ACMG to Continue as the National Coordinating Center

Submitted by Michael S. Watson PhD, Director and Judith Benkendorf, MS, CGC, Project Manager, NCC

The ACMG was awarded a $4 million dollar, five-year grant to continue as the National Coordinating Center (NCC) for the Regional Genetics and Newborn Screening Collaborative Groups (RCs), as a cooperative agreement with the Maternal and Child Health Bureau, HRSA.

The synergistic relationship that exists between the NCC, RCs, and the ACMG will continue in the 2007-2012 funding cycle, with new connections arising between emerging and existing activities. All efforts will continue to foster collaborations between public health, primary care and specialist providers to improve quality and access to genetic and NBS services.

Workgroup initiatives in the areas of disaster preparedness, telegenetics, and the genetic service provider network will move forward and a new workgroup dedicated to long-term NBS follow-up (LTFU) and data collection will form, with the NCC/RC system as a critical component of larger national efforts. LTFU data collection programs for patients identified through NBS programs will assist the States in the evaluation and quality assurance of their NBS programs and provide a useful perspective on natural history of the treated condition and a patient resource for clinical trials of second-generation therapeutics.

Progress is expected in the incorporation of the NBS ACT Sheets and diagnostic confirmation algorithms as point-of-care educational content and clinical decision support tools for electronic medical record systems. ACT sheets addressing positive genetic testing results for tests often ordered by primary care providers, such as fragile X testing and cystic fibrosis carrier testing/screening, are forthcoming.

We look forward to working together on these and other activities to fill an important gap in ensuring the quality and continuity of care for genetics and NBS patients.

http://www.nccreg.org
Genetics Education in Underserved Communities: The GENE Project

The March of Dimes Foundation (MOD) is a nationally recognized non-profit consumer health organization that provides community services, education, research and advocacy in maternal and child health, with enduring programmatic emphasis on the use of genetics to improve health. In 2005, the MOD completed the five-year Genetics Education Needs Evaluation (GENE) Project, which was funded by the Health Resources and Services Administration (HRSA/MCHB) to investigate and improve consumer access to genetics information. The long-range vision of the GENE Project was to create a collaborative network for the development and dissemination of culturally and linguistically appropriate human genetics information, resources and services that would assist underserved populations in making informed decisions about their health. The project resulted in the development of partnerships and community-based, participatory strategies in consumer genetics education for minority populations that could serve as a model for future programs.

MOD first developed partnerships at a national level with Family Voices and Genetic Alliance to examine effective collaboration and local outreach strategies for genetics education. Then MOD and the national partners engaged the communities of Washington Heights/Inwood, NY and Flint and Lansing, MI in the development of coalitions/consortiums to conduct needs assessments using community-based participatory approaches. The two projects conducted numerous community dialogues, focus groups, and face-to-face surveys to assess knowledge, attitudes and behaviors relating to genetics in African American and Latino communities.

Not surprisingly, the results of these community assessment activities confirmed the need for genetics education and outreach to these traditionally underserved populations. Both communities believe that certain chronic diseases have a strong genetic basis and expressed the desire to know more. However, differences emerged regarding preferred methods of health communication and perceived genetics information needs. For example, Latinos expressed interest in genetics as it relates to pregnancy outcomes, while African Americans preferred to discuss the ethical, legal and social implications of genetics research and testing. In response to the findings, each community developed an action plan that prioritized topics of interest, specific health communication and outreach strategies, and recommendations for the development of culturally appropriate educational materials.

