



FOR IMMEDIATE  
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**Newborn Screening Blood Spots:  
How Can We Preserve Both This National Treasure and Patient Privacy?**

*Public/Professional Forum on Blood Spots, Genetic Research & Privacy  
To Be Held in Bethesda on Sept. 23, 2009*

BETHESDA, MD – August 22, 2009 – Newborn Screening is an invaluable public health program that saves lives and helps to prevent the development of serious disease and debilitation. But how can privacy and autonomy best be maintained regarding the residual dried blood spots which are collected from newborns shortly after birth? To address this and other compelling issues surrounding the use of newborn screening blood spots, experts from across the US from a number of renowned institutions including the Mayo Clinic, the March of Dimes, the American College of Medical Genetics and Genetic Alliance will host a public/professional forum and Internet webinar on "Blood Spots, Genetic Research and Privacy."

Sponsored by the American College of Medical Genetics, the American College of Medical Genetics Foundation and Genetic Alliance, this session is free and appropriate for the public, parents, health professionals, policymakers, the media and anyone with an interest in newborn screening.

The Forum will be held at the Bethesda North Marriott Hotel and Convention Center on Wednesday, September 23 from 7:00 – 9:00 pm and is free. Pre-registration is REQUIRED. Email Claudia McNatt at ACMG at [cmcnatt@acmg.net](mailto:cmcnatt@acmg.net) to register as space is limited. The session will also be broadcast over the Internet as a webinar. Visit <https://www2.gotomeeting.com/register/989705827> to register for the free webinar.

The topics and speakers include:

**Welcome:** *Michael S. Watson, PhD, FACMG* | Executive Director  
American College of Medical Genetics

**Blood Spots, Genetic Research, and Privacy:** Moderator – *Sharon Terry, MA*  
President and CEO | Genetic Alliance

**Overview of Newborn Screening, Potential Uses of Residual Dried Blood Spots, and Protection of Privacy:** *Alan R. Fleischman, MD* | Senior Vice President and Medical Director  
The March of Dimes

**The Public's Perceptions Related to Uses of Newborn Screening Dried Blood Spots:**

*Sharon Kardia, PhD* | Professor and Chair, Department of Epidemiology  
University of Michigan School of Public Health

**The Many Lives of the Newborn Screening Dried Blood Spot:** *Piero Rinaldo, MD, PhD*

*FACMG* | Professor of Laboratory Medicine | T. Denny Stanford Professor of Pediatrics,  
Mayo College of Medicine

**Newborn Screening and its Improvement: A Consumer Perspective:** *Jana Monaco* |

Parent

**Summary and Questions and Answers:** *Sharon Terry, MA* | Genetic Alliance

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***About the American College of Medical Genetics and ACMG Foundation***

*Founded in 1991, the American College of Medical Genetics ([www.acmg.net](http://www.acmg.net)) is the national non-profit professional organization that 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 health care 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 health care 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](http://www.acmg.net)) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Medical Geneticist Locator. The educational and public health programs of the American College of Medical Genetics are dependent upon grants and contracts and charitable gifts from corporations, foundations, and individuals. The American College of Medical Genetics Foundation ([www.acmgfoundation.org](http://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.*

***About Genetic Alliance***

*Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit <http://www.geneticalliance.org>.*