



Community Faces

A Genetics and Health Forum Project
Salt Lake City, Utah 2009-2010

FINAL REPORT

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Executive Summary

In 2009, the Genetic Science Learning Center (GSLC) at the University of Utah received funding from the Education and Community Involvement Branch of the NIH National Human Genome Research Institute (NHGRI) to collaborate with diverse community organizations in the Salt Lake City area to facilitate dialogues about the connections between genetics and health. The funding provided five mini-grants of \$5,000 each for diverse community organizations; funding for two additional organizations was provided by the University's Center for Clinical and Translational Science and Department of Pediatrics. Based on their applications, the following community organizations received mini-grants to participate in the project: Calvary Baptist Church, 39th Chinese LDS Ward, Hispanic Health Care Task Force, Indian Walk-In Center, National Tongan American Society, Native Research Network, and United Africans of Utah.

Between November 2009 and May 2010, each community organization held one or more mini-forums to educate leaders and members of their community about the connections between genetics and health. The organizations identified the health conditions of highest concern in their community, planned the mini-forum format they thought would work best for their community, advertised the forums and recruited participants. The GSLC provided educational materials (adapted for each community) to assist with learning about the connections between genetics and health. It also assisted with identifying and inviting guest speakers who were knowledgeable about specific topics. Representatives from the GSLC and NHGRI participated in the mini-forums, if requested.



Hispanic Health Care Task Force mini-forum

One or two representatives from each community organization that received a mini-grant participated in the Community Faces Leadership Team. The Team met monthly to share their mini-forum experiences and to plan the culminating multi-cultural forum, which involved all of the communities. Through their interactions, the Team built trusting relationships that facilitated collaborative decision-making in planning a forum event that recognized and honored each community's experiences and addressed health concerns common to all.



The multi-cultural Community Faces: A Genetics and Health Forum was held on Saturday, May 1, 2010 at the Salt Lake Center for Science Education, a science-focused charter school of the Salt Lake City School District, which is located in an area where many community members reside. Approximately 360 people participated in the Forum. A slide show with photographs from the mini-forums, accompanied by a music selection from each community, welcomed attendees to the event. The Forum began with a presentation by each community, sharing its history in Utah. Sessions on heart disease, diabetes and cancer included community members sharing their personal experiences with these diseases as well as presentations by clinicians and researchers from NIH and the University of Utah Center for Clinical and Translational Science (funded by the Clinical and Translational Science Award program of the NIH National Center for Research Resources). A question and answer session at the end provided an opportunity for attendees to dialogue with the presenters. A concurrent children's program provided healthy lifestyle experiences and education.



A Genomics and Healthcare forum, held on April 30 at the University of Utah, engaged members of the Salt Lake City research community in dialogue with NHGRI researchers and staff about integrating genetics into electronic medical records and genetic approaches to investigating common diseases. Researchers from the University of Utah, NHGRI, Intermountain Healthcare, and the Veterans Administration Salt Lake City Health Care System participated. A genomics career discussion for graduate students and post-docs with NHGRI researchers and staff followed this forum.

Community Faces: A Genetics and Health Project

Vision

The Community Faces: A Genetics and Health Project emerged from the belief that understanding the relationship between genetics and health is important to making informed, preventive healthcare decisions for ourselves, our children, our families, and our friends. By increasing our knowledge we become empowered to improve health for our families and our community. We also believe that diverse community organizations and institutions can fruitfully dialogue and collaborate to build trust, learn from each other, and work together to enhance our communities' health.

Background

The Community Faces project built on the health-related education and work being carried out in the participating communities. Community leaders continually seek ways to improve health and health access for their members, to educate members about chronic diseases common in their community, and to address health disparities.

The Community Faces project was initiated by the University of Utah Genetic Science Learning Center. It grew out of the Family Genetics Education Through School and Community Partnerships project, which was part of the Consumer Genetics Education Network (CGEN) project. The CGEN project was facilitated by the March of Dimes and funded by the Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch. The Family Genetics Education project involved collaborations among a Hispanic/Latino Community Advisory Committee, the National Tongan American Society, the Utah Department of Health's Chronic Disease Genomics Program and Center for Multicultural Health, and the Genetic Science Learning Center. The first part of the Family Genetics Education project involved a collaboration with a Hispanic/Latino Community Advisory Committee, recruited by the Center for Multicultural Health; Center staff also participated in the Committee. The Committee adapted introductory genetics curriculum materials for fifth grade students and family health history curriculum materials for secondary students, so that the materials were culturally and linguistically appropriate for Utah's diverse Spanish-speaking community. They also developed ideas for take-home activities, designed to extend students' learning to their families. Both sets of curricula were tested with teachers, students and their families in Salt Lake City and Ogden, Utah and shown to be highly effective.



The second part of the Family Genetics Education project involved a collaboration with the National Tongan American Society and a Community Advisory Committee it recruited. This group selected the most appropriate genetics education materials for their community from among ones that had originally been developed for elementary and secondary students. They adapted these materials so that they were culturally and linguistically appropriate for use in adult education classes that foc

on the connections between genetics and health. The fifth grade curriculum materials used in the Family Genetics Education project had originally been developed by the Genetic Science Learning Center (GSLC) with input from fifth grade teachers. The secondary level curriculum materials had originally been developed by the GSLC and the Chronic Disease Genomics Program in collaboration with high school science teachers.

The proposal for what became the Community Faces: A Genetics and Health Project was based on the recommendations of two leaders who had participated in the Family Genetics Education project – Sylvia Rickard, Conference Chair of the Hispanic Health Care Task Force, and Fahina Tavake-Pasi, Executive Director of the National Tongan American Society. To engage communities in education and dialogue about the connections between genetics and health, they suggested mini-grants to community organizations to engage their members in appropriate ways, a leadership team within each community, a project leadership team composed of representatives from each community, and a culminating multi-cultural forum. These recommendations formed the initial framework for the Community Faces project, which evolved as it was implemented throughout the project year.

Community Mini-Grant Application Process

To initiate the Community Faces project, the GSLC identified potential community organization partners from previous collaborative projects, prior relationships, and conversations with the Utah Department of Health’s Center for Multicultural Health. The Center’s Community Liaison scheduled face-to-face meetings with individual community leaders to describe the project and to extend an invitation to complete and submit a mini-grant application. She also provided each leader with a binder of genetics and health education materials (including ones on family health history) that they might use with their community. The binder included materials from NHGRI, the Genetic Science Learning Center (including materials developed for the CGEN project) and the Genetic Alliance, and, as appropriate, materials developed by the CGEN project at Howard University. The project description that was shared with the leaders and the Mini-Grant Application are included in the Appendix to this report.

Twenty applications from organizations representing the African, African American, Asian, Hispanic/Latino, Native American, and Pacific Islander communities were received. The applications revealed a broad range of experience in grant-writing and identified this as a potential area for future training. Organizations were selected to represent each of the communities that applied. Funding for five organizations was provided by NHGRI. Through its partnerships, the GSLC was able to secure funding for two additional organizations from the University of Utah’s Center for Clinical and Translational Science (which is funded by a Clinical and Translational Science Award from the NIH National Center for Research Resources) and the Department of Pediatrics. The seven community organizations that received mini-grants were Calvary Baptist Church, the Chinese 39th Ward of The Church of Jesus Christ of Latter Day Saints, the Hispanic Health Care Task Force, the Indian Walk-In Center, the Native Research Network, the National Tongan American Society, and the United Africans of Utah.



United Africans of Utah mini-forum

Community Faces Partners

Each partner in the Community Faces project provided the following information about their organization and community.

Calvary Baptist Church

History: In 1892, a small group of women called "The Baptist Prayer Band" came together and organized the Calvary Baptist Church. The congregation has always been located in downtown Salt Lake City, Utah. The approximately 850 members of Calvary seek first and foremost to meet the spiritual needs of the community, then to help people wherever they hurt including education, housing, food, and health. The congregation consists predominately of African Americans and of people of various backgrounds and experiences. The Holy Bible informs our belief and behavior. We believe God created all human beings with worth and value.

For the Community Faces project, the African American community came together across several communities--Salt Lake County, Weber County, Davis County, and Utah County. Known leaders, medical professionals, and individuals from religious and secular backgrounds met and talked about numerous health disparities and strategies to deal with each. We left with a commitment to continue our education and to change our lifestyles for better health. Sharing this journey together makes for stronger community. We are determined to apply ourselves to study and growth.

-Pastor France A. Davis

United Africans of Utah

After realizing that African communities in Utah did not have a way of expressing their opinions and needs to the authorities, a group of Africans who lived in Utah got together and organized United Africans of Utah (UAU). The purpose of UAU is to serve as an umbrella for different African communities in Utah.

One of the challenges facing African communities in Utah, is health. This is due to many reasons, such as lack of education, the language barrier, low-paying jobs that do not provide medical insurance, lack of knowledge about how to access health resources and benefits, etc.

The United Africans of Utah has been working with its member communities in different ways to find solutions to these challenges. One approach has been to provide health workshops through the Utah Department of Health and other health providers. These workshops primarily educate community leaders who also educate their community members at large.

Some Africans came to Utah with high levels of education and degrees in the health field. However, their education is not recognized in the USA. Therefore, they have had to take low-paying jobs so that they can support themselves. UAU has been particularly speaking out for African doctors, so that they can be given an opportunity to practice their career.

-Valentine Mukundente

Chinese 39th LDS Ward

The Chinese 39th Ward of the Church of Jesus Christ of Latter Day Saints (LDS) has a history of half a century. Currently it is located on the campus of the University of Utah in Salt Lake City, Utah. It has 250 members of record of which approximately 160-170 attend weekly. Approximately one third of the people are from mainland China, one third from Taiwan and one third from Hong Kong. The Chinese community in Utah is becoming more highly educated. Each year more and more Chinese people come here as students and researchers. By and large they are younger people who are coming to Utah and they do not seem to have a lot of ailments.

From the Community Faces: A Genetics and Health Forum experience, there are a large number of people who would like to become more educated in the study of chronic diseases and genetics, especially illnesses that are particularly common in Chinese people. Some of these illnesses include diabetes, arthritic conditions, fertility issues and dietary problems.

-Yun Jones

Utah Hispanic Health Care Task Force

The Hispanic Community in Utah is the largest and fastest growing minority in our state. In 2004 Utah Hispanic Leaders recognized that the health care needs of our community were not being met and decided to form the Hispanic Health Care Task Force to find solutions to our community's healthcare barriers. This is a diverse population with roots in North, Central and South America as well as Europe. The HHCTF decided that in order to improve and empower our community we needed to educate healthcare providers at all levels, policy makers and community organizations who are trying, but not succeeding very well, to do outreach in our communities about the best ways to best serve our community.

Some of the barriers that exist to better healthcare in our community are a lack of health insurance due to poverty, a lack of education on the need for health insurance, and getting healthcare in a timely way. Another is a lack of trust in the U.S. healthcare system due to the fact that a number of Hispanics are either undocumented or have some family members with documents while others do not. Language, culture and a need for transportation for those in rural areas are big barriers. The need for medical providers from our own community who can speak our language and know our cultural has been a big barrier. The hunger exists in our community for more health knowledge to improve our healthcare and that of our families. To that end the Community Faces program has been very successful.

-Sylvia Garcia Rickard and Tatiana Allen

Indian Walk-In Center

The Indian Walk-In Center is a Title V Urban Indian Clinic providing health referrals, health education, and behavioral health services to the approximately 19,000 American Indians that live along the Wasatch Front (from Payson to Ogden in the state of Utah). Our service area is determined by the Phoenix Area Office of Indian Health Services, which is the main funder for our programs. Our mission is "healing the People by strengthening the community". Grants from the State of Utah, the federal government, and other funders allow us to reach to Utah's seven tribal/reservation communities and urban areas with prevention education, technical assistance, and trainings.

