ACMG NEWS

For Immediate Release

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One Simple Test Can Save Your Baby's Life: Newborn Screening Experts Discuss What the CDC Has Called "*One of the Ten Great Public Health Achievements of this Century*" on "*Life, Love & Health*" Radio Program

BETHESDA, MD – May 23, 2011 | Newborn screening is a vital public health program and it's been called one of the most significant, lifesaving and important public health programs in the United States of the past 50 years.

Newborn screening saves lives every day. Through early screening, diagnosis and treatment we can now prevent the truly dire consequences of a number of treatable conditions. With the current expansion of newborn screening panels nationwide, it is estimated that about 12,000 of the 4.1 million babies born each year in the United States will be identified with one of the conditions for which early treatment will have a significant impact on the child's life and long-term health.

Advances in technology have indeed made it possible, feasible and cost-effective to test newborns for a number of extremely serious, disabling or deadly conditions with a simple gathering of a drop or two of blood from the newborn's heel.

In this edition of "*Life, Love and Health*" radio program (America's most listened-to daily health, prevention and wellness program) will first air on May 27th at 5PM Eastern time on www.healthradio.net, experts and a parent discuss how, with advances in medicine, it is now possible to diagnose, treat and even more importantly, actually PREVENT the negative outcomes of death and disability of these diseases.

Guests include:

Judith Benkendorf, MS, CGC, a board certified genetic counselor, Special Assistant to the Executive Director at the American College of Medical Genetics (www.acmg.net) and Associate Project Director of the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (www.nccrcg.org).

Kelly Rosso Leight, JD, founder of the CARES Foundation (www.caresfoundation.org) and the coordinator of the Preserving the Future of Newborn Screening Coalition (http://www.newbornbloodspots.org/).

Tracy Trotter, MD, a pediatrician in private practice with an interest in genetics.

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Korissa Olson, parent and advocate. As a healthy expectant mother in Minnesota, whose preference is for less medical intervention, Ms. Olson declined newborn screening upon the birth of her son Everett. It was not until a nurse clearly delineated the benefits that she changed her mind, only to learn that Everett is affected with galactosemia, one of the conditions in the universal newborn screening panel. This knowledge has not only been life saving to her robust 3-year old, but it was also life giving, as his diagnosis was known when the first signs of the condition showed up—symptoms so general that he could have received treatment that would have made him sicker. With this experience, she has become a strong advocate for universal newborn screening.

To hear "***The Remarkable Public Health Program of Newborn Screening***" broadcast, tune into "*Life, Love & Health: Special Edition*" at 5PM Eastern on May 27, 2011 at www.healthradio.net. The program will be available at a later date at both www.acmg.net and www.nccrcg.org and will in the coming weeks reach an audience of 3.1 million listeners on multiple traditional and New Media platforms, including Sirius XM Satellite Radio including CNN, Fox, ESPN and Bloomberg; selected Public Radio affiliates; plus HealthRadio.net, WomensRadio.com, RightHealth.com Internet radio; plus American Forces Network international.

In the program, Dr. Trotter states, "It's (newborn screening) giving all newborns a chance for a normal life….It can't be stated too, too strongly or too many times that this (newborn screening) gives us a chance to be proactive, be on the prevention side rather than reacting to crisis."

"When we talk about newborn screening as a program, it is really a process that goes from birth and the heel stick through the analysis of the blood sample in the laboratory to the reporting out of a positive result, which means finding those newborns as quickly as possible and getting them into their primary care providers for follow-up, diagnosis, management and treatment and then lifelong care. So this program really is a process with many, many steps…" explains genetic counselor Judith Benkendorf.

Benkendorf adds, "I think one of the most important things for parents to know is that when doing screening tests, we are looking at large populations of people and casting a very wide net. We are going to pick up, in that net, more people than are actually affected by the condition. It's critical that a screen positive test is followed-up on immediately, but not every baby with a screen-positive test actually has a diagnosis of one of the disorders in the newborn screening panel."

For this reason and many more, experts from the ACMG and many other organizations believe that all expectant parents should be versed in the nuances and more importantly, the lifesaving benefits of newborn screening.

About the American College of Medical Genetics and ACMG Foundation

Founded in 1991, the American College of Medical Genetics (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 physician geneticists, biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. ACMG's website (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) is a 501(c)(3) not-for-profit organization dedicated to funding the College's diverse efforts to translate genes into health.

About the HRSA Genetics Collaboratives

The seven HRSA/MCHB-funded HRSA Genetics Collaboratives and their National Coordinating Center (NCC) are working to improve access to local genetic and newborn screening services, information, and resources for individuals and families with heritable disorders. A major component of the NCC/Genetics Collaboratives system involves using a variety of approaches to link primary care providers, geneticists and other specialist providers, and public health services into a comprehensive medical home that meets all the needs of individuals and families with heritable conditions. Activities at all levels engage consumers and families, with new opportunities for partnerships continually emerging. Its website is www.nccrcg.org. The NCC 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.

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National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives