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Accomplishments and Barriers

The Mountain States Genetics Regional Collaborative Center (MSGRCC) serves a region with great diversity, covering almost one-third of the entire United States. The Rocky Mountains present a physical barrier to the provision of clinical services. Providers in these areas are often called “windshield doctors” because of the time spent traveling to see patients. The patients also carry a travel burden and must travel long distances to receive services.

Arizona, Nevada, New Mexico, and Texas have larger concentrations of Hispanic/Latino populations than the US average. The Mountain States Region is home to a higher percentage of Native Americans than the US as a whole, and in the four states along the US-Mexico border, a language other than English is spoken at home in one quarter to one third of all households.

As a result, the Mountain States Region is challenged to improve systems of care that deliver genetic services to unique populations of Americans, many of whom are culturally and linguistically distinct from the majority population. During the reporting period, the MSGRCC has continued implementing communication, outreach, and programmatic strategies to meet the unique needs of the Mountain States Region.

Communications Accomplishments and Barriers

The www.MountainStatesGenetics.org website continues to provide updated content for both health professionals and consumers. A catalogued list of resources is available and MSGRCC staff enlists workgroup members to help identify new resources. In the past year, a webpage for each state has been developed and includes demographic data, state resources and a link to the directory of genetic services. From 2009 to 2010, the MSGRCC website had an 89% increase in unique visitors, and a 117% increase in the number of page loads. According to the website statistics¹, approximately 33% of visitors stay on the website for greater than five minutes. MSGRCC is grateful to the Western States Genetics Collaborative for assisting with website adjustments and maintenance while MSGRCC explores options for replacing a staff member with a contracted webmaster.

MSGRCC continued the monthly communication email distributed via a web-based marketing tool featuring a message from the Project Director (PD). This monthly message provides a short update on current MSGRCC activities and relevant regional and national projects. For the first seven months of this fiscal year, 112-152 individuals opened the message per month, exclusive of direct opens from the MSGRCC website or from the monthly THI newsletter. In addition to tracking the number of opens, MSGRCC has received feedback from MSGRCC members, and partners outside of the region, describing their satisfaction with the PD message.

Joyce Hooker, MSGRCC Project Manager, and Liza Creel, MSGRCC Project Coordinator, implemented monthly calls with the co-chairs of each MSGRCC-supported workgroup. The calls offer time to discuss current activities, review work products, and convene the full workgroup as needed.

MSGRCC held its Annual Meeting in Denver on July 13-16, 2010. The meeting included project meetings, workgroup meetings, an Advisory Council meeting where small grant projects were reviewed, and a series of plenary presentations, including project updates, a keynote by Dr. Ned Calonge from the Colorado Department of Public Health and Environment, a presentation by Dr. Ricky Bass from Louisiana State University, and a panel presentation with three youth who described their transition experiences.

¹ www.StatCounter.com

MSGRCC planned to hold only one in-person workgroup meeting during the '10-'11 FY, due to fiscal constraints. Fortunately, with the reallocation of funding not needed for the Hemoglobinopathies meeting (described below) and with funding support from NNSGRC, MSGRCC was able to fully implement mid-year workgroup meetings in February, 2011.

Other communication activities include participation in all NCC workgroups, publication of articles in the quarterly NCC Collaborator, disseminating information related to the SACHDNC to RC stakeholders, and working with HRSA and the NNSGRC to help states improve data reporting practices to NNSIS.

Outreach Accomplishments and Barriers

Consumer participation is of utmost importance for the MSGRCC. In Year 4, MSGRCC recruited new consumer members from Nevada and Texas. During the July, 2010 and February, 2011 workgroup meetings, two or more consumer members participated in the Newborn Screening, Telemedicine, and Emergency Preparedness workgroup meetings.

During the previous fiscal year, MSGRCC finalized a white paper, entitled *The Life Rope: Engagement of Diverse Populations for Recruitment and Representation in Genetics*. The white paper was presented to other RCs on the June 2010 PD/PM conference call and to the SACHDNC Education and Training subcommittee in May 2010. A poster on the white paper was presented at the Academy for Health Equity Annual Conference in August, 2010.