The Community Faces "Inherited Health" project has allowed us to introduce the concept of inherited health to our community in a culturally competent manner. This approach has garnered interest and support, whereas in the past, native people have been very skeptical about any project that includes words such as genes, DNA and research. Native people that we have been able to make contact with have shown a great interest, especially when discussions have included some of the chronic diseases that affect native communities in disparately high numbers. Although funding limited our direct activities to the Salt Lake Valley, some tribal communities invited members of our team, including staff from the University of Utah Genetic Science Learning Center to conduct discussions/workshops on their reservations.

The most important impact of the project to date has been the realization that early detection or chronic disease symptom monitoring, along with an awareness of family health histories and lifestyle changes, may help delay or prevent the onset of chronic diseases.

-Ed Napia

National Tongan American Society

The National Tongan American Society (NTAS) is a 501 (c) 3 non-profit organization that conducts business under an 11-member Board of Directors. It is located in Salt Lake City, Utah and has been serving the Pacific Islander population, with a focus on the Tongan population, since 1994. Outside of Hawaii, Utah has the largest percentage of Pacific Islanders in the nation. The majority of NTAS programs seek to decrease health disparities among Utah's Pacific Islanders. In addition to its health programs, NTAS also services the community in efforts to increase college graduation, sustain cultural preservation, improve employment opportunities, and promote good citizenship.

The Community Faces project has enabled our community to learn a very scientific concept in such a way that they were able to personalize it and to see the impact of genetics and risk behaviors in their lives. Most moving were the opportunities that it allowed for our community members to "talk stories" - - sharing stories and memories of their families who were burdened with genetic diseases - - and most important, the opportunity that this program provided participants to connect the glaring impact that they have as parents on the health and the future of their children's lives. Several parents have shed tears as they have played some of the games and come to this realization and many have set goals to change their eating and physical activity behaviors for the benefit of their children.

-Fahina Tavake-Pasi

Native Research Network

The Native Research Network, Inc. (NRN) was established in 1997 as a network and professional organization for those who are involved in any aspect of research in native populations.

The vision of NRN is to establish a leadership community of American Indian, Alaska Native, Native Hawaiian and Canadian Aboriginal persons promoting integrity and excellence in research. The NRN mission is to provide a proactive network of American Indian, Alaska Native, Native Hawaiian and Canadian Aboriginal persons to promote and advocate for high quality research that is collaborative, supportive and builds capacity and to promote an environment for research that operates on the principles of integrity, respect, trust, ethics, cooperation and open communication in multi-disciplinary fields.

The Native Research Network, Inc. logo is a stylized drawing of the hawk. The hawk circles his environment, continuously studying and observing. Like the hawk, NRN is a vehicle for studying the research environment. The circular pattern of the wings symbolizes the guidance, mentorship and nurturing the network offers its members and constituents.

In recent years, the NRN has begun holding an annual Native Health Research Network meeting, mentoring students who are the next generation of researchers in our communities, and conducting training in respectful research. One project that we accomplished within the current Community Faces project was to hold a series of focus groups via conference calls to discuss the role of genetic research in native communities. Results indicated that we need to learn more about genetics and genomics; that we ought to be aware of the conflict between our traditional and scientific realms of inquiry; and that we need to educate more students in science and begin at earlier stages.

-Lillian Tom Orme

Initial Project Plan

Based on the suggestions of the community leaders who participated in planning the project proposal, the following project plan was initially proposed to the collaborating communities. Each organization would bring together a community leadership team to learn about the connections between genetics and health, to identify the needs and interests of their community around this topic, and to carry out at least one mini-forum that addressed genetics and health concerns. The suggested community leadership team would consist of two leaders and eight other key community members. At least fifty community members (total) would attend one or more community mini-forums, to be held between December 2009 and May 2010. Two leaders from each community would participate in the project Leadership Team. This Team would meet monthly to share their experiences and to plan the culminating multi-cultural spring forum.

Community Mini-Grant Implementation

Each community signed a formal contract, negotiated with the University of Utah's Office of Sponsored Projects, which laid out expectations for their mini-grant, including the mini-grant project timeline from their proposal. Mini-grant funding was disbursed to the community organizations in three installments. Each community received \$2,000 after their contract was signed. Written reports, due in January and April, described the community's progress in meeting their project goals and outcomes, as outlined in their mini-grant application (see Appendix for report format). These reports and community leaders' attendance at the monthly project Leadership Team meetings were required for funding to be distributed to the organizations in January (\$2,000) and June (\$1,000).

Community leadership teams. The structure of the leadership team within each community varied, depending on the organization's prior involvement in community-based partnerships. One organization brought together a leadership team that mirrored the proposed community leadership team model, four communities had two key leaders, and two communities had one leader.

Materials created for community use. The following materials were created for use by the communities in their mini-grant projects:

- **Education needs assessment.** The GSLC provided an Education Needs Assessment that was reviewed and approved by the project Leadership Team (see Appendix). One community used this assessment and another community created their own assessment. Many of the other communities already knew their community's needs due to previous genetics and health collaborative experiences, or to their other work around healthcare issues. Several chose to create their own needs assessments due to the short project timeline and a desire to assess their community's needs as soon as possible.
- **Knowledge and behavior assessment.** The GSLC provided a Knowledge and Behavior Assessment that was reviewed and approved by the project Leadership Team (see Appendix). All communities used this Assessment at the end of each mini-forum as an evaluation tool. The Center's Evaluator summarized the Assessment data and the Community Liaison sent the report to the community leaders after the mini-forums. The assessment reports guided the community's leadership in preparing for subsequent mini-forums. These reports also provided information for the project Leadership Team as it planned the spring multi-cultural forum.

- **Templates for brochures and posters; spring forum registration form.** The GSLC provided templates for brochures and posters that communities could use with their mini-grant programs. Each leader received a CD-Rom with the templates as well as photographs with individuals representing their community that could be used on these materials. Calvary Baptist Church and the Native Research Network used the brochure templates. The GSLC also provided a registration form for the spring forum. The Hispanic Health Care Task Force created their own poster/flier and registration form for the spring forum.
- **What's Your Family Health Story?** The GSLC's family health history collection tool was individualized for each community that wished to use it with photographs representing individuals from their community. (http://learn.genetics.utah.edu/content/begin/traits/activities/pdfs/What's%20Your%20Family%20Health%20History_Public.pdf)

Community mini-forums. Each community held one or more mini-forum events designed to educate members about the connections between genetics and health and to elicit dialogue. The GSLC's Community Liaison and Director were available, if invited, to give presentations on inherited traits, the connections between genetics and chronic diseases, and family health history. These presentations used activities and materials developed for the Consumer Genetics Education Network (CGEN) project (adapted for each community), including "Pick the Risk", "Risk Continuum" and "What's Your Family Health Story?" These activities (along with others) are available on the Center's Learn.Genetics website at <http://learn.genetics.utah.edu/content/begin/traits/activities/>. The presentations also used adaptations of the slide set the Center had previously developed for NHGRI for DNA Day speakers. The slide set is available on the NHGRI website at <http://www.genome.gov/20519692>.

The GSLC's Community Liaison was in frequent contact with the leaders of each collaborating community as they planned and held their mini-forums. She found that email, followed by phone calls was often the best way to communicate; she also met with leaders in person and used texting. The GSLC's Community Liaison and/or Director attended each mini-forum. Each community gave a report on their mini-grant progress at the monthly project Leadership Team meetings.

The mini-forums each community held are briefly described below.

Calvary Baptist Church organized a leadership team led by Pastor France A. Davis with assistance from Doriene Lee. Pastors and leaders from 10 other churches in the area that serve the African American community participated. A mini-forum presentation by the GSLC Community Liaison and Director introduced this group to the connections between genetics and health. Calvary Baptist Church held four additional 2-3 hour mini-forums that included members of their church as well as representatives from the collaborating churches. Vence Bonham, director of the NHGRI Education and Community Involvement Branch, gave a mini-forum presentation on issues related to race, genetics and health. Finie Richardson, from the Department of Community and Family Medicine at Howard University, gave a mini-forum presentation on family health history, using materials Howard developed for the CGEN project. Pastor Davis led two mini-forums, eliciting rich discussions among participants about health issues of concern to them, such as prostate cancer, diabetes, heart disease, and high blood pressure.

The **Chinese 39th LDS Ward** held one large mini-forum. This 4-hour mini-forum included presentations on genetics, chronic disease and family health history as well as genetic counseling, cancer, diabetes, heart disease, and infertility. Presentations were made by representatives from the University of Utah's Diabetes Center, Department of Cardiology, Huntsman Cancer Institute, and Genetic Counseling program as well as the GSLC Community Liaison and Director. Several of the



presenters were Chinese and gave their presentations in Chinese. Simultaneous translation of the other presentations was provided by a community member through headsets. Breakout sessions provided opportunities for participants to meet with the presenters and learn more about each topic.

The **Hispanic Health Care Task Force** held two 4.5-5 hour mini-forums. Both forums included presentations on genetics, chronic disease and family health history as well as diabetes and cancer. The first forum included community leaders from the Salt Lake Valley, Ogden, and Park City, Utah. Presentations were made by representatives from the University of Utah's Diabetes Center and Huntsman Cancer Institute as well as the GSLC Community Liaison and Director. The second forum, for community members, also included a presentation on statistics, nutrition and prevention among Hispanics. This forum included the same presenters, as well as a presentation on healthy lifestyles by the Utah Department of Health Diabetes Program. Several of the presentations were in Spanish; translation was provided for presenters who did not speak Spanish.

The **National Tongan American Society** held four mini-forums for community members that focused on inherited traits, how genetic risk factors are passed through generations, lifestyle and genetic contributions to disease risk, and family health history. The NTAS Executive Director gave these presentations in Tongan, using the interactive activities on heredity and family health history developed for the Tongan community as part of the CGEN project.

Native populations?," "Do we have genetic counselors in our communities? In what ways could they be helpful?," "How do we best provide information about genetics and health or health conditions that affect us as Native people?" and "How can we encourage Native American students to pursue careers in science?"



The ***Indian Walk-In Center*** held four mini-forums that focused on inherited health, chronic disease, and family health history. The first mini-forum included health leaders from 5 local Utah tribes, who represent Uniting for One: A Health and Wellness Prevention Coalition. The second mini-forum was held at a Ute Community town hall meeting on the Uintah reservation. The third was held at the Ute Health Education Fair for middle and high school students and educators at Uintah River High School on the Ute Reservation. The fourth mini-forum was held at the Paiute Reservation Community Center. The audience included tribal leaders, tribal community members, and health care workers on the Reservation and in Cedar City, Utah. Presentations were provided by the GSLC Community Liaison; the Director also participated in the first mini-forum.

The ***United Africans of Utah*** held four mini-forums. These 1-hour forums were held monthly after the UAU business meetings that bring together representatives from each of the UAU-affiliated communities. The topics covered at the mini-forums included genetics, chronic disease and family health history as well as hypertension, high blood pressure, and mental health. Presentations were provided by representatives from the Utah Department of Health's Center for Diabetes, the University of Utah Social Services, and the University of Utah College of Pathology (Medical Microbiology) and the GSLC Community Liaison and Director.

