CollegeNews

Did You Know? The HRSA Genetics Collaboratives Are Bringing Genetic and Newborn Screening Services to Local Communities Around the United States: Visit The Newly Revised Website

Overcoming the challenges of bringing quality and cutting edge genetic and newborn screening (NBS) services to local communities and to children and families with hereditary diseases is inarguably extremely complex. It requires coordinated, multifaceted and multidisciplinary efforts that are national, regional, and local and include public, private and not-for-profit partnerships. In order to meet these challenges, the Health Resources and Services Administration/ Maternal and Child Health Bureau's Genetic Services Branch (HRSA/MCHB/GSB) awarded the American College of Medical Genetics (ACMG) a cooperative agreement first in 2004 and later renewed it until 2012 to serve as the National Coordinating Center (NCC) for seven similarly-funded Regional Genetic and Newborn Screening Service Collaboratives known as the HRSA Genetics Collaboratives.

While the HRSA Genetics Collaboratives have had a website for several years, great effort was put into totally revamping the site so that it is now more comprehensive and user friendly. Please visit the new site at www.nccrcg.org

"Hundreds of professionals including public health officials, newborn screening program staff members, primary care providers, physician geneticists, genetic counselors, consumer advocates, and families are active in the HRSA Genetics Collaboratives. The Collaboratives are bringing genetic discoveries into local communities in every state in the country. They are working hard to improve local access to newborn screening and genetic services for everyone by addressing the unique needs of the community," says Judith Benkendorf, MS, CGC, a genetic counselor and Project Director of the NCC.

"Each regional Genetics Collaborative has fostered a variety of approaches to building linkages between public health, genetics specialists, primary care/the Medical Home and families. Some of their activities are being replicated nationally. A benefit of the current coordinated system is that each HRSA Genetics Collaborative has access to national expertise, positioning it to be a "go to" resource for information about genetic and newborn screening services" added pediatrician Tracy L. Trotter, MD, FAAP, Senior Partner, San Ramon Valley Primary Care.

Annual Meeting Registration Deadlines

Discounted registration fees are still available through the Advance Registration Deadline of February 19, 2010. Registrations will be accepted February 20 through on-site – but late fees will apply. Go to www.acmgmeeting.net to register now. Preregistered attendance is at a record high – so don't miss out on the opportunity to learn and network with your peers and the leaders in the field of medical and clinical genetics.

ACMG Exhibits

With a record number of poster sessions accepted and booth space reserved – the 2010 Exhibit Hall is anticipated to be the largest ever at the ACMG Annual Clinical Genetics Meeting and will be an exciting feature of the Annual Meeting. The detailed list of exhibitors and poster sessions can be found on the ACMG Meeting Website.

Special Session Added to the ACMG Annual Meeting

A special satellite session has been added for **Wednesday evening, March 24 from 7:00 pm - 9:00 pm**–"Genetics and Genetic Research - Native American Perspectives." Sponsored by the Regional Genetics and Newborn Screening Collaboratives and their National Coordinating Center, leaders and representatives of the Navajo (Diné) Nation will participate in this discussion with the medical genetics community. An invited panel includes a Navajo Medicine Man, the head of the Navajo Nation IRB, representatives of the Navajo Nation Health Department and the Diné Policy Institute, and consumers.

ACT Sheets, New and Revised

Appearing shortly "at a theater near you"– or more appropriately, on the ACMG website, the much anticipated revised and expanded ACTion Sheets (or ACT Sheets as they are commonly known). The result of diligent work by the Work Group, chaired by Richard King, PhD, FACMG, and Harvey Levy, MD, FACMG, and with input from additional subject matter experts as needed, the Sheets represent an updating of ones previously posted and new ones that address topics related to Colon Cancer, Cystic Fibrosis, Fragile X Syndrome, Duchenne and Becker Muscular Dystrophies, additional Hemoglobin Disorders, and Adult PKU. The new ACT Sheets are intended to provide information, not only for the primary care provider undertaking the assessment and management of the patient with a test-positive result from newborn screening but also the physician responding to a positive family history, to the results of carrier screening, or to the sometimes-difficult transition between pediatric/adolescent care and adult medicine. ACT Sheets outline points for consideration by the practitioner in the initiation or continuation of care for the patient with some of the clinical diagnoses not always common to "front line" medical settings. ACT Sheets should be interpreted as informal guidance and not as definitions of standards of care.

Laboratory Quality Assurance Committee Updates Clinical Cytogenetics Prenatal Diagnosis Technical Standards and Guidelines: Now on ACMG Website

One of the charges of ACMG's Laboratory Quality Assurance Committee is maintaining its virtual laboratory manual, Standards and Guidelines for the Clinical Genetics Laboratories, on the ACMG website. The Prenatal Diagnosis Guidelines from the Clinical Cytogenetics section (Section E) have just been updated to include new techniques and technologies, including updates on tissue culturing, analysis of XX and XY mixed cell lines, and processing standards for chorionic villi. Section E of the Technical Standards Guidelines can be found on the ACMG website at www.acmg.net/StaticContent/SGs/Section_E.html.

Social Media and the ACMG Annual Clinical Genetics Meeting

Be sure to follow the ACMG Annual Clinical Genetics Meeting highlighted on ...