




NCC Collaborator

Expanding Genetic and NBS Services Through Multifaceted Partnerships



NCC/RC System Forges Exciting New Plans

regional population needs; development of emergency preparedness systems; creation of provider education tools and programs addressing commonly seen heritable disorders and the conditions on the national newborn

ways in which the RCs approached the planning process—from the use of surveys and other virtual tools to the engagement of broad cadres of stakeholders and experts in structured exercises. These activities have resulted in new partnerships and a variety of innovative proposals for addressing unmet needs in genetic services and public health. During the next cycle, the NCC looks forward to continuing its work with its regional and national partners, but with an increased focus on evaluating the extent to which the RCs and the NCC have a positive impact on the health of individuals with genetic conditions. Genetic Alliance has teamed with ACMG, and the two organizations are proposing to incorporate a National Genetics Education and Consumer Network into the NCC/RC system.

On May 31, 2012, the second funding cycle for the seven Regional Genetic and Newborn Screening Service Collaboratives (RCs) and their National Coordinating Center (NCC) will conclude. Since 2004, funding and ongoing technical assistance from the Genetic Services Branch in the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) have allowed the NCC/RC system to build robust regional and national infrastructures that have benefited children with heritable disorders, their families, healthcare providers, and communities in multiple ways.

screening panel; formation of new linkages between primary care and specialty (including medical genetics) providers that incorporate medical home principles and recognize the challenges facing individuals with genetic disorders as they transition from pediatric to adult care; and the building of sustained relationships with other MCHB National Centers.

In preparation for the new funding cycle that begins in June, the RCs and the NCC engaged in needs assessments and strategic planning initiatives that have led to the identification of new priorities, particularly around improving and measuring health outcomes for individuals with heritable disorders. In this issue of the *NCC Collaborator* you will read about the diverse

The future holds much promise for the improved care of individuals with genetic disorders across the lifespan. We look forward to exciting new collaborations that will turn this promise into a reality.

Many of these successes have been highlighted in previous issues of the *NCC Collaborator*. They include: growth in the use of telemedicine; testing and implementation of new genetic service delivery models tailored to local and

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From a Successful Foundation to Impact: Evaluating the NCC/RC

Submitted by Gloria Weissman, MA, Evaluation Consultant, NCC

From its inception, the NCC/RC system has focused on evaluation. Data from the national evaluation of the RCs and from the evaluation of the NCC, briefly discussed below, indicate that there has been significant progress in accomplishing the initiative's major goals. Recognizing both the maturation of the NCC/RC system and the need for more robust outcomes data on the impact of the initiative on individuals, particularly children, with heritable disorders and their families, the NCC proposes to expand and refocus its evaluation during the next three years.

The RCs' National Evaluation

During 2007, the NCC convened an Evaluation Workgroup to develop a national evaluation that would: 1) measure the progress being made by the RCs toward the major goals of this initiative *as defined by HRSA and the RCs working together under their cooperative agreements*; 2) identify particular activities and strategies that have been helpful in achieving progress toward these goals; and 3) identify areas in which collaboration among and technical assistance from the RCs, the NCC, and HRSA could be helpful in moving the goals of this initiative forward. To accomplish the first of these purposes, the Evaluation Workgroup agreed upon seven evaluation domains and 10 common outcome measures, along with definitions and reporting schedules. Four of the 10 outcome measures used in the national evaluation were adopted by MCHB's Genetics Services Branch as official program measures for the RCs. For the past four years, the RCs have provided the NCC with annual data on the 10 outcome measures, along with

information on activities completed during that year that are relevant to their accomplishing each outcome. Four years of evaluation results have been disseminated through annual reports to HRSA and presentations at RC and NCC meetings; several noteworthy achievements are described later in this article.

The NCC's Evaluation

The NCC's evaluation framework, established in 2008 by the NCC Evaluation Consultant and key staff working in collaboration with HRSA, was designed to measure progress in achieving the goals agreed upon in its cooperative agreement with HRSA. Each year the NCC reports on 17 measures along seven domains. NCC activities are also listed in Activity Matrices and regularly updated. In addition, the NCC saw the development and dissemination of the ACT Sheets (a series of point-of-care clinical decision support [CDS] tools for managing patients with positive newborn screening results and other common genetic diagnoses) as one of its most important activities to improve access to services for children with genetic disorders, and contracted with the American Academy of Pediatrics to conduct an independent study on the utility of the ACT Sheets for primary care providers using its Quality Improvement Innovation Network (QuIIN) process.

