
# NCC Collaborator

*Expanding Genetic and NBS Services Through Multifaceted Partnerships*


## Musings on a Pedigreed Theme: The Genetic Family History Then and Now

*Submitted by Judith Benkendorf, MS, CGC, Project Manager, ACMG*

Roughly forty years ago, as newborn screening (NBS) was moving genetic services into public health, medical genetics professionals—positioned primarily at academic medical centers—were providing genetic evaluations, risk assessment and counseling services based on what is still the most sensitive screening tool in the industry, the genetic pedigree. With the expansion of genomic knowledge and its applications to healthcare, the geneticists' pedigree has been adapted into the consumer-friendly, family health history and made a parallel move into public health.

The classic genetic pedigree, with its hieroglyphic nomenclature and terms-of-the-trade such as proband, index case, and consanguineous union, functions as a medical and counseling tool. The family is the expert and constructing a pedigree engages them in the genetic evaluation process. Family relationships become apparent and both family attitudes toward genetic diagnoses and patterns of disease transmission are gleaned. This information becomes the basis for genetic risk assessment and counseling. Geneticists also communicate with other team members in the universal language of "pedigree," through a picture on a single page that can follow the patient/family over time and be updated continuously.

The genetic pedigree remains a cornerstone of geneticists' present armamentaria as we move from treating rare, single gene disorders affecting a few to common complex conditions involving multiple genes and their environmental interactions, for which no family health history is exempt.

This issue of the *NCC Collaborator* highlights public health activities that are bringing heightened awareness of the importance of family health history to diverse communities. Not only is family health history the point-of-entry of genetic services into primary healthcare (just as NBS brought genetics into public health in the last century), but everybody has a family history and will need to develop a way to collect, record, store and communicate this information with caregivers and relatives. On pages 2 and 10 you will read about MCHB-funded initiatives being carried out within selected communities by the March of Dimes and their partners, and Genetic Alli-

*Continued on page 12*

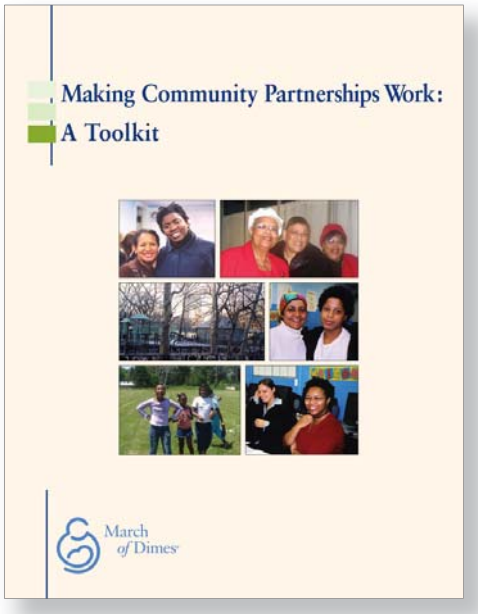

December 2007 Edition Volume 1. Number 4

# Making Community Partnerships Work: The GENE and CGEN Projects

*Submitted by EmyLou Rodriguez, Manager, Community Genetics Education, March of Dimes Foundation*

March of Dimes (MOD) and MCHB/HRSA are working together with communities to address the need for genetics information, resources and services that meet the cultural and language needs of diverse, minority populations. The Genetics Education Needs Evaluation (GENE) Project, completed in 2005, addressed the challenge of determining what information consumers need to know about genetics and how best to provide that information given the complexity of the subject and barriers to communication. MOD and HRSA, along with national partners Genetic Alliance and Family Voices, supported two community-driven needs assessments that determined baseline knowledge, attitudes and behaviors in the Latino and African American communities. As a result, much more is known about the genetic information and service needs of African Americans and Latinos. In addition, more is known about the benefits and challenges of using a participatory approach to building partnerships between national organizations and communities.

Building community partnerships is key to delivering information, resources and services to traditionally underserved communities. The GENE Project was unique in its use of a community-based participatory research (CBPR) approach to engage minority communities in identifying their genetics education needs. Lessons learned from this process have been summarized in a toolkit developed by MOD titled "Making Community Partnerships Work." The toolkit describes a three-stage process for initiating and building meaningful community-based participatory partnerships (CBPPs) using the principles of CBPR and cultural competency. Case stories from the GENE Project demonstrate how certain strategies were applied. The toolkit will be available through MOD's website: www.marchofdimes.com/genetics.




