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## Use of Genetic Testing to Reunify Families Separated as a Result of Immigration Enforcement Policies: A Statement from the American College of Medical Genetics and Genomics (ACMG)

**BETHESDA, MD – June 29, 2018** | Genetic testing has been proposed as a means for identifying and reuniting families that have been separated as a result of recent immigration enforcement policies. The American College of Medical Genetics and Genomics (ACMG) does not support the use of such testing for the reasons described below and strongly encourages the exploration of other methods for the purpose of family reunification.

ACMG believes that genetic testing should only be performed after appropriate informed consent has been obtained from the person being tested or that person's legal guardian. We have released multiple past <u>statements</u> regarding considerations for informed consent as well as testing of children. In the case of minors who have been separated from their parents, informed consent cannot be obtained.

The ACMG has also issued policy <u>statements</u> on the privacy of genetic information. Through informed consent a person or their legal guardian may agree to certain risks relating to privacy and further use of their genetic information, but such risks should not be forced upon persons without their proper informed consent.

The ACMG strongly encourages pursuit of other methods for reunification of families separated as a result of recent immigration enforcement policies.

## About the American College of Medical Genetics and Genomics (ACMG)

Founded in 1991, ACMG is the only nationally recognized medical society dedicated to improving health through the clinical practice of medical genetics and genomics. The American College of Medical Genetics and Genomics (<u>www.acmg.net</u>) provides education, resources and a voice for nearly 2,200 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals, nearly 80% of whom are board certified in the medical genetics specialties. The College's mission is to develop and sustain genetic initiatives in clinical and laboratory practice, education and advocacy. Three guiding pillars underpin ACMG's work: 1) Clinical and Laboratory Practice: Establish the paradigm of genomic medicine by issuing statements and evidence based or expert clinical and laboratory practice guidelines and through descriptions of best practices for the delivery of genomic medicine. 2) Education: Provide education and tools for medical geneticists, other health professionals and the public and grow the genetics workforce. 3) Advocacy: Work with policymakers and pavers to support the responsible application of genomics in medical practice. *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

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programs of the American College of Medical Genetics and Genomics are dependent upon charitable gifts from corporations, foundations, and individuals through the ACMG Foundation for Genetic and Genomic Medicine (<u>www.acmgfoundation.org</u>.)

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