Selected Evaluation Findings

As noted earlier, the national evaluation of the RCs and the evaluation of the NCC have yielded data indicating significant progress in accomplishing the major goals set out for this HRSA initiative—goals primarily related to the improvement of collaboration and infrastructure in order to produce out-

comes at the institutional, state, regional, and national levels that would, in turn, lead to improved outcomes for individuals with genetic conditions and their families. For example:

- Over a four-year period, RC-facilitated state/territorial collaborations between primary care and specialty (including genetic) providers to improve care coordination for people with heritable disorders increased from 48 to 80 percent.
- The number of individuals accessing the ACT Sheets section of the NCC website grew from 635 to 23,407 over a three year period, and the QuIIN project found them to be a valuable tool for primary care providers.¹
- From 2007 to 2011, the number of states/territories that received assistance from the RCs on emergency preparedness/contingency planning for newborn screening (NBS) and genetic services increased from 48 to 91 percent, and the percentage of regions receiving technical assistance supported by the NCC on implementing an emergency preparedness protocol increased from 14 to 86 percent.
- Significant progress has also been documented at the national, regional, and state levels in improving follow-up for conditions diagnosed through newborn screening.

Proposed New NCC Evaluation Activities

ACMG and its partner in the next funding cycle, Genetic Alliance, have proposed to HRSA a multi-faceted plan for expanding and refocusing the national evaluation of the NCC/RC system. The NCC is bringing an evaluator on staff to: 1) identify, collect, and analyze data on at least five national *Healthy People 2020 (HP 2020)* outcome measures (see textbox on next page); 2) work with the RC Evaluators

o Measuring Health System

to develop additional program outcome measures for an annual national evaluation; and 3) work with the NCC's new Improvement Advisor, an expanded Evaluation Workgroup, and four QI Learning Collaboratives—each focused on a distinct aspect of improving access to and quality of genetic services—to identify, collect and analyze data to measure improvements using the national outcome measures. The Learning Collaboratives will examine:

1. Improving access to medical home and transition services for individuals with genetic conditions and their families;
2. Improving effective follow-up of children identified with genetic conditions through NBS;
3. Using ACT Sheets and other CDS tools to improve co-management of individuals with genetic conditions; and
4. Improving access to genetic services through telemedicine.

The NCC will also be working with national partners such as the National Data Resource Center for Child and Adolescent Health, the Newborn

Screening Technical Assistance and Data Repository, the National Coordinating Center for Regional Hemophilia Networks, and the Clearinghouse of Newborn Screening Information, to identify and improve data sources for the evaluation of the NCC/RC system.

Reference

¹Hinton, CF, Neuspiel DR, Gubernick R, et al. Improving Newborn Screening Follow-Up in Pediatric Practices: Quality Improvement Innovation Network (QuINN). Submitted to *Pediatrics* (2012).



Selected HP2020 Outcome Measures

At a minimum, the NCC proposes to provide annual data to HRSA on the following five HP2020 measures. Additional HP2020 and other national program outcome measures may be identified by the Evaluation Workgroup and or the Learning Collaboratives as part of their work.

- DH-5. Increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare.
- MICH-30. Increase the proportion of children, including those with special healthcare needs, who have access to a medical home.
- MICH-31. Increase the proportion of children with special healthcare needs who receive their care in family-centered, comprehensive, coordinated systems.
- MICH-32.2. Increase the proportion of screen-positive children who receive follow-up testing within the recommended time period.
- MICH 32.3. Increase the proportion of children with a diagnosed condition identified through newborn screening that have an annual assessment of services needed and received.

