

## Save the Dates

**Mountain States Genetics Network (Regional Collaborative Center) Annual Meeting**  
July 13, 14, and 15, 2006  
Sheraton Denver Tech Center Hotel  
Greenwood Village, Colorado

### Sneak Preview:

- Hot topic: Issues in the Transition from Pediatric to Adult Genetics
- Keynote presentation: Surveillance Strategies for Genetic Disorders
- Matthew Kaplan, PhD, from Arizona: "Telling the World When Where and Y" from familytreedna.com and genographic.com
- Leslie O'Leary, PhD, from the Centers for Disease Control and Prevention: "Public Health Surveillance of Birth Defects and Other Childhood Conditions"
- David Sheppard Memorial Lecture by David Viswanatha, MD, from the Mayo Clinic in Rochester: "Clinical and Technical Aspects of Hematological Malignancies"
- Amanda Sozer, Ph.D., from DNA Technology Consulting Services. "The Role of Geneticists in the Hurricane Katrina DNA Identification Effort"
- Fun and dinner: The Trail Dust Restaurant where no ties are allowed (they'll cut them off!)
- Much More!!!

Please join us for a great learning opportunity, for a chance to network, to see what's new, and to have some fun in Denver. Look for the brochure and registration on the web site soon.

### Join the Mountain States Genetics Network Regional Collaborative Center

#### Who should join?

- ♂ Professionals involved or interested in genetics
- ♂ First Year Professionals - valid for one year to assist recent graduates
- ♂ Students - open to undergraduate or graduate students
- ♂ General - open to all consumers interested in genetics services and issues

**Why join?** The Mountain States Genetics Network (Regional Collaborative Center) is the primary voice advocating and supporting education, awareness and access to medical genetics information. MoStGeNe is better than ever! New activities, accredited educational symposia, an updated and growing website, and exciting, expanded networking opportunities are a small part of what drives our vision of improved health and quality of life for all populations through education and greater understanding of medical genetics.

#### Where can I find more information about joining?

[www.mostgene.org/membership](http://www.mostgene.org/membership)

Send this newsletter to a friend and encourage them to join us in changing and positively affecting the quality of life and medicine in the 21st century by sharing our knowledge and experience as equals.



### Network News

We at "headquarters" have been very busy over the last two months submitting federal grant proposals. The first responded to an RFP specifically directed at the Regional

Collaborative Centers for "supplemental" funding for improvement of state infrastructure and data systems coordination with regard to newborn screening. Rebecca Anderson of Utah responded to this announcement with a proposal to regionalize follow-up and surveillance of patients identified in NBS. Janet Thomas in Colorado is already spearheading an effort for a regional NBS/metabolic registry with some standardization of treatment. Colorado and Utah received previous federal funding to develop data systems integration, and Rebecca proposes to work with the other states not already integrated to streamline the process. The funding will also allow for a pilot study of the systems already developed in Colorado and Utah to assess their functionality. Integrated systems utilize data from birth certificates, newborn screening, Medicaid, Children's Special Services (equivalent), etc. to assure identification and follow-up (tracking) of children at high risk based upon metabolic or birth defect disorders.

The second proposal was submitted in response to funding available through the Agency for Healthcare Quality Research for meeting support. Funding of up to \$50,000 is available if the meeting meets some of the four objectives of AHRQ meetings: Research Development, Design and Methodology, Dissemination and Methodology, and Research Training and Career Development. We feel that different elements of our annual meeting meet all four of these objectives, and we developed a proposal breaking down the components of our meeting by the objectives listed. The newly funded MSRGCC research projects especially meet the requirements (research on quality health care delivery), and we will be hearing at least about the proposals, if not some data, this year – with more to come. As the federal funding of the Regional Collaborative Center does not completely support of our annual meeting, we hope to offset those costs with AHRQ funding.

We should be able to announce the results of these proposals at the annual meeting. Hope to see you there!

*John P. Johnson, MD, President, Board of Directors,  
Mountain States Genetics Foundation*

## More Information on Supplemental Grants

The MSGRCC applied for Health Resources and Services Administration Supplemental funding for Regional Genetic and Newborn Screening Services, HRSA 06-065. The funding applied for is approximately \$300,000 for one year, June 2006 through May 2007. The problem that this application will address is that programs in the region don't collect data of the outcome of newborn screening. This dearth of data limits the ability to assess and characterize the efficacy of NBS programs and their influence upon health and economic outcomes. This evaluation data is necessary to enhance efficiency and effectiveness of NBS programs in the future.