Participatory approaches to genetics education now guide the work of the Consumer Genetics Education Network (CGEN). MOD and MCHB/HRSA are now collaborating with the National Human Genome Center at Howard University (DC), Charles B. Wang Community Health Center (NY), Dominican Women's Development Center (NY), and the Genetic Science Learning Center at the University of Utah in partnership with the Utah Department of Health Chronic Disease Genomics Program (UT) to develop and pilot culturally sensitive genetics education programs and materials for the African American, Latino/Hispanic, Asian and Pacific Islander populations. The overarching goals of the CGEN Project are to:

- facilitate consumers in making informed healthcare decisions
- increase awareness of family health history
- increase consultation with healthcare providers and use of genetic services among high risk populations, and
- promote lifestyle changes that reduce genetic-based health risks.

The Regional Collaboratives and CGEN Project share common interests and the community sites welcome opportunities for collaboration and dissemination. Specific details about each community project will be featured in future issues of the *NCC Collaborator*.
*http://www.marchofdimes.com/*

To read about outcomes of the GENE Project, see "Genetics Education in Underserved Communities: The GENE Project," Vol. 1, No. 2 (June 2007) of the *NCC Collaborator*, page 2.

# New England Regional Genetics & Newborn Screening Collaborative

*Submitted by Amy Philbrick Schwartz, MPH, Project Manager*

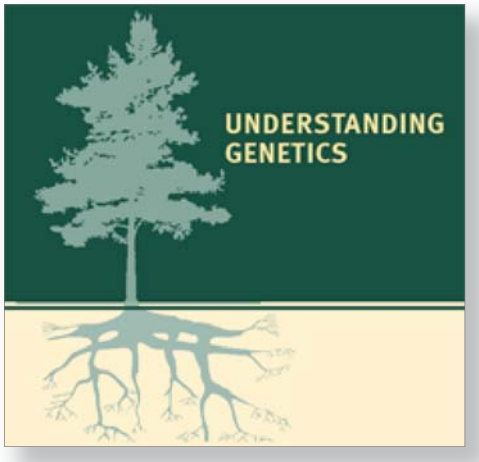
## Public Health Education Thrives in the New England Genetics Collaborative (NEGC)

The NEGC Dissemination, Marketing and Education working group, chaired by Dr. Leah Burke, is working with the long-established New England Public Health Genetics Education Collaborative (NEPHGEC) to identify, develop and promote genetics education strategies in the region with the goal of maximizing the impact of genomic information to improve health outcomes. The group, which is comprised of professional and consumer representatives from all New England States, has coordinated a number of on-going projects that specifically address the advancement of public health, professional health education and genetic science.

Current projects include the New England Genetics Resource Directory, a genetics outreach project for community health centers, a family health history training module project and the publication of *Understanding Genetics: A Guide for Patients and Professionals*. In addition, the group has developed a regional newborn screening brochure that has been translated into multiple languages and is available for download at the New England Regional Genetics Group website: http://www.nergg.org/nbsbrochures.php

*Understanding Genetics: A Guide for Patients and Professionals* was developed in conjunction with the Genetic Alliance. The straightforward and intuitive guide covers basic genetic concepts complemented with in-depth information about the diagnosis of genetic conditions, newborn screening, collecting family health histories, genetic counseling, and genetic tests and their applications. Information focuses on patient care, patient and provider education, and genetic services in the New England area. The guide provides baseline genetics information that can be accessed by providers at all levels, working with patients from any community. This guide can be downloaded at the Genetics Alliance website: http://www.geneticalliance.org/ws_display.asp?filter=understanding.genetics.download.

The working group continues to enhance the Family Health History Awareness curriculum and intends to expand it into a multi-media format, using innovative ways to reach new audiences. They are also developing modules to meet the needs of targeted audiences such as primary care providers, nurses, social workers and public health staff. Information presented includes why family history is important, how to take and interpret a family history, the tools available for compiling a family health history, and what to do with the information. The curriculum will soon be presented to various audiences throughout the region. These sessions will be evaluated and the presentations refined to meet the needs of target audiences as appropriate.




