



ACMG NEWS

For Immediate Release

ACMG Media Contact:

Kathy Ridgely Beal, 301-238-4582

kbeal@acmg.net

***Hearing Loss, Genetics & Your Child* – A New Brochure for Parents of a Child With Hearing Loss is Now Available from the American College of Medical Genetics and the HRSA Genetics Collaboratives**

Spanish Version Also Available

BETHESDA, MD – October 4, 2010 | The American College of Medical Genetics (www.acmg.net) and the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (also known as The NCC – www.nccrcg.org) are offering a new, free brochure, *Hearing Loss, Genetics and Your Child*.

"Most people are surprised to learn that there is about a 50% chance that a child's hearing loss is due to a genetic cause," says Kathleen S. Arnos, PhD, FACMG, Professor of Biology and Genetics Program Director at Gallaudet University in Washington, DC, who led the development of the brochures. "A child can have a genetic-related hearing loss even if no one in his or her family has hearing loss. Therefore, it is very important that parents know to make an appointment with a clinical geneticist—a doctor with advanced training in genetics."

"The state-based Early Hearing Detection and Intervention (EHDI) programs are doing a wonderful job with follow-up, but with families often focusing on hearing and communication issues as their primary concerns, genetics often gets lost in the shuffle without the appropriate referral occurring," says Judith Benkendorf, MS, CGC, a genetic counselor and Associate Project Director for the NCC.

The goal is to have the *Hearing Loss, Genetics and Your Child* brochures available at the point of care, such as waiting rooms in primary care settings and ENT and Audiology centers, where infants and children with hearing loss are most often seen. The brochure was designed both as a tool to assist medical professionals to convey information about the purpose and process of genetic evaluation and to increase parents' comfort with genetic services by empowering them with information about the importance of genetic services in the etiologic diagnosis of hearing loss, thus complementing the referral.

The *Hearing Loss, Genetics and Your Child* brochure covers topics that families of a child who has been diagnosed with hearing loss or is being tested for hearing loss should know, such as:

- Why should I have a genetics doctor see my child?
- How can I prepare for the genetics appointment?
- What happens at the genetics appointment?
- What should I know about genetics, genes and hearing loss?
- Will insurance pay for genetic testing?

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

The brochure also has space for individuals to take notes and write down questions, making it especially handy for taking to medical appointments.

This important, free brochure was developed by a team of medical geneticists, genetic counselors, audiologists, parent advocates, and health science information specialists. It is written at a low-literacy level and is available in both English and Spanish. Downloadable brochures are available online at www.nccrcg.org (under the Resources tab) at no cost and contain modifiable space for adding local resource information. Print copies may be ordered by contacting Matthew Tranter (mtranter@acmg.net). The minimum order for printed copies is 100 brochures for \$15.00, plus shipping and handling.

The development of this brochure was partially 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 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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