Community Faces: A Genetics and Health Forum

Multi-cultural Spring Forum

Planning. The project Leadership Team included the leaders representing each community as well as Dulce Diaz, a Health Program Specialist with the Center for Multicultural Health at the Utah Department of Health, and the Genetic Science Learning Center's Community Liaison and Director. The Team met and collaborated monthly to plan and prepare for the multi-cultural spring forum. The GSLC's Community Liaison prepared an agenda for each meeting, facilitated the meetings, prepared meeting minutes, and disseminated the minutes to each community leader within a week of the meeting via email. The Community Liaison drew on her experience as an elementary teacher in schools with diverse students and as an instructor in the University's preservice teacher education program to facilitate and create a safe environment at each Team meeting, where each individual's voice could be heard and honored. Recording comments and suggestions on a white board or large paper helped recognize everyone's ideas. Taking time to discuss until consensus was reached, supported building Team collaboration. As our work together unfolded, several Team members who had originally felt they had little to contribute discovered they had skills and knowledge that made important contributions to the success of the project.

Informal feedback from the community leaders suggested the following strategies helped build a safe and successful collaborative relationship of trust:

The goal for the spring forum was to provide genetics and health education for approximately 400 Salt Lake City, Utah community members. The Team collaborated to determine the topics and structure for the educational experiences at the spring forum that would meet the needs of all participating communities. Potential topics that were discussed included cancer, diabetes, heart disease, drug addiction, asthma and mental health. The final forum topics—cancer, diabetes and heart disease—were identified using each community's mini-forum knowledge and behavior assessments. Every detail of the spring forum event was planned, prepared, and discussed by the Leadership Team, including the

name of the forum, the details of the forum program, the food that was served, the children's program, volunteers that would be needed, and logistics for the event.

The Team decided to hold the forum at the Salt Lake Center for Science Education, a Salt Lake City School District middle school, located on the west side of the city, where many of the participating communities are located. The GSLC has long-standing collaborative relationships with the principal, leaders, and teachers at this school, which facilitated making this arrangement.

- Well-organized preparation for Leadership Team meetings, including written agendas, prior research, slide presentations and meeting minutes, set high expectations for participation.
- The Director and Community Liaison researched potential objectives and goals from past NHGRI Community Genetics Forum projects and shared these with the Community Faces team to initiate their thinking and planning. This preparation became the springboard for the Community Faces team to dialogue and express exactly what they did and did not want the Spring Forum to look like, sound like, and feel like.
- Every planning meeting began with each leader sharing their past month's mini-forum learning experiences. This enabled the community leaders to share resources, presenters, mini-forum models, best practices and lessons learned as well as participate in each other's community events. For example, the National Tongan American Society was invited to present at a United Africans of Utah mini-forum about how the NTAS organizes diabetes prevention and education in their community. Communities empowering communities.
- A conference call line was available for Leadership Team meetings so that those who were not in town at that time were able to participate.
- Promptly beginning and ending meetings as scheduled exhibited respect and honor of everyone's time.
- Weekly emails kept everyone informed about Team progress.
- The Community Liaison was available 24/7 via cell phone for phone conversations.
- Open communication was facilitated by in-person conversations on a weekly basis. Conversations were requested by community leaders or took place when the Community Liaison felt inspired to stop by an organization for a visit.
- Time spent building individual personal relationships with each community and its leaders enabled the Community Liaison to recognize and draw on community strengths at the Leadership Team meetings.
- The Community Liaison and Director participated in collaborative mini-forum planning meetings with the leaders of each community. This enabled the mini-forum presenters to make culturally appropriate adjustments to their presentations and to address specific needs.
- The Community Liaison and Director attended many community events, building relationships of cultural understanding and trust. For example, they participated in celebrating the three-year anniversary of the United Africans of Utah and danced with the community, attended services at Calvary Baptist Church and participated in a special event honoring Martin Luther King, Jr., and participated in the Hispanic Health Care Task Force conference, organizing a session on a topic they requested.
- All commitments were accomplished with 100% follow-through.

The project Leadership Team meetings also impacted the planning of individual community mini-forums. As leaders shared their mini-forum experiences, other leaders were given support, direction, and inspiration to see the potential of possibilities that could exist at each mini-forum. Over time, powerful relationships of trust were established that empowered the leaders to collaborate openly among each other.

Each community was asked to collect registration information from members who planned to attend the spring forum. The registration form provided information for planning, including lunch preferences and children who would participate in the children's program.

Communication among the project Leadership Team members and with the GSLC Community Liaison occurred frequently—often daily—and was done through telephone, email, and personal visits. The Community Liaison attended many community events to build trust, support, and gain a greater understanding of each cooperating community; the Director also attended, when possible.

The GSLC's Community Liaison and Director were in frequent contact with the NHGRI ECIB director and staff to report progress on the project and to plan NHGRI involvement in the forum. Once the project Leadership Team had identified the disease foci for the spring forum and the format, the ECIB team recruited a NIH clinician or researcher to give a presentation on each topic. They also arranged NHGRI speakers for the research community forum held the day before the community forum, at the University of Utah. The ECIB arranged for Dr. Eric Green, the new NHGRI Director, to videotape a welcome for each of the two forums.

The GSLC's Community Liaison served as the project manager for the spring forum, organizing the myriad of logistical details required. She also recruited presenters for the youth program. The entire GSLC team contributed to the effort. The art team created posters, a website, artwork for forum tote bags, and banners that were used at the event as well as assembling the introductory slide show with music selected by the communities, and providing a seamless AV presentation during the event. The media team ran the sound system and did videotaping and photography to capture the forum in action. Everyone assisted during the forum to help it run smoothly.

The GSLC used its team wiki to record and keep track of project information. All experiences with communities were recorded on the Wiki for reflection and to use as a reference in collaborating with each community as well as preparing for the monthly Leadership Team meetings. Using the wiki enabled the GSLC team to make notes in conjunction with documents—an advantage over a shared file server. It also facilitated sharing information and documents among multiple members of the team. This was particularly important for the spring forum, which involved all GSLC team members.

The days before the forum saw a flurry of activity. Leadership Team members, GSLC staff and volunteers placed materials in the tote bags that attendees received. A caravan of vans and trucks transported beverages for the day and food for the continental breakfast, purchased at Costco. A dress rehearsal provided an opportunity for the Leadership Team and community members on the program to practice their presentations and walk through the staging.

Community Faces: A Genetics and Health Forum. The Saturday, May 1, 2010 spring Forum was attended by approximately 360 individuals. Members from all participating communities, presenters, and volunteers gathered together to learn about genetics and health. The efforts of the Community Faces Leadership team, the Genetic Science Learning Center, the University of Utah Clinical and Translational Science Center, the Utah Department of Health's Center for Multicultural Health, and the

National Human Genome Research Institute successfully merged together despite the early morning cold wind and rain. Greetings were shared and conversations about genetics and health filled the air of the Salt Lake Center for Science Education middle school in Salt Lake City, Utah. An event that had been carefully planned and hoped for finally arrived.

A slide show with photographs from the community mini-forums and other community events played while attendees gathered in the auditorium. Each community had selected a song representing their community to play with their slides. The Forum began with a welcome from Pastor France A. Davis, pastor of Calvary Baptist Church. A representative from each community then shared their history in Utah. Additional welcomes were made by Louisa Stark, GSLC Director; Eric Green, NHGRI Director (via video); and Vence Bonham, Chief of the Education and Community Involvement Branch at NHGRI. The Forum then focused on three diseases of high concern to all of the communities – heart disease, cancer and diabetes. The session on each disease began with two community members sharing stories about their and/or their community’s experiences with that disease. A speaker then provided clinical information about the disease and another speaker addressed research advances and directions related to the disease. One of these speakers was associated with NHGRI and one was associated with the University of Utah’s Center for Clinical and Translational Science. Forum participants had the opportunity to write and submit questions on cards during and after the talks. A panel of the day’s clinical and research speakers responded to these questions in the final session. Pastor Davis gave the closing dialogue, sharing the experiences of all of the communities that had participated in the project.

The schedule for the Forum is provided on the next several pages, followed by the schedule for the concurrent youth program, which focused on health and wellness.





**Community Faces:
A Genetics and Health Forum**

Saturday, May 1st, 2010
Salt Lake Center for Science Education
1400 West Goodwin Avenue (1400 W. 1150 N.)
Salt Lake City, Utah 84116
801.578.8226

- 8:15-9:00** Check-In Registration and Continental Breakfast
- 9:00-9:45** **MC: Pastor France A. Davis, Calvary Baptist Church**
"We are the Faces of Utah" slideshow
-Native American Community Member- Penelope Pinnecoose
-African American Community Member- Dr. Ron Coleman
-African Refugee Community Member- Hajaie Goll
-Chinese Community Leader- Yun Jones
-Hispanic/Latino Community Member- Olga Rubiano and Laura Leon
-Tongan Community Member- Supi Mailei
Review Forum Agenda
- 9:45-10:00** Welcome
Louisa Stark, Ph.D., Director, Genetic Science Learning Center, University of Utah
Eric Green, M.D., Ph.D., Director, NIH National Human Genome Research Institute
Vence Bonham, Jr., J.D., Chief, Education and Community Involvement Branch, NIH National Human Genome Research Institute
- 10:00-10:10** **MC: Fahina Tavake-Pasi, National Tongan American Society**
Story Telling: Genetics and Heart Disease
Fahina Pasi-Tavake, Executive Director, National Tongan American Society
Dr. Dai Di Jiang, General Medicine, China
- 10:10-10:55** Genetics and Heart Disease
Clinical Speaker: *Greg Feero, M.D., Ph.D., Special Advisor to the Director for Genomic Medicine, NIH National Human Genome Research Institute*
Research Speaker: *Dean Li, M.D., Ph.D., Distinguished Professor of Medicine and of Oncological Sciences, and of Human Genetics, H.A. and Edna Benning Endowed Professor, Division of Cardiology, Department of Internal Medicine, School of Medicine, University of Utah*
- 10:55-11:15** Dialogue Break, submit questions
- 11:15-11:25** **MC: Sylvia Rickard, Hispanic Health Care Task Force**
Story Telling: Genetics and Cancer
Sylvia Rickard, Director, Utah Breast Cancer Network, Hispanic Health Care Task Force Conference Chair, Field Coordinator for the National Breast Cancer Coalition for Utah and Idaho
Pastor Harold O. Fields, Unity Baptist Church

11:25-12:10 Genetics and Cancer

Clinical Speaker: *Jean Jenkins, R.N., Ph.D., Senior Clinical Advisor to the Director, NIH National Human Genome Research Institute*

Research Speaker: *Deborah Neklason, Ph.D., Research Assistant Professor Department of Oncological Sciences Investigator, Huntsman Cancer Institute, University of Utah*

12:10-1:10 Lunch

1:10-1:20 MC: Ed Napia, Indian Walk-In Center

Story Telling: Genetics and Diabetes

Ed Napia, Substance Abuse and Prevention Manager, Indian Walk-In Center

Lillian Tom-Orme, R.N., M.P.H., Ph.D., FAAN, Native Research Network

Marla Pardilla M.P.H., M.S.W., Native Research Network

1:20-2:05 Genetics and Diabetes

Clinical Speaker: *Donald McClain, M.D., Ph.D., Director, Center for Clinical and Translational Science, and Professor, Division of Endocrinology, Metabolism and Diabetes, School of Medicine, University of Utah*

Research Speaker: *Edward Ramos Ph.D., Research Fellow and Science Policy Analyst, NIH National Human Genome Research Institute*

2:05-2:25 Dialogue Break, submit questions

2:25-2:55 MC: Lillian Tom-Orme, Native Research Network

Question and Answer Panel, from questions submitted to dialogue box

2:55-3:15 MC: Heather Aiono, Genetic Science Learning Center

Pastor France A. Davis, Calvary Baptist Church Shares Closing Dialogue

3:15-3:30 Check-Out, Complete Forum Feedback Surveys

Sponsored By:

Department of Health and Human Services

National Institutes of Health

National Human Genome Research Institute

Genetic Science Learning Center

University of Utah

Center for Clinical and Translational Science

University of Utah

Department of Pediatrics

University of Utah

Utah Department of Health, Center for Multicultural Health

Salt Lake Center For Science Education, Salt Lake City School District

Community Faces: A Genetics and Health Forum
Youth Program Schedule
Saturday, May 1st, 2010

The activities may require a light, fun workout. The following are recommended but not required:

- Comfortable clothing, pants, athletic wear
- Tennis shoes

If a child needs a nap, please bring a blanket for the child to lie down on.

