

CollegeNews

Hearing Loss, Genetics & Your Child— A New Brochure for Parents of a Child With Hearing Loss Now Available

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?

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.org). The minimum order for printed copies is 100 brochures for \$15.00, plus shipping and handling.

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 provid-

ers, 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.

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.

Support the Future of Your Profession; Help a Genetics Trainee

The ACMG Foundation is still accepting contributions to its campaign to raise money for partial scholarships to the ACMG Annual Meeting.

In the past, we've received requests for help from trainees who are new in their career and can't afford to attend the Annual Meeting on their own, from geneticists who don't have travel budgets, and from geneticists whose institutions have moratoria on meetings and travel.

To contribute to this worthy cause, please donate online at the ACMG Foundation website located at www.acmgfoundation.org, or contact David Cotter at 301-718-2014 or dcotter@acmgfoundation.org.

For more information on applying for a partial scholarship, please check the Foundation's website for eligibility requirements and an application.

2011 ACMG Genetics Review Course

The next Genetics Review Course will be held June 2-5, 2011 at the Hilton DFW Lakes Executive Conference Center in Grapevine, Texas. Program, registration and hotel information will be available at www.acmg.net in January 2012.



2011 ACMG Annual Clinical Genetics Meeting March 16-20, 2011 Vancouver, British Columbia Canada

Online Abstract Submission, Registration and hotel information is now available. Go to the ACMG meeting website at www.ACMGmeeting.net for more information and to register.

- **Abstract Submission**
Deadline is December 10, 2010.
- **Early Bird Registration**
Deadline is December 15, 2010.
- **Advance Discount Registration**
Deadline is February 9, 2011. After February 10, 2011, late registration fees will apply.

Those planning on attending the 2011 ACMG meeting are reminded that as of June 1, 2009, everyone traveling between the United States and Canada by land, sea (including cruises and ferries) or air will be required to present a valid passport or other documents as determined by the Department of Homeland Security to cross the border. For information regarding visas and entry requirements for Canada, please call Immigration Canada at 1-888-242-2100 (in Canada) or visit their website at www.cic.gc.ca, or visit the Canadian Border Services Agency website at <http://www.cbsa-asfc.gc.ca/menu-eng.html>.