Peer Commentary Proposal  
in response to Friesen et al, "Rethinking the Belmont Report?"*

Sara Chandros Hull, PhD  
Director, NHGRI Bioethics Core  
Faculty, CC Department of Bioethics  
National Institutes of Health

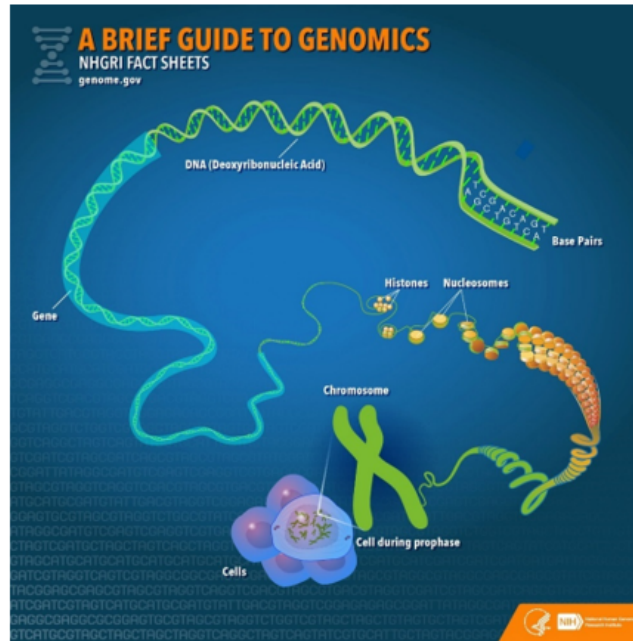
David R. Wilson, PhD (Diné)  
Director, Tribal Health Research Office  
National Institutes of Health

Word Count: 1312 (not including footnotes or references)

Corresponding author: Sara Chandros Hull, PhD  
10 Center Drive, Suite 1C118  
National Institutes of Health  
Bethesda, MD 20892-1156  
301-435-8712



- Created in collaboration with NHGRI
- Multi use document



1 Image from <https://www.genome.gov/18016863/a-brief-guide-to-genomics/>

### *What is the human genome and why is it important?*

Genome is just a fancy word for all your DNA. Your genome contains all the instructions for you to grow throughout your lifetime. These instructions are passed down from your biological mother and father. Half of your genome comes from your mother, and half from your father. These passed-down instructions influence such traits as your height, eye color, and whether or not you are protected

or at risk for some diseases, including some types of cancer.

Humans are very similar; we share 99.5% of DNA with each other. The differences, or genetic variants, are what result in the differences in our physical traits. They are what make you unique.

However, your genome is only one part of what determines your health and traits – your genome is not your destiny. Sometimes, changes in the genome will definitely result in a certain trait or disease. These include such diseases as Huntington's disease, cystic fibrosis, or sickle cell disease. But most of the time, many genes act together and can be influenced by the environment. These

interactions can affect your traits and disease risks. For example, if a person is at higher risk than average for becoming diabetic because she has three or four gene variants that elevate her risk, it does not mean that she will definitely become diabetic. Instead, what she eats, how much she exercises, and other factors influence her overall risk of becoming diabetic.

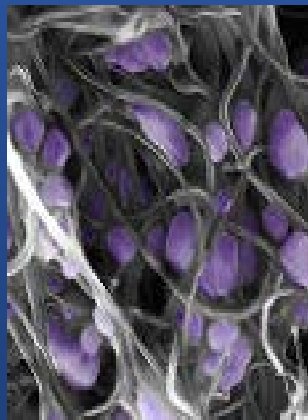
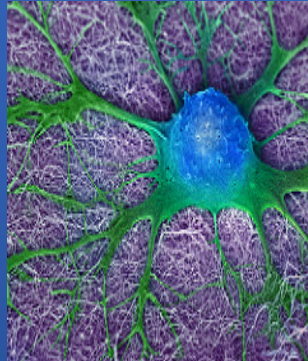
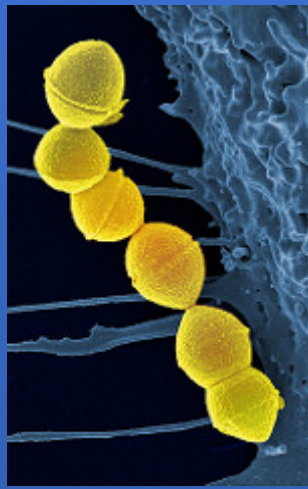
### *How do we learn about our individual genomes?*