The goal of this proposal is to support comprehensive planning activities involving regional collaboration to strengthen newborn screening follow-up programs in the Mountain States with the use of integrated information. This will ensure programs' efficiency and effectiveness by the planning for the tracking of outcomes of newborn screening to provide needed data for the programs, policy makers, and the medical home.

**Objective 1:** Establish a protocol through regional collaboration to evaluate the follow-up system for newborn screening using integrated information systems by February 2007.

**Objective 2:** Develop a pilot study of the protocol with Utah and Colorado's integrated data systems by April 2007.

**Objective 3:** Collaborate with the Mountain States and share information of the established integrated child health operating system models in use in the region with those states in need of integrated systems by May 2007.

**Objective 4:** Build upon the current partnership with the Public Health Informatics Institute, expand the partnership to all the states in the region, and further develop a body of knowledge and resources to support the public health programs in the Mountain States as they build the infrastructure to ensure an effective newborn screening follow-up program by May 2007.

 Kudos to Rebecca Anderson of Utah for writing this grant. Her hard work on behalf of the Network is appreciated.

## 2006 Midyear Meeting Update

Midyear meetings are underway. We have been making arrangements for video conferences or face-to-face meetings, depending upon the needs of the committee.

To date, three of the standing committees have had their midyear meetings. **The Newborn Screening Committee** met on March 17. **The Public Health Committee** met on February 25. Colorado, New Mexico, Texas (by phone), Utah, and Wyoming were represented. Arizona and Montana provided written reports. **The Clinical Services and Consumer Advocacy Committees** had a combined meeting on February 17 via video and teleconference – a first for the network! All states but Wyoming were represented. The focus of the meeting was transition. The committees have agreed to focus on two aspects of transition (out of many possibilities). The Consumer Advocacy Committee will focus on identifying the five top issues facing adult consumers, resources available in the seven-state network, and finding samples of a health information form for clients to use when transitioning and/or seeking care outside their usual care provider network. The Clinical Services Committee will focus on finding out what is available in the individual states – such as: are there reimbursement/billing codes for those practitioners providing chronic care not being used or are new codes needed? A quick survey of the video conference attendees revealed a very positive overall support for the video conference format. It is a very cost and time efficient format. There are “bugs” that have to be worked out of the process itself. The primary problem is a need for “etiquette” protocol. The format requires some changes in how the meeting is structured to improve communication.

**The Laboratory Practice Committee** will meet on April 17 from 1 to 4 pm via video conference. **The Prenatal Diagnosis and Education Committees** are in the process of scheduling their midyear meetings.

## Year 2 Selected Grants for Funding

**Selection Committee:** *Dr. John Johnson (Clinical), Dr. Gurbax Sekhon (Laboratory), Lynn Martinez (Public Health). These individuals were chosen for their expertise and knowledge of related activities in their sphere of influence. Joyce Hooker assisted as Director of the Mountain States Regional Collaborative Center.*

We received 23 applications from partners in Arizona, Colorado, Montana, Texas, and Utah. The applications were read and ranked by the selection committee using the application review form. The selection committee convened by phone and thoroughly discussed those applications with the highest rankings. It was essential that the projects have regional application, could be replicated elsewhere in the region or nationally, or included other sites. After prudent consideration, the following nine applications were selected for funding ranging from \$2,600 to \$30,000.



**Mile High Down Syndrome Association of Denver:** The MHDSA was established in response to the concerns of parents that had not received information and support needed at the time of their child's diagnosis nor did the child's primary care provider have the knowledge, skills, and resources needed to provide the level of care required. This project addresses the medical home for children with Down Syndrome and the tracking of contacts. They will build partnerships with health care providers to improve the quality of service to families. This project was selected for the following outcomes: it will form public/private collaborative partnerships, improve access to services (especially the underserved and geographically remote), provide patient follow-up and tracking, and be a patient management model.

**University of Colorado Cancer Center:** This project will provide educational outreach about genetic testing to individuals at risk for hereditary colon cancer. This project will use the Bethesda Criteria for Hereditary Non-Polyposis Colon Cancer and the Colorado Central Cancer Registry (Colorado Department of Public Health and Environment). This project will determine how useful the registry data is and how it can best be used. This project was selected for the following outcomes: it will enable and improve access to services (especially to the underserved and geographically remote), utilize web-based resources, utilize established registries, and be a model for patient management.

**University of Utah/Utah Department of Health:** This project will develop a comprehensive plan for population-based outcome surveillance and longitudinally tracking of people identified through genetic screening programs in Utah and other Mountain States. This project was selected for the following outcomes: the development of patient tracking models and outcomes registries to support medical home initiatives and the facilitation of efficient patient management utilizing the state's Birth Defects Network and Monitoring System.