MSGRCC funded a project in 2006 to develop the Nevada state genetics plan, but the political environment in the state was not conducive to creating a useful, long-term plan for the state. Since 2009, with personnel changes within the Nevada public health system, there is renewed interest and support for developing the state genetics plan. After dealing with some contractor challenges, THI was approved by HRSA to finish the Nevada State Plan with current MSGRCC staff. Planning, which will be done in close collaboration with HRSA staff, is underway, and the plan will be completed in the '11-'12 FY.

MSGRCC had representation from two clinical sites (Shodair Hospital in Montana and Cook Children's in Texas) at the July 2010 Annual Meeting. Since then, MSGRCC has recruited four new physicians (or their designated representatives) to participate in Telemedicine Workgroup activities. In addition, MSGRCC held a special session during the July 2010 Annual Meeting to bring genetic clinicians, telemedicine providers, and consumers together. The keynote speaker was Dr. Dale Alverson, current President of the American Telemedicine Association and Medical Director of the Center for Telehealth at the University of New Mexico Health Sciences Center. The goal of the presentation and discussion was to inform and excite clinicians around telemedicine.

Following the success of the April 2009 Community Conversation with the Navajo Nation, MSGRCC was awarded supplemental funding to expand the project. MSGRCC proposed to conduct focus groups of family members in the Navajo Nation, to plan and implement a follow-up conversation with the Navajo Nation, and to implement a second Community Conversation in another Native American community. MSGRCC is currently planning for each of these activities, although implementation has proven difficult, due in part to cultural considerations. On March 17 & 18, the MSGRCC will lead two listening sessions in Farmington and Gallup, NM. The other activities are pending identification of key community partners. We are exploring partnerships with the Arizona Intertribal Council and the Hopi tribe.

In July, 2010 MSGRCC hosted presentations about six regional projects impacting newborn screening and genetic services in the Mountain States Region. These projects are complementary to many MSGRCC-funded activities and are listed in the attached Work Plan.

In February, 2011 MSGRCC hosted its second Medical Home Visiting Professorship Workshop featuring Dr. Chuck Norlin as the visiting professor. The workshop seemed to create strong relationships between states and the Medical Home Portal. More outcome data will be available in the next three to six months.

Programmatic Accomplishments and Barriers

In the current fiscal year, MSGRCC provided funding support for several projects, and also participated in external projects benefitting the Mountain States Region. These projects help MSGRCC meet its goals of strengthening the infrastructure for genetic services, improving care coordination for people with heritable disorders, and enhancing the delivery of services related to newborn screening.

The largest funded project is the **Metabolic Newborn Screening Long-term Follow-up Study**, led by Janet Thomas, MD at the University of Colorado. In December, 2010 *Genetics in Medicine* included an article on this project as part of a journal supplement.² A meeting of the Metabolic Consortium was held on July 13, 2010 and included the finalization of additional shared datasets. Many of the shared datasets, and accompanying parent handouts, are available on the MSGRCC website (http://msgrec.org/NBS_Project_Materials/MCAD_Menu.html). Parent handouts are available in Spanish for three disorders, and translation for additional disease specific handouts is underway. Similar materials are currently being developed for nurses and emergency personnel.

To pilot the project and assess data availability and assessment for a specific disease, the project team collected data on newborn screening results, basic diagnostic laboratory data, initial radiology data, and clinical data on patients in Colorado and Wyoming identified through newborn screening with glutaric acidemia, type I. These data were presented as a poster at the Association of Public Health Laboratories' Newborn Screening Symposium in May, 2010. Data from Arizona, New Mexico, and Utah were not included in this initial report because of limited patient numbers in Arizona and New Mexico; the data collected in Utah were analyzed and submitted for publication separately.

In 2009, the project team selected standardized developmental questionnaires to use in regional metabolic clinics to assess patient development, and these tools were piloted in Denver this year. The developmental assessment includes yearly parental questionnaires, basic developmental evaluations, and neuropsychological evaluations at age specific increments. A neuropsychologist in Denver scores the questionnaires. Distribution to other metabolic clinics throughout the region for use in the coming year is underway.

Finally, the project team planned to open the CHIRP database to other interested metabolic clinics in the region for data collection. Because of major revisions in the database this year through the HRSA-funded Colorado Effective Follow-Up Project, this goal has not yet been achieved. When the database becomes available, there will be other barriers to overcome before regional clinics can begin entering data, including addressing interstate health information exchange issues and obtaining an IRB protocol to consent patients. Colorado has offered its IRB protocol as a template for other metabolic centers. Plans for this project in Year 5 are included in the Work Plan, and letters of support from regional clinics are also attached.

² Wright, EL.; Van Hove, J.L.K.; Thomas, J; writing for the Mountain States Metabolic Consortium. Mountain States Genetics Regional Collaborative Center's Metabolic newborn screening long-term follow-up study: a collaborative multi-site approach to newborn screening outcomes research. *Genetics in Medicine*. 12(12):S228-S241.

During Year 4, MSGRCC has continued support for **Improving Medical Homes and Transition Outcomes for Youth with Special Health Care Needs**, with Laura Pickler, MD, as Project Director. Dr. Pickler received additional support for this project through the National Health Care Transition Center led by Dr. Carl Cooley. This larger project focuses on transition services for all youth and young adults. MSGRCC funding allows Dr. Pickler to contribute experiences of IMD/Genetics patients to the national project. Since receiving funding from MSGRCC for Year 4, Dr. Pickler has completed or scheduled approximately half of the 30 proposed interviews of intellectually disabled adult patients in the IMD/Genetics clinic at The Children's Hospital in Aurora, CO. These are patients who transitioned to adult care and then returned to pediatric providers, or who did not successfully transition at all by 18 or 21 years of age. Additionally, half of the 20 proposed interviews with cognitively normal siblings (all at least 18 years of age) of patients in the IMD/Genetics clinic to assess their transition experience to adult health care have been completed or scheduled. The remaining interviews will be completed by the end of the '10-'11 FY. The final deliverable for this project in Year 4 is to conduct one focus group with adult providers to assess their perspectives on transition services. This session is planned for late March or early April in conjunction with a meeting hosted by the National Center on Health Care Transition.

Synergy with the National Center on Health Care Transition is essential to the success of this project in the future. Dr. Pickler's role as a cabinet member at the National Center makes synergy possible. Specific activities for this project in Year 5 are detailed in the Work Plan.

Dr. Pickler and her project team have provided technical assistance to the Heartland Regional Genetics Collaborative for their transition work. Specifically, they have offered expert opinion, methodology advice, document review, and resource utilization advice. In addition, Dr. Pickler has included the Heartland Region in several of the National Center on Health Care Transition activities. Dr. Pickler has also represented the Mountain States Region with Dr. Chuck Norlin and Brad Thompson on the National Coordinating Center for the Regional Genetic & Newborn Screening Collaboratives Medical Home Workgroup.

In the '10-'11 FY, MSGRCC proposed funding for a large portion of the **Hemoglobinopathies Newborn Screening and Follow-up Project**, led by Kathryn Hassell, MD. After receiving project and budget approval from HRSA, MSGRCC learned that NNSGRC would be providing additional support for the project, resulting in reduced need for MSGRCC funding. After budget reconciliation, MSGRCC supported the travel-related activities for the annual meeting of the Hemoglobinopathies Work Group, which was held in conjunction with the 2010 MSGRCC Annual Meeting in Denver, Colorado. Representatives, including physicians, nurse practitioners, nurses, state health department NBS staff, and community members from five states in the region (Arizona, Colorado, Montana, Texas, and Wyoming) were supported by travel funds. The group addressed four ongoing and emergent areas, including sickle cell trait demographics, sickle cell trait and athletes, the minimum dataset for the Newborn Screening Translational Research Network, and the Primary Care Sickle Cell Trait Education Module.

MSGRCC currently supports travel for staff and review committee members on the **Laboratory Quality Assurance Project**. A meeting with the review committee and project participants was held in July, 2010, during which the educational challenges and materials were discussed. In Year 4, ARUP Laboratories is supporting other project functions, including preparation of the educational challenges and development of the educational materials. MSGRCC will continue to provide space on its website for sharing these materials. MSGRCC also provides time at the annual and mid-year workgroup meetings for project presentations.

The MSGRCC was awarded supplemental funding in May, 2010 for innovative projects in telehealth and telemedicine to improve access to genetic and newborn screening services and information in the region. Two projects were funded in September, 2010.

The Montana Tele-genetics Project: Improving Access, Educating Providers, and Consumers, led by Susan Landgren, MS, is working to increase access to this service in a time- and cost-effective manner by implementing and expanding telemedicine genetic counseling. To date, there have been four oncology and one OB/GYN genetic counseling consultations conducted over telemedicine. Billings Clinic and the Eastern Montana Telehealth Network also partnered with Shodair Hospital to provide additional genetic services. Since the beginning of this project, two genetics consultations have been conducted with Shodair and two with Denver Children's Hospital. Raising awareness and changing practice patterns have been the greatest challenges. The Billings Clinic oncology department has fully integrated telemedicine into their practice pattern. Adding genetic counseling broadens the depth and breadth of service available to their patients. There has been less progress with OB/GYN physicians. Making genetic counseling available earlier in the patient care process is a new model of care that has proved to be challenging for the OB/GYN physicians to embrace.

To publicize this project, a press release was developed and distributed to multiple news sources in the first month of the project. Press coverage of the project was included in the Billings Gazette and on local TV stations (<http://www.ktvq.com/news/tele-genetics-project-increases-access-to-genetic-counseling-for-patients-in-region/>). A post card announcing the new telegenetics services and advertising future continuing education programs was mailed to 900 providers in Montana, Wyoming, western North and South Dakota.

Other accomplishments include building an appointment scheduling protocol document, writing a telemedicine genetic counseling protocol document, developing a patient satisfaction assessment tool, and developing a referring provider satisfaction assessment tool. Invitations to continuing education seminars using telemedicine have been mailed and target OB nurses, prenatal providers, and the general public. Upcoming activities will focus on process improvement and evaluation of the telemedicine delivery system using telemedicine.

The Colorado Early Hearing Detection and Intervention Telemedicine program, led by Vickie Thomson, PhD, is housed at the Colorado Department of Public Health and Environment, Children with Special Health Care Needs unit, in partnership with the Marion Downs Hearing Center and The Children's Hospital (TCH). The goal of this telemedicine project is to include genetic counseling in a community based comprehensive system of care for families and their children identified with hearing loss using a medical home approach. The objective is to increase the number of families with children identified with permanent hearing loss receiving genetic counseling services from 100 to 150 by 2012. The single hearing loss genetic counselor in Colorado will use telehealth equipment for counseling sessions with families in remote areas. A pediatric audiologist in Durango, Colorado has selected families with newly diagnosed infants to participate in the project. The Colorado Hearing Resource Coordinator facilitates the referral and assists the family with the equipment setup in their home. Several genetic counseling visits are scheduled for the coming months.

The main obstacle encountered during project implementation has been selection of the most appropriate telehealth equipment. The selected equipment was recently installed and is currently undergoing testing. The project team has identified two other communities that are interested in genetic telehealth.

MSGRCC also participates in regional and national projects that have significance for the Mountain States Region. In July 2009, MSGRCC supported the Genetic Alliance application to HRSA for the Newborn Screening Clearinghouse cooperative agreement. Genetic Alliance received the award and MSGRCC has participated in Clearinghouse activities since its inception. Specifically, MSGRCC has responded to requests to make recommendations on the development of policies and guidelines for the inclusion of resources in the Clearinghouse. Celia Kaye, M.D., Ph.D., Project Director of MSGRCC, serves on the Clearinghouse advisory committee where she provides information about the needs in the Mountain States Region and collaborates to develop the policies, guidelines, and evaluation tools for the Clearinghouse. Liza Creel, MPH, Project Coordinator for the MSGRCC, serves on the Public Education Workgroup.

Finally, during this past year the MSGRCC contracted evaluator, Leslie Burkholder, Director of Idea Infusion Consulting, continued to build off previous work with MSGRCC in the first three years of this cycle, including the evaluation framework and comprehensive logic model completed in Year 2. During Year 3, internal data tracking and collection tools were created in collaboration with members of the management team, allowing for more strategic implementation of data collection activities to correlate directly with program goals and objectives. In accordance with Year 4 evaluation goals, emphasis was placed on the continued enhancement of data collection tracking and tools. Each member of the management team was assigned a lead role(s) for specific program goals and objectives for Year 4, and collected data in support of the activities related to program implementation. Furthermore, tracking, completion, and submission of NCC data sheets took place during the year. Lastly, process evaluations were collected following the Annual Meeting and the mid-year workgroup meetings. The evaluator maintained communication with members of the management team and initiated planning for summative evaluation activities in Year 5.