Subsequently, MOD was awarded additional funding from MCHB/HRSA for the Consumer Genetics Education Network (CGEN). In collaboration with four communities, genetics education materials tailored for the African American, Hispanic, Asian, and Native American populations are being developed. The Regional Collaboraives (RCs) have shared interests with current CGEN initiatives and may benefit from their forthcoming products to deliver accurate, appropriate information about genetic and NBS services to hard to reach communities. RCs interested in working with CGEN to pilot materials should contact EmyLou Rodriguez at 914-997-4543 or erodriguez@marchofdimes.com. More information on this project as well as some of the lessons learned in the areas of partnership development, community engagement, and minority genetics education will be discussed in a future issue of the NCC Collaborator.  

http://www.marchofdimes.com

Submitted by EmyLou Rodriguez, Manager, Community Genetics Education, March of Dimes Foundation
New England Regional Genetics and Newborn Screening Collaborative (Region 1): Under New Leadership

The Mission of the New England Regional Genetics and Newborn Screening Collaborative ("The New England Region") is to promote and improve health and social well being of those with inherited conditions through collaborations among public health professionals, private health professionals, educators, consumers and advocates.

As in many regions across the country, newborn screening in Region 1 has expanded recently in response to increased technical capability of tandem mass spectrometry and national leadership advocating for expansion. The New England RC will build upon the experience with regionalized newborn screening to enhance genetic service capacity for genetic conditions identified by newborn screening (NBS) and those identified clinically in Region 1. During the next five-year funding cycle, the RC will address the following goals:

Goal 1: Establish and maintain a Regional Coordinating Center (NE RCC) for genetics and NBS at the University of New Hampshire.

Goal 2: Collaborate to facilitate access to genetics services, expertise and technology particularly for underserved populations and in rural areas.

Goal 3: Develop effective practice models for adolescents and young adults with genetic conditions who are transitioning from pediatric to adult healthcare.

Goal 4: Develop effective partnerships to further medical home practices in the region.

Goal 5: Serve as the focal point for effective genetics education and dissemination of genetics information.

Goal 6: Demonstrate effective collaborations with other regional and national stakeholders.

Goal 7: Examine public policy and ethical, legal and social issues affecting individuals with genetic conditions, their families, and healthcare providers and educators.

Goal 8: Utilize a small project program to accomplish unanticipated and innovative activities that emerge within the region.

Goal 9: Provide opportunities to increase discussions with school systems and state special education leaders to improve access and support to educational services in the least restrictive environment.

Goal 10: Complete both quantitative and qualitative evaluations of processes and outcomes of all goals, activities and projects undertaken by the New England RC.

Working Groups, a Collaborative Council of Working Group Leaders, the NE Regional Coordinating Center, and an Advisory Committee will accomplish the goals of the New England RC. An independent evaluator will conduct both formative and summative evaluations. A recent two-day working meeting of the key stakeholders and representatives of the genetics field in New England continued to develop year one goals for all Work Groups.

The New England RC is now a partnership of the New Hampshire Institute for Health Policy and Practice (NHIHPP) and the Institute on Disability at the University of New Hampshire (UNH), in collaboration with the Dartmouth-Hitchcock Medical Center Department of Pediatrics, Center for Medical Genetics. John Moeschler, MD, MS, Professor of Pediatrics and Director of Clinical Genetics at Dartmouth Hitchcock Medical Center, is the Project Director. Amy Philbrick-Schwartz, MPH, Associate Director of the NHIHPP, serves as Project Manager for the Region 1 Genetics and Newborn Screening Collaborative.

http://www.nergg.org
New York – Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC)

Consumer Focus Groups
This spring NYMAC hosted consumer focus group meetings in New Brunswick, NJ, Bethesda, MD, and Binghamton, NY, to discuss medical support services for people with special healthcare needs. Specific topics included medical home and health promotion; access to health insurance and adequate reimbursement for services; special resources for education, transportation and parent and child support; and transition of adolescents and young adults to adult medical care. The facilitated roundtable discussions were structured to allow participants about an hour for each topic.