These measures were chosen because they reflect the major goals of both the NCC and the RCs, and represent the HP2020 measures chosen by the RCs. The NCC will also be using five HP2020 measures (including two of the five above) to evaluate the National Genetics Education and Consumer Network, led by Genetic Alliance (see page 1), which will be an important aspect of the NCC's work going forward.

the new england **negc** genetics collaborative

Submitted by Peter Antal, PhD, Project Evaluator, NEGC

NEGC Perspectives: Reflecting on the Past Five Years and Looking Ahead to the Future

It has been helpful for the NEGC to reflect on our efforts of the past five years as we prepare to address new challenges and opportunities. In addition to the activities that fulfill our core objectives (e.g., new data systems to enable quality improvement (QI) activities, a range of supports to medical home and transition practices in the region, improvements in testing for genetic conditions, legal authority for long-term follow-up (LTFU) systems established in two states, funding of multiple innovative projects, a national resource for supporting children in schools, and the formation of a strong collaborative network), the NEGC has also made substantial contributions to the knowledge base in our field through more than 40 regional and national presentations, 19 peer-reviewed articles, and a book chapter.

Last fall, to assist us with planning for the next five years, we asked 141 stakeholders to rate the topic areas most in need of additional support from a list of 18 topics identified through past stakeholder surveys, annual meetings, and project reports. As illustrated in Table 1, each of these areas was identified as very or critically important by a substantial portion (40% or more) of the 53 respondents, who included service providers, clinicians, researchers,

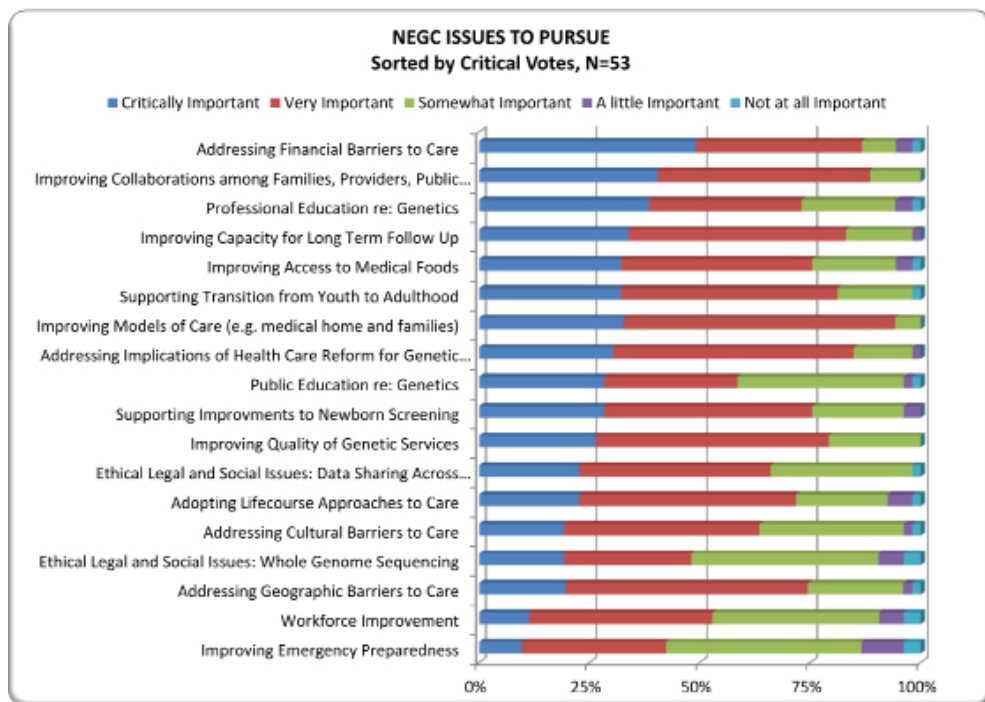


Table 1: Stakeholder perceptions of the RC's needs.

state agencies, advocates, and family members.

To address the breadth of needs identified by our stakeholders, the NEGC will focus on both strengthening existing partnerships and forming new ones. Current approaches that have demonstrated the potential to create long-term and sustaining change will continue to be supported—particularly the Genetics Education Materials for School Success online tool, expansion of quality QI data collection systems, improving and expanding the maternal child health workforce, expanding opportunities for medical home and transition efforts, learning from LTFU systems, and emergency preparedness. New approaches and partners will be pursued as well. Partnerships with regional Leadership Education

in Neurodevelopmental and Related Disabilities (LEND) programs will be enhanced to support access to expertise in the genetics field, new models of care will be explored by partnering genetics specialists with primary care providers and expanding on the roles of school nurses, targeted research and educational efforts will be undertaken with the Catalyst Center and Johnson Group Consulting to represent family perspectives in the implementation of the Patient Protection and Affordable Care Act, and expanded collaborations with public health will support the development of effective critical congenital heart disease (CCHD) screening protocols.

<http://www.negenetics.org>

Submitted by Bonnie L. Fredrick, MS, Project Coordinator and Katharine B. Harris, MBA, Project Manager, NYMAC

Strategic Planning to Improve Health Outcomes in the NYMAC Region

NYMAC's plan for the 2012-2017 funding cycle is the result of many conversations with our Advisory Council and other champions, during which we reviewed past accomplishments, identified remaining barriers, and developed projects and activities that address our overall goal of improving access to genetic services for people with special healthcare needs (PSHCN).

In order to improve **access to treatment in the context of a medical home**, we are proposing a pilot program to help rural primary healthcare providers determine diagnoses for all positive newborn screening results by providing them with information about the specific genetic conditions in question. We will also pilot the use of telehealth networks for long-term medical management of children who have genetic conditions and must otherwise travel long distances for care. Finally, we will continue our "transition navigator" projects for an additional year and develop outreach and education strategies to recruit adult healthcare providers for transitioning youth and young adults.

NYMAC will help **build capacity in our state public health departments for newborn and child screening** by convening an expert group to identify the resources needed within these departments regarding newborn screen-



ing, child screening, and genetic disease. We will then implement opportunities for learning. We are eager to reach out to state Medicaid programs, as well as to private insurers, to start a dialogue about the necessary coverage for PSHCN and the best way to provide it. Our very strong Newborn Screening (NBS) Laboratory interest group will continue its efforts to maintain quality and improve standardization and interoperability among the programs. Recognizing that NBS cannot be effective if states lack equally effective processes for communicating screening results to physicians and families, we will create a learning collaborative with the NBS follow-up programs to standardize and improve these processes.

NYMAC has already begun conversations with some of the Primary Care Organizations in our region about how to **strengthen public-private partnerships** to improve care for their patients with genetic conditions. We will focus on linking Federally-Qualified Health Centers and school-based

health clinics with specialty centers and on developing pilot projects in education and other areas.

NYMAC's new co-project director, Dr. Joann Bodurtha, has long been involved with the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program in Virginia. Expanding to other LEND programs is one of our strategies for improving **collaboration and partnerships with HRSA/MCHB-funded programs**. We will also work with the federally-funded hemophilia and thalassemia treatment centers at Children's Hospital of Philadelphia to develop guidelines for optimal integration of specialty and primary care for individuals with these conditions.

NYMAC will continue to **address emergency preparedness** among NBS laboratories, with sample exchanges planned for this coming spring. In the next funding cycle we will work with the specialty care centers in our region and the patients and families they serve in order to help ensure that they have access to the expertise and other resources that might be needed during an emergency. We will also be implementing emergency preparedness drills and will post links to emergency preparedness resources on the NYMAC website.

<http://www.wadsworth.org/newborn/nymac>



SOUTHEAST NBS & GENETICS COLLABORATIVE

Submitted by Rita Underwood, MD, MPH, Project Manager, SERC

SERC Celebrates Optimistic Future

SERC serves one of the poorest regions in the country, as well as one with significant geographic and ethnic diversity, a substantial rural population, and a shortage of primary care professionals. All of these factors make the delivery of coordinated public health and clinical care systems for individuals with heritable disorders a significant challenge. Although SERC has made strides in addressing inequities in access to newborn screening (NBS) and short-term follow-up services, our recent needs assessment demonstrates an on-going lack of accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care throughout the life cycle for individuals with genetic disorders. This paucity of long-term follow-up (LTFU) services, along with the current shortage of trained workforce qualified to provide this continuum of care, has led us to focus our future efforts on bridging gaps in access and utilization of genetic services throughout the life course.

SERC has established a region-wide infrastructure, state and federal collaborations, partnerships with many communities, and relationships with experts in the fields of clinical and public health genetics. Moving forward, SERC is developing models of best practices for regional dissemination in order to promote patient and family-centered community-based transition services. We also plan to collaborate with NEGC and NYMAC in this area.



