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Special Satellite Meeting And Film Viewing: Emerging from Darkness to Shed Light on Genetics and Cultural Taboos in Native American Populations: A Community Conversation Including the Highly-Acclaimed Film "Sun Kissed"

Bethesda, MD – Feb. 28, 2013 | The tension between the potential knowledge that can be gained through genetics research and medicine, and cultural beliefs within the Native American Populations of the United States, was explored at the inaugural Community Conversation held at the 2009 ACMG Annual Meeting ("Genetics and Genetic Research: Native American Perspectives".) With the release of the documentary, "Sun Kissed," (http://sunkissedthefilm.com/) these tensions are further highlighted as one family, the Nez's, works to understand why their children were born with Xeroderma Pigmentosum (XP) and why the prevalence within the Navajo community is 1 in 30,000 versus 1 in one million in the general population. "Sun Kissed" follows the Nez's as they negotiate between the cross-cultural norms of their community and their information and support needs as parents of children with an incurable genetic condition.

This special satellite session will provide ACMG meeting attendees an opportunity to view "Sun Kissed" and participate in a panel discussion with the Nez's and the filmmakers. ACMG conference participants, families, health care providers, public health professionals and the media are invited to join the conversation.

It is expected that the Community Conversation will discuss the challenges Native American families face in merging genetic research and information with their cultural norms and the ways the genetics community can improve cultural awareness to strengthen dialogue and improve partnerships with Native American populations. Alisha Keehn, MPA (NCC Project Manager) said, "We hope this interactive session will help attendees to better appreciate the challenges of modern Native Americans in balancing western medicine, their personal desires and needs, and the norms and expectations within their communities."

Date:

March 19, 2013, Time: 7:00—9:00 PM
Location: Ballroom 120D - Sheraton Phoenix

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the Maternal and Child Health Bureau/Health Resources and Services Administration, Genetic Services Branch, and the American College of Medical Genetics and Genomics. The Mountain States Genetics Services Collaborative is funded by H46MC24095, awarded as a grant from the MCHB, HRSA, Genetic Services Branch to the Texas Health Institute.

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About the ACMG and ACMG Foundation

Founded in 1991, the American College of Medical Genetics and Genomics (www.acmg.net) advances the practice of medical genetics and genomics by providing education, resources and a voice for more than 1600 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 ACMG Foundation for Genetic and Genomic Medicine** (www.acmgfoundation.org), a 501(c)(3) nonprofit organization, is a community of supporters and contributors who understand the importance of medical genetics and genomics and genetic counseling in healthcare. Established in 1992, the ACMG Foundation supports the American College of Medical Genetics and Genomics' mission to "translate genes into health" by raising funds to promote the profession of medical genetics and genomics to medical students, to fund the training of future medical geneticists, to support best-practices and tools for practicing physicians and laboratory directors, to promote awareness and understanding of our work in the general public, and much more.

About the National Coordinating Center and the Seven Health Resources and Services Administration Genetic Services Collaboratives

In 2004, 2007, and 2012, the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA), Genetic Services Branch (GSB) awarded grants to develop seven Regional Genetic Services Collaboratives (RCs) and a National Coordinating Center (NCC) as part of on-going efforts to improve the health of children and their families by promoting the translation of genetic medicine into public health and health care services. The mission of the seven Regional Genetic Services Collaboratives (RCs) and their National Coordinating Center (NCC) is to strengthen and support the genetic and newborn screening capacity of the states and to improve the availability, accessibility, and quality of genetic services and resources for individuals with, or at risk for, genetic conditions and their families. Please go to www.nccrcg.org for more information and to access additional information about each of the seven RCs.

About the Mountain States Genetics Services Collaborative

The Mountain States Genetics Regional Collaborative (MSGRC) is one of seven regional collaboratives covering the nation. The MSGRC covers an 8 state region that includes Arizona, Colorado, Montana, New Mexico, Nevada, Texas, Utah and Wyoming. MSGRC is federally funded through Grant H46MC24095 from the US. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Genetic Services Branch. The Texas Health Institute (THI) administers the MSGRC, which began a new five-year grant cycle on June 1, 2012. The MSGRC ensures that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home. The MSGRC facilitates regional collaboration, encourages involvement of diverse populations, and supports innovative mini-projects that inform quality improvement and systems change in the newborn screening and clinical genetics health care delivery systems. These collaborative efforts bring together clinical providers, public health professionals, and affected families to fulfill the MSGRC mission.

About the Film Makers

http://www.sunkissedthefilm.com/images/Sun%20Kissed_Press_Kit.pdf