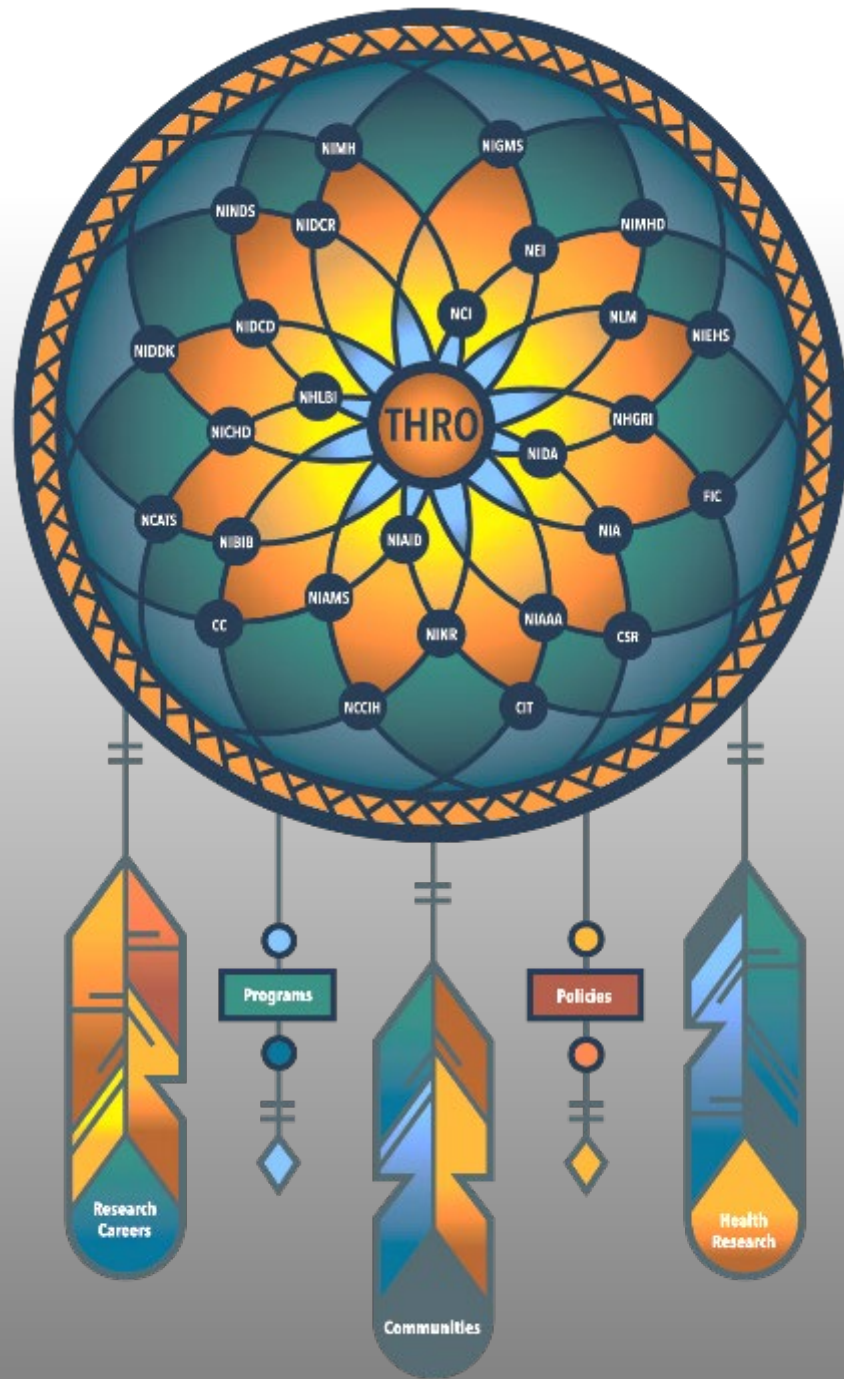


# NIH Tribal Health Research Office Update

Tribal Advisory Committee Meeting  
March 21-22, 2019

**David R. Wilson, Ph.D.**

*Director of the Tribal Health Research Office*



# THRO Timeline

Year 1. Communication and Engagement

Year 2. Professional Development

Year 3. Research

Year 4. Implementing the Strategic Plan





# THRO Activity Update

- National Institutes on Aging Council
- National Institute of Minority Health and Health Disparities Council
- Office of Science Policy
- Office of AIDS Research
- Soon to meet with Dr. Fauci at NIAID
- Congressional visits
- Coordinating with NIMH and NIMHD our 2<sup>nd</sup> in person meeting in Fairbanks, AK
- Traditional Medicine Summit
- NIH Tribal Consultation on Intellectual Property Rights
- Fact Sheets
- Regional Training Hubs
- Strategic Plan
- Midwest Alliance of Sovereign Tribes (MAST)
- IHS Annual TEC Directors Meeting



# More Activities

- THRO Publication
- AI/AN Portfolio Analysis 2017
- 2019 THRO Website Redesign
  - Consultation page w/outcomes

© American College of Medical Genetics and Genomics

ARTICLE | Genetics in Medicine

Constructing identities: the implications of DTC ancestry testing for tribal communities

Hina Walajahi, BS<sup>1</sup>, David R. Wilson, PhD<sup>2</sup> and Sara Chandros Hull, PhD<sup>1,3</sup>

**Purpose:** Direct-to-consumer (DTC) genetic ancestry companies have rapidly increased in popularity, with top testing services maintaining genetic databases of several million consumers. While genetic ancestry tests are often characterized as recreational, companies invoke deeply personal concepts of individual identity, group membership, and kinship when marketing their services. In particular, many companies claim to be able to determine Native American heritage, claims that are not supported by the state of the science and may have significant cultural and political consequences for US tribal communities. This study aims to fill the gaps in empirical work on this issue and characterize how genetic ancestry companies articulate indigenous identity through their marketing strategies.

**Methods:** We conducted a qualitative content analysis of the public facing websites for 25 DTC genetic ancestry companies that offer services measuring Native American ancestry.

**Results:** Our findings describe how genetic ancestry companies promote a causal relationship between genetics and self-identity through marketing language such as "Discover Yourself" and "Are you Native American?" and how this may affect US tribal communities.

**Conclusion:** Genetic ancestry company claims regarding genetic ancestry, personal identity, and cultural membership are problematic and challenge how US tribal nations currently identify and create potential obstacles for tribal sovereignty.

*Genetics in Medicine* (2019) <https://doi.org/10.1038/s41436-018-0429-2>

**Keywords:** indigenous identity; direct-to-consumer; commercial ancestry test; Native American; empirical bioethics

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NIH National Institutes of Health Tribal Health Research Office

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Tribal Health Research Office (THRO)

Welcome to THRO  
The central hub of coordinating tribal health research and related activities across the NIH.

Learn more »

Strategic Plan | Portfolio Analysis | Grant Finder | THRO News | Stay Informed

Who We Are

Established in 2015, the Tribal Health Research Office is located in the Division of Program Coordination, Planning, and Strategic Initiatives in the Office of the Director (OD), NIH. The office was created in recognition of the importance of ensuring meaningful input from and collaboration with tribal nations on NIH programs and policies. The Tribal Health Research Office functions are to:

- coordinate tribal health research-related activities across NIH
- serve as a liaison to and NIH representative on tribal health related committees and working groups
- coordinate and support the NIH Tribal Advisory Committee
- collaborate with NIH Institutes and Centers on the development of reports on tribal health topics
- manage information dissemination related to tribal health research coordination
- convene trans-NIH committees, workshops, meetings and other activities related to tribal health research and scientific priorities
- coordinate with NIH Institutes and Centers (ICs) to leverage resources or develop initiatives to support tribal health research
- convene at least yearly Tribal Consultation sessions

Learn more About us.

THRO Director & Staff

David R. Wilson, Ph.D., Director

Director's Bio  
THRO Staff

# State of the Union pledge: Ending HIV transmissions by 2030

The push to end AIDS in the United States will concentrate on improving diagnosis, treatment, and prevention efforts in 48 counties; Washington, D.C.; and one municipality in Puerto Rico; those locations account for more than half of the nearly 40,000 new HIV diagnoses each year.

They also will target seven states that account for the majority of infections in rural populations, including Native American communities that have had sharp increases in HIV diagnoses in men who have sex with men.

A key part of the plan is to better coordinate the contributions of 19 Centers for AIDS Research (CFARs) that together receive \$45 million a year from the National Institutes of Health.

- THRO initiated a listening session in Seattle to eliminate HIV in Indian Country
- Dr. Maureen Goodenow met with key Native researchers in the Pacific Northwest to hear about HIV research priorities and challenges in Indigenous communities.





Communicating our efforts to Congress

# 2019 Fall In-Person Tribal Advisory Committee Meeting



## **Suicide Prevention All Hubs Steering Meeting**

August 19-22, 2019

Fairbanks & Emmonak, Alaska

- National Institute on Mental Health
- National Institute on Minority Health and Health Disparities



# Traditional Medicine Summit

Sept 30-Oct 2, 2019

Aurora CO

## Planning Committee:

Dr. David Begay

Dr. Michelle Kahn-John

Chairman Antone

Tyler LaPlant

Dr. Donna Galbreath

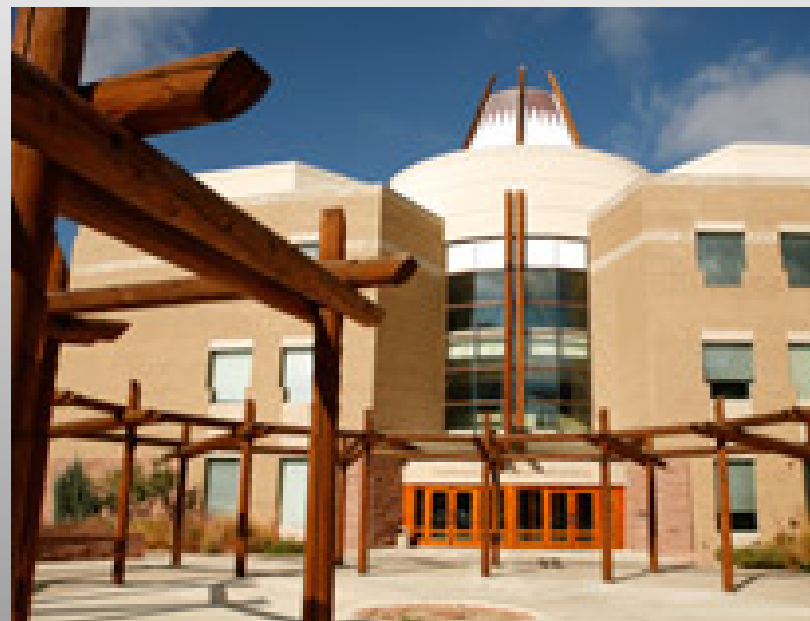
Angela Michaud

## Other Agency Collaborators:

CMS

CDC

HHS



Nighthorse Campbell Native Health Building



# Creating a Path to Success



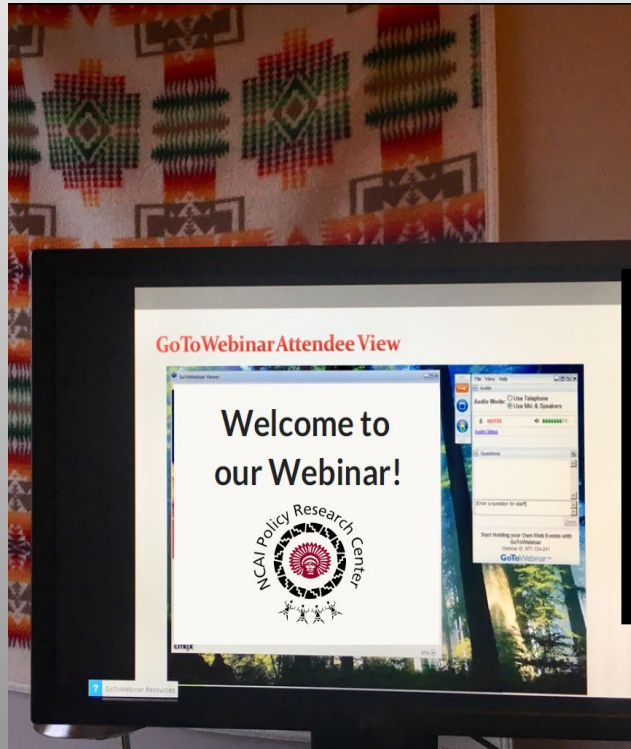
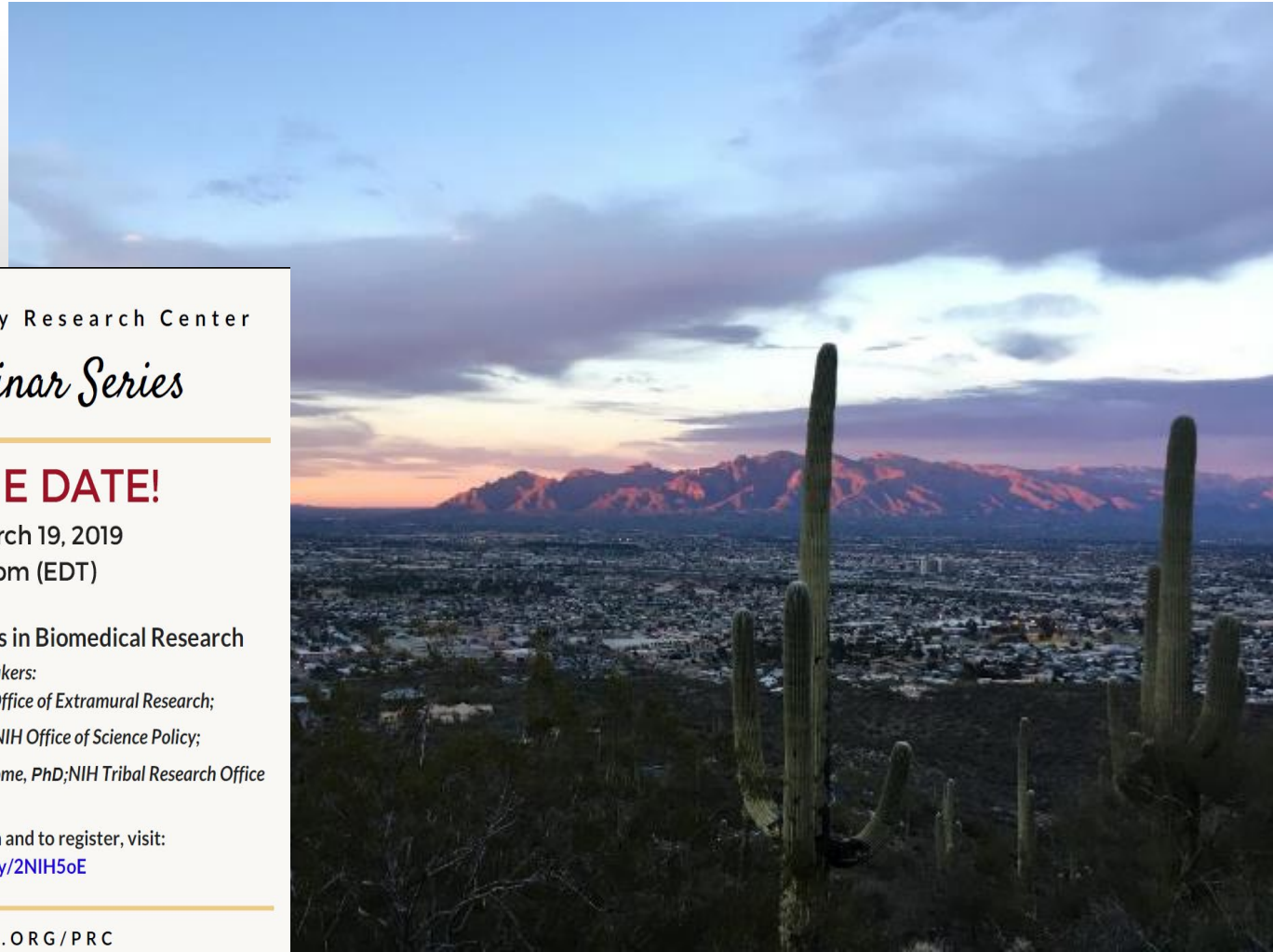
Path to successful Biomedical Research



# 2019 NIH Tribal Consultation on Intellectual Property

June 24, 2019

Reno, NV



NCAI Policy Research Center

*Webinar Series*

**SAVE THE DATE!**

Tuesday, March 19, 2019

3:00-4:00pm (EDT)

Intellectual Property Rights in Biomedical Research

*Speakers:*

Ann M Hammersla JD, NIH Office of Extramural Research;

Mark Rohrbaugh PhD JD, NIH Office of Science Policy;

David R. Wilson PhD, Juliana M. Blome, PhD; NIH Tribal Research Office

For more information and to register, visit:

<http://bit.ly/2NIH5oE>

WWW.NCAI.ORG/PRC





# THRO FACT SHEETS for NIH Research



## Tribal Health Research Office

Division of Program Coordination, Planning, & Strategic Initiatives  
National Institutes of Health (NIH)

### Chronic Wasting Disease (CWD) in the Deer Family

#### The Disease

- Chronic wasting disease (CWD) is a disease that affects deer, elk, reindeer, sika deer and moose, collectively referred to as Cervids or the deer family<sup>1</sup>.
- CWD is a fatal disease of the central nervous system (neurodegenerative disease) which may infect animals for up to a year before the animal develops symptoms such as weight loss (wasting), stumbling, listlessness and other neurological symptoms. Some animals die without ever developing the disease<sup>1</sup>.
- The disease results when naturally occurring proteins found in abundance in the brain, called prions, become misfolded or undergo structural change<sup>2</sup>.
- Other examples of prion diseases include bovine spongiform encephalopathy (BSE) in cattle<sup>3</sup>, (also known as 'mad cow disease'), scrapie in sheep and goats<sup>4</sup>, and Creutzfeldt-Jakob disease (CJD) in humans<sup>5</sup>.
- There are no available treatments or vaccines for CWD<sup>1</sup>.

#### Disease Occurrence

- CWD was first recognized in captive deer in a Colorado facility in the late 1960s and in wild deer in 1981.
- CWD has now been detected in 25 U.S. states as well as in Canada, South Korea, Norway, and Finland<sup>6</sup>.

#### Transmission

- The disease spreads between members of the same species and may be transmitted through saliva, feces and urine.
- The spread of CWD has been linked to both human transportation of infected animals to new locations and the natural movement of infected wild populations into new geographic areas<sup>7</sup>.
- CWD infectivity can enter the environment through live animal feces and carcasses where it remains in the soil.
- Prions excreted into the environment by infected animals may persist for years and might facilitate transmission of the disease<sup>1</sup>.

#### Location of Reported CWD in Free-ranging Deer Family in the US

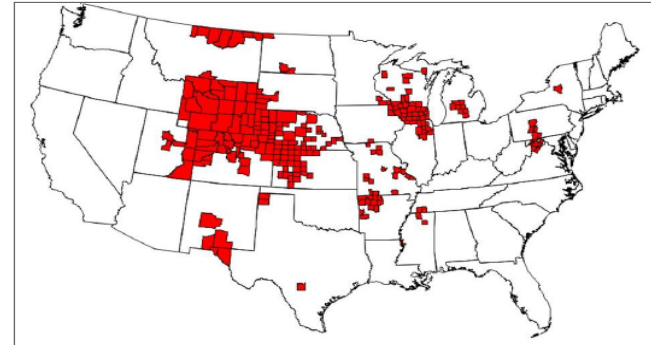


Fig. 1. CWD Among Free-ranging members of the deer family in 25 states based on the best available information from multiple sources, including wildlife agencies and the United States Geological Survey<sup>1</sup>

#### Risk of Transmission from Animals to People

- To date, there have been no reported cases of CWD infection in people. However, some animal studies have shown that CWD can be transmitted to certain types of non-human primates, like squirrel monkeys. Infection by prions from multiple species has been demonstrated in this model, including sheep scrapie, which does not infect humans; thus, this animal may not demonstrate species restriction similar to humans.
- No human cases have been linked to CWD from infected animals<sup>1</sup>.

#### Prevention

- Since 1997, the World Health Organization (<http://cwg-info.org/fag/>) has recommended preventing agents of all known prion diseases from entering the human food chain<sup>1</sup>.
- The CDC provides guidelines to decrease potential risk to exposure (<https://www.cdc.gov/prions/cwd/prevention.html>).

