NCC Collaborator
Expanding Genetic and NBS Services Through Multifaceted Partnerships

The State of the National Coordinating Center

Submitted by Michael S. Watson, PhD, FACMG, Director

As we approach the end of the first three-year cycle of the Regional Genetics and Newborn Screening Collaborative (RCs) groups and the National Coordinating Center (NCC), a group of cooperative agreements funded by the Maternal and Child Health Bureau (MCHB) of the US Health Resources and Services Administration (HRSA), it is timely to reflect on the program's successes. In the future, it is expected that the programs and relationships that are being built will translate into progress in meeting the program's basic goals. These include improving access to genetics and newborn screening related services at local levels while enhancing relationships between public health, primary care, and specialist care providers.

Each of the 7 RCs entered into this system at quite different points in their development. Some had maintained prior relationships that allowed them to have some regional programs and relationships already in place while others had to rebuild their infrastructure. Despite growing pains, all the RCs are now organized with active programs in place to address their regional needs and are looking forward to the next phase of the program. Inter-RC collaborations are increasing as successful regional activities have begun to spread to other regions as evidenced by participation in Region 4's Laboratory Performance Program and new collaborations in data collection and long-term follow-up for newborn screening and genetic patients are forming. Each of the RCs describes their own activities inside this newsletter.

Program goals include improving access to genetics and newborn screening related services at local levels

The NCC was formed at the time the RCs were established. As the RCs developed their own infrastructure and programs, the NCC was developing its infrastructure and programs. Judith Benkendorf has ably served as the project coordinator of the NCC and Gloria Weisman consults to the NCC on Maternal and Child Health programs.

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American Academy of Pediatrics
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Committed to the attainment of optimal, physical, mental, and social health and well-being for all infants, children, adolescents, and young adults.

Submitted by: Anne Gramiak, MPH, CHES, Manager, Screening Programs, Division of Children with Special Needs, American Academy of Pediatrics

The American Academy of Pediatrics (AAP) is an organization of 60,000 pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health, safety, and well being of infants, children, adolescents and young adults. Local, state and national initiatives are implemented through 10 AAP districts, 59 AAP chapters, committees, councils, and sections. More than 30 committees within the AAP translate clinical evidence derived from child health initiatives into policy. More than 40 sections cultivate ideas and develop programs within their subspecialty or special interest. Although their primary goal may be education of colleagues, Sections are also involved in policy development, public education, and advocacy for children.

AAP chapters are organized groups of pediatricians and other health care professionals working to implement AAP policy at the state and local level. Chapters are independently incorporated and have their own set of bylaws. Chapters provide advocacy, leadership, and education for members. Chapters vary in size from 49 members to over 2,500 members. Financial resources vary from chapter to chapter and can range from an annual income of $3,000 to $3 million. For more information on the AAP chapter in your state, go to (http://www.aap.org/member/chapters/chapters.htm) and click on your state.

The National Center of Medical Home Initiatives for Children with Special Health Care Needs at the AAP has several resources available for health care professionals and families. First, the website (www.medicalhomeinfo.org) provides material to help establish the medical home. The website contains a listing of the medical home activities in all 50 states with contact information. There is information on training programs, screening initiatives, grant and funding opportunities, as well as tools to assist practices in the development of the medical home. A section of the website is focused on genetic and metabolic screening (http://www.medicalhomeinfo.org/screening/newborn.html). This page links to fact sheets, policy statements, articles, reports, and tools related to newborn screening (NBS).

In partnership with the MCHB and Louisiana State University, the AAP is distributing NBS parent and provider materials. The first 25 copies are free, additional copies are available at the at-cost printing price of $.28 apiece. The following titles are available:

- *A Provider's Quick Reference/Seven Things Parents Want to Know about Newborn Screening*
- *Can Your Baby Hear? Your Baby's First Hearing Test*
- *Your Baby Needs Another Hearing Test*
- *These Tests Could Save Your Baby's Life. Newborn Screening Tests*

Another NBS resource is the MCHB-funded Pediatrics e-supplement, *A Look at Newborn Screening: Today and Tomorrow.* Published in May 2006, this supplement contains articles on the current status of NBS programs, the use of tandem mass spectrometry, conditions included in NBS panels, financing NBS programs, communication to parents regarding NBS, and the future of NBS. A limited supply of copies will be available by request.

For more information on AAP activities or to request copies of the resources described above, please contact Anne Gramiak at 847.434.4311 or agramiak@aap.org.

Fan Tait, MD, Director, Department of Community and Specialty Pediatrics represents AAP on the NCC Advisory Committee.

NERGG, Inc.

New England Regional Genetics Group

Submitted by Mary Frances Garber, MS, CGC, NERGG Project Coordinator

The New England Regional Genetics and Newborn Screening Collaborative is engaged in a number of newborn screening (NBS) activities that span from parent education to data collection and the development of national program assessment measures.

The New England Public Health Genetics Education Collaborative

The New England Public Health Genetics Education Collaborative has developed a regional NBS brochure and translated it into six high-need languages (Spanish, Vietnamese, Chinese, Portuguese, French and Arabic). The translated brochures are available on the NERGG website. Translation into at least five more languages is planned. **The New England Genetic Resource Directory** provides improved public health access to information and services for health professionals, consumers, and affected families. A benefit of the directory is greater regional availability of information regarding services and other genetic resources. This directory is also available on the NERGG website. The **Family Health History Project** is in development, in collaboration with the Genetic Alliance. Our goal is to implement the existing family history tools to improve quality patient care and to educate health care providers and consumers about the importance of the family health history in clinical care.

The New England Newborn Screening Program (NENSP)

The NENSP generates, collects, and analyzes screening and outcome data for feedback to regional collaborators and for quality improvements in screening program activities. Formal regional forums for such activities include:

- CF Workgroup (meets at least twice a year);
- Hemoglobin Workgroup (meets twice a year as part of the New England Pediatric Sickle Cell Consortium);
- Metabolism Workgroup (meets about six times per year); and
- Regional states' NBS Advisory Committees.

Regional collaborators include state NBS and genetics coordinators, regional Title V Directors, and providers of care for those identified with newborn screening conditions.

The New England Consortium of Metabolic Programs

The New England Consortium of Metabolic Programs, working with the HRSA-sponsored Collaboratives focuses on parental response to expanded NBS and long-term follow-up. Projects include efforts to incorporate aspects of the Benchmarks for Fairness in national assessment programs for expanded NBS, the development of transition to adult care

programs and completion of follow-up protocols for diseases identified by expanded NBS. Stakeholders include patients, public health personnel from each New England State and primary care physicians who will assist in creating the specific assessment items and the materials and pathways to adult care. The outcomes will be national assessment tools that include concepts of fairness and long-term follow-up, increased adult participation of metabolic patients in the designated healthcare centers and trained medical homes, and follow-up protocols that can be used nationally.

New York – Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC)

Submitted by Katharine B. Harris, MBA, NYS Genetic Service Program Administrator, NYMAC Project Director

NYMAC has seven active workgroups that address three overarching goals:

- standardization of newborn screening panels and emergency back-up of newborn screening programs;
- education of patients, families, primary care providers and insurers about the needs of people with special health care needs; and
- ensuring access to specialty care and medical homes for such individuals.

Workgroup members are recruited from the NYMAC master list and other sources as appropriate. Discussion of workgroup objectives and determination of activities to accomplish them are done through annual face-to-face meetings and frequent conference calls. Volunteer workgroup members and the NYMAC staff perform the assigned work.

Workgroup Projects

Current workgroup projects include:

- development of an ages-and-stages series of genetic service brochures;
- interviews of specialty and primary care providers on current medical home practices;
- creating laminated credit-card-sized cards with disease and treatment center-specific emergency triage and contact information to be carried by patients and parents for use during medical emergencies;
- formalizing emergency inter-state and inter-regional back-up plans for newborn screening programs;
- mapping of specialty care centers and the residences of the people they serve to identify gaps in service;
- creation of a virtual repository of newborn screening diagnosed-positive blood-spots for conditions in the newborn screening panels; and
- formalizing confirmatory laboratory testing protocols for children who screen positive.

Other Activities

NYMAC has contracts with specialty care centers to develop long-term case management systems in Delaware, New Jersey, New York, Pennsylvania and Virginia. They include centers for metabolic, endocrine and hemoglobin disorders. The contractors submit quarterly narrative and statistical reports of their progress.