To improve LTFU clinical practices, SERC is continuing to establish evidence/consensus-based guidelines for disease-specific treatment of metabolic disorders using methodology designed by our LTFU Workgroup. SERC is taking an innovative approach to expanding care delivery to remote areas and strengthening the genetics workforce capacity by using information technology (IT). For example, a web-based inventory of telemedicine and outreach tactics (TOT) is being used to create a comprehensive regional TOT plan. We will also use IT to transform our ongoing Lunch & Learn Series and Metabolic Nutrition Symposium into a broad workforce enhancement education program that will make materials available to professionals responsible for the care of individuals with heritable disorders.

SERC remains dedicated to overcoming the many challenges that exist in our region. We will continue to build on partnerships with local, state and federal agencies to coordinate activities

and prevent fragmentation or duplication of efforts. We will also work to bridge public health efforts with those of the SERC Consumer Alliance to improve health outcomes across the lifespan. Our consumer alliance group and patient registry, NBS Connect, will renew its focus on patient/parent access to educational resources and provide families with assistance in navigating through the maze of genetic services. NBS Connect will also capture and analyze information related to inborn errors of metabolism in an effort to assess gaps in services and access to care, develop best practice standards for clinical management, and connect families to research opportunities. We are optimistic about our future strategic initiatives, all aimed at streamlining systems of care for patients and families with heritable disorders.

SERC will convene for its annual meeting in Ponte Vedra Beach, Florida July 19-21, 2012.

<http://southeastgenetics.org/>



Region 4 Genetics Collaborative

Submitted by Cynthia Cameron, PhD, Director, Region 4

Region 4's Strategic Plan Optimizes Health Across the Lifespan

Members of the Region 4 Genetics Collaborative believe that newborn screening, follow-up, and access to high quality genetic services can have tremendous impact on the life course of children with genetic conditions. This belief was the driving force behind the development of our work plan for 2012 to 2017. The planning process took place in two stages. First, the Region 4 Advisory Group agreed on major priorities to be included in the plan. Next, more than eighty-five Region 4 members selected the goals and strategies to be addressed.

Goal 1: Facilitate collaboration within Region 4

An enhanced infrastructure will facilitate collaboration within the region by supporting both stakeholder forums and workgroups. The forums are designed to encourage sharing among groups of like stakeholders, such as families, genetic services providers, newborn screening laboratorians, and leaders in public health genetics. Each forum will select an area of focus to improve screening, follow-up, and/or treatment. Once the area of focus is identified, a workgroup that includes all interested stakeholders will design strategies to address it.



Goal 2: Improve effective follow-up for children with genetic conditions

Fully functioning state follow-up systems are essential to ensure that children with genetic conditions receive needed treatment and services. Region 4 will work with the Newborn Screening Translational Research Network to define a fully functioning public health long-term follow-up system, review the current status of state systems, and determine methods to collect and integrate long-term follow-up data.

Goal 3: Improve access to genetic services for children with genetic conditions and their families

Both families and genetic services providers need to be knowledgeable about how the Patient Protection and Affordable Care Act (PPACA) impacts access to services. Region 4 will work with the Catalyst Center to disseminate updates on the PPACA to families and providers using social media.

Goal 4: Increase the number of children identified through newborn screening who receive quality services

During the current grant cycle, Region 4 collected data that suggest the following:

- In some cases, treatment is discontinued for children with a positive screen for congenital hypothyroidism (CH) without a TSH challenge. To address this issue, Region 4 will analyze data from a CH follow-up study and prepare guidelines for state follow-up systems, as well as educational materials for primary care providers and families.
- Emergency department (ED) providers often lack knowledge about appropriate treatment protocols for children with sickle cell disease (SCD) who are experiencing a pain episode or other complication. Region 4 will modify the previously published guide, *Partnering with Your Doctor*, to include issues specific to families of children with SCD, including how to work with providers to get the best care during an ED visit.

By addressing these goals, Region 4 will take action to give children with genetic conditions the full range of services they need to optimize their health and development across the lifespan.