The NEGC considers health education to be a cornerstone issue in program development for the region. New technology and rapid advances in the science of genomics require extensive collaboration to best distribute highly specialized information to medical professionals and consumers. The outstanding work of the NEPHGEC is one example of regional cooperation that allows the most efficient and consistent distribution of state-of-the-art resources to benefit communities.
For more information, please contact Amy Schwartz at (603) 862-5099 or by email: amy.schwartz@unh.edu.
*http://www.nergg.org*

# NYMAC

NEW YORK-MID-ATLANTIC CONSORTIUM FOR GENETIC AND NEWBORN SCREENING SERVICES

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

## Autumn Updates from NYMAC

Recent activities in the New York–Mid-Atlantic Consortium for Genetic Newborn Screening Services took many forms:

- NYMAC's Evaluation Consultant, Susanna Ginsburg, reviewed NYMAC's activities and participated in the NCC Evaluation Workgroup. She is facilitating each workgroup's discussion of its goals, objectives and activities as part of the development of the NYMAC evaluation plan.

- Kate Tullis has joined NYMAC as the Patient and Family Coordinator.

- NYMAC recently hosted a Medical Home Seminar. Panel members spoke about their experiences with medical home from four perspectives: primary care-based medical home; specialty care-based medical home; parents of children with special health care needs (CSHCN); and a patient and parents of young adults with special health care needs.

- The NYMAC maps of patient residence/treatment center location for newborns with PKU, congenital hypothyroidism and sickle cell disease were displayed at the New York State GIS Conference. An abstract about the mapping project submitted to AMCHP was accepted for a skills-building workshop at the annual conference in March 2008.

- NYMAC is working with the Long-term Follow-up Subcommittee of the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children to develop, evaluate and distribute a survey about medical foods. A focus group of parents of children with metabolic diseases reviewed the questions and offered comments and clarification to the survey. Their insight will enable the Subcommittee to revise the survey to ensure that the information gleaned will be useful.

- NYMAC is sending mass spectrometer technicians from West Virginia, Delaware and New York to the Region 4 MS/MS training session, in December.

- The NYMAC Transitions and Distance Strategies Workgroups met in October. The former group's goal is to identify/develop and pilot models of transitioning for CSHCN from pediatric to adult medical care. They will address guardianship issues for people with special health care needs who cannot assume responsibility for themselves, collect transition protocols from Children's Hospitals in the region, and examine health insurance issues.

- The Distance Strategies Workgroup's goal is to improve access to medical care for people with special healthcare needs by developing distance strategies. They will focus on issues related to expansion of the newborn screening panel in West Virginia and access to clinical and metabolic genetic services. This group will also use the maps created during the last funding cycle to pilot distance strategies to ensure the availability of specialty care services in rural areas.

- The other four workgroups will meet in November. All groups get information about NCC inter-regional activities and about the other regions' activities that parallel or complement their goals and objectives. They also incorporate the NCC Evaluation Workgroup's matrix into their plans.

*http://www.wadsworth.org/newborn/nymac/*


*Submitted by: Alisha Keehn, MPA, Program Director*

## Region 3 Collaborative Holds Annual Meeting and Celebrates Consumer Alliance Kickoff

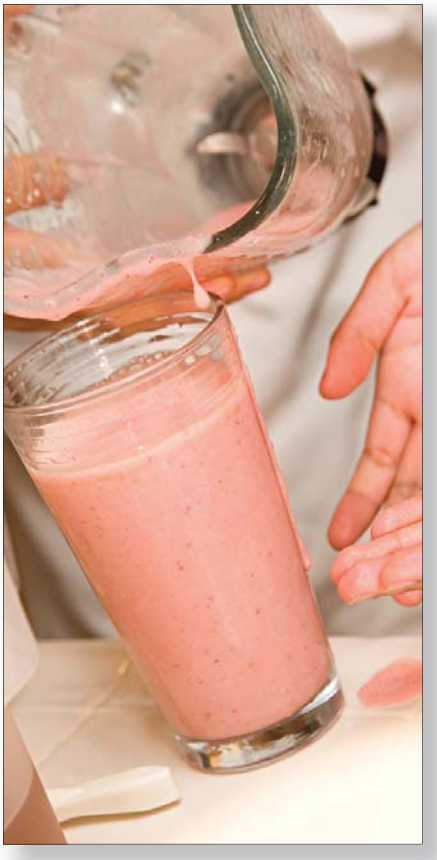
Summer 2007 was a fast moving and exciting time within Region 3. Following our metabolic camp and initiation of new grant year activities, Region 3 held its Annual Meeting on July 26, 2007 in New Orleans as part of the Southeastern Regional Genetics Group (SERGG) Annual Meeting. From a brief reporting of the prior year's activities to a broad overview of future plans and activities underway, the annual meeting gave extensive representation and welcome to the Region 3 Collaborative.

