



# *Make Family Health History a Tradition*

November 2005

Project Summary

## **Background**

The Utah Department of Health (UDOH) Chronic Disease Genomics Program's (CDGP) primary goal is to help people understand how genomics affects their lives. Family health history is a practical, cost-effective, and engaging tool that can be used to teach people how genetics, environment, and behaviors interact to affect health. Family history is also a risk factor for many health problems including heart disease, asthma, cancer, diabetes, stroke, and even pregnancy related problems. By knowing a family health history, individuals and families can make targeted lifestyle and screening choices to lower their risk of developing a health problem that runs in their family.

In 2004, the U.S. Surgeon General, Dr. Richard H. Carmona, launched a Family History Initiative in which he encouraged all Americans to sit down with their families during the holiday season and collect their family health history. Thanksgiving Day was declared National Family History Day and will continue to be an annual event sponsored by the U.S. Surgeon General. A recent survey also demonstrated a growing interest in family health history with the public. Results showed that 96% of Americans felt knowing their family health history was important but only 30% had actually collected information from their relatives to develop a family health history (Centers for Disease Control and Prevention. Awareness of family health history as a risk factor for disease. *MMR Weekly*. 2004; 53(44):1044-1047. Available at URL: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5344a5.htm>). Building upon the UDOH 20-year experience using family health history in high schools and a growing national interest, the CDGP gathered together stakeholders and implemented the "Make Family Health History a Tradition" project in November 2005. Funding for the project was provided by a cooperative agreement with the Centers for Disease Control and Prevention (grant CDC U58/CCU 8222802-02).

## **Family Health History Committee**

The CDGP recruited individuals to serve on a Family Health History Committee during July 2005. Letters of invitation were sent to each individual and/or organization and

followed up with an email or phone call to confirm participation on the committee.

Committee members represented diverse organizations and included:

- **UDOH** – Jenny Johnson (CDGP), Rebecca Giles (CDGP) and Cody Craynor (Public Relations, Information, Marketing and Outreach department)
- **Local health department** – Toni Fenn-Bolton (Tri-County Health Department) and Judith Kregel (Davis County Health Department)
- **Family History Library** – Judy Jones, Wilma Adkins, and Carol Woodruff
- **Huntsman Cancer Institute** – Angela Schwab and Vickie Venne
- **Intermountain Health Care, Clinical Genetics Institute** – Janet Williams
- **American Heart Association** – Robin Rice
- **Utah Genealogical Association** – Starr Campbell and Warren Bittner
- **Heirlines Genealogy and Family History** – Jim and Mary Petty
- **Modern Display (representing Thanksgiving Point)** – Howard Miller
- **Salt Lake County Aging Services, Healthy Aging Program** – Amanda Lawlor, Janet Wallentine, and Dee Dee Lobato
- **University of Utah Spencer S. Eccles Health Science Library** – Sally Patrick

Committee meetings were held monthly from July to November 2005. Committee members also communicated via email to review materials. The committee was responsible for developing the goals of the project and approving materials and the media plan. The committee provided substantial support in the development of the project and several members have expressed an interest and commitment in continuing the project throughout the upcoming year.

### **Project Goals**

The goal of the project was to increase awareness about the importance of family health history in Utah. By accomplishing this goal, the CDGP hoped to 1) encourage families to talk about their family health history during the holiday season, 2) write down what they learned, 3) and share it with their health care provider and family members. “Make Family Health History a Tradition” was chosen by the committee as the project slogan to generate interest in the topic during the holiday season.

## **Family Health History Toolkit**

A free, six-page, color booklet was developed to help families collect their family health history and thus increase awareness of the importance of family health history in Utah. The toolkit was based on the National Kidney Disease Education Program “Your Family’s Health: Make a difference at your family reunion” project (available at <http://nkdep.nih.gov/familyreunion/index.htm>). It provided tips for talking about and sharing family health history information and was broken into three sections 1) Talk about it, 2) Write it down, and 3) Share it. The Utah Health Family Tree (HFT) tool was also included as a way to document a family health history. Several fact sheets were developed for the toolkit as well, although they not included in the actual six-page toolkit. The fact sheets were referenced in the toolkit but kept separate to increase the likelihