

A SPECTRUM OF PERSPECTIVES

SMITHSONIAN
NATIONAL MUSEUM OF THE AMERICAN INDIAN
RASMUSON THEATER

NATIVE PEOPLES AND GENETIC RESEARCH

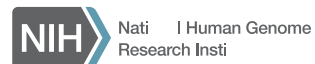
JUNE 23, 2014



A Spectrum of Perspectives: Native Peoples and Genetic Research

This meeting is hosted by the National Congress of American Indians, the National Human Genome Research Institute, and the National Museum of the American Indian as part of the Genome: Unlocking Life's Code exhibit at the Smithsonian's National Museum of Natural History.

The symposium demonstrates the range of perspectives in Native communities on genomics, highlights key topics for ongoing community conversation, and will create a video recording of the conversations that can be shared with Native communities as they host similar conversations across Indian Country.



Program Agenda

8:00 am - 8:55 am

Registration

8:45 am - 9:15 am

Welcome and Introductions

Eric Green, MD, PhD

Director | National Human Genome Research Institute, National Institutes of Health

Jacqueline Pata (Tlingit)

Executive Director | National Congress of American Indians

David Penney, PhD

Associate Director | Museum Scholarship, National Museum of the American Indian

9:15 am - 9:50 am

Framing the Conversation

Malia Villegas, EdD (Sugpiaq/Alutiiq)

Director, National Congress of American Indians Policy Research Center

Vence Bonham, JD

Chief, Education and Community Involvement Branch, National Human Genome Research Institute

9:55 am - 11:20 am

Can Genetics Research Improve Native Health?

Panelists:

Francine Gachupin, PhD, MPH, CIP (Pueblo of Jemez)

University of Arizona Cancer Center

Jeff Henderson, MD, MPH (Cheyenne River Sioux Tribe)

Black Hills Center for American Indian Health

Terry Powell, BBA

Alaska Area Specimen Bank Working Group

Moderator: **David Wilson, PhD (Diné)**

Society for Advancement of Chicanos and Native Americans in Science

11:25 am - 12:25 pm

Lunch on your own

12:30 pm - 1:55 pm

Genomics & Ancestry: Ethics, Origins, and Policy

Panelists:

Rosita Worl, PhD (Tlingit)

Sealaska Heritage Institute

Shane Doyle, EdD (Crow Nation)

Montana State University, Native American Studies

Sarah Anzick, PhD

Rocky Mountain Laboratories, National Institutes of Health

Moderator: **Dr. David Penney**, *National Museum of the American Indian*

2:00 pm - 3:25 pm

Insights from the Field: Next Generation Native Researchers

Panelists:

Keolu Fox, MS (Kingdom of Hawai'i)

University of Washington, Genome Sciences

Abigail Echo-Hawk, MS (Kitkehanki Band of Pawnee Nation),

University of Washington, Partnerships for Native Health

Deana Around Him, DrPH (Cherokee Nation of Oklahoma)

Johns Hopkins University

Moderator: **Dorothy Aguilera-Black Bear, PhD (Choctaw Nation)**, *American Indian College Fund*

3:25 pm - 3:40 pm

Break

3:45 pm - 5:10 pm

The Ethics of Blood

Panelists:

Ngairé Brown, MD (Yuin Nation of New South Wales)

National Aboriginal Community Controlled Health Organisation, invited

Nanibaa' Garrison, PhD (Navajo Nation)

Vanderbilt University, Center for Biomedical Ethics & Society

Ron Whitener, JD (Squaxin Island Tribe)

University of Washington Native American Law Center

Presiding judge, Confederated Tribes of the Chehalis Indian Reservation

Moderator: **Mark Trahant (Shoshone-Bannock Tribe)**, *University of Alaska-Anchorage*

5:15 pm - 5:30 pm

Closing Remarks

6:00 pm - 8:00 pm

Reception at the Embassy of Tribal Nations

1516 P Street NW, Washington, DC 20005

National Congress of American Indians Policy Research Center

Launched in 2003 by the leadership of the National Congress of American Indians (NCAI), the Policy Research Center is a national, non-profit think tank dedicated to generating research and policy analyses that advance tribal sovereignty and emphasize the strengths of American Indian and Alaska Native cultures. Guided by a diverse and distinguished advisory council, the NCAI Policy Research Center works with its partners—in tribal communities, academia, and beyond—to provide the necessary tools and resources to inform public policy debates. Its work is focused on shifting Native policy discourses from problem-focused approaches to proactive strategy development with the overarching vision of supporting Indian Country in shaping its own future.

The Center develops, coordinates, and disseminates policy-focused research. It applies this body of work to Native policy issues on the horizon of federal, state, and tribal policymaking. The Center operates within the NCAI, whose membership's priorities both contribute to the development of the Center's research agenda as well as benefit from the direct dissemination of policy research findings and think tank policy scenarios. It is up to the elected tribal leaders from their respective communities and the national tribal organizations that serve them to apply the research findings, come to consensus on positions where possible, and move their advocacy agenda forward.

Advancing its work on research regulation in Indian Country, the NCAI Policy Research Center has created a Genetics Resource Center, housed online at genetics.ncai.org. The site is designed to support tribal leaders and researchers in making informed decisions about engagement with genetics research in Native communities.

National Museum of the American Indian

A diverse and multifaceted cultural and educational enterprise, the National Museum of the American Indian (NMAI) is an active and visible component of the Smithsonian Institution, the world's largest museum complex. The NMAI cares for one of the world's most expansive collections of Native artifacts, including objects, photographs, archives, and media covering the entire Western Hemisphere, from the Arctic Circle to Tierra del Fuego.

The National Museum of the American Indian operates three facilities. The museum on the National Mall in Washington, D.C., offers exhibition galleries and spaces for performances, lectures and symposia, research, and education. The George Gustav Heye Center (GGHC) in New York City houses exhibitions, research, educational activities, and performing arts programs. The Cultural Resources Center (CRC) in Suitland, Maryland, houses the museum's collections as well as the conservation, repatriation, and digital imaging programs, and research facilities. The NMAI's off-site outreach efforts, often referred to as the "fourth museum," include websites, traveling exhibitions, and community programs.

Since the passage of its enabling legislation in 1989 (amended in 1996), the NMAI has been steadfastly committed to advancing knowledge and understanding of the Native cultures of the Western Hemisphere—past, present, and future—through partnership with Native people and others. The museum works to support the continuance of culture, traditional values, and transitions in contemporary Native life.

National Human Genome Research Institute

The National Human Genome Research Institute (NHGRI) is part of the National Institutes of Health. NHGRI led the National Institutes of Health's (NIH) contribution to the International Human Genome Project, which had as its primary goal, the sequencing of the human genome. This project was successfully completed in April 2003. Now, the NHGRI's mission has expanded to encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease.

To that end, NHGRI supports the development of resources and technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal, and social implications (ELSI) of genome research. NHGRI also supports the training of investigators and the dissemination of genome information to the public and to health professionals.

For more information: genome.gov

Genome: Unlocking Life's Code (Second Floor, Hall 23 Special Exhibits Gallery, National Museum of Natural History) is a temporary traveling exhibition that immerses museum visitors in a high-tech environment that captures the revolutionary nature of genomic science.

The 4,400-square foot exhibition focuses on several areas of genomic science: "The Genome Within Us" introduces the human genome and the role genomics plays in modern life; "The Natural World" presents the fascinating diversity of living things, how their genomes differ, and their surprising similarities; "Our Genomic Journey" illustrates how genomics has added to archaeological and fossil evidence, increasing knowledge of human origins and helping to answer questions about recent ancestry; and "Genomic Medicine" shifts the focus to a future in which knowledge of how genomic variants affect disease risk may point to lifestyle changes, choices of medications, or ways to stop deadly epidemics in their tracks. Throughout the exhibit, Genomics and Society confronts the ethical, legal, and social concerns raised by advances in genomic science. The "Genome Zone" is the ancillary gallery where hands-on activities are available to the young and young at heart. The exhibition was developed by the Smithsonian National Museum of Natural History and the National Institutes of Health, National Human Genome Research Institute. The exhibition will remain at the National Museum of Natural History until September 2014. It will then travel across North America for the next four to five years.

For more information: unlockinglifescode.org