Goals and Objectives – Progress to Date

Objective:	Status:	Progress:
Goal 1: To enhance the delivery of genetic services and newborn screening in Region 6.		
<i>Objective a: Provide enhanced electronic communication with the MSGRCC partners via a newsletter (published twice a year) during the '10–11 FY.</i>	In progress	Staff plan to distribute a newsletter summarizing the mid-year meetings and MHVP by May 31, 2011.
<i>Objective b: Provide enhanced electronic communication with the MSGRCC partners via the MSGRCC web site (updated monthly) during the '10–11 FY.</i>	Ongoing	Website maintenance activities being supported by Western States Genetics Collaborative
<i>Objective c: Provide enhanced electronic communication with the MSGRCC partners via the monthly PD message during the '10–11 FY.</i>	Ongoing	Produced monthly
<i>Objective d: Improve communication between staff and workgroups by planning and scheduling monthly conference calls during the '10–11 FY.</i>	Ongoing	Consumer Advocacy – First Tuesday of every month; Telemedicine – Second Wednesday of every month, full WG call every other month; Newborn Screening – Second Tuesday of every month; Emergency Preparedness – Third Tuesday of every month
<i>Objective e: Improve collaboration between providers and consumers in Region 6 by implementing one (1) in-person meeting for each workgroup during the '10–11 FY. Participants may include partners of the RC who are not currently members of the workgroups.</i>	Completed	Workgroups were able to meet in-person twice during the '10-'11 FY, in July, 2010 and February, 2011.
<i>Objective f: Plan and implement an annual</i>	Completed	The Annual Meeting was held in July, 2010 in Denver,

Objective:	Status:	Progress:
<i>meeting for Region 6 by July 2010.</i>		CO.
Goal 2: To expand and fortify the infrastructure for genetic services in Region 6.		
<i>Objective a: Plan and conduct site visits in two (2) states within Region 6 during the '10-11 FY.</i>	Planning underway	MSGRCC staff are still planning the two state site visits for the '10-'11 FY. Original plans included visiting Nevada and Wyoming, but scheduling has made this difficult. In Nevada, MSGRCC had planned to combine a site visit with a series of focus groups designed to inform the Nevada State Genetics Plan. Since development of that plan has been delayed due to contract challenges, the site visit has also been delayed. Staff are still hopeful that another site visit will occur before the end of the '10-'11 FY.
<i>Objective b: Ensure active participation of a minimum of two (2) individuals who are consumers, family members and/or consumer advocates in each workgroup's activities and meetings during the '10-11 FY. This may include recruitment of new partners, particularly consumers from underserved populations.</i>	Completed	At least two Consumer Advocacy Workgroup members serve on each of the other MSGRCC-supported workgroups.
<i>Objective c: Participate in all scheduled NCC meetings and workgroups during the '10-11 FY.</i>	Ongoing	Designated MSGRCC staff and representatives participated in all NCC meetings and workgroup activities. Three staff members, Celia Kaye, Joyce Hooker, and Liza Creel attended the June PI/PM meeting in Chicago, IL and the November NCC annual meeting in Washington, DC. Regional representatives to each of the NCC workgroups also participate in meetings and conference calls when scheduled. In addition, at least two staff members attend all NCC PD / PM conference calls. Joyce Hooker also participates in the Interregional Transition Workgroup.
<i>Objective d: Monitor implementation of small grant and pilot projects by scheduling monthly calls with project leads and obtaining quarterly progress reports from each during the '10-11 FY.</i>	Ongoing	The MSGRCC funded program activities for four small grant projects and provided travel support for two other regional projects during Year 4. The projects are described in detail in the previous section. Four projects have obtained external funding to sustain project activities beyond MSGRCC funding.
<i>Objective e: Plan and implement quarterly Advisory Council meetings, in-person and/or via teleconference, during the '10-11 FY.</i>	Ongoing	In Year 4, MSGRCC convened the Advisory Council in-person twice and via phone once (with one more conference call anticipated before the end of the year). Advisory Council members also participate in other workgroup activities.
<i>Objective f: Disseminate recommendations from the recruitment white paper developed by the Consumer Advocacy Workgroup to other regions and the SACHDNC Education and Training subcommittee during the '10-11 FY.</i>	Completed	Presented on a PD/PM conference call, to the SACHDNC Education and Training Subcommittee, and as a poster presentation at the Academy for Health Equity conference.
<i>Objective g: Distribute a request for proposals for innovative projects focusing on distance strategies; evaluate, select, and fund at least one (1) project within three (3) months following notification of funds. Dependent upon the availability of funds and release date of said funds to the RC.</i>	Completed	Two projects funded