The New Jersey meeting was hosted by the Statewide Parent Advocacy Network of New Jersey (SPAN-NJ). The Genetic Alliance was asked to provide assistance for the Maryland meeting. Ferre Institute, the Binghamton community genetics program, hosted the program in New York. NYMAC announced the meetings to about 350 consumers on its mailing list and SPAN-NJ, the Binghamton Community Genetics Program and the Genetic Alliance encouraged their clients to attend. There were 50 consumer attendees in New Jersey, including a large contingent of people who spoke only Spanish (SPAN-NJ provided translators), 8 in Maryland and 33 in Binghamton. Healthcare providers and public health professionals were discouraged from attending to ensure that patients and families would feel comfortable discussing their experiences.

The discussions were very lively. Attendees were generous in sharing their trials and triumphs regarding the medical, financial and psychosocial care they and their family members needed. Once the facilitators complete the discussion summaries, NYMAC will share these with the attendees and seek their ideas about next steps, including projects to address specific barriers, which will be assigned to existing work groups or to a new Consumer Work Group.

Teratogen Information Services (TIS)
Representatives from several of the regional TIS met in Washington, DC on April 27th. This meeting was held in conjunction with the three NYMAC subcontracts awarded to improve TIS infrastructure and consumer knowledge. Although these services have been operating for several years, this provided a first opportunity to compare techniques, resources and experiences.

Advisory Council Meeting
The NYMAC Advisory Council met in Baltimore on May 30-31. Brief presentations of past cycle activities preceded discussions of the next cycle. An after-dinner panel presentation on medical home included pediatricians who have incorporated the medical home model into their practices and their parent partners. Council members reviewed and provided suggestions to NYMAC on the conditions of their 2007-2012 award from MCHB.

http://www.wadsworth.org/newborn/nymac/
Southeastern Regional Genetics Group (SERGG)

SERGG (Region 3) activities directly support achieving three core goals:

- Addressing existing gaps in Genetic Services (GS) affecting the health and development of children and adults with heritable disorders;
- Expanding existing and developing new regional capabilities and resources to address identified GS gaps and maldistributions of genetic resources;
- Improving the regional communication infrastructure.

Current Activities

With the goal of promoting lab quality and expertise advancement, the Laboratory Performance Workgroup’s (LPW) regional sample exchange program final protocol review and approval is underway. Other on-going LPW activities include examining the region’s cutoffs and performance data from Region 4’s lab project. Finally, in recognition of the dearth of formalized interstate back-up lab agreements, two states are working towards a model formalized MOU to provide emergency lab back-up services.

A Florida mini-grantee offered two trainings, held in Puerto Rico and the U.S. Virgin Islands. These trainings provided newborn screening (NBS) program knowledge and skills training to help reduce morbidity and mortality in the territories and improve the communications infrastructure between the region and the territories. Over 150 NBS professionals attended each of these trainings.

Furthering the region’s commitment to extending teleconferencing and tele-genetics to underserved populations, the region held a successful multi-point videoconference between Alabama, Georgia, Louisiana, South Carolina, and Tennessee on May 4th.

In recognition of the dearth of formalized interstate back-up lab agreements, two states are working towards a model formalized MOU to provide emergency lab back-up services.
Expansion of the Region 4 Newborn Screening by Tandem Mass Spectrometry Project

In 2004, the newborn screening (NBS) programs of all seven states included in Region 4 (IL, IN, KY, MI, MN, OH, and WI) agreed to participate in a project aimed to improve the analytical quality of NBS by tandem mass spectrometry (MS/MS). In June 2006, Region 4 received supplemental funding to expand the project to include states from other regions. The goal of this project was to facilitate the transition of the Region 4 NBS by MS/MS project from a regional to a national project.

The rationale to expand participation beyond Region 4 relates to the reality of dealing with rare conditions. Greater participation in this project implies larger sets of data available for calculation and progressive definition of the disease and cutoff ranges. The minimum target was to include at least 50 cases of each condition included in the HRSA/ACMG panel.

The grant has resulted in the following:

- Active participation has expanded substantially beyond the boundaries of the region and even of the US, to include a total of 38 US states from all seven regions and 34 international participants from 20 countries.
- A total of 3,910 true positive cases have been submitted (for updated information, go to http://www.region4genetics.org/cluster1_information.aspx). Fifteen of the 20 primary targets listed in the uniform panel have reached, and in some cases greatly exceeded the initial goal of 50 cases (MCAD: n=798); three of the 22 secondary targets have also reached this goal.