### Region 3 Consumer Alliance Kickoff

Perhaps the most exciting feature of the annual meeting was the successful inaugural Region 3 Consumer Alliance meeting held on July 27, 2007 in parallel to the SERGG Annual Meeting. Families from each state and territory were invited, and all but three attended. Recognizing the importance of including consumers and parents of children with heritable disorders beyond those identified by MS/MS, the Consumer Alliance has taken the critical step of involving families with hemoglobinopathies and galactosemia who participated in the meeting as well.

The day focused on providing consumers with a broad overview of the newborn screening process from screening and confirmatory testing to lifespan treatment and management. Each session began with an informational professional panel and concluded with consumer discussions focusing on their roles in each area and means of resolving identified gaps. A list of action items from each session was generated and now serves as the foundation for Consumer Alliance activities and focus. Since this inaugural meeting, monthly conference calls have maintained the group's momentum and the group is working closely with Region 3 to ensure that consumer and collaborative activities occur in partnership.

Of particular note, the group is currently tackling the critical and enormous medical foods issue within the region and beyond. In partnership with Deanna Harner of *United to Support Metabolic Disorders (USMD-PKU) In America* (based in Texas), the Region 3 Consumer Alliance is actively collaborating with national partners through several avenues to develop a Patient Assistance Program for Medical Foods and has begun soliciting and receiving commitments from medical food companies.



### Telegenetics RT1 Session

Another highlight of the annual meeting was the successful RT1 demonstration and training. Sixteen participants tested the latest version of RT1 and worked through identifying and resolving potential technical problems. A follow-up regional RT1 session is planned for the end of this month as part of the regular videoconferencing between states.
*http://region3genetics.org/*

> Region 3 Consumer Alliance is collaborating with national partners to develop a Patient Assistance Program for Medical Foods.

Region4
Genetics Collaborative

*Submitted by Susan Berry, MD, Project Lead and Abby Shannon, Region 4 Staff*

## Long-term Follow-up After NBS: The Inborn Errors of Metabolism Information System (IBEM-IS)

In the absence of protocols based on clinical evidence, clinicians caring for children with very rare disorders are faced with challenging treatment decisions. Practitioners often determine how they will treat children with inborn errors of metabolism based on how their mentors approached treatment, what they have read in a manual or text, or what they have learned from their own clinical experiences. Very few controlled trials exist and evidence-based medicine is therefore lacking due in large part to the rarity of these conditions. With only a handful of children diagnosed with inborn errors of metabolism each year in any given state, the lack of controlled studies and evidence based standards is not surprising.

Aware of the challenges and the need to develop evidence-based standards, dedicated professionals in Region 4 recognized that through regional collaboration, the number of children diagnosed with selected disorders is large enough to establish protocols. With the support of the Region 4 Genetics Collaborative, metabolic clinicians and NBS specialists representing all seven states began working together on a project to address the need for long-term outcome data.

The collaborative group began by defining disease-specific data elements for treatment of Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD) through a review of existing literature and all available plans for treatment. Work done by the Mountain States Collaborative around disease-specific planning elements was also incorporated. A database using web-based electronic medical records technology was designed with emphasis on HIPAA compliance, ease of entry at point of service, and ability to generate reports.