<http://region4genetics.org>



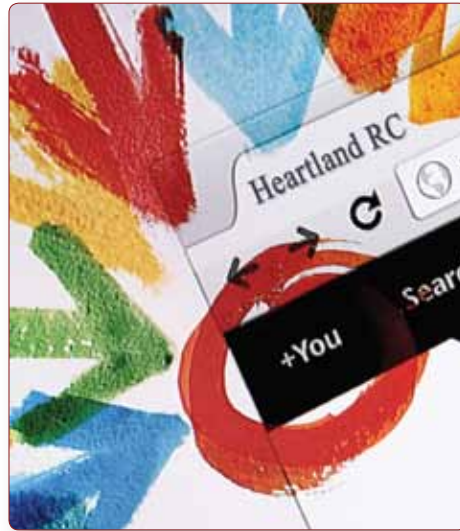
Heartland Genetics and Newborn Screening Collaborative

Submitted by Lori Williamson Dean, MS, CGC, Project Manager and Barbara Jackson, PhD, Project Evaluator, Heartland

“Where There’s a Will (and Technology), There’s a Way:” Strategic Planning in the Heartland Region

During the last six months of 2011, the Heartland Genetics and Newborn Screening Collaborative (Heartland) undertook a multi-stage strategic planning process that was facilitated by Heartland’s evaluator, Dr. Barbara Jackson. In order to engage as many stakeholders as possible, we used a number of methods to gather information and solicit feedback, including online surveys, conference calls, and an in-person meeting at Heartland’s Annual Meeting.

First, Heartland leadership (Advisory Board, Project Directors, Project Manager, and Project Coordinator) completed a SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis of the region. They also looked at a draft of vision and values statements and a revised mission statement for the region. The SWOT analysis was used to help provide a context that would later inform the identification of objectives. Results of the initial SWOT analysis and drafts of the statements were sent via SurveyMonkey™ to the Heartland membership for review and comment, using the Heartland ListServe. Members were also asked to identify strategic areas for the region to address in the next five years.



The survey results were analyzed based on the clustering of themes and grouped into what we called “strategic areas.” A second survey of the Heartland membership was conducted, to rank these strategic areas in order of their importance. The ranking process allowed the evaluator to identify priority areas, which were presented to attendees at the Heartland Annual Meeting in August. Attendees were divided into small groups and asked to identify strategies that could be undertaken to address the priority areas. Each group moved through each priority area in a round-robin fashion. This inclusive yet expedient process allowed for input from each member in attendance. Once all groups had contributed to the strategies, all were asked to “vote” on three strategies for each area. Results of the cumulative process were presented to Heartland leadership and provided to each workgroup for clarification and refinement.

The priority areas and strategies identified by the Heartland were then matched against those delineated in

“Using multiple methodologies . . . allowed for broad participation and demonstrated that strategic planning can be accomplished within a network through a variety of approaches.”

the HRSA guidance. The Heartland leadership selected those HRSA priority areas that are strategically important to the region and on which we thought the Heartland Collaborative could make realistic and potentially systematic changes. The five priority areas selected were medical home; expanding the workforce; enhancing states’ capacity for NBS; long-term follow-up; and “other,” with emphasis on the Genetic Systems Assessment, a targeted pilot projects program, emergency preparedness, and facilitating communication and linkages.

Using multiple methodologies for our strategic planning process allowed for broad member participation and demonstrated that strategic planning can be accomplished within a network through a variety of approaches. Advisory Board members welcomed the opportunity to receive comprehensive feedback from across Heartland’s membership. Heartland leadership found that the results of this multi-layered strategic planning process provided an excellent foundation and clear guidance for the development of the Heartland’s five-year plan.

<http://www.heartlandcollaborative.org/>



Submitted by Celia I. Kaye, MD, PhD, Project Director; Kathryn Hassell, MD, Associate Project Director; Joyce Hooker, Director of Regional Outreach; and Liza Creel, MPH, Project Manager, MSGRCC

MSGRCC Plans to Expand Regional Outreach and Collaboration

In 2005, the Mountain States Genetics Regional Collaborative Center (MSGRCC) conducted an in-depth needs assessment to identify specific regional priorities related to newborn screening and genetic services. Based on a regional survey and sixteen focus groups, stakeholders from around the region identified the following needs: improved education; increased access to genetic services; strengthened medical home; an expanded workforce; and sustainable reimbursement models.