Objective:	Status:	Progress:
<i>Objective h: Increase participation of the Nevada Newborn Screening program in the RC by assisting with implementation of the Nevada state genetics plan during the '10–11 FY.</i>	Ongoing	Planning in progress with MSGRCC staff team and HRSA
<u>Goal 3: To improve care coordination for people with heritable disorders in Region 6.</u>		
<i>Objective a: Improve transition outcomes by implementing newly developed transition model based on Medical Home standards, within a specialty clinic that serves youth with IMD during the '10–11 FY.</i>	Ongoing	See project update in previous section
<i>Objective b: Improve long-term follow-up for individuals with inborn errors of metabolism by systematically analyzing the factors that affect long-term outcomes during the '10–11 FY.</i>	Ongoing	See project update in previous section
<i>Objective c: Improve newborn screening follow-up for individuals identified with sickle cell trait through better identification of demographics of infants with sickle cell trait and culturally appropriate education and information provided during follow-up during the '10–11 FY.</i>	Ongoing	See project update in previous section
<i>Objective d: Ensure participation of a minimum of two (2) clinicians on the telemedicine workgroup, to ensure representation of all stakeholders, by July 2010.</i>	Completed	MSGRCC had representation from two clinical sites (Shodair Hospital in Montana and Cook Children's in Texas) at the July 2010 Annual Meeting. Since then, MSGRCC has recruited four new physicians (or their designated representatives) to participate in Telemedicine Workgroup activities.
<i>Objective e: Complete quarterly updates to the MSGRCC directory of genetic resources (i.e., services and service providers) within Region 6 during the '10–11 FY.</i>	Ongoing	The MSGRCC staff and/or hired interns routinely update to provide stakeholders in the Mountain States Region with improved access to accurate information on available services.
<u>Goal 4: To improve access to and delivery of genetic and newborn screening services for people with heritable disorder in Region 6.</u>		
<i>Objective a: Plan and implement a special session to strategize new collaborations between telemedicine providers and genetics providers during the Annual Meeting in July 2010.</i>	Completed	MSGRCC held a special session during the July 2010 Annual Meeting. The keynote speaker was Dr. Dale Alverson.
<i>Objective b: Develop educational materials for consumers and providers, through the telemedicine workgroup, that describe the benefits of distance strategies in the delivery of genetics services, by March 2011.</i>	In progress	MSGRCC has drafted two marketing brochures that describe the benefits of telemedicine for the delivery of genetic services. The drafts are under review by workgroup members.
<i>Objective c: Participate in the Genetic Alliance Congenital Conditions project during the '10–11 FY.</i>	In progress	The scope of work for MSGRCC has not been finalized. MSGRCC has responded to Genetic Alliance surveys and other requests related to the Congenital Conditions Program.
<i>Objective d: Develop and implement a series of meetings with Native American people to promote understanding of principles of genetics and newborn screening among tribal members, and to foster an understanding of the views of tribal members on genetic testing and newborn screening among genetics and public health providers and community educators during the '10–11 FY.</i>	In progress	Listening sessions scheduled for March 17 & 18 with two Native American family support groups.