As the project evolved, treatment centers in Region 4 were engaged and staff began entering MCADD data as soon as IRB approval and client permission had been obtained. Using the process piloted with MCADD as a template, additional inborn errors of metabolism are being added to the database. To date, elements have been defined for 19 additional disorders. As new elements are added to the database and patients have given consent, centers will begin adding new disorder data. Future plans include defining a research agenda, implementing an MCADD intervention project (low vs. high dose carnitine), and integrating data with the departments of health and emergency services. The enthusiasm, team work, and commitment of those involved in the IBEM-IS have opened the door for the development of evidence-based treatment protocols with the potential to improve the care, health, and quality of life for children diagnosed with these rare conditions.

*http://www.region4genetics.org/*

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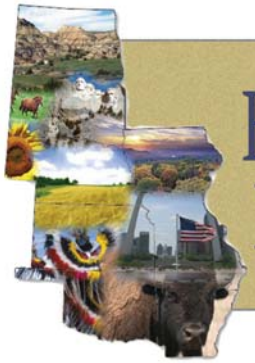
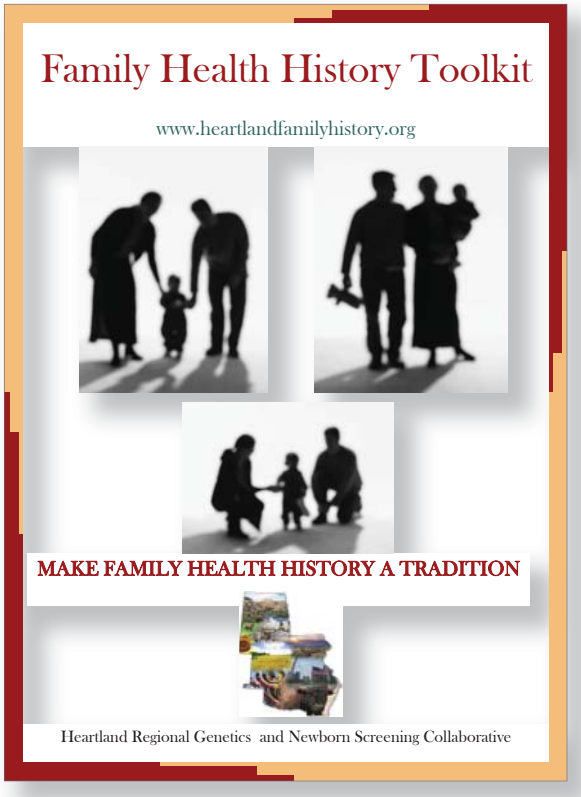


# Heartland Genetics and Newborn Screening Collaborative

*Submitted by Lori Williamson, MS, CGC, Project Director*

## Heartland RC Takes Multifaceted Approach to Promoting Family Health History




"The family health history is the cheapest genetic test," says Dr. John Mulvihill, PI of the Heartland Regional Genetics and Newborn Screening Collaborative. From our inception, public education about the family health history has been a major focus of both the pilot project program and the Education Committee. Debra Collins, genetic counselor, was awarded one of the first pilot projects grants to do a family health history public awareness campaign for the greater Kansas City area. A major product of that project was the website: http://www.kcfamilyhistory.org/ which provides family health history information in Spanish and English, information on genetic counseling, and it lists clinical services in Kansas City metro area.

Likewise, the Heartland Education Committee, under the leadership of Kim Piper, conducted three activities on this topic. First, the committee created a regional website devoted to family health history: http://www.heartlandfamilyhistory.org/. This website explains the importance of collecting the family health history, provides a video clip of a genetic counselor explaining how to collect the information, provides a toolkit which was adapted from one developed in Utah, identifies existing national and local resources on the family health history, and provides suggestions for what to do with the information after it is obtained. Additionally, a toll-free number was established to provide a mechanism for consumers with limited or no Internet access to request a hard copy of the tool kit.

The second activity targeted the hundreds of genealogy societies in our region, with a concept that could be called "medicalizing American genealogy." Letters from the region's state genetics coordinators were sent to genealogy societies informing them of the family health history resources. It is our belief that educated genealogists will significantly advance this public health initiative.

Third, we submitted an article on family health history to each of our states' rural electric cooperative magazines in an attempt to reach the rural, older generation. These magazines are of interest to rural families, and many of our rural families—especially the older generation—do not have Internet access in their homes.