**University of Arizona:** This project will provide targeted informational seminars aimed at helping Native American groups better understand the issues involved in genetic research, particularly as it affects these specific groups and provide public seminars on topical subjects to the lay public. The Mountain States Region is home to many tribal nations. There have been conflicts between some of these nations and genetic researchers in the past. This has created discomfort at best and antagonism at worst. The University of Arizona application demonstrated that it has the knowledge and skill to implement the desired changes. This project is an admirable attempt to offer an olive branch and to enter into discussions to end these misunderstandings. All states in the region can benefit from the experience of this effort. This project was selected for the following outcomes: it attempts to improve access to underserved and geographically remote populations and is a model for other states.

**The Children's Hospital of Denver:** Targeting cystic fibrosis heterozygotes, this project will provide a pilot study on delivering genetic services (a "virtual" genetic counseling system) to geographically remote communities using video conferencing and web-based technologies. This project was selected for the following outcomes: it will provide a model for a group counseling approach which is easily replicable for other programs and disorders, and it is directed at underserved and geographically remote populations.

**University of Colorado Sickle Cell Treatment and Research Center:** This project addresses the recent emphasis on sickle cell trait counseling and will create a system which will reduce financial and access barriers to services and determine the actual community interest in sickle cell trait counseling in the Mountain States. Data from the newborn screening programs will be used. All states (via state health departments) in this region screen for sickle cell disease. This project was selected for the following outcomes: it will provide a model for a variety of genetic diseases and carrier states, it is directed at an underserved population, and it enhances the public health infrastructure and capacity for provision of genetic services.

**Texas Tech University Health Sciences Center:** Nurses are ideally positioned but often undereducated to provide genetic information and appropriate referrals. This project seeks to build the capacity of the workforce to provide genetic services. This project was selected for the following outcomes: it will improve access in underserved and geographically remote areas and improve public health infrastructure for genetic services, it is easily replicated and needed throughout the region, and it utilizes web resources.

**The Children's Hospital of Denver:** This project will provide a revised neurodevelopmental review of long-term outcomes for Recombinant 8 syndrome children. This syndrome occurs with greater frequency in children in the Mountain States Region. This project was selected for the following outcomes: it will develop a patient management model for patients with this disorder and patient tracking models and outcomes registries to support Medical Home initiatives and will facilitate efficient patient management for an underserved and geographically remote population.

**Sickle Cell Treatment and Research Center:** This project will look at the potential shift in the at-risk population (Latinos) for sickle cell trait and disease by tabulating selected data from the newborn screen form from the Colorado Department of Public Health and Environment. Latinos are the fastest growing population in most of the states in this region. Knowing which populations are more at risk for this condition will aid in more focused outreach and education in these communities. This project was selected for the following outcomes: it focuses on underserved populations, enhances the public health infrastructure, and is easily replicated.

## Additional News in the World of Genetics

11th Annual Genetics and Ethics Meeting  
Engineering Immortality: The End of Death  
July 21-22, 2006  
The Given Institute of the University of Colorado  
Aspen, Colorado



What will happen if we discover there are no "natural" biological limits to how long can people live? How quickly might genetic advances permit life expectancy to surge? How will ethical, legal, and social influences, as well as legal considerations, affect decisions to use these advances to extend life, as well as treat and prevent diseases?

These and other questions will be the focus of the eleventh conference in an annual series that addresses current ethical and legal issues related to genetics. Conference attendees will explore the scientific promise of advances in genetics and cloning aimed at life extension, balanced against the ethical, legal, and societal issues this progress will raise. Although most

everyone agrees on the fundamental virtues of advances in treating and preventing diseases associated with aging and perhaps even slowing the aging process itself, the extent and purposes to which such manipulations should be used remain debatable. The discussions will incorporate wide-ranging and diverse perspectives, including views that champion a "traditional life-span," "life cycle traditionalists," and proponents of, as well as critics of, "health span extension," and "growing old while staying healthy."

All attendees will have the opportunity to participate actively in all phases of the conference. At the conclusion of the conference, attendees will engage in moderated discussions of vignettes that assume varying degrees of success in research to extend the human life span with or without concomitant reduction in morbidity. This broadly-based conference targets all health care professionals and physicians, researchers, business people, ethicists, attorneys, ethics committee members, institutional review board members, and individuals interested in the impact of genomic medicine on people and institutions.

For more information, contact Mark Yarborough, PhD, Director and Associate Professor, Center for Bioethics and Humanities, University of Colorado at Denver and Health Sciences Center, Box B137, 4200 East 9th Avenue, Denver, CO 80262, 303-315-5177, 303-315-0820 (fax), mark.yarborough@uchsc.edu, www.uchsc.edu/cbh.