In 2009, the MSGRCC Advisory Council reviewed this needs assessment in the light of regional and national priorities and determined that education and access, particularly around medical home, were the most appropriate needs for the MSGRCC to address. The Advisory Council reaffirmed these needs in 2011, during an extensive strategic planning process initiated by MSGRCC in preparation for the competitive application to HRSA for five new years of funding.

Our most recent strategic planning process began with a thorough review of the May 2011 report summarizing the results of the strategic planning process conducted by the Genetic Services Branch (GSB) of the Division of Services for Children with Special Health Needs in HRSA's Maternal and Child Health Bureau. This report, *Creating a Strategic Plan for the Genetic*

Services Branch, identified four priorities for GSB:

1. Improving quality of and access to genetic services;
2. Integrating data collection and assessment systems;
3. Integrating genomic information into medical home; and
4. Developing best practices that include support services for families.

The MSGRCC leadership team then used GSB's findings to brainstorm opportunities to address these overarching national priorities. We identified the following two *new* priorities for the Mountain States region:

1. Identifying and managing treatable genetic disorders through the use of family history, innovative family and medical home partnerships, and transition tools; and
2. Incorporating newborn screening into the medical home.

In addition, MSGRCC plans to continue existing work in two priorities areas:

1. Using telehealth (and other distance strategies) as an educational and clinical tool; and
2. Improving access to genetic services for diverse populations (*e.g.*, hemoglobinopathy carriers, Native American populations, hearing impaired individuals and their families).

In July 2011, at the MSGRCC Annual Meeting, our Advisory Council reviewed these priorities and spent an afternoon participating in a facilitated discussion to identify a vision, mission, values, goals, objectives, key strategies, and major outcomes for



each priority. This valuable process culminated with a report that was used to guide the development of the competitive continuation application submitted to HRSA in January 2012.

These priorities represent an expansion of the MSGRCC and will require the formal involvement of many new regional partners, including primary care providers, health information technology experts, and program teams from other HRSA-funded initiatives. Implementation of new projects to address these priorities will take time as new relationships are cultivated and diverse implementation teams are organized. Attention to these priorities will serve the Mountain States region by improving access to genetic services, information, and expertise for individuals with or at risk for heritable disorders.

<http://www.msgrcc.org/>



Submitted by Jacquie Stock, MPH, Evaluator; Lianne Hasegawa, MS, CGC, Project Coordinator; and Sylvia Au, MS, CGC, Project Director, WSGSC

Stakeholders Prioritize Projects in Recent Needs Assessment

During the past eight years, the WSGSC has partnered with genetics stakeholders, including family advocates, public health genetics and newborn screening (NBS) leaders, medical geneticists, genetic counselors, metabolic nutritionists, primary care providers, academics, and insurers, in an ongoing regional needs assessment process designed to respond to the rapidly changing environment in which we operate. At our 2011 Regional Summit, stakeholders reconvened and identified current regional genetic services needs and strategies to address these needs. In January 2012, the stakeholders prioritized the proposed strategies via an online survey, voting to address the following five areas over the coming years:

1. Improved health insurance reimbursement for genetic testing, counseling, and medical foods;
2. Genetic/genomic services as integral to a person-centered medical home;
3. Dissemination of emerging genomic information to primary care providers, public health professionals, and the public;
4. Evidence-based clinical guidelines for genetic tests and genetic and NBS services; and
5. Knowing when and how to use telemedicine and outreach to improve access to genetic and NBS services for remote populations.

Two years ago, WSGSC began using a workgroup-based or project approach that allows interested stakeholders and

those with expertise in an area to work together to plan and implement strategies to address targeted regional needs. As part of the needs assessment process, stakeholders designed approaches or projects to address specific needs and developed strategies to pursue within each project. Key projects and strategies to be pursued in the coming years include:

Genetics/Genomics in the Medical Home—Ready for Healthcare Reform: Workgroup members will research regional health systems' policies related to providing genetics care in light of healthcare reform, disseminate relevant findings, and determine the feasibility of addressing service gaps.