NYMAC has contracts with teratogen services in New Jersey, New York and Pennsylvania for projects to raise awareness of the potential problems created by exposures to toxins to embryos and fetuses.

In April 2006, NYMAC hosted a symposium titled Pharmacogenetics: Individual Genetic Responses to Drugs and Medications. Held in Baltimore, Maryland, it was attended by more than 80 people.

In March 2007, NYMAC and the NNSGRC hosted a PEAS Evaluation and Genetic Plans meeting attended by state newborn screening representatives and genetic coordinators.

In April and May 2007, NYMAC will host consumer focus groups to identify consumer concerns, needs and activities on four topics: transitioning from pediatric to adult care, educational resources, health insurance and medical home/health promotion. These meetings will be held at three different sites in the region. The outcomes of these meetings will be creation of a Consumer Workgroup focusing on specific projects and integration of additional consumers into existing workgroups to ensure that projects are responsive to their needs.

NYMAC maintains a mailing list of over 3,700 individuals who have professional and/or personal interest in genetics and newborn screening. All members may participate in any of the workgroup conference calls and activities. This list is used to disseminate regional and national items of interest.

Submitted by Mary Rose Lane, BS, Administrative Assistant and Alisha Keehn, MPA, Program Manager

Goals

Although SERGG (Region 3) has outstanding genetics expertise and resources, existing limitations such as funding inequities and health professional shortages result in a maldistribution of Newborn Screening (NBS) and genetic services (GS). Professional and programmatic linkages and access to medical homes are needed. Three goals were developed by SERGG (Region 3) in order to meet these needs:

- Continue addressing existing gaps in GS that affects the health and development of children and adults with heritable disorders;
- Expand existing regional capabilities and resources and develop new regional systems to address identified GS gaps and the maldistributions of genetic resources;
- Improve regional communication infrastructure to facilitate information sharing among providers of GS and consumers and establish partnerships with other professional organizations.

Activities Addressing Goals

To address the provider gaps, two pilot projects, four funded mini-grants, and two workgroups were implemented. One pilot project focused on telecommunications and the development of GS infrastructure; the second addressed the need for continuing education for metabolic dietitians in the field through a three-day conference (which had international impact). Mini-grants were awarded following a request for proposals addressing regional gaps in GS. One successful mini-grantee created an online educational resource for consumers entitled AsktheGeneticist℠ (www.askthegen.org) with links to world research libraries.

Using collaborations developed through SERGG, relationships with eight states and two territories were established. Academic and public health representatives from each state have been identified and provided key information on GS in their state. A Laboratory Performance Workgroup, comprised of laboratory representatives and follow-up personnel was established and is currently examining the number of analytes screened, cutoff levels and other parameters to reduce the false positive rate in the region. This workgroup is in the final stages of developing a regional sample exchange program that will promote lab quality and expertise advancement. Relationships have also extended to Region 4 and other professional organizations.

In order to address long-term medical management needs, increase profes-sional knowledge, and decrease GS gaps intra-regionally the region will implement two training courses. The first, an intra-regional public health nurse training, focuses on public health/GS knowledge gaps. The second, an upcoming nutrition management pilot course for dietitians and medical fellows, will use expertise and case studies to provide practical training to regional professionals.

Hurricane Katrina revealed that SERGG (Region 3) was lacking all the basic components and systems needed to prepare for managing patients with rare genetic disorders during emergencies. The Emergency Preparedness Workgroup was established to develop a flexible and serviceable protocol for meeting emergencies without disastrous interruption of GS.

Activities described above spring from the potential of SERGG to bring together professionals and consumers in working groups and annual meetings to address regional needs. Harmonization of laboratory analytes and cutoffs, and emergency preparedness efforts continue, and a forum to address needs for long-term follow-up is being planned. Mini-grants are underway to locally address ongoing priority gaps in the Newborn Screening System.

The Emergency Preparedness Workgroup was established to develop a flexible and serviceable protocol for meeting emergencies without disastrous interruption of genetic services.

Region 4 Genetics Collaborative

Submitted by Cynthia Cameron, PhD, Program Director

Providing optimal services to children with heritable disorders and their families requires experts in new genetic technologies, related service delivery, and development of best practice models to share information. When the Region 4 Genetics Collaborative Project was first initiated, there was little exchange of information and expertise among the seven states within the region as no forum existed to support such activities. The Region 4 Genetics Collaborative has provided the infrastructure to promote sharing of ideas between our seven states (IL, IN, KY, MI, MN, OH and WI) with many accomplishments within and across the public health, laboratory, and clinical systems.