- 8:00-9:00** Parents check in children at Youth Program Desk
Child and Parent receive identification bracelet for the day; parents sign liability waiver. Child meets their volunteer guide for the day.
Children eat breakfast (muffins, fruit, juice, and a bottle of water).
Storytelling in English and Spanish about planting and eating healthy foods, and exercising
Gloria Nielsen, Librarian, Salt Lake Public Library
- 9:00-10:30** Planting Healthy Foods and Jordan River Field Trip
Children will learn the importance of being a part of a healthy world and how healthy foods grow. Each child will plant a seed to take home and watch grow.
Nick Rothacher, Outreach Specialist, Red Butte Garden
- 10:30-11:30** Eating Healthy Foods Art Education
Children will learn the importance of eating healthy using the food pyramid and the art of Italian Artist, Giuseppe Arcimboldo. Each child will receive an art kit to use for the activity and to take home.
Patrice Isabella, Nutrition Coordinator, Utah Department of Health
Shelly Rich, Art Specialist, Salt Lake School District
Hanani Aiono, 8th grade student, Hillside Middle School, Salt Lake City School District; Eagle Scout Project to provide and donate art kits
Snack: Granola Bars
- 11:30-12:30** Health Promotion Education Family Fun Lesson
Health education through language arts activities.
Joaquin Fenollar, Graduate Student, Department of Health Promotion and Education, University of Utah
- 12:30-1:15** Lunch
- 1:15-2:15** Importance of Exercise Lesson/Activity
Children will learn the importance of exercise. Each child will receive a rugby ball to use for the activity and to take home.
Highland High School Rugby Sophomore and Freshman Team and Coaches
Nehemiah Aiono, 10th grade student, Highland High School, Salt Lake City School District; Eagle Scout Project to provide and donate rugby balls
- 2:15-2:30** Snack: Fruit
- 2:30-3:00** Genetic Science Learning Center's Traits Trivia Game
Volunteers will teach children how to play the game. Children will take the game home to share with their family.
- 3:00-3:30** Storytime
Gloria Neilson, Librarian, Salt Lake Public Library
- 3:30** Parents pick up children
Volunteers allow parent with matching identification number to pick up child.

University of Utah Forum

University of Utah researchers were interested in taking advantage of NHGRI's presence for the community forum to engage in dialogue about genetics and healthcare. The GSLC Director met with the University's Center for Clinical and Translational Science leadership and researchers, who identified the following topics as ones in which Utah researchers are actively engaged, and which they would like to discuss at the forum: incorporation of genetics into electronic medical records, research studies to investigate common diseases, and NHGRI research priorities. This group also identified individuals to lead planning of the first two sessions. Joyce Mitchell, Professor and Chair of the Department of Biomedical Informatics, planned and moderated the genetics and electronic medical records session. Lynn Jorde, Professor and Chair of the Department of Human Genetics planned and moderated the research studies on common disease session. He indicated that a presentation by NHGRI researcher Teri Manolio would be very welcome. The NHGRI ECIB staff arranged for Teri Manolio to give this presentation, for Greg Feero to participate in the electronic medical records session, and for Laura Rodriguez to give the presentation on NHGRI research priorities.

The researcher forum was held at the University of Utah on April 30, 2010, the day before the community forum. A genomics career discussion for graduate students and post-docs followed the forum, led by Carla Easter and Edward Ramos from NHGRI. The forum schedule is listed on the following pages.



**A Dialogue with the NIH National Human Genome Research Institute
Genomics and Healthcare**
University of Utah
Friday, April 30, 2010

Eccles Institute of Human Genetics Auditorium (1st floor)

7:30-8:00 Registration and continental breakfast

8:00-8:15 Welcome

Louisa A. Stark, Ph.D., Director, Genetic Science Learning Center, University of Utah

Thomas N. Parks, Ph.D., Vice President for Research, University of Utah

Vence Bonham, Jr., J.D., Chief, Education and Community Involvement Branch, NIH
National Human Genome Research Institute

Eric D. Green, M.D., Ph.D., Director, NIH National Human Genome Research Institute (via
video)

Lynn B. Jorde, Ph.D., Chair, Department of Human Genetics, University of Utah

8:15-10:00 **Integrating Genetics into Electronic Medical Records**

Joyce Mitchell, Ph.D., F.A.C.M.I., F.A.C.M.G. Professor and Chair, Department of Biomedical
Informatics, University of Utah (Moderator)

Elaine Lyon, Ph.D., Division Medical Director, Genetics, ARUP Laboratories, and Associate
Professor, Department of Pathology, University of Utah

Bruce Bray, M.D., Associate Professor, Departments of Biomedical Informatics and
Cardiology, University of Utah

Marc Williams, M.D., Director, Intermountain Healthcare Clinical Genetics Institute

Laurence J. Meyer, M.D., Ph.D., Associate Chief of Staff, Research and Development,
Veterans Health Care, Salt Lake City and Professor, Departments of Dermatology and
Internal Medicine, University of Utah

Greg Feero, M.D., Ph.D., Special Advisor to the Director for Genomic Medicine, NIH
National Human Genome Research Institute

Panel Discussion

10:00-10:30 Break

10:30-11:30 **Investigating Common Diseases**

The Uses and Benefits of the Utah Population Database for the Genetic Study of Common Diseases

Ken R. Smith, Ph.D., Associate Director, Utah Population Database

Ontology-Driven Analyses of Personal Genome Sequences

Mark Yandell, Ph.D., Associate Professor, Department of Human Genetics, University of Utah

11:30-12:30 Lunch

12:30-1:30 **Genome Wide Association Studies and the Importance of Diversity**

Teri Manolio, MD, PhD, Director, NHGRI Office of Population Genomics and Senior Advisor to the Director for Population Genomics

1:30-2:00 Panel Discussion

2:00-3:00 **Research priorities at NIH NHGRI**

Laura Rodriguez, PhD, Acting Director, NHGRI Office of Policy, Communications and Education and Senior Advisor to the Director for Research Policy

Career Discussion for Grad Students and Post-Docs

Eccles Institute of Human Genetics, 6th floor conference room (Room 6400)

3:00-4:00 **NHGRI career discussion with graduate students and post-docs**

Edward Ramos Ph.D., Research Fellow and Science Policy Analyst, NIH National Human Genome Research Institute

Carla Easter, Ph.D., Science Education Specialist, NIH National Human Genome Research Institute

Debriefing with NHGRI

On May 19, 2010 a meeting was held for the project Leadership Team to debrief the Community Faces forum. Vence Bonham and Sarah Harding from NHGRI participated in the meeting via a conference call. The Leadership Team agreed that all of the communities still need to learn more about diabetes, heart disease, and cancer and voiced a need to:

- Address Health Promotion and Prevention Education
 - Educating the younger generation is a priority.
- Expand their expertise in genetics and health
 - Learn the language of research
 - Gain a greater understanding of clinical trials
 - Increase access to research opportunities
- Dialogue between community leaders, healthcare providers and researchers
 - Educate local healthcare providers and medical students so they can learn about the importance of being culturally competent in their practice and how to do this.

A second conference call debriefing with the NHGRI Director and leaders, NIH NCRR leaders and the project Leadership Team was held on June 17, 2010. Similar themes were expressed.

Next Steps

The project Leadership Team has indicated a strong desire to continue working collaboratively together and within their communities to facilitate learning that empowers individuals, families, and communities for better health. The Team agreed to adjourn meetings during the summer months and to reconvene monthly meetings from September 1, 2010 through June 2011. The Director of the University of Utah Center for Clinical and Translational Science (CCTS) is providing funding for the Community Liaison to participate as a member of the CCTS Community Engagement Core (CEC). She and other members of the CEC will continue to work with the Leadership Team as they build their capacity and plan their next projects.

Presentations at national meetings have elicited interest by other programs across the country in utilizing aspects of the community engagement model used for this project as well as the educational materials that were used. Presentations to date include:

- Campus Community Partnerships for Health, “Community Genetics Forum: A model engagement program” workshop, May 13-16, 2010, Portland, OR. Sarah Harding, NHGRI ECIB, Fahina Tavake-Pasi, National Tongan American Society, and Heather Aiono, Community Liaison.
- GenoCommunity Think Tank panel presentation, September 20-21, 2010, St. Louis, MO. Sylvia Richard, Hispanic Health Care Task Force and Heather Aiono, Community Liaison
- American Public Health Association round table presentations, November 6-10, 2010, Denver, Colorado. “Improving our health legacy: The Indian Walk-In Center inherited health project”, Ed Napia, Indian Walk-In Center and “Addressing chronic disease risk from a family health history perspective among Utah Pacific Islanders”, Fahina Tavake-Pasi, National Tongan American Society.

Community Engagement Reflections

The GSLC Community Liaison provided the following reflections about collaborative work with communities, from her viewpoint as a University-based facilitator:

Best Practices

- Learn as much about a community as possible prior to collaborating.
- It is important to attend community functions outside of the forum events to build trust.
- Never assume, always communicate, ask questions, and get advice from the Leadership Team.
- Be flexible; weekends and nights are the best times to work with communities.
- Collaboration requires time.
- The Community Liaison must keep organized “to do” lists, organized by each community.
- Realize that each community mini-forum structure will vary dependent on previous community partnership work, culture, and tradition.
- Community leaders appreciate having the mini-forum evaluation data a week after the event; this builds trust and validity to the experience.
- An organized agenda for the Leadership Team meetings is necessary, with detailed minutes sent within a week after the meeting to the Team. Starting and stopping meetings promptly is important. All of these details build trust and strong partnerships.
- The Community Liaison needs to model appropriate communication for the Leadership Team and be sensitive to genetics and health discussion topics at all times. Listening and asking questions is important.
- Promptly fulfill promises; when it is stated that something will get done, do it and communicate that it has been done immediately to the Leadership Team.
- Delegate and use the leadership talents on the Leadership Team to prepare for the Community Faces forum. Each community was responsible for providing five volunteers to attend the Community Faces forum, this could also have been useful in set-up and clean-up of the event.
- Adapting previously-developed educational materials for each community is a time-effective approach.
- Community members want to see a product after the Community Faces forum to see how their efforts impacted society or Salt Lake City, Utah, NHGRI, and University of Utah programs in the field of genetics and health.

Lessons Learned

- The Community Liaison position is a full-time position for a project that involves collaborations with several communities. This person will need to spend time building relationships and collaborating with each community. In addition, they will need to build relationships outside of the project experience.
- On the mini-grant application, ask for co-partners’ name and contact information, to assist with contacting them. Add a budget chart to be filled in like the timeline; this would make it easier for the contract to be written. Request applicants’ availability for meeting times to facilitate scheduling the first meeting.