  - A culture of data sharing and open communication, constructive inter-laboratory comparison, and ready exchange of methods, reagents, and specimens has developed among participants.
  - The Region 4 website (http://www.region4genetics.org) was updated to include standard operating procedures, data collection tools, and folders for each participant to enter data.
  - On May 6, 2007, 48 participants representing all seven regions as well as Canada, Australia and Lebanon met in Minneapolis to review their performance metrics and to compare them with that of their peers. The group agreed to collect additional data on pre-analytical variables, analytical variables, and acquisition parameters for amino acids and acylcarnitines.

With the beginning of the new grant cycle, the project will move into a new phase with the custom creation of a dedicated computer program capable of (1) supporting a web-based, password protected system where participants enter their own data; (2) generating customized reports; and (3) adding new conditions and markers (with potential applicability beyond MS/MS panel).

http://www.region4genetics.org
Heartland Regional Genetics and Newborn Screening Collaborative

Our first report in the NCC Collaborator introduced our region’s activities. This update focuses on Heartland committee activities. Key work of each committee is reviewed below. All products, meeting announcements, and minutes are posted on the Heartland website: http://heartland.ouhsc.edu.

Clinical Services
This committee assessed the region’s telemedicine capacity and catalogued the regional clinical genetics services. Their work produced three significant outcomes:

- Roundtable presentations at the American Telemedicine Association conference
- “How to” manual on setting up a telegenetics program (in progress)
- Linking and contributing to clinical data on the GeneTests Clinic Directory http://www.genetests.org

Education
This committee developed a comprehensive Family Health History educational plan targeting genealogy groups; Hispanic, African American, and Native American communities; rural citizens and students. The committee is collaborating with Utah Department of Health and the Genetic Alliance to accomplish their activities. The committee’s products include:

- Regional consumer website and toll free number http://www.heartlandfamilyhistory.org
- Video press release during Thanksgiving/Christmas 2006
- Genealogy societies promotion (in progress)
- Rural citizens’ education through rural electric cooperative magazines (in progress)
- Public service announcements for Hispanic, African American, and Native American communities (upcoming)

Policy
This committee has two major activities underway: a ‘white paper’ on newborn screening (NBS) blood spot retention, and a Genetics Education Day toolkit containing resources for states planning such an educational event for policymakers.

Newborn Screening
This committee identified and distributed English/Spanish educational videos on NBS for expectant parents to publicly funded prenatal clinics. Four states’ videos were customized with state-specific information. They are also comparing and standardizing verbiage used in reporting transfusion status during NBS.

Laboratory
This committee tackled the problem of disaster preparedness in our region. The committee’s efforts culminated in a proposal, to be implemented next year, for developing and testing a disaster-preparedness plan for the region.

Research
Until recently, this committee focused exclusively on creating and conducting the pilot project program. The committee has added an external funding update on the Heartland website. Funding opportunities pertaining to genetics or public health are updated weekly.

Lay Advocates
Heartland’s lay advocacy group keeps us centered on whom the project ultimately serves—the affected individuals and their families. The group serves on each committee, reviewed each pilot project application, reviews all documents produced by the collaborative, and is planning an advocacy training program at the annual meeting. Each member’s biographical sketch will be posted soon on their webpage. http://heartland.ouhsc.edu
Mountain States
Genetics Regional Collaborative Center

Annual Meeting
The Mountain States Genetics Regional Collaborative Center (MSGRCC) Annual Meeting will be held July 12th-14, in Denver, Colorado. It is being co-sponsored by the Mountain States Genetics Foundation to provide participants a range of topics, beyond the Regional Collaborative Center’s objectives. This will be the first meeting of the MSGRCC being led by the Center’s new Co-PI, Jeffrey Botkin, MD, MPH, with Co-PI John Johnson, MD under the HRSA Cooperative Agreement for the project period of 2007-2012. More information and the Agenda can be found at http://mostgene.org/annualmeeting07.htm.