Cluster 1: Newborn Screening by MS/MS

Activities in Cluster 1 focus on: (1) achieving universal tandem mass spectrometry testing of newborns for a uniform panel of disorders including CAH; (2) improving overall analytical performance; (3) setting and sustaining the lowest achievable rates of false-positive results; and (4) improving and standardizing confirmatory testing and short-term follow-up. The collection of true positive data has been a great success and has grown beyond our expectations. As of January 29, 2007, 3,328 true positive cases have been contributed by 35 US states (34% of these cases came from Region 4), and 16 foreign countries. Fifteen conditions have reached the target of at least 50 cases. A summary of the data can be viewed at (http://www.region4genetics.org/screening.aspx).

Cluster 2: Clinical Diagnosis and Management

The goal of Cluster 2 is to reduce inequities in access to clinical genetic services. Activities include developing a searchable database of genetics professionals and their areas of specialization, and providing long-distance consultation for children with birth defects and genetic disorders who can benefit from assessment by an experienced clinician. This Cluster also is working to improve services for individuals transitioning from childhood to adulthood. The following Cluster 2 products are available on the Region 4 website (http://www.region4genetics.org/cdm_workinggroup.aspx):

- Telemedicine Literature Review
- Telegenetics Summary Document
- Model Action Plan for Transition
- Transition Resources
- Summary of Region 4 State Licensure Laws

Cluster 3: Public Health Infrastructure

Cluster 3 consists of seven working groups focused on improving the public health infrastructure. The efforts of these groups have resulted in the following:

- The Region 4 *Implementation of Medical Homes* website which provides primary care physicians and families with information and resources related to disorders diagnosed through newborn screening (http://medhomes.region4genetics.org/nbscreening.asp).
- An online course for registered nurses designed to increase understanding of newborn screening, *Newborn Screening: What Caregivers Need to Know.* This course includes free CEUs upon completion. (http://www.region4genetics.org/course.aspx)
- An MCADD Disease Registry that will assist in defining the natural history of the disease and the effect of various interventions on long-term outcomes. Thirty-two metabolic specialists from 27 clinics in Region 4 have agreed to participate in data collection. The database went live in January 2007 with Minnesota being the first state to enter cases.
- A white paper describing "best practices" in the role and responsibilities of a hospital-based Newborn Screening Coordinator.

Additional current efforts include the distribution of marketing materials promoting the *Newborn Screening: What Caregivers Need to Know* online course and *Implementation of Medical Homes* website, the development of a self-assessment guide to assist genetic centers in evaluating and improving family-centeredness, and the addition of a "frequently asked questions" section on the Region 4 website to address questions families have about genetic services.

Heartland Regional Genetics
And Newborn Screening Collaborative

Submitted by Lori Williamson, MS, CGC, Project Coordinator

Mission Statement: The Heartland Genetics and Newborn Screening Collaborative includes health professionals and advocates who promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy.

The Heartland collaborative includes Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota, and the regional coordinating center is located at the University of Oklahoma Health Sciences Center with one team member located in Columbia, Missouri. Based on multiple needs assessments, our regional strategic plan has four major goals: **improve access** to quality clinical and laboratory genetics services; provide **educational interventions** to improve genetic literacy of the public and attract students to the field of genomics; improve **public health genetics infrastructure** in the region; and maintain a strong coordinating center. We use four major strategies to achieve these goals.

First is our **pilot project program**. To date, we have funded eight pilot projects. These projects have led to program growth within states, collaborations between key stakeholders and states, and preliminary findings to support further investigation. More information about our pilot project program can be found on our website; click on the "Pilot Projects" tab.

Second, we support committee and state activities, which address state/local, regional, or national needs. Examples include: a **telemedicine** collaboration between Nebraska and Kansas to provide Kansan newborns with access to metabolic genetic services; inventory of the region's capacity in telehealth, which has led to a national presentation of the work; **newborn screening education** through videos and DVDs distributed in prenatal clinics across the region; **family health history** educational campaigns via websites, video press releases, and genealogy societies; model approach for **legislator education,** workshop on disaster preparedness and laboratory readiness for **expanded newborn screening**; and **inter-regional collaboration** on a large **newborn screening data collection** effort.

