



American College of Medical Genetics

Medical Genetics: Translating Genes Into Health®

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ACMG Media Alert

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What is the Native American Perspective on Genetic Testing and Research?: Navajo Tribal Leaders to Meet with Medical Geneticists at American College of Medical Genetics Annual Conference in Albuquerque, New Mexico on March 24, 2010

BETHESDA, MD— March 10, 2010 | Most American Indian governments have instituted a moratorium on genetic studies, and the controversy over genetics and newborn screening among Native Americans has complex roots. The American College of Medical Genetics (ACMG) will hold a special panel discussion with tribal leaders and representatives of the Navajo (Diné) Nation at the upcoming ACMG annual meeting in Albuquerque, New Mexico that will address the controversies around genetic testing, services and research in the Native American community.

The first forum of its kind to be held at a national medical genetics meeting, this panel discussion is designed to open up ongoing dialogue within the Navajo community and between the Navajo and the regional genetics community to a national conversation. Tribal leaders will present the complex historical roots of the Navajo's views on genetic screening, testing and research. Family members will join them as they explore many perspectives on the ways the Navajo population stands to benefit from modern genetics.

“This national conversation is a critical first step for the Navajo and medical genetics communities to define common ground and foster partnerships to promote the Navajo People's ability to benefit from modern genetic advances in public health, while remaining respectful of their world view and spiritual beliefs,” said Judith Benkendorf, MS, CGC, ACMG's Special Assistant to the Executive Director and Co-Project Director of the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives.

In addition, a concurrent scientific session to be held from 1:00-3:00 PM on Thursday March 25, “Navajos and Genetic Disease: Genetic, Medical, and Educational Issues,” will provide an overview of the genetic diseases of the Navajo, a promising newborn screening program for SCID, and views on genetics and genetic education among the Navajo from both an “outsider” and an “insider.”

Where/When: The Genetics and Genetic Research – Native American Perspectives, two-hour session is sponsored by The Regional Genetic and Newborn Screening

- more -

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Service Collaboratives and their National Coordinating Center (www.nccrcg.org) and takes place between **7 and 9 PM at the Bravos/Galisteo/Aztec, Albuquerque Convention Center on Wednesday, March 24, 2010.**

Registration: Pre-Registration is required. Complimentary Media registration is available for members of the media on assignment. Contact Kathy Beal at kbeal@acmg.net for information. General registration is available at www.acmgmeeting.net.

Panelists include:

Nanibaa' Garrison, PhD, Stanford Center for Biomedical Ethics;

Johnson Dennison, Indian Health Service;

Yolanda E. Sandoval-Nez, Native American Disability Law Center;

Patricia Thomas, Family Voices;

Robert Yazzie, Diné Policy Institute; and

Beverly Becenti-Pigman, Navajo Division of Health.

Acknowledgement: This session is sponsored by the HRSA Genetics Collaboratives and their National Coordinating Center. The National Coordinating Center for the Genetic and Newborn Screening Services Collaboratives is funded by U22MC03957, awarded as a cooperative agreement between the Maternal and Child Health Bureau/Health Resources and Services Administration, Genetic Services Branch, and the American College of Medical Genetics.

About the American College of Medical Genetics

Founded in 1991, the American College of Medical Genetics (www.acmg.net) advances the practice of medical genetics by providing education, resources and a voice for more than 1400 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. ACMG's activities include the development of laboratory and practice standards and guidelines, advocating for quality genetic services in healthcare and in public health, and promoting the development of methods to diagnose, treat and prevent genetic disease. *Genetics in Medicine*, published monthly, is the official ACMG peer-reviewed journal. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Find a Geneticist tool. The educational and public health programs of the American College of Medical Genetics are dependent upon charitable gifts from corporations, foundations, and individuals. **The American College of Medical Genetics Foundation** (www.acmgfoundation.org) is a 501(c)(3) not-for-profit organization dedicated to funding the College's diverse efforts to translate genes into health.