- Email is not the most effective means to communicate with community leaders. Email can be used, but phone calls or personal meetings work best.
- Develop assessments with more input from the community leaders; this takes time.
- Determine a realistic length of time community members can attend a forum event. While the community leaders thought a longer event was appropriate for the spring forum, many community members left the spring forum at mid-day or right after lunch.
- Serve food at the end of forum events, such as the spring forum, to encourage participants to stay to the end.
- Provide transportation for community members to forum events. Some communities' lack of spring forum attendance was due to transportation challenges.
- Require that each community have interpretation and translation services available at all events, whether or not the community leaders think it is needed. Community members may attend who need these services in order to fully participate.
- Plan to have a photographer attend at least one mini-forum for each community. We did not think of this until after several events had taken place.
- Establish very clear procedures for handling forum surveys, including collection, translation, and data entry.
- If you plan a forum event for the research community, begin discussions and planning with that community at the same time you begin working with other communities.
- Prepare the grant application in collaboration with the leaders of as many communities as possible; involve your state or local health department, if appropriate.



Indian Walk-In Center mini-forum

Acknowledgements

A project of this magnitude could not have taken place without the contributions of many organizations and individuals. The project Leadership Team and the Genetic Science Learning Center team would like to thank everyone who participated and contributed.

Department of Health and Human Services

National Institutes of Health
National Human Genome Research Institute
Education and Community Involvement Branch

Utah Department of Health

Center for Multicultural Health
Diabetes Prevention and Control Program
Physical Activity, Nutrition and Obesity Program

University of Utah

Center for Clinical and Translational Science
Department of Biomedical Informatics
Department of Cardiology
Department of Pediatrics
Department of Health Promotion and Education, College of Health
Department of Human Genetics
Department of Pathology, School of Medicine
Department of Social Work
Graduate Program in Genetic Counseling, Department of Human Genetics
Office of Public Affairs and Marketing, University Health Care
University Hospital and Clinics Interpreter Services
Urban Institute for Teacher Education, College of Education
Utah Diabetes Center
Utah Population Database
Vice President for Research

Salt Lake City School District

Salt Lake Center for Science Education
Art Specialist
ARUP Laboratories
Boy Scout Troup #1083, Salt Lake City, Utah
Gold Cross Ambulance
Highland High School Rugby Team and Coaches
Department of Community and Family Medicine, Howard University
Huntsman Cancer Institute
Intermountain Healthcare Clinical Genetics Institute
Red Butte Garden
Salt Lake City Public Library
Veterans Health Care, Salt Lake City, Utah

Members and volunteers from:

Calvary Baptist Church & collaborating African American Churches
Chinese 39th LDS Ward
Hispanic Health Care Task Force
Indian Walk-In Center
National Tongan American Society
Native Research Network
United Africans of Utah

Project Evaluation

Outline

- I. Community Mini-Forum Surveys
 - A. Knowledge and Behavior Assessment: Description and Development of Survey
 - B. Education Needs Assessment
 - C. Mini-Forum Survey Results
 - a. Calvary Baptist Church
 - b. Chinese LDS Ward
 - c. Hispanic Health Care Task Force
 - d. Indian Walk-In Center
 - e. National Tongan American Society
 - f. United Africans of Utah
- II. Community Faces: A Genetics and Health Forum
 - A. Survey Development and Description
 - B. Survey Results
 - C. Panel Questions

I. Community Mini-Forum Surveys

A. Knowledge and Behavior Assessment: Description and Development of Survey

At the onset of the project, the Evaluator, Community Liaison, and GSLC Director collaboratively developed a logic model for the project, which was refined through a continuous process of feedback from one another and from community partners (see Community Genetics and Health Program Model in Appendix). The logic model provided a foundation for the development of the Mini-Forum Knowledge and Behavioral Assessment survey.

We continued to use the collaborative process between the project Evaluator, Community Liaison, and GSLC Director in the development of the survey. We used our collective experiences from previous community-based partnership programs with diverse communities to develop a survey that was appropriate in both content and reading level. First, the survey was developed with English Language Learners' needs in mind, at an approximately fifth-grade level (appropriate language). Second, we made several choices on the design of the mini-forum survey based on: (a) the short duration of the mini-forum sessions, which were typically 1 - 2 hours, and (b) the scope and focus of each mini-forum, which differed both among mini-forums held *within* a community, and *between* communities.

Therefore, we made the following choices:

1. We opted to do a posttest only design (instead of a pretest-posttest design), as we felt using a pre/post design was not appropriate or necessary in order to understand the learning gained.
2. We opted to use open-ended only items because we felt these types of items would inform our understanding of knowledge gain and intentions regarding behavioral change that we could not gain from Likert-scale or multiple-choice items.

The final survey was comprised of three open-ended items that asked participants about knowledge gain and intentions for behavioral change (see Appendix). The first item asked participants to name two things they learned from the session, in order to guide participants specifically in how to report their knowledge gain. The next two items asked participants about their intentions for behavioral change, which served as proxy measures for actual behavioral change. Question two asked participants about their intent to share the new information they gained with others, and if so, with whom.

Question three asked whether there was anything the participants would do differently based on what they learned during the session, and if so, what.

After the survey was finalized, we applied for, and received University of Utah Institutional Review Board approval for both the Mini-Forum Survey (the Knowledge and Behavior Assessment Survey) and the Community Faces Forum survey. Participants received copies of the Questionnaire Cover Letter at the end of each Forum session, as they completed the surveys (see Appendix). The surveys were analyzed by the Evaluator and a report was created for each Mini-Forum session. The Community Liaison emailed the reports to the appropriate community leaders.

B. Education Needs Assessment Survey

An Education Needs Assessment Survey was developed in order to assess the learning needs of the partnership communities (see Appendix). This survey was administered in Fall 2009 at the discretion of the community leaders, depending on whether they felt it would be beneficial for their communities in the development of their Mini-Forum sessions.

C. Mini-Forum Survey Summaries

A summary of the survey results for each community's mini-forums are provided on the following pages. If a community held more than one mini-forum, the results are combined into one summary.

a. Evaluation Summary, Calvary Baptist Church Mini-Forums

Demographic data. Participant attendance range = 11 – 36

Age Range	Session 1-9-10	Session 2-6-10	Session 2-27-10	Session 3-27-10
18-25	N/A	4%	6%	0%
26-35		0%	6%	9%
36-45		24%	13%	27%
46-55		18%	25%	18%
56-65		27%	31%	36%
66-75		18%	6%	9%
76-90		9%	0%	0%
Female	N/A	62%	75%	66%
Male		38%	25%	44%

Participant Learning from the Sessions (most common categories of responses)

Category	Rank (highest to lowest in frequency)
Specific health issue or concern/name of disease/intent to obtain screening for specific disease. In order of frequency: 1. Rise of STDs in black females 2. Cancer (prostate, pancreatic) 3. Depression 4. Diabetes	1
Benefits of collecting family health history	2
Resources available to the general public	3

Importance of being knowledgeable about health issues/family health history	4
Important differences between race and family health history	5
Importance of gaining knowledge about health and communicating the knowledge to others	5
Some health issues are specific to this community	6
Need for follow-through and continued work in health--related issues	7
Self education, and education = empowerment	8
Importance of collecting family health history	9
Access to physicians/physician awareness of community-specific needs	10
Genetics and race	11
Disease is not a race issue	11
Health disparities in the African American community	11
More research must be conducted on health issues specific to the African American community	11

Intent to Share New Information with Others

At least 80% of respondents indicated an intent to share the information with others.

Recipient	Session 1-9-10	Session 2-6-10	Session 2-27-10	Session 3-27-10
Family members	59%	70%	86%	40%
Friends/church members/community members	41%	26%		40%
Doctors	18%			
Colleagues	<1%			
Everyone (or general "yes")	<1%	17%		30%
Young people				10%

Change in Behavior

Depending on session, between 40% and 98% of respondents indicated an intent to change behavior. Specific behaviors are listed below.

Session 1-9-10	Session 2-6-10	Session 2-27-10	Session 3-27-10
Use resources to answer my questions/ask more questions/educate myself (29%)	Increase amount of exercise (29%)	Eat a more healthy diet and increase frequency of exercise (41%)	Increase frequency of exercise (40%)
Increase knowledge about health-related topics, such as: Conduct more research into personal health/check family health history/obtain information before visiting doctor (29%)	Increase knowledge about health-related topics, such as: Conduct more research into personal health/check family health history/obtain information before visiting doctor (29%)	2. Increase awareness of health issues and healthcare (40%)	Increase awareness of health issues and healthcare (40%)

Ask more questions of health care provider (14%)	Improve diet (24%)		Get a checkup and seek better information on the medical history already acquired through family health history (40%)
Invite others to the forum (11%)	Visit doctor more/work to obtain commitment from medical professional (14%)		

b. Evaluation Summary, Chinese 39th LDS Ward Mini-Forum

Held 1-16-10

Demographic data

Participants = 43

Age Range	Percent
18-25	9%
26-35	31%
36-45	38%
46-55	13%
56-65	3%
66-75	6%
76-90	0%
Female	72%
Male	28%

Participant Learning from the Sessions (most common categories of responses)

Category	Percent
Lifestyle choices/the environment can affect chances of getting a disease	26%
Name of a disease /use of term “risk factor”/use of term “genetic disease” with no explanation	24%
There is a connection between genetics and health	17%
Mention of diet, exercise, or diet plus exercise without connection to health or genetics	11%

Intent to Share New Information with Others

Almost 100% of respondents indicated an intent to share the information with others.

Recipient	Percent
Family members	80%
Friends	35%

Change in Behavior

Almost 100% of respondents indicated an intent to change behavior. Specific behaviors are listed below.

Responses	Percent
Eat a more healthy diet	57%
Exercise more	54%
Have a more healthy lifestyle	16%

c. Evaluation Summary, Hispanic Health Care Task Force Mini-Forum
 Session held 1-30-10

Demographic data

Participants = 10

Age Range	Percent
18-25	0%
26-35	0%
36-45	50%
46-55	40%
56-65	10%
66-75	0%
76-90	0%
Female	90%
Male	10%

Participant Learning from the Sessions (most common categories of responses)

Category	Percent
Relationship between genetics and health	23%
Importance of collecting family health history	19%
Genetics and lifestyle choices influence health	19%
Information about diabetes	14%

Intent to Share New Information with Others

100% of respondents indicated an intent to share the information with others.

Recipient	Percent
Students	60%
Family	50%
Friends	20%
Hispanic Community	10%

Change in Behavior

78% of respondents indicated an intent to change behavior. Specific behaviors are listed below.

Responses	Percent
Check family health history to identify future health risks	29%
Improve diet	29%
Share health-related information with others	29%

Note: the HHCTF held a second mini-forum on February 27, 2010, that was attended by 35 community members. Unfortunately, the surveys from this event were lost.

d. Evaluation Summary, Indian Walk-in Center Mini-Forum

Session held 1-18-10

Demographic data

Participants = 8

Age Range	Percent
18-25	N/A
26-35	
36-45	
46-55	
56-65	
66-75	
76-90	
Female	N/A
Male	

Participant Learning from the Sessions (most common categories of responses)

Category	Percent
How to collect family health history	36%
Relationship between genetics, health, and understanding risk factors	36%
The importance of knowing one's family health history	21%

Intent to Share New Information with Others

100% of respondents indicated an intent to share the information with others.