Mid-Year Committee Meetings
Mid-year committee meetings occurred in January, March and April. The meetings were well attended with representation from the eight states that comprise the Mountain States region, and consumers. Each committee addressed the following items in addition to topics specific to the committee:

2007-12 MSGRCC Grant Submission: Content of grant application and process for approval.

Emergency Preparedness: Individual facility plans and state plans.

Medical Home: Activities and grants in each state supporting medical home.

Telemmedicine: How telemedicine is used in each state.

Small Grant Projects: Committees have oversight of small grant projects and reported on their progress to date.

For more information on each committee meeting, access the minutes on our website at http://www.mostgene.org.

MSGRCC Projects
Project accomplishments since our last newsletter update include team building with our underserved population, review of metabolic protocols, data analysis of NBS analyte stability and NBS Registry development.

Nations. They are planning a meeting for Summer 2007 that will provide a forum for information exchange between the genetics community and the Nations regarding Genetics. Janet Thomas, MD and Erica Savino are having the Shared Baseline Protocols for the ACMG-recommended metabolic disorders final review done by a metabolic specialist from each state in the region. Marzia Pasquali, PhD, is preparing the results of our long-awaited analyte stability under various storage conditions for publication. Finally, under the direction of Jeff Botkin, MD, MPH, and Nicola Longo, MD, Reid Holbrook MS is conducting an information follow-up systems analysis of metabolic clinics in our region and planning to visit other metabolic clinics in the nation pursuing NBS long-term follow-up data collection activities. This will inform the development of the MSGRCC NBS Registry.

http://www.mostgene.org

Submitted by Rebecca Anderson BS, RN and Joyce Hooker
Western States Genetic Services Collaborative

The ultimate aim of our project is to optimize the health and well being of Alaska, California, Guam, Hawai‘i, Idaho, Oregon, and Washington children with conditions detected by the newborn screening (NBS) blood test, congenital malformations, and other genetic disorders, by taking a regional approach to coordinating, sharing, and improving access to services.

Our activities over the next five years focus on: (1) maintaining and expanding our Practice Model that improves access to specialty genetic services, comprehensive primary care, and care coordination for children with heritable conditions living far away from comprehensive genetics and metabolic centers; and (2) increasing the capacity of collaborating states’ and territory’s public health agencies to perform their genetics-related assessment, policy development, and assurance functions.

We call our collaboration strategy the “Give and Get” model. Each of our states contributes expertise, knowledge, and/or other resources useful to the other states and territory, and receives expertise, knowledge, and/or resources. The Collaborative provides funds and staffing where needed. Here are some examples of the “Gives” and “Gets.”