Evaluation of uptake by genealogy societies and the magazines is pending. Our future plans include maintaining our regional website with new family health history resources; collaboration with Utah on a school curriculum for health, science, and family and consumer science teachers; adapting the Genetic Alliance materials for our region; and working with our Native American population on this topic. *http://heartland.ouhsc.edu*



Mountain States Genetics
Regional Collaborative Center

*Submitted by: Camille Miller, MSSW, Project Director; Joyce Hooker, Project Manager; and Liza Creel, MPH, MSGRCC*

## MSGRCC Genetics Policy Education Project: A Regional Assessment of Assets and Needs

For this issue of the *NCC Collaborator*, the MSGRCC would like to highlight the family history component of our Genetics Policy Education project, which focuses on systemic issues impacting or affecting the genetic services delivery system. Under this initiative, staff are surveying all eight states in the Mountain States Region to assess:

1. Assets such as current projects, materials and resources contributing to and eliminating barriers to gathering family histories.

2. Needs and gaps in family history services within the region that a variety of stakeholders may address.

Key to this project is the guidance, leadership and participation of the MSGRCC's Public Health Workgroup, made up of experts in areas of family history, medical home, emergency preparedness and telemedicine. When complete, this assessment will be used to inform and educate local and state policy decision makers and other stakeholders (especially primary care providers) on implementation, models of care and relevant solutions affecting the genetic services delivery system region-wide.

### MSGRCC Announces New Workgroups

We are also pleased to introduce our five newly formed workgroups that will achieve our goal of ensuring individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home.

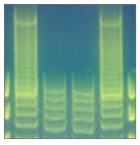
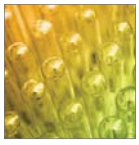
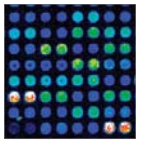
**Consumer Advocacy Workgroup**: The consumer workgroup will examine and advise the MSGRCC to ensure consumer focus and cultural sensitivity. At least one consumer will represent this workgroup on all other workgroups.

**Public Health Workgroup:** The public health workgroup will examine and advise the MSGRCC to ensure the use of public health practices. This workgroup is where issues such as emergency preparedness, medical home, telemedicine and family history will be addressed. At least one public health member will represent this workgroup on all other workgroups.

**Standards and Emergent Technologies Workgroup:** This workgroup will collaborate on initiatives for continuous quality improvement for regional genetics laboratories and education related to clinical laboratory testing of heritable disorders to primary care physicians and families by direct collaboration among participants in the region.

**Quality Improvement Workgroup:** This workgroup's mission is to improve the quality and accessibility of clinical genetics services in the Mountain States.

**Newborn Screening Workgroup:** Newborn Screening Workgroup members share expertise and resources between laboratory and follow-up aspects of newborn screening in order to assure quality in biochemical genetics screening and to promote state-of-the-art follow-up of affected newborns in this region.
*http://www.mostgene.org*

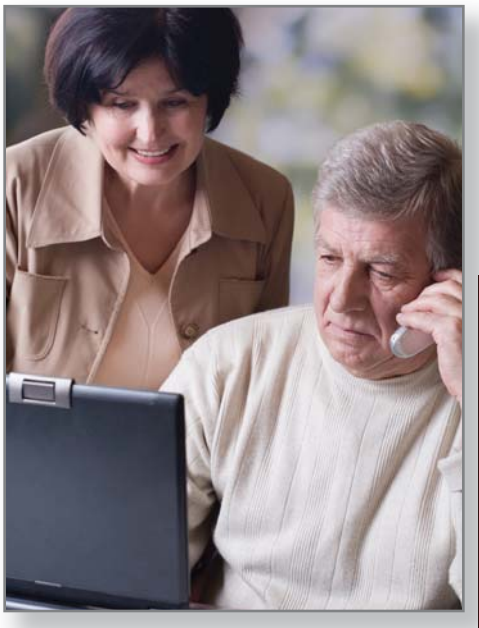





*Submitted by Lianne Hasegawa, MS, CGC, Project Coordiantor*

## WSGSC Adds Family Health History to the Thanksgiving Menu

With Thanksgiving rapidly approaching, several states in the Western States Genetic Services Collaborative have developed diverse family history activities. Here are a few highlights: **The Washington State Genetic Services Section** conducted presentations about family health history for employees at the state's Department of Health and for members of their diabetes support group. In addition, they distributed the Surgeon General's information sheets to healthcare providers. These colorful, one-page information sheets use concrete case examples to illustrate the importance of taking a family history, and they provide a link to the Surgeon General's family history tool. The Genetic Services Section is in the planning stages of a large- scale family history promotion effort that will occur next year.

The **Oregon Genetics Program** worked with Oregon Healthy Worksites to integrate information about the benefits of family health history into an October *You Have the Power to Stay Healthy* campaign. To prepare for this, the Genetics Program held a brown bag workshop about how to record family history information. In addition, the Genetics Program organized a display in the lobby of their state office building with materials about family history, including the Surgeon General's family history tool in both English and Spanish and the Utah Department of Health's Family



Health History Toolkit. Copies of six two-page fact sheets about family history of diabetes, heart disease, depression, colon cancer, prostate cancer, and breast cancer were also available and are posted on the genetics program website, www.oregongenetics.org.

The **Hawai'i Genetics Program** is dedicating the winter issue of its newsletter, *GeneNews*, to the importance of family history for clinical care. It will include an article discussing why knowing one's family history is important, a case scenario to illustrate the importance of family history, and information about family history tools such as My Family Health Portrait developed by the U.S. Surgeon General, and the Family Health History Toolkit created by the Utah Department of Health. The newsletter is distributed to health care providers, public health staff, educators, and families and is available on the Program website, www.hawaiigenetics.org.

…our hope is that these activities will help families begin conversations about their health history.

In addition to these activities, family history resources are available on the regional website: www.westernstatesgenetics.org. Whether it is during commercials between quarters of a football game, over old pictures pulled from ancient photo albums, or around a large dinning room table filled with turkey and gravy, our hope is that these activities will help families begin conversations about their health history.
*http://www.westernstatesgenetics.org/*

### Looking for Nevada?

Please check any documents your RC has generated that list the states in each regional collaborative group. Nevada recently moved from the Western States RC to the Mountain States RC.

# A Family Health History Tool to Fit Every Community

*Submitted by James O'Leary, Chief Operating Officer, Genetic Alliance*

Family health history is more than the classic genetic pedigree. It encompasses genetics, behavior, environment, and culture. As such, it is the natural choice for integrating genetics into medicine and public health.

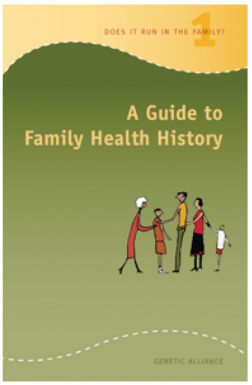
Genetic Alliance is partnering with a diverse group of communities to create customized family health history tools. We hypothesize that accessible tools produced by the community, for the community, will promote conversations about health within families and translate knowledge of family health history into healthy choices. Each community involved in the project adapts the *Does It Run In the Family?* toolkit, disseminates it to community members, and evaluates its usefulness through baseline and follow-up surveys. Evaluation of the project serves the dual purpose of measuring the utility of family health history in promoting healthy choices and determining necessary modifications of the toolkit for the creation of an online customizable version.

The online version (available in early 2008) will streamline this process by allowing users to choose photos, personal health stories, and quotations from an online file library or add their own. In addition, Genetic Alliance will be releasing an RFP for national and community organizations to beta test the customizable online tool.

For further information, go to www.geneticalliance.org/familyhealthhistory

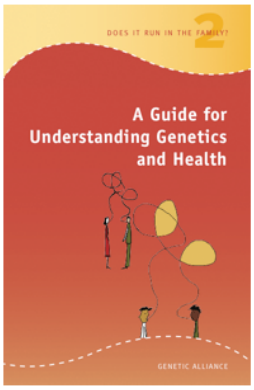
This work was funded in part by a grant (U33 MC06836) from the Maternal and Child Health Bureau, Health Resources and Services Administration. *http://www.geneticalliance.org*

## *Does It Run In the Family?* Toolkit



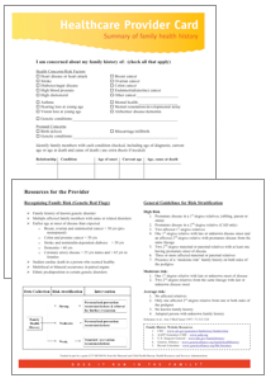

**A Guide to Family Health History**

This booklet provides information to help families collect, organize, and understand their family health history. Each section includes choices of activities, as well as useful resources and health stories.