There are different ways to look at the genome, depending on what information you're seeking.

Healthcare providers and researchers can perform genetic tests to learn a variety of things about your genome. In order to conduct these tests, DNA is collected from blood, saliva, or tissue. Currently, in clinical care, health care providers use genetic tests to diagnose or assess genetic risk for specific diseases.

The genome can be read in its entirety, or in parts. Reading an entire genome is a laboratory technique called whole genome sequencing. Right now, whole genome sequencing is usually used for research studies, and not yet utilized in routine clinical care.

*For more in depth information, please see the Resources at the end of this booklet.*







THRO Home

TAC

THRCC

Tribal Consultation Sessions

Policies and Guidance

Reports and Funding

Health Information

## TAC Members, Technical Advisors and THRO Director Dr. Wilson

**Front row (from l to r):** Alison Ball\*, Denise Dillard\*, Beverly Cook\*, Chester Antone\*, Walter Phelps\*, David Wilson. **Middle row (from l to r):** Marcia O'Leary, Kori Novak, Breannon Babbel, Lynn Malerba\*, Liana Onnen\*, Debra Danforth\*, Donna Galbreath\*, Christy Duke, Karol Dixon, Deana Around Him. **Back row (from l to r):** David Foley, L. Jace Killsback\*, Joshua Saxon-Whitecrane\*, Jeromy Sullivan\*, Lisa Rey Thomas, Malia Villegas\*, Renee Robinson, Bobby Saunkeah\*, Michael Peercy. **Not pictured:** Allison Barlow, Lyle Best, Harold Frazier\*, Aaron Payment\*, and Teshia G. Arambula Solomon (TAC members\*)



DPCPSI » THRO » TAC

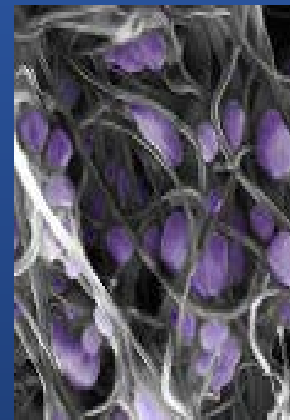
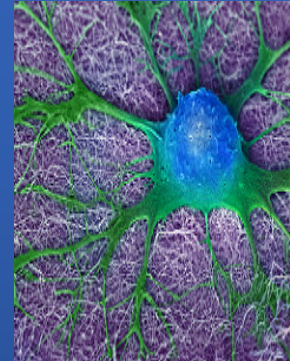
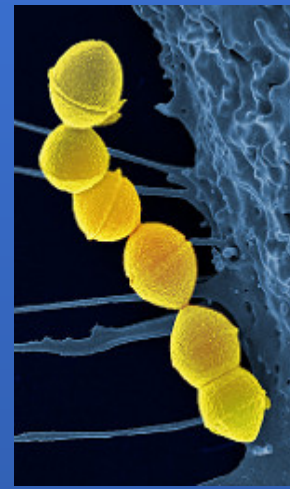
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### Additional Info

- [Charter](#)
- [Members](#) [pdf](#)
- Meetings
  - [Sept. 14-15, 2017](#) (Upcoming)
  - [Mar. 9-10, 2017](#)
  - [Sep. 15-16, 2016](#)
  - [Feb. 25-26, 2016](#)
  - [Sep. 29-30, 2015](#)
- [Monthly Call Agendas](#)







Thank you