http://www.westernstatesgenetics.org/

---

**Western States Genetic Services Collaborative**

<table>
<thead>
<tr>
<th>Receives (“Gets”)</th>
<th>Shares with Other States (“Gives”)</th>
<th>Collaborative Provides</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All States</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evaluation tools and analysis for face-to-face and telemedicine visits</td>
<td>Strategies to improve access to genetic services</td>
<td>Funds and logistics for Regional Summit and workgroups</td>
</tr>
<tr>
<td>Assistance and resources for improving financing of services</td>
<td>Input about telemedicine visit evaluation tools</td>
<td>Funds and logistics for web-assisted audio conferences</td>
</tr>
<tr>
<td>Genetic health outcomes measures for program planning &amp; evaluation</td>
<td>Input about NBS prenatal care provider education</td>
<td>Funds, logistics, and staff resources to develop and pilot services evaluation tools and do analysis</td>
</tr>
<tr>
<td><strong>AK</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funds to pilot practice model</td>
<td>Strategies for addressing sustainability</td>
<td>Funds to conduct needs assessment</td>
</tr>
<tr>
<td><strong>CA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance translating NBS education materials</td>
<td>Strategies for evaluating NBS long-term follow-up</td>
<td>Funds and arrangements to translate NBS materials</td>
</tr>
<tr>
<td><strong>HI</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funds to pilot practice model</td>
<td>Genetic specialists’ expertise to Guam</td>
<td>Travel funds to set up genetic services in rural HI</td>
</tr>
<tr>
<td><strong>ID</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician geneticist and metabolic dietician expertise</td>
<td>Education articles for primary care providers</td>
<td>Funds for genetic specialists for outreach clinics</td>
</tr>
<tr>
<td><strong>Guam</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician geneticist and genetic counselor expertise</td>
<td>Input about telemedicine genetics visit evaluation tools</td>
<td>Travel funds for HI specialists to provide genetic clinics</td>
</tr>
<tr>
<td><strong>OR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funds to pilot practice model</td>
<td>Genetic specialists’ expertise to Idaho</td>
<td>Funds for public health nurses to staff telemedicine sites</td>
</tr>
<tr>
<td><strong>WA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funds to pilot telehealth in rural WA</td>
<td>Strategies for improving funding for genetic services</td>
<td>Funds for genetic specialists for telemedicine</td>
</tr>
</tbody>
</table>

---

Medical Home Webcast Archived for One Year

In February, the American Academy of Pediatrics (AAP) and the National Conference of State Legislators hosted a web conference, *Finding a Medical Home for Children: A Discussion for Healthcare Practitioners, Policymakers, and Public Health Agencies*. The webcast brought together the private and public sectors to discuss their roles in helping all children obtain a medical home to coordinate health services and improve the quality of care. The program highlights AAP’s definition and vision of the medical home, demonstrates the benefits of medical homes using a genetics co-management case study, and identifies policies that support efforts to provide all children with medical homes. The webcast is archived for one year and can be viewed at no cost: http://www.ncsl.org/programs/health/webcastfeb07.htm#medical%20home
The Association of University Centers on Disabilities (AUCD) is a national, non-profit organization that promotes and supports a network of 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs. LENDs are funded through the Health Resources and Services Administration’s Maternal Child Health Bureau (MCHB) and train the next generation of interdisciplinary leaders in maternal child health (MCH) and disabilities. Members of a LEND team include trainees from 13 or more core disciplines. LEND programs strive to produce interdisciplinary, culturally competent, family centered leaders in MCH, and each works with its university or medical school and community to address local needs.

LENDs offer partnership opportunities in genetic counseling and disabilities

Genetic Counseling Grants
With the support of MCHB’s Training and Genetics Branches, AUCD conducted an online grant competition for LENDs to increase the number and diversity of genetic counselors (GC) serving children with special healthcare needs and their families. Seventeen LENDs submitted full proposals, demonstrating a strong network capacity in interdisciplinary training and genetics. Three were selected based on objective review results: Partnership for People with Disabilities of Virginia Commonwealth University in Richmond, VA, Rose F. Kennedy Center of Yeshiva University/Albert Einstein College of Medicine in the Bronx, NY, and Waisman Center at the University of Wisconsin in Madison, WI. Each program is currently in the second of their expected three-year grant period, pending the availability of federal funds.

Activities and Results
In the first year, the three grantees have had a significant impact on the training of interdisciplinary and diverse genetic counselors:

- More than 80 LEND GC trainees were supported through tuition and stipend payments.

- Over 20% of the GC trainees identify with a minority group based on race, ethnicity, gender, disability, or rural location.

- Programs created innovative partnerships to recruit a diverse pool of GC trainees.

- Programs created products and leadership opportunities including a web-based learning module on genetic awareness, a Special Interest Group on disabilities within the National Society of Genetic Counselors (NSGC), an eight-week summer college internship in GC and disabilities, and more.

- The grant benefits other LEND trainees by highlighting the interdisciplinary nature of the program:

“...The trainees learn from one another by sharing their disciplinary perspective and working in a team context using their clinical skills and knowledge of the field.”