**A Guide to Understanding Genetics and Health**

This booklet explains the basics of how genetics impacts health and how knowledge of family health history can be used to help individuals stay healthy. It also describes multiple diseases that "run in the family", who is at risk, and hints for health.




**Healthcare Provider Card**

This card is for individuals to fill out and bring to their healthcare provider.
*Side 1*: Concerns about your family health history.
*Side 2*: Information for the provider on how to best use your family history to determine risk.


**Family Health History Questionnaire**

This document can be used to quickly collect and record health information from relatives without doing a complete interview. Individuals can also send it out to get health updates.

Materials are available in English and Spanish.

# NCCCalendar

## REGIONAL MEETINGS

| | | |
|---|---|---|
| **Mountain States Genetics Regional Collaborative Center** | | |
| Kick-off Meeting | Jun 19-21, 2008 | Austin, TX |
| **Region 3 and Southeastern Regional Genetics Group, Inc.** | | |
| Annual Meeting | Jul 31 - Aug 2, 2008 | Charleston, SC |

## NATIONAL CONFERENCES

| | | |
|---|---|---|
| **Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDGDNC)** | | |
| Meetings: | Jan 14-15, 2008 | Bethesda, MD |
| | May 15-16, 2008 | Washington, DC |
| | Sep 22-23, 2008 | Washington, DC |
| **American College of Medical Genetics (ACMG)** | | |
| 2008 Annual Clinical Genetics Meeting | Mar 13-16, 2008 | Phoenix, AZ |
| 2009 Annual Clinical Genetics Meeting | Mar 25-28, 2009 | Tampa, FL |
| **American Society of Human Genetics (ASHG)** | | |
| Annual Meeting | Nov 12-15, 2008 | Philadelphia, PA |
| **Association of Public Health Laboratories (APHL)** | | |
| Annual Meeting | May 18-21, 2008 | St. Louis, MO |
| NBS and Genetic Testing Symposium | Nov 3-6, 2008 | San Antonio, TX |
| **Association of University Centers on Disability (AUCD)** | | |
| 2008 Disability Policy Seminar: Advancing Disability Policy in an Election Year | Mar 2-4, 2008 | Washington, DC |
| Annual Meeting and Conference | Nov 8-12, 2008 | Washington, DC |
| **Genetic Alliance** | | |
| Annual Conference | Jul 10-13, 2008 | Washington, DC |
| **National Birth Defects Prevention Network** | | |
| Annual Meeting | Feb 11-13, 2008 | Washington, DC |
| **National Society of Genetic Counselors (NSGC)** | | |
| Short Course | Oct 23-24, 2008 | Los Angeles, CA |
| 27th Annual Education Conference | Oct 24-28, 2008 | Los Angeles, CA |
| **Public Health Genetics Summer Institute** | | |
| Hosted by Emory University and the Centers for Disease Control and Prevention | Jun 10-12, 2008 | Atlanta, GA |
| **Secretary's Advisory Committee on Genetics, Health & Society (SACGHS)** | | |
| Meetings | Feb 12-13, 2008 | Bethesda, MD |
| | Jul 7-8, 2008 | Bethesda, MD |

**Musings on a Pedigreed Theme: ...,** continued from page 1.

ance, respectively. The Regional Collaborative reports also feature efforts to inform health professionals and the public about collecting and interpreting family health histories. These range from more traditional public health education campaigns to outreach through rural electric cooperatives, genealogy societies and groups of retirees, for whom the greatest gift they can leave their progeny is the information that will allow them to take advantage of the new genetic medicine (complete with its computerized risk assessment profiles), an accurate family health history.

*Note: A future issue of the NCC Collaborator will feature point-of-care decision support and provider education tools related to family history.*

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