Objective:	Status:	Progress:
<i>Objective e: Foster collaborations between a federally funded Sickle Cell project initiated by start-up funds from the RC during the '10-11 FY.</i>	Ongoing	MSGRCC hosted a presentation about the Colorado Sickle Cell Care Network, on which Dr. Kathryn Hassell is key staff. MSGRCC continues to explore potential partnerships and provide opportunities for its stakeholders to learn about activities of the Network.
<u>Goal 5: To serve as a catalyst in the development of emergency backup systems for newborn screening services in Region 6.</u>		
<i>Objective a: Participate in all scheduled NCC Emergency Preparedness meetings during the '10-11 FY.</i>	Ongoing	The designated MSGRCC representative, one of the MSGRCC Emergency Preparedness Workgroup co-chairs, has participate in all NCC Emergency Preparedness workgroup meetings and conference calls to date.
<i>Objective b: Plan and implement a special session to discuss improved collaboration between clinicians and emergency preparedness planners during the Annual Meeting in July 2010.</i>	Postponed; Tabletop exercise scheduled for April 29	Original plans to hold a special emergency preparedness session during the 2010 Annual Meeting were postponed to allow for exploration of a regional emergency preparedness tabletop exercise. A tabletop exercise is scheduled for April 29, 2011. MSGRCC staff are working closely with Bill Perry, NCC's EP Consultant, to develop the exercise scenario, identify stakeholders, and implement the tabletop.
<i>Objective c: Disseminate recommendations from the Emergency Preparedness and Planning Project to clinicians, other regions, and the NCC Emergency Preparedness Workgroup by December 2010.</i>	Completed	MSGRCC submitted an article on the Emergency Preparedness and Planning project to the NCC's December 2010 issue of the <i>Collaborator</i> newsletter. The scenarios described in the report will also be reviewed in preparation for the preparedness tabletop exercise.
<i>Objective d: Ensure participation of a minimum of two (2) clinicians on the emergency preparedness workgroup, to ensure representation of all stakeholders, by July 2010.</i>	Completed	Two clinicians (from NM and TX) participated in the July 2010 Emergency Preparedness Workgroup meeting.
<u>Goal 6: To enhance delivery of services related to newborn screening in Region 6.</u>		
<i>Objective a: Disseminate and/or present publications, activities, and other information related to SACHDNC to RC partners at the Annual Meeting in July 2010.</i>	Completed	Dr. Chris Kus, member of the SACHDNC, presented updates on SACHDNC activities during the July 2010 Annual Meeting. The monthly PD messages also highlight current SACHDNC reports, recommendations, and meetings.
<i>Objective b: Ensure participation of a minimum of one (1) primary care provider on the newborn screening workgroup, to ensure representation of all stakeholders, by July 2010.</i>	Not completed	With new primary care providers identified, this objective should be completed by July, 2011.
<i>Objective c: Initiate a data sharing group of RC partners focused on supporting consistent and reliable newborn screening data in Region 6 during the '10-11 FY.</i>	In progress	This group will convene by summer, 2011.
<i>Objective d: Maintain quarterly contact with NNSGRC representatives to address ongoing improvements to data reporting practices to NNSIS during the '10-11 FY.</i>	Ongoing	MSGRCC helps coordinate improved data reporting when necessary.
<i>Objective e: Foster collaborations between federally funded newborn screening projects initiated by start-up funds from the RC during the '10-11 FY.</i>	Ongoing	Presentations by other regional newborn screening projects were hosted at the 2010 MSGRCC Annual Meeting
<i>Objective f: Participate in the Genetic Alliance Newborn Screening Clearinghouse project</i>	Ongoing	Staff participate on the National Advisory Committee and the Public Education Workgroup; also respond to related

Objective: <i>during the '10–11 FY.</i>	Status:	Progress: surveys for the project
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Significant Changes

During the reporting period, one significant contractual change occurred in the MSGRCC. A contract to develop the Nevada State Genetics Plan was terminated because the agreed upon deliverable was not completed by the contractor. A portion of the funding was returned to Texas Health Institute (MSGRCC fiscal agent), and MSGRCC intends to take the following steps to complete the Nevada state genetics plan: 1) Communicate with Jo Malay, NV Early Childhood & Women's Health Section Manager, to reinitiate the plan development process and identify any new strategic directions for the state; 2) Distribute the stakeholder survey developed by the original contractor to current and new contacts in Nevada; 3) Review the needs assessment performed by the Western States Genetics Collaborative in 2006 & 2007, and validate the needs with state newborn screening staff; 4) Further validate the genetic service needs and gaps through two focus groups, which will be facilitated by a contracted facilitator; 5) Write the draft report using data and information collected through the above activities, and gather feedback from stakeholders; and 6) Finalize report with stakeholder feedback.

Staff from MSGRCC will lead preparation of the report. MSGRCC will contract with a facilitator to develop and manage the focus groups. The final report would be available in approximately nine months.