Recipient	Percent
Family members	63%
Community members	50%
Colleagues	25%
Future clients	13%

Change in Behavior

100% of respondents indicated an intent to change behavior. Specific behaviors are listed below.

Responses	Percent
Talk to family about family health history	40%
Take steps toward a healthier lifestyle	40%
Better understanding of what to teach clients about screenings	20%

Note: The Indian Walk-In Center held two additional mini-forums. The mini-forum held on April 29, 2010 at Fort Duchesne, Utah, on the Uintah Reservation, was a health fair style educational experience and was not conducive to formal evaluation feedback. Evaluations were not distributed at the mini-forum held on May 5, 2010 in Cedar City, Utah with members of the Paiute Tribe, due to the sensitive nature of the experience.

e. Evaluation Summary, National Tongan American Society Mini-Forums

Demographic data. Participant attendance range = 11 – 27

Age Range	Session 2-27-10	Session 3-23-10
10-17	13%	0%
18-25	33%	9%
26-35	4%	27%
36-45	17%	27%
46-55	13%	36%
56-65	17%	18%
66-75	0%	0%
76-90	4%	0%
Female	79%	62%
Male	21%	38%

Participant Learning from the Sessions (most common categories of responses)

Category	Rank (highest to lowest in frequency)
Inherited traits Learned behaviors Inherited traits <i>versus</i> learned behaviors	1
Taking action to improve health	2

Intent to Share New Information with Others

80% of respondents indicated an intent to share the information with others.

Recipient	Session 2-27-10	Session 3-23-10
-----------	--------------------	--------------------

Family members	59%	73%
Friends, colleagues, church members	19%	
Everyone	17%	
Smokers and anyone who needs to lose weight	17%	
Nonspecific		27%

Change in Behavior

Almost 100% of respondents indicated an intent change behavior. Specific behaviors are listed below.

Session 2-27-10	Session 3-23-10
Eat a more healthy diet and increase frequency of exercise (89%)	Change habits (45%)
Yes (no elaboration) (11%)	Eat a more healthy diet (45%)
	Increase exercise and amount of sleep (27%)
	Visit doctor more/work to obtain commitment from medical professional (14%)

f. Evaluation Summary, United Africans of Utah Mini-Forums

Demographic data. Participant attendance range = 12 – 29

Age Range	Session 2-14-10	Session 3-14-10	Session 4-11-10
18-25	15%	0%	0%
26-35	23%	18%	8%
36-45	23%	27%	50%
46-55	31%	9%	25%
56-65	8%	0%	8%
66-75	0%	18%	0%
76-90	0%	0%	8%
91+	0%	9%	0%
Female	31%	21%	50%
Male	38%	57%	17%
N/A	31%	21%	N/A

Participant Learning from the Sessions (most common categories of responses)

Category	Rank (highest to lowest in frequency)
Types of diabetes	1
Depression is real and can affect many people	2
Stress, managing stress	3
Symptoms/signs of diabetes	3
How to prevent diabetes	3
Relationship between health (including mental health) and genetics	4
Prevention of disease (including chronic diseases and mental illness) is best	4

Intent to Share New Information with Others

100% of respondents indicated an intent to share the information others.

Recipient	Session 2-14-10	Session 3-14-10	Session 4-11-10
Family members	76%	38%	57%
Friends/ Community members	24%	81%	50%
Everyone (or general "yes")		8%	

Change in Behavior

Depending on session, between 79% and 100% of respondents indicated an intent to respondents indicated an intent to change behavior. Specific behaviors are listed below.

Session 2-14-10	Session 3-14-10	Session 4-11-10
Learn more about spouse's family health history before marriage (27%)	Increase awareness about stress/ control stress (42%)	Increase amount of exercise and attention to diet (50%)
Have a healthier lifestyle (27%)	Importance of communication (25%)	Teach community members (40%)
Prevention (unclear what type of prevention) (18%)	Trust, openness, relating better to others (25%)	
Collect own family health history (9%)		

Note: The survey was not distributed at the first UAU mini-forum, held on January 10, 2010. Fifty-five individuals participated.

II. Community Faces: A Genetics and Health Forum

A. Survey Development

The development of the Multi-Cultural Forum questionnaire was an iterative and collaborative process between the program Evaluator, Community Liaison, and GSLC Director. Because previous NHGRI-funded Community Genetics Forums have had a similar foundation but different goals than the Utah Community Faces Forum, we used one of these Forum questionnaires, developed by the University of Michigan, as a base from which to work.

We discussed each item on the University of Michigan survey and eliminated the items whose purpose did not match the purposes and goals of the Utah Forum. We then began a process of discussion and deliberation over each remaining item, keeping a constant focus on the population of the participants in the Utah Forum and the goals of this Forum. We eliminated several more items and rewrote others, in order to align with the average reading level of our participants. Because of the wide range of English language abilities and comfort levels, we adhered to a fifth-grade reading level standard.

After a draft of the survey was complete, we went through several more rounds of discussion and question refinement. Through this process, we further refined the central goal of the Utah Community Faces Forum, which was to increase understanding in the partner communities about the relationship between genetics and health. For example, we replaced the word “genomics” with “genetics and health.” We also refined other questions to align with other Community Faces Forum goals, such as questions that asked about general satisfaction from the Forum and the hopes/aspirations participants’ had for their community regarding genetics and health education. The survey items then reflected the Forum content goals.

We also decided that we wanted the survey items to elucidate *what* the participants had learned rather than *whether* they had learned. This affected our choice of item type. We discussed the types of information that are conducive to Likert scale items and the types that are more appropriate for open-ended items. Based on these discussions, we decided to use several open-ended items, which we felt would enable us to achieve our goal of understanding *what* the participants had learned. Again, we used the University of Michigan’s survey items as a starting point for the development of the open-ended items, and through a process of discussion and refinement we developed items that met our criteria for content and readability.

The final instrument was a 12-item survey (see Appendix). Items 1- 9 were Likert scale items, and asked participants about their comfort level during the Forum in asking questions, whether the speakers were easy to understand, whether participants found the topics interesting, whether they would be more likely to collect their family’s family health history after the Forum, how much they knew about genetics and health previously, and whether they learned more about genetics and health from the Forum. Other questions asked about the usefulness of the presentations on cancer, heart disease, and diabetes.

The open-ended items, items 10-12, asked participants to name two things they learned today, to write about what they would like to see happen next in their community regarding genetics and health education, and whether they had any other comments to share.

The final three questions were demographic in nature. They asked participants to circle their age range, their gender, and their community membership.

In order to maximize responses by all Forum participants, the survey was translated into Chinese and Spanish.

B. Survey Results

Introduction

In order to understand participants' knowledge gain, general experiences, and satisfaction from the Forum conference, they were asked to complete a 12-item anonymous survey at the end of the conference. Nine of these items were Likert-scale and three were open-ended. An additional three items asked demographic questions regarding participants' gender, age range, and community membership.

All adult community members who attended the Forum conference (not including the children and youth program facilitators) were provided with a copy of the survey in their folder. Of these, 74 completed the survey (see table below).

Results: Demographics

Participants completed three demographic items at the end of the survey: gender, age range, and community membership.

Gender

Nearly twice as many females participated in the Forum as males. Total participants who answered this question: 61.

Gender	Numbers of participants	Percentage of participants
Female	40	66%
Male	21	34%

Age Range

Participants represented a diversity of age ranges. Total participants who answered this question: 68.

Age range	Number of participants	Percentage of participants
18 - 25	14	21
26 - 35	6	9
36 - 45	9	13
46 - 55	15	22
56 - 65	11	16
66 - 75	9	13
76 - 90	4	6

Community Membership

All communities were represented in the survey results except for the United Africans of Utah. The Tongan community returned the highest number of surveys. Total participants who answered this question: 70.

Community membership	Number of participants	Percentage of participants
African American	8	11%
Chinese	8	11%
Hispanic/Latino	8	11%
Native American	3	4%
Tongan	34	50%
United Africans of Utah	0	0%
University of Utah	5	7%
Other	4	6%

Results: General Learning and Understandings

Participants were asked to evaluate their Forum experience by indicating their level of agreement with six statements or questions about their general learning as a result of attending the Forum. Answers were scaled from one to four with the following coding scheme:

- 1 No (None)
- 2 A little
- 3 Some
- 4 A lot

In general, participants strongly agreed that the speakers were easy to understand (average score = 3.74) and agreed *some/what*/or *a lot* that they felt comfortable asking questions (3.22). Participants were extremely positive about whether they felt the topics covered in the Forum were interesting (3.84). Participants also felt strongly that after the Forum session they would be more likely to collect their family health history (3.77). Participants agreed *some/what* that they knew about genetics and health before the Forum session (2.94). Finally, participants strongly agreed that they learned more about genetics and health from attending the Forum (3.78). The table below provides details about participants' responses.

	FREQUENCIES AND PERCENTAGES OF RESPONSES				AVERAGE SCORE
	1 No	2 A Little	3 Some	4 A Lot	
1. The speakers were easy to understand.	0	0	19 (28%)	49 (72%)	3.74
1. I felt comfortable asking questions.	5 (8%)	10 (16%)	13 (21%)	34 (55%)	3.22
1. Today's topics were interesting.	0	1 (1%)	9 (13%)	57 (85%)	3.84
1. After today, I am more likely to collect my family health history.	0	1 (1%)	14 (18%)	64 (81%)	3.77
1. Before today, how much did you know about genetics and health?	3 (43%)	20 (29%)	24 (35%)	22 (32%)	2.94
1. Did you learn more about genetics and health today?	0	2 (3%)	10 (15%)	55 (82%)	3.78

Usefulness of Each Presentation about a Specific disease

Participants were asked to evaluate their Forum experience by indicating their level of agreement with three statements about the usefulness of the presentations that focused on one specific disease. These diseases were: cancer, heart disease, and diabetes. Answers were scaled from one to four with the following coding scheme:

- 1 Not
- 2 A little
- 3 Some
- 4 Very

In general, participants agreed that the presentations about cancer (average score = 3.53) and heart disease (3.52) were *some[what]* or *very* useful to them. They agreed *very* much that the presentations about diabetes were useful to them (3.76).

	FREQUENCIES AND PERCENTAGES OF RESPONSES				AVERAGE SCORE
	1 Not	2 A Little	3 Some	4 Very	
1. Cancer	3 (4%)	4 (6%)	18 (26%)	44 (64%)	3.53
1. Heart Disease	3 (1%)	1 (4%)	21 (78%)	2 (7%)	3.52
1. Diabetes	2 (3%)	1 (1%)	8 (12%)	57 (84%)	3.76

Open-ended items

The open-ended items were intended to elicit knowledge gain, elicit what participants envisioned next for their communities in terms of genetics and health, and to provide an opportunity to add any additional comments. The results are reported in terms of themes found in the responses, from most frequent to least frequent.

1. Name two things you learned today.

The eight most common categories of responses are reported below. Examples of responses are reported under each category. The categories are reported by percentage of total answers and are placed in order of frequency from most to least frequent.