Three regional meetings, the RC **website, listserv,** and the pilot project program have resulted in improved state and regional communication. Our region's directory, meeting minutes, meeting dates/times, conference information, regional calendar, and important links can be found on our website. The **2007 Annual Meeting** will be held **September 6-7** in Oklahoma City. All are welcome to attend!

Finally, improving the public health genomics infrastructure in each state is the only way to sustain current progress and ensure future growth. To this end, we funded a **scholarship** for an RC member to attend the Public Health Genomics Certificate Program at Sarah Lawrence College; provide a weekly listing of **external funding opportunities** (basic science, education, service, and public health) on the website; conducted continuing education for lay advocates; emphasized the importance of **strong state genetics coordinators** in each state; and funded the development of **state needs assessments and state plans**.

Improving the public health genomics infrastructure in each state is the only way to sustain current progress and ensure future growth.

MOUNTAIN STATES GENETICS REGIONAL COLLABORATIVE CENTER

Submitted by: Rebecca Anderson BS, MSc, RN, Liza Creel, MPH and Joyce Hooker

The Mountain State Genetics Regional Collaborative Center is a dynamic project that incorporates the knowledge and practices of public health, newborn screening and genetics experts in Arizona, Colorado, Nevada, New Mexico, Montana, Texas, Utah and Wyoming. The MSGRCC accomplishes its mission by supporting state public health genetics programs, informing both lay and professional stakeholders about the role genetics plays in human health, promoting standards and quality assurance programs, and sharing available education and training resources. The MSGRCC exists as an open forum allowing all members—consumers and genetics professionals—the opportunity to participate as equals in addressing genetic services and issues.

Newborn Screening, Long-Term Follow-Up Projects

The MSGRCC is pleased to collaborate with the Genetic Science in Society (GeneSIS) Center, in the office of Jeffrey Botkin MD, MPH, University of Utah. The GeneSIS Center fosters collaborative research on the efficacy, safety, ethics, and economics of emerging genomic technologies with diverse regional and national partners. The MSGRCC and GeneSIS, along with regional and national collaborators, are partnering in the development of a long-term outcomes registry and surveillance system that will provide data on the natural history of rare conditions, identify variations in treatments, examine factors that influence and predict outcomes, assess costs associated with care, and offer a mechanism to provide feedback to primary stakeholders including families, the Medical Home, and subspecialty care providers. In December 2006, Dr. Botkin hosted a meeting of twenty-eight regional and national collaborators. During this meeting the group developed a collaborative implementation strategy for the registry, which was incorporated into the Mountain States' grant application under Priority 2 funding.

Other projects within the MSGRCC include:

- A system analysis of data flow in three metabolic clinics, designed to monitor data flow so systems can be developed to capture all needed data;
- A process analysis of electronic and manual data abstraction into an electronic registry;
- A national review of metabolic care plans (protocols);
- An analysis of metabolic care plan data elements to serve as a foundation for future data collection activities;
- The MS/MS Analyte stability analysis, which is nearing completion and will have published results in the next six months;
- A survey of parents of children with metabolic disorders to determine their attitudes about a registry; and
- A national review of registry systems to determine similarities and differences.

Quality Improvement

In December 2006, Dr. Marc S. Williams of the Intermountain Healthcare Clinical Genetics Institute hosted a meeting in Salt Lake City on quality improvement of genetic services. Day one provided an introduction to quality improvement by Dr. Brent James, an expert on healthcare quality improvement. Day two included presentations of genetic quality projects, strategic planning to identify and prioritize key quality improvement processes and group discussion of potential projects for the region. In addition to these quality improvement projects, Dr. Williams will be advising the MSGRCC on incorporating quality improvement into all future regional projects.