Family Health History (FHH) and Innovative Technology Enhances Partnerships within Medical Homes: WSGSC will: 1) partner with Family Voices and F2F HICs to promote FHH knowledge among middle and high school students; 2) partner with family advocates to test technology for integrating FHH into electronic health records; and 3) assess the feasibility of using mobile or iPad applications to collect FHH.

Technology Innovations for Public Health Genetics/Genomics: WSGSC family advocates will partner with other advocates and primary care or specialty providers to explore the use of technology to enhance public and clinical health practice, including the use of text message reminders to enhance treatment adherence.

Translating Genomics into Clinical Practice and Public Health: Workgroup members, together with public health agencies and primary care providers, will determine and address primary care pro-

viders' genomic information needs and best practices for its delivery.

Medicaid and Third Party Insurer Reimbursement Tools for Genetics/Genomics Services: Working with University of Washington and regional Medicaid agencies, WSGSC will develop and evaluate decision models for coverage of autism spectrum disorders microarrays, disseminate findings, explore the feasibility of expanding to decision modeling for whole exome sequencing, and work with Medicaid and private insurers to adopt decision models in determining coverage.

Regional Genetics/Genomics-Medicaid Review Board: WSGSC will work with academic and insurance partners to explore the feasibility of creating a sustainable, regional group of experts to review evidence and make recommendations for coverage of genetics/genomics services.

Telemedicine Education, Training, and Expansion: WSGSC will develop a telemedicine training program for genetic counseling, clinical geneticist trainees, and recent graduates.

Clinical Guidelines for Heritable Conditions: WSGSC will develop and evaluate clinical guidelines for diagnosing and treating VLCADD, and expand these to other disorders, as identified.

Improving Genetic and NBS Services in Guam: WSGSC staff will work with Guam's public health agency to establish and improve NBS and genetic services.

<http://www.westernstatesgenetics.org/>



NCC & RC MEETINGS

MSGRCC Annual Meeting	Jun 28-30	Denver, CO
SERC/SERGG Annual Meeting	Jul 19-21	Ponte Vedra Beach, FL
Region 4 Genetics Regional Meeting	Sep 10-12	Lansing, MI
Heartland Annual RC Meeting	Oct 3-5	St. Louis, MO
NCC/RC PD/PM Annual Face-to-Face Meeting	Nov 15-16	Washington, DC area

NATIONAL CONFERENCES

Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Meetings	May 17-18 Sep 13-14	Alexandria, VA Washington, DC
University of Miami Miller School of Medicine Why We Can’t Wait: Conference to Eliminate Health Disparities in Genomic Medicine	May 31-Jun 1	Miami, FL
American Public Health Association (APHA) Midyear Meeting: The New Public Health—Rewriting the Future Annual Meeting	Jun 26-28 Oct 27-31	Charlotte, NC San Francisco, CA
Galactosemia Foundation 2012 Conference	Jul 19-21	Dallas, TX
University of New Mexico Center for Development and Disability Southwest Conference on Disability: <i>Access for All</i>	Oct 9-12	Albuquerque, NM
Health Care Transition Research Consortium Symposium	Oct 17	Houston, TX
American Academy of Pediatrics (AAP) National Conference and Exhibition	Oct 20-23	New Orleans, LA
National Society of Genetic Counselors (NSGC) Annual Education Conference	Oct 24-27	Boston, MA
American Society of Human Genetics (ASHG) Annual Meeting	Nov 6-10	San Francisco, CA
Association of University Centers on Disabilities (AUCD) Annual Conference	Dec 2-5	Washington, DC



CCHD Interest Group Now Meeting Monthly

If your RC, or individual states in your RC, are in the process of developing or implementing newborn screening for critical congenital heart disease (CCHD), then the NYMAC CCHD Interest Group—which meets monthly by conference call—needs your participation! The group is led by Lori Garg (New Jersey DOH) and Debbie Bawawi (Maryland DOH), and calls are held on the second Friday of the month, at 1:00 PM ET. The call schedule for the remainder of the year is May 11, June 8, July 13, August 10, September 14, October 12, November 9 and December 14. For more information or to join the mailing list, please contact Katharine Harris, NYMAC Project Manager at kbh02@health.state.ny.us.



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