Theme 1: Relationship between genetics, health, and lifestyle choices = 16% (14 of 85)

- “How genetics impacts health, family health history and cancer are related “
- “Better habits, health, and genetic history”
- “Most health issues are limited to diet and exercise habits”
- “How to control environmental factors like diet and exercise in our lives”
- “Diabetes, and my choices have affected my children”
- “How to control diabetes and exercise and eat right”

Theme 2: Diabetes: General facts (or misconceptions) – 16% (14 of 85)

- “Diabetes can be cured if caught early”
- “You can start developing diabetes at a young age, not only in my culture but in other cultures”
- “Differences in types of diabetes”

Theme 3: Important role of family health history – 14% (12 of 85)

- “History is best indicator of certain diseases”
- “Genetic history has a very important role in my life, my community and family”
- “Family history could prevent a lot of diseases”

Theme 4: Health issues specific to certain communities - 14% (12 of 85)

- “Native American diabetes rate, African American disparities”
- “Specific health issues within communities”
- “I’ve learned that although we are of different nationalities we share common illnesses, when people come here their diets change dramatically”

Theme 5: Name of disease or just listing the word *genetics* – 13% (11 of 85)

- “Colon cancer, obesity, and diabetes”
- “Genetic”
- “Obesity and diabetes”
- “Diabetes, cancer”

Theme 6: Importance and need for research and information – 11% (9 of 85)

- “Need more information for prevention”
- “We are not alone, new need to be more education about our risk to ill in our families”
- “I learned that together we can make amazing advances”
- “How research helps to find answers to diseases”
- “Be information seeking, don’t always accept the assumption and status quo”

Theme 7: genetics and disease (no explanation) – 6% (5 of 85)

- “Heart disease and DNA”
- “Obesity and genetic DNA”
- “Genetics and cancer prevention”

Theme 8: General: Prevention and early intervention – 5% (4 of 85)

- “Prevention”
- “Early intervention”
- “Prevention and taking care of my family”

11. *You have learned about genetics and health. What would you like to happen next in your community?*

The five most common categories of responses are reported below. Examples of responses are reported under each category. The categories are reported by percentage of total answers and presented in order of frequency from most to least frequent.

Theme 1: More information on topics in health, genetics, and/or lifestyle change - 31% (18 of 59)

- “Exercise and diet information”
- “More diabetes information”
- “I want more information for my Tongan community”
- “More education of cancer prevention and food safety”
- “Scientific information about genetics”

Theme 2: Taking action for community - 22% (13 of 59)

- “I would love to exercise more and encourage my community to do so”
- “Help them how to keep away diabetes”
- “Talk to others about what would be important and valuable”
- “Better nutrition”
- “High blood pressure and screenings within community”
- “Helping people understand how to access care, and understand benefits”

Theme 3: Awareness for community - 14% (8 of 59)

- “Hopefully my community can be more aware of disease, and government will fund more”
- “I want my community to be more aware of education such as the one given today”
- “Widespread education for all community members”

Theme 4: Have another conference/dialogue - 8% (5 of 59)

- “Another genetics forum at the U of U, with more involvement from entire community, especially women”
- “Another conference”
- “Have sessions like this one”

Theme 5: More information and action for youth - 8% (5 of 59)

- “I would like to see the youth program made available at schools”
- “More resources for youth and community, community involvement in science and research”

12. Any other comments?

The five most common categories of responses are reported below. Examples of responses are reported under each category. The categories are reported by percentage of total answers and placed in order of frequency from most to least frequent.

Theme 1: General statements regarding enjoyment of day 47% (20 of 43)

- “Good presentations”
- “Good information on health genetics”
- “Love the way you have all prepared. Thanks!”
- “This is the best conference in Utah that I have been to, by far!”
- “Very informative”
- “Coverage was good”
- “Good free stuff, I liked the food and info packets”
- “Thank you for the call to encourage youth to go into science”

Theme 2: Recommendations for future conference 14% (6 of 43)

- “We need another session, sometimes too loud or soft”
- “I would like to know who attended”
- “Microphone system needs improvement. “
- “Cold, some speakers could not be heard, spoke too fast, very technical language, sitting too long”
- “People with disabilities need handicap parking/why no black doctors on panel? Need representation of all cultures!”

Theme 3: Hopes for education for community/future forums 12% (5 of 43)

- “Need to educate community and do it every day”

- “This kind of workshop needs to be done regularly”
- “I hope we do this again! Great for community.”
- “We want another conference and breakout sessions, how to get culturally appropriate healthcare”

Theme 4: Plans for action-taking (individual level) 7% (3 of 43)

- “See doctor every month”
- “Improve lifestyle”
- “Will pass this on to children”

Theme 5: Positives about program facility 5% (2 of 43)

- “Liked having all presentations in the same room”

In addition, the project Leadership Team reported informal comments from participants, who said that holding the forum in a neighborhood school made it feel more welcoming and less

Community membership	Number of participants per community who signed in to the conference	Number of participants per community who completed a survey (Percentage of those who signed in)
African American	42	8 (19%)
Chinese	33	8 (24%)
Hispanic/Latino	42	8 (19%)
Native American	2 (NRN) 12 (IWIC) = 15	3 (20%)
Tongan	50	34 (68%)
United Africans of Utah	14	0 (0%)
University of Utah	20	5 (25%)
Other (community at large, does not include children or volunteers)	27	4 (15%)

intimidating than if the forum had been held at the University of Utah or at a conference center.

C. Limitations

A limitation on the conclusions that can be drawn from the forum survey responses is that only 26% of individuals who received surveys, completed them. This may have been due to several factors:

- Many people left after lunch without completing a survey. The length of the conference and the poor weather may have affected survey completion.
- Literacy issues may have played a part in survey completion. Despite our efforts to word questions at a fifth grade level, individuals may still not have been able to read the survey well. They also may have lacked writing skills. The surveys may not have been in an individual’s primary language. The Hispanic/Latino and Chinese community leaders decided to translate the survey. The other communities that include members for whom English is not their first language decided that there were too many languages for translation.

D. Panel Questions

During the conference the participants were encouraged to record on note cards any questions they had for the presenters during the panel discussion. Many of these questions were read out loud by the session moderator and answered by the speakers during the panel discussion. These questions are categorized below into four broad themes and one miscellaneous category.

Theme 1: Specific health-related questions (mostly diabetes-related)

- I am Chinese. I am a diabetic patient. Every morning, I need to have an insulin shot about 10 mls. Can I improve my lifestyle, improve my overall health, and eat healthier food? Is it possible that I will no longer need any more insulin shots? Can I be cured? Patient Mr. KO.
- Our people are suffering. Diabetes is a higher rate and hearing the triggers, one of it is cold weather and seeing that cold weather is not very conducive to good circulation. What's your advice on this particular trigger?
- With type 2 diabetes is it more common to get insulin shots or take medication for this disease?
- Is type 2 diabetes reversible? (Curable)
- For Dr. Neklason: Please explain an example of what education was provided that prevented cancer?
- What types of diabetes are most commonly found in all communities?

Theme 2: Future forum-related questions

- Is there a website or group to stay posted on upcoming community education forums?
- The important information is crucial not only for parents but for younger generations. I wonder if these kinds of forum could be credit for college students and assisting some community workers with a certificate. (My college student who came with me, asked me this.) Also, citizenship hours could be earned by high school students, as they participate in forum preparations.

Theme 3: Research-related questions

- How can we make sure research is not like the Tuskegee studies?
- Is there any current studies in Diabetes that involve Asian and Pacific Islander communities and if so how can we participate?
- Experts on Diabetes research: What kinds of main outcomes do you look at when you do diabetes research? Is there any effective drug to cure diabetes type 2? Disease management?

Theme 4: National/Policy/Society-related questions

- Where do you guys stand with the Health Reform? More people now are without insurance. No prescreening can be done. More physicians now are not taking Medicaid and Medicare.
- How does all the medications and food we take will affect the future generations? Also the food processed? Genetic future for our children will have more disease?
- In my job as a health educator, I am really disturbed to see that I must fight "the Goliath" of junk food served in lunchrooms. Students are offered 4 choices; pizza, nachos, hamburger, and a healthier dish everyday. The director of food services said that they serve pizza because

students will eat it and it is cheaper. So, why does this happen? How do we want to raise healthier children if most schools serve terrible food? What is being done to change this? Furthermore, exercise classes are taken away from elementary schools, why?

- Could someone address prevention early in life such as preconception- bring in good health, prenatal care and then the significance of breastfeeding to decrease incidence of disease. Thank you!
- Who pays for early screening? Often insurance follows guidelines recommended, so is it possible to get screenings paid for?

Miscellaneous

- My son was interviewed by a U of U professor: What got you to where your are at? (Starting full back for Saints, Super Bowl 44) He told of all the sacrifice, but he concluded with acknowledging the make up of his DNA and he said there is no doubt my Genetics. I'm involved in these as my mission to help family and community. Genes- His father was named the National Athlete. He is now hooked us all up on Healthy Diet (lifestyle)

APPENDIX

Project Summary for Communities

Community Mini-Grant Application

Mini-Grant Progress Report Guide

Education Needs Assessment

Community Genetics and Health Program Model

Knowledge and Behavior Assessment Cover Letter

Mini-Forum Knowledge and Behavior Assessment

Community Faces Forum Registration

Community Faces Forum Knowledge and Behavior Assessment



New scientific discoveries are revealing the connections between genetics and health. A basic understanding about these associations is increasingly important to making informed healthcare decisions. However, many community members are not yet aware of the connections between genetics and health. Many common health conditions have a genetic component that can run in families and increase one's risk of developing the disease. These conditions include diabetes, asthma, heart disease, cancer, high blood pressure, stroke, osteoporosis, and addiction. However, genetics is often viewed as topic that is difficult to understand. In addition, due to past experiences, some communities have concerns about the use of genetic information.

In an effort to address these issues, the National Institutes of Health (NIH) has developed the Community Genetics Forum program to engage in dialogues about genetics with diverse communities across the US. The program is run by the Education and Community Involvement Branch of the National Human Genome Research Institute at NIH. Each year the program funds an organization in a different region of the country to facilitate the dialogues in its area. Past Forum programs have been held in WA, NC, and MI/IL/IA/MN/MO. This year, the Genetic Science Learning Center at the University of Utah worked with community representatives to plan and apply for this grant. The funding was awarded and provides for:

- **Five mini-grants of \$5,000 each for diverse community organizations.** Between November 2009 and March 2010, each organization is asked to:
 - Hold meeting(s) with their community leaders to discuss:
 - The genetics-related topics that they feel are most important to their community
 - How to engage other community members in discussions about these topics
 - Hold at least one meeting/event with members of their community to learn about and/or discuss the topics identified by community leaders.

The Genetic Science Learning Center can provide educational materials to assist with learning about the connections between genetics and health. Representatives from the Center and the NIH also will be available to participate in these discussions, if requested.

- **A Saturday, multi-cultural forum in April 2010**, during which the community dialogues will be shared. This forum will provide an opportunity for:
 - Diverse Utah community voices, along with any issues and concerns, to be heard by representatives from the National Institutes of Health
 - Sharing among communities and with University researchers

A representative of each community that receives a mini-grant will participate in planning the forum. Genetics and health-related activities will be provided for children.

Co-sponsors of the project include:

Community Engagement Core, Center for Clinical and Translational Science, University of Utah
Center for Multicultural Health, Utah Department of Health

We invite your organization to apply for a mini-grant to participate in this exciting project!

For more information, contact:

Heather Aiono, Senior Education Specialist
Genetic Science Learning Center, Univ. of Utah
Phone: 801-585-0019 Email: heather.aiono@utah.edu



Community Dialogues About Genetics and Health

-Mini-Grant Application-

Deadline for Application: Must be post marked or emailed by October 30, 2009

**Please read program summary prior to completing application to fully understand the forum purpose and requirements.*

Send to:

Genetic Science Learning Center
Attention: Heather Aiono
15 North 2030 East
Salt Lake City, Utah 84112-5330

Email:

heather.aiono@utah.edu

FAX:

801-585-9557

Mini-Grant Award: \$5,000

Date:

Organization:

Primary Contact:

Title:

Mailing Address:

City:

Zip:

Email Address:

Phone:

Description of Project

1. Describe the community population you serve.

2. How do you plan to engage your community in dialogues about how genetics relates to their health?

2a. Are you able to commit the following for this project?

- Bi-weekly conference calls with the Genetic Science Learning Center to discuss your progress on the project (the Center is required to report bi-weekly to the funder)
- Monthly meetings with the Genetic Science Learning Center for planning the final Spring Forum
- Holding at least 1-2 meetings with approximately 10 leaders in your community. The meetings may be held within an existing program. We are open to ideas.
- Planning and hosting at least 1-2 meetings/programs with at least 50 community members. The meetings may be held within an existing program. We are open to ideas.

2b. What topics do you think may be important to discuss in your community that relate to genetics and their health?

2c. How might you engage community members in learning about and discussing the decided topics?

3. What is your timeline for meeting with community leaders and community members?

Target Date(s)	Project Meeting

4. Briefly describe how the \$5,000 will be spent in engaging your community in dialogues about how genetics relates to their health. *Some possible expenses are food, room rental, advertising, program materials, staff time, etc.*

Community Dialogues about Genetics and Health Progress Report Guide

The purpose of the Mini-Forums is to provide education about the relationship between genetics and your health.

Progress Reports are due: January 4 and March 1, 2010

- Send to Heather Aiono: heather.aiono@utah.edu

The Progress Reports provide an update on your planning process, the Mini-Forum experiences, and the Mini-Forum follow-up process.

In your written report, please provide detailed descriptions of the following:

1. Your planning process

- Report on your planning meetings
 - Attach the agenda for each meeting and the meeting minutes
 - Include a list of attendees
- Compare your progress on this project to the timeline you submitted you're your mini-grant application.
 - How has your timeline changed? What are the reasons for any changes?

2. The Mini-Forum experience

If applicable:

- How many Mini-Forums have you held?
- Attach an agenda or outline for each Mini-Forum.
- What topics were covered?
- How were these topics covered?
- How did participants respond to the topics?
- What topics were of most and least interest to participants?
- What questions did participants ask?
- What concerns did participants have?
- Did you serve refreshments? If so, what?
- If you have not yet conducted a Mini-Forum, when will it take place?

3. Mini-Forum(s) feedback and follow-up

- What did you learn from the Mini-Forum experience(s)?
- What would you have done differently?
- What did you learn from the assessment results from the Mini-Forum(s)?
- What will you do differently at the next Mini-Forum (if applicable)?

Community Dialogues about Genetics and Health Education Needs Assessment

The purpose of the Mini-Forums is to provide education about the relationship between genetics and your health.

We would like to know how interested you are in learning more about the following topics about genetics and your health. Please circle your response below.

How interested are you in learning more about:

1. What makes you unique, or one of a kind

Very Interested	Somewhat Interested	Not Interested
-----------------	---------------------	----------------

2. Why family members look alike

Very Interested	Somewhat Interested	Not Interested
-----------------	---------------------	----------------

3. Why some diseases like diabetes or cancer run in families

Very Interested	Somewhat Interested	Not Interested
-----------------	---------------------	----------------

4. How learning your family health history can help you stay healthy

Very Interested	Somewhat Interested	Not Interested
-----------------	---------------------	----------------

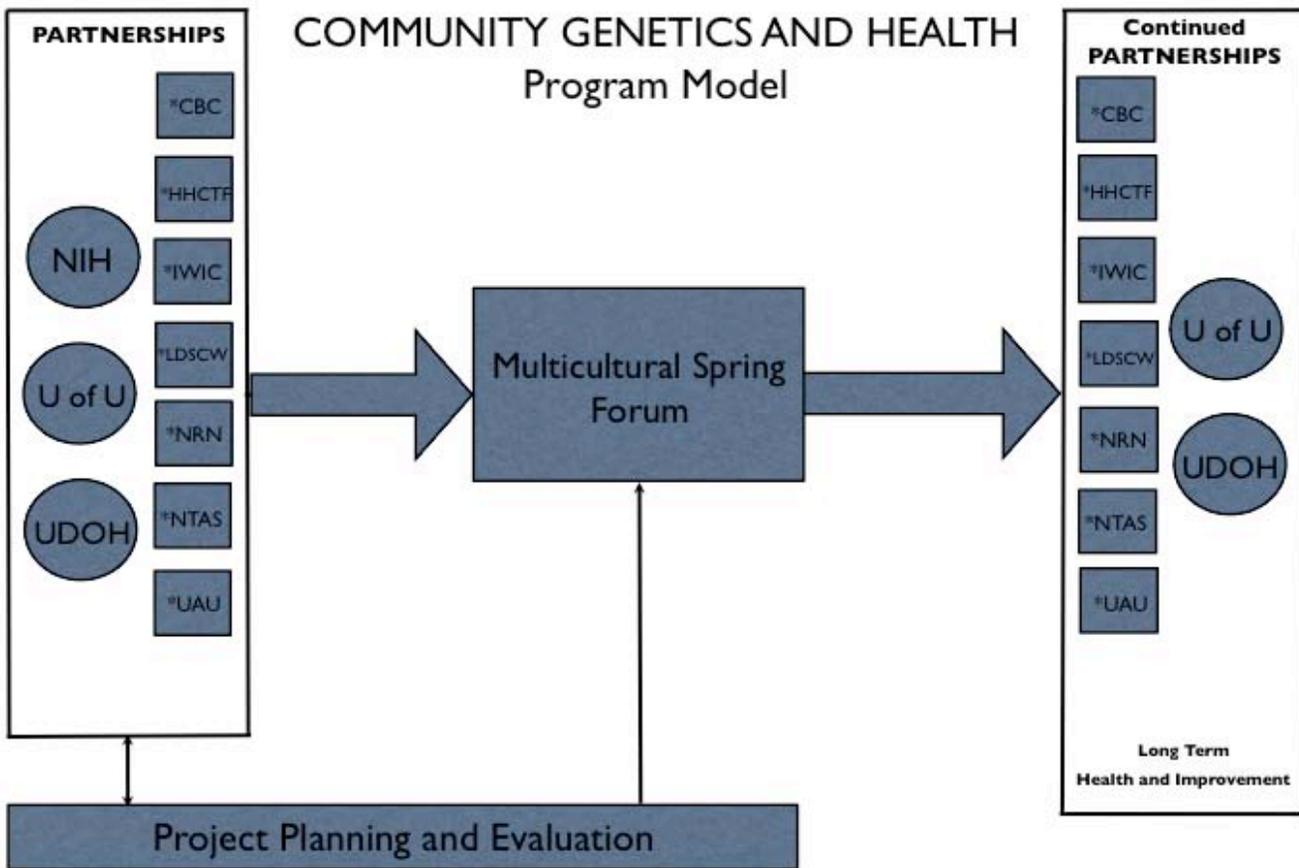
5. How interested are you in learning more about the role of genetics in the following diseases?

Please indicate your interest level for each disease with an X.

Disease Type	Very Interested	Somewhat Interested	Not Interested
Heart disease			
Asthma			
Diabetes			
Cancer			
Drug Addiction			
Stroke			
Osteoporosis			
High Blood Pressure			
High Cholesterol			
Depression/Mental Illness			

6. What questions do you have about these diseases?

COMMUNITY GENETICS AND HEALTH Program Model



*=Mini-Forum

Engaging Diverse Utah Communities in Dialogues About Genetics

The purpose of this research study is to evaluate the *Engaging Diverse Utah Communities in Dialogues about Genetics* project. We are doing this evaluation because we would like to understand your experience and your learning from participating in the Mini-Forum and Spring Forum sessions.

We would like to ask you to complete the assessment survey that will be distributed at the end of today's Forum session. Please complete the survey before you leave.

The survey is anonymous. Your name will not be linked to any of the information in the survey. The community leaders and the project evaluator will see the completed surveys. A summary of the information from the surveys will be reported to the National Institutes of Health, National Human Genome Research Institute, which is funding this project.

If you have any questions, concerns, or complaints or if you feel you have been harmed by this research, please contact Louisa Stark, Ph.D., Director, Genetic Science Learning Center, University of Utah, at 801-585-0019.

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

It should take 5 - 10 minutes to complete the survey. Participation in this study is voluntary. You can choose not to take part and you can also choose not to finish the survey or omit any question you prefer not to answer without penalty.

By returning this survey, you are giving your consent to participate.

Thank you very much for assisting us with this evaluation. Your feedback is very important to us.

Community Dialogues about Genetics and Health

(Name of Community) Mini-Forum

Assessment

(Date of Mini-Forum)

The purpose of the Mini-Forums is to provide education about the relationship between genetics and your health.

We would like you to complete a short survey based on today's Mini-Forum session. All answers are anonymous.

1. Name two things you learned from the session.

a.

b.

2. Do you intend to share this new information with anyone? If so, who?

3. Is there anything you will do differently based on what you learned in today's session? If so, what?

Your Age Range (please circle)

18 – 25 26 – 35 36 - 45 46 – 55 56 – 65 66 – 75 76 – 90

Male or Female (please circle)

COMMUNITY FACES

**A Genetics and Health Forum
Registration**

**Registration form is due Friday, April 23, 2010 to Heather Aiono.
For questions contact Heather at 801.598.0018 or heather.aiono@utah.edu**

Event:

Date: Saturday May 1st, 2010
Time: 8:15 a.m. - 3:30 p.m.
Location: Salt Lake Center for Science Education
 1400 West Goodwin Avenue (1400 W. 1150 N.)
 Salt Lake City, Utah 84116

Name: _____

Address:
 Street: _____

City: _____ State: _____ Zip: _____

Phone Number: _____

Email: _____

Is Interpretation Needed? Yes No If yes, what language? _____

Adult/Teen Lunch Choice:

Please write your first and last name and the first and last name of each person attending the conference with you. Then mark the lunch choice for each person.

Name (First and Last)	Roast Beef Sandwich	Turkey Sandwich	Tuna Sandwich	Veggie Wrap	Chef Salad

Children Attending and Lunch Choice:

Please write the first and last name and age of each child who will be attending. Then mark the lunch choice for each child.

Name (First and Last)	Age	Peanut Butter and Jelly Sandwich	Ham Sandwich	Turkey Sandwich	Roast Beef Sandwich

**Community Faces
A Genetics and Health Forum**

**May 1, 2010
Survey**

Please circle your answers.

(1) The speakers were easy to understand.	No	A little	Some	A lot
(2) I felt comfortable asking questions.	No	A little	Some	A lot
(3) Today's topics were interesting.	No	A little	Some	A lot
(4) After today, I am more likely to collect my family health history.	No	A little	Some	A lot
(5) Before today, how much did you know about genetics and health?	None	A little	Some	A lot
(6) Did you learn more about genetics and health today?	No	A little	Some	A lot

How useful was each presentation? Circle your answer.

(7) Cancer	Not	A little	Some	Very
(8) Heart Disease	Not	A little	Some	Very
(9) Diabetes	Not	A little	Some	Very

10. Name two things you learned today.

a.

b.

11. You have learned about genetics and health. What would you like to happen next in your community?

12. Any other comments?

Please answer:

Your Age Range (please circle)

18 – 25 26 – 35 36 - 45 46 – 55 56 – 65 66 – 75 76 – 90

Male or Female (please circle)

Your Community (please check)

- African American
- Chinese
- Hispanic/Latino
- Native American
- Tongan
- United Africans of Utah
- University of Utah
- Other (optional)

Thank you!