#### Current Research

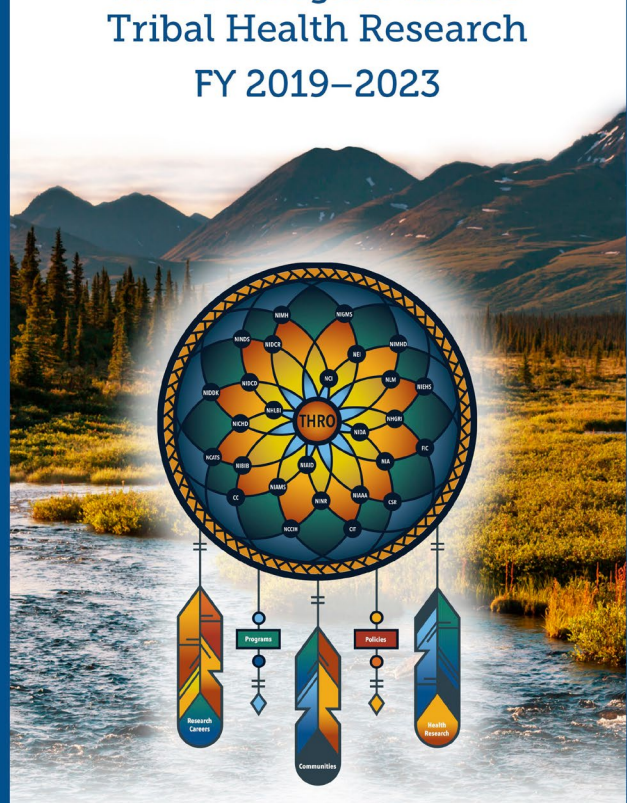
- As of March 11, 2019 search on active NIH projects on chronic wasting disease, deer and prion using NIH RePORTER, an online reporting tool (<https://projectreporter.nih.gov/reporter.cfm>), reveals that there are



# Regional Training Hubs



# NIH Strategic Plan for Tribal Health Research FY 2019–2023



NIH Strategic Plan for Tribal Health Research  
FY 2019–2023

Research Centers

Programs

Policies

Health Resources

Communications

Tribal Health Research Office

## Strategic Goal 4: Enhancing Cultural Competency and Community Engagement

# Updated Grant Finder



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**Tribal Health Research Office (THRO)**

DPCPSI - THRO - AI/AN Health Research Grant Finder

## AI/AN Health Research Grant Finder

FY 2017

Select a Report Year

FY 2017  
FY 2016  
FY 2015  
FY 2014

Select a Tribal Area

Alaska Area  
Albuquerque Area  
Bemidji Area  
Billings Area  
California Area  
Great Plains Area  
Nashville Area  
Navajo Area  
Oklahoma City Area  
Phoenix Area  
Portland Area  
Tucson Area

Please note, this page provides highlights found in the more exhaustive FY 2017 Report [pdf](#).  
To submit feedback, email [NIHTribalCommittee@od.nih.gov](mailto:NIHTribalCommittee@od.nih.gov).

This page last reviewed on March 8, 2019

Contact DPCPSI | Bookmark & Share | YouTube | Social Media & Outreach



# An Update from THRO's first Post-Bac



**Madison Esposito** is a member of the Tyme Maidu tribe and a graduate from Oregon State University with a Bachelors of Science. Inspired by her great-grandmother's role as a tribal healer, Ms. Esposito has pursued a career in medicine.

Ms. Esposito will be joining the Harvard Master of Public Health program in their Health and Social Behavior concentration. In this program she plans to investigate the social determinates of health relevant to tribal communities and urban natives along with how policy can be used to alleviate health disparities experienced in these communities.

Her long-term goals are to serve as a general practitioner in tribal hospitals and assist tribal communities in public health policy.

# Tribal Health Research Office Staff

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## Tribal Health Research Office (THRO) Staff

Name	Position	Phone	Fax	Email
David R. Wilson, Ph.D.	Director	301-402-9852	301-480-4632	<a href="mailto:dave.wilson2@nih.gov">dave.wilson2@nih.gov</a>
Juliana Blome, Ph.D.	Assistant Director	301-402-9852	301-480-4632	<a href="mailto:juliana.blome@nih.gov">juliana.blome@nih.gov</a>
Edmund (Ted) Keane, MSPH	Health Science Policy Analyst	301-594-1228	301-480-4632	<a href="mailto:edmund.keane@nih.gov">edmund.keane@nih.gov</a>
Maria (Jay) Jamela R. Revilleza, Ph.D.	Health Science Policy Analyst	301-827-5859	301-480-4632	<a href="mailto:mariajamela.revilleza@nih.gov">mariajamela.revilleza@nih.gov</a>
Laura LaRue Gertz, MSW	Health Science Policy Analyst	301-451-4710	301-480-4632	<a href="mailto:laura.gertz@nih.gov">laura.gertz@nih.gov</a>