Outcome Measures

Outcome Measure A1: Increase in the percentage of states/territories in the region with collaborations facilitated by the Regional Collaborative between primary care providers (PCPs) and specialty (including genetic) providers to improve care coordination for people with heritable disorders. MSGRCC reported seven of eight states with these collaborations. Specific activities include supporting Dr. Laura Pickler's project in Colorado, Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics, which involves PCPs in developing transition protocols; supporting Dr. Kathryn Hassell's project, Hemoglobinopathies Newborn Screening and Follow-up, through which she is working in Colorado and other states to involve PCPs in education of sickle cell carrier families; supporting Dr. Janet Thomas's project, Metabolic Newborn Screening Long-term Follow-up Study, which develops information for PCPs in the region. Arizona, Colorado, Montana, New Mexico, Texas, Utah and Wyoming participate in the project; and facilitating planning activities related to delivery of services via telemedicine in Colorado, Montana and Wyoming. This included connecting primary care providers, specialty providers, and telemedicine providers to identify gaps and barriers and outline a strategy for moving forward.

Outcome Measure E1: Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening programs. All states in the region have these systems in place. MSGRCC supports a newborn screening workgroup that provides a forum for interchange of information on state processes for tracking; provides a forum for report of the Texas Newborn Screening Performance Measures Project, which has criteria for improving post-analytical outcomes; and provides a forum for meetings for the Colorado and Utah HRSA-funded effective follow-up projects.

Outcome Measure E3: Increase in the percentage (number) of states/territories in the region with systems in place to track receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) mandated by their State-sponsored newborn blood

spot screening program and/or with hearing loss through their State-sponsored newborn hearing screening programs. Two of eight states in the region have these systems in place for all NBS disorders screened. MSGRCC supports a newborn screening workgroup that provides a forum for interchange of information on state processes for tracking; provides a forum for report of Texas Newborn Screening Performance Measures Project, which has criteria for improving post-analytical outcomes; provides a forum for Colorado's HRSA-funded effective follow-up project; supports the Metabolic Consortium, the purpose of which is to develop the database and reporting systems for long term follow-up; provides a forum for the Utah effective follow-up project to report their results; and reports to regional partners on the activities of SACHDNC, including the activities of the LTFU subcommittee, of which Celia Kaye is a member.

Outcome Measure F1: Increase in the percentage of states/territories in the region whose newborn screening (NBS) programs disseminate "just-in-time/point-of-care" information on specific heritable disorders to primary care providers (PCPs). All states in the region provide this information to PCPs. To assist in these activities, MSGRCC provides updated resources to states via the website and email communication and relays relevant / updated national information to regional partners.

Plan for Upcoming Budget Year

In the upcoming budget year, MSGRCC will build on previous successes and accomplishments. MSGRCC plans to continue funding activities that support improved communication, regional outreach, and programming in the region. MSGRCC will fund four small grant projects and issue a Request for Applications for one to two additional small projects. MSGRCC will host an Annual Meeting from July 12-14 in Denver, Colorado. A keynote presentation on health reform, updates from national partners, updates from regional projects, workgroup meetings (4), and an Advisory Council meeting are planned. At this time, MSGRCC does not have the funding to support mid-year workgroup meetings. Staff plan to pursue external funding sources to implement these valuable in-person meetings for the volunteer workgroup members. Specific details can be found in Attachment 2: Work Plan Matrix 2011-2012.

The staffing structure of the MSGRCC will also change in the upcoming year. On June 1, 2011 Liza Creel, MPH will become the MSGRCC Project Manager. Joyce Hooker, who has served as Project Manager during the past funding cycles, will become the Director of Regional Outreach. This new position fills a critical need in this geographically disparate region, and, in addition to supporting ongoing regional activities, will include recruitment of new state and organizational partners.

In Year 5, it is anticipated that evaluation activities will continue to build on the strategic foundation developed in the first four years of this project cycle and shift into a summative focus. Evaluation activities for Year 5 will include, but are not limited to:

- 1) data collection and tracking for Year 5 activities;
- 2) cumulative data gathering and sorting from year one through year four;
- 3) data analysis;
- 4) preparation of recommendations based on this cycle for the next cycle of program implementation;
- 5) continued participation in NCC evaluation efforts; and
- 6) maintain open communication with the management team.

These activities will incorporate all data management and tracking systems developed during this cycle, e.g., Program Evaluation Overview from Years 1 and 2, the original and revised logic model for this program, and all NCC-related documents, among others.