Although only three LENDs currently receive these grants, nearly all incorporate GC trainees and instruction in their LEND training. Each is working to better integrate genetics in leadership education programs and to emphasize the need to train a diverse GC workforce that can partner with families with children with neurodevelopmental disabilities, many of whom were diagnosed through newborn screening (NBS). The LEND programs around the nation offer the Regional Collaboratives an excellent opportunity to bring their public health genetics activities to partners who are sensitive to genetic and NBS issues. To learn more, visit our website. http://www.aucd.org/template/page.cfm?id=329

Submitted by: Crystal Pariseau, MSSW, AUCD LEND Coordinator
REGIONAL MEETINGS

Heartland Genetics and Newborn Screening Collaborative
2007 Annual Meeting
Sep 6-7, 2007 Oklahoma City, OK

Mountain States Genetics Regional Collaborative Center
2007 Annual Meeting
Jul 12-14, 2007 Denver, CO

Southeastern Regional Genetics Group (SERGG)
2007 Annual Meeting
Jul 26-28, 2007 New Orleans, LA

Western States Genetic Services Collaborative
Regional Summit
Sep 27-28, 2007 Portland, OR

NATIONAL CONFERENCES

Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDGDNC)
Meetings:
Sep 17-18, 2007 Washington, DC

American Academy of Pediatrics (AAP)
The Future of Pediatrics: Community Pediatrics, Medical Home and Beyond
Jun 29-July 1, 2007 Orlando, FL

American College of Medical Genetics (ACMG)
2008 Annual Clinical Genetics Meeting
Mar 13-16, 2008 Phoenix, AZ
2009 Annual Clinical Genetics Meeting
Mar 25-28, 2009 Tampa, FL

American Society of Human Genetics (ASHG)
2007 Annual Meeting
Oct 23-27, 2007 San Diego, CA

Genetic Alliance
2007 Annual Conference
Jul 27-29, 2007 Bethesda, MD

Maternal and Child Health Bureau (MCHB)
State Partnership Meeting (Title V Programs)
Oct 13-17, 2007 Washington, DC

National Coalition for Health Professional Education in Genetics (NCHPEG)/ Genetics Resources on the Web (GROW)
Annual Meeting
Jan 31-Feb 1, 2008 Bethesda, MD

National Coordinating Center
Advisory Committee Meeting
Nov 8-9, 2007 Washington, DC
### National Society of Genetic Counselors (NSGC) Conferences

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Course 2007</td>
<td>Oct 11-12</td>
<td>Kansas City, MO</td>
</tr>
<tr>
<td>26th Annual Education Conference</td>
<td>Oct 13-16</td>
<td>Kansas City, MO</td>
</tr>
<tr>
<td>Short Course</td>
<td>Oct 23-24</td>
<td>Los Angeles, CA</td>
</tr>
<tr>
<td>27th Annual Education Conference</td>
<td>Oct 25-28</td>
<td>Los Angeles, CA</td>
</tr>
</tbody>
</table>

### Secretary’s Advisory Committee on Genetics, Health & Society (SACGHS)

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meetings</td>
<td>Jul 10, 2007</td>
<td>Washington, DC</td>
</tr>
<tr>
<td></td>
<td>Nov 19-20, 2007</td>
<td>Bethesda, MD</td>
</tr>
</tbody>
</table>

### Sickle Cell Disease Association of America (SCDAA) & National Institutes of Health (NIH)

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007 Annual Convention</td>
<td>Sep 17-22, 2007</td>
<td>Washington, DC</td>
</tr>
</tbody>
</table>

### US Department of Health and Human Services’ (HHS)

#### Office of Disease Prevention and Health Promotion & the Centers for Disease Control and Prevention (CDC)

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Prevention/Health Promotion Summit</td>
<td>Nov 27-29, 2007</td>
<td>Washington, DC</td>
</tr>
</tbody>
</table>