Other Activities

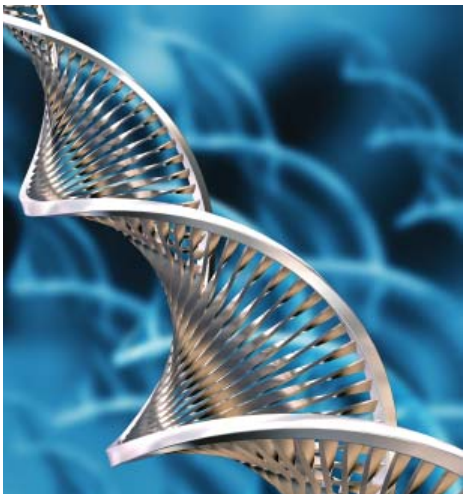
The MSGRCC is also very excited about regional projects focusing on transitioning from pediatric to adult services, cultural competency and underserved populations; geographic disparities, and consumer-driven projects such as the Mile High Down Syndrome Association.

Submitted by Kerry Silvey, MA, CGC, Project Co-Director

Western States Collaborative activities are focused in two areas: (1) planning, implementing, and evaluating a Practice Model to deliver genetic services outside our large metropolitan areas, and (2) states'/territories' genetics and newborn screening programs assisting each other to perform their genetics-related public health functions.

Telemedicine Activities

One component of the Practice Model is telemedicine visits between genetics specialists (clinical and metabolic geneticists, genetic counselors, and metabolic nutritionists) at three genetics centers and families living further than two hours travel time away. Specialists based in Honolulu conduct visits with Hawai`i neighbor island families; Portland specialists conduct visits with Oregon and Idaho families; and, Seattle specialists conduct visits with Washington families.



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One premise of the Practice Model is to use telemedicine equipment and community resources already in place. When we were preparing our 2004 Collaborative grant application, technical and administrative staffs were optimistic that a minimum of additional work and expense would be required to set up visits between existing telemedicine sites. Once implementation began, we learned that telemedicine visits between providers and families were not actually being held in Oregon or Idaho, and that many Hawai`i sites in existence in 2004 were no longer operational. Thus, before beginning visits, we needed to solve multiple unanticipated logistical and legal problems, in addition to completing the anticipated tasks of developing relationships with community collaborators, writing protocols, and developing and piloting evaluation tools.

One premise of the Practice Model is to use telemedicine equipment and community resources already in place.

We were able to see our first Idaho, Oregon, and Hawai`i visits in early 2006. Seventeen telemedicine visits were held between January and June. In addition, the previously established Washington State Telemedicine Pilot Project has conducted 27 visits. Preliminary review of evaluation forms and discussion with patients, on-site facilitators, and genetic specialists indicate that patients and providers are satisfied with the visits. Some technical problems have been encountered, including delays in establishing the connection and pictures freezing. These have decreased with experience.

We are evaluating the telemedicine visits extensively. Among the data being collected are: patient and specialist satisfaction; costs to families; costs for delivering the service; and time spent. Next steps include: holding additional visits and refining approaches at current sites, adding new sites in Guam, HI, and OR; exploring the possibility of adding additional sites in AK, ID, and WA; streamlining logistics; and formal analysis of

Submitted by Alissa Johnson, MA, Program Principal, NCSL Genetic Technologies Project

NCSL is a bipartisan organization that serves legislators and their staffs in the 50 states, DC, and the US territories. NCSL staff members primarily focus on state legislative activities in specific policy areas while several NCSL lobbyists address state concerns in federal legislation. Alissa Johnson has been the policy staff member dedicated to genetics issues since 1999. Through Ms. Johnson, NCSL participates on the NCC advisory committee, and the Telegenetics and Emergency Preparedness Workgroups. NCSL is also available to assist the RC's in a variety of ways.

State legislators frequently contact NCSL to learn what other states are doing—a perspective that also may be of value to the RC's. NCSL can research state approaches regionally or nationally for handling a genetics or newborn screening (NBS) policy issue. NCSL conducts surveys, provides information about legislation, shares the experiences of other states with an issue, and analyzes alternative solutions to a policy problem. The organization reaches out to its membership, the federal government, state agencies, the media and others through publications, meetings, web/audio conferences, technical assistance presentations, and its website.

NCSL publications include policy briefs, magazine articles, booklets and reports. Recent genetics articles in *State Legislatures*, NCSL's magazine, include a March 2007 article on genetic discrimination and a February 2006 article on NBS. *State Legislatures* is sent to all state legislators, members of Congress and other subscribers. NCSL has genetics policy briefs on a variety of topics, such as treatment for disorders identified through NBS, genetic counselor licensing and predictive genetic testing of minors, available on its genetics project website at (www.ncsl.org/programs/health/genetics.htm). Two booklets—*Genetics: A Snapshot for State Legislatures* and *Stem Cell Research: A Guide for Policymakers*—were released at NCSL's Annual Meeting, in August 2006 and are available for purchase through NCSL's bookstore.

One issue of interest to the RC's—telemedicine—was a topic of discussion at NCSL's 2006 Annual Meeting. NCSL also held a web conference on medical homes with the American Academy of Pediatrics in February 2007. A free archive of the conference is available through January 2008 at (www.ncsl.org/programs/health/webcast2.htm).

Tracking and analysis of pending state genetics legislation and laws, updated monthly, also is available on NCSL's genetics project website (see above). Policy issues covered in the database include NBS, discrimination, privacy, and genetic counselor licensing.

NCSL would like to hear from the RC's about their technical assistance needs, proposed topics for publications or meetings, and other suggestions. Alissa Johnson is currently on leave until August 2007. While she is away, please contact Amy Rohm with NCSL's Health Program at (amy.rohm@ncsl.org) with any questions or comments.

State of the National Coordinating Center, continued from page 1

The NCC seeks to facilitate communication through monthly conference calls, an annual meeting, its website (www.nccrcg.org), and this quarterly newsletter. National teleconferences provide another form of education. The NCC also coordinates multi-region and national projects involving both the RCs and NCC with other HRSA partners including the National Newborn Screening and Genetics Resource Center (NNSGRC), the National Conference of State Legislators (NCSL), the Public Health Informatics Institute (PHII) and the American Academy of Pediatrics (AAP). Among current activities are the development of: 1) a national emergency preparedness plan for newborn screening and genetics patients for which a workgroup representing all regions met recently with federal and State agencies involved in the implementation of such plans with the intent of providing guidance to the RCs on how their affiliated providers and institutions can develop their own plans; 2) a national system to improve the evidence base for genetic diseases through follow-up of patients and associated data collection, a program being developed in partnership with the National Institute for Child Health and Human Development (NICHD) and the Office of Rare Diseases at NIH; and 3) practice guidelines (e.g., ACT Sheets) for addressing the genetics needs of patients being seen by non-genetics providers.

NCC Calendar

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
New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services (MYMAC)		
Consumer Meetings	Apr 28, 2007	New Brunswick, NJ
	May 15, 2007	DC/MD/VA Area
	May 19, 2007	Binghamton, NY
Advisory Council Meeting	May 30-31, 2007	Baltimore, MD
Southeastern Regional Genetics Group (SERGG)		
2007 Annual Meeting	Jul 26-28, 2007	New Orleans, LA
Genetic Metabolic Nutrition and Expanded NBS: Practical Training for Metabolic Dietitians	Apr 10-14, 2007	Atlanta, GA

NATIONAL CONFERENCES

Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children		
Meetings:	May 17-18, 2007	Washington, DC
	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)		
2007 Annual Clinical Genetics Meeting	Mar 22-25, 2007	Nashville, TN
2008 Annual Clinical Genetics Meeting	Mar 13-16, 2008	Phoenix, AZ
2009 Annual Clinical Genetics Meeting	Mar 25-28, 2009	Tampa, FL
Association of Public Health Laboratories (APHL)		
NBS and Genetic Testing Symposium	May 7-10, 2007	Minneapolis, MN
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

National Coalition for Health Professional Education in Genetics (NCHPEG)		
Genetics Resources on the Web (GROW) Annual Meeting	Jan 31-Feb 1, 2008	Bethesda, MD
NSGC Conferences		
Short Course 2007	Oct 11-12, 2007	Kansas City, MO
26th Annual Education Conference	Oct 13-16, 2007	Kansas City, MO
Short Course	Oct. 23-24, 2008	Los Angeles, CA
27th Annual Education Conference	Oct 25-28, 2008	Los Angeles, CA
Secretary's Advisory Committee on Genetics, Health & Society (SACGHS)		
Meetings:	March 26-27, 2007	Adelphi, MD
	July 9-10, 2007	Bethesda, MD
	November 19-20, 2007	Bethesda, MD
Society for Inherited Metabolic Disorders (SIMD)		
Annual Meeting	March 25-28, 2007	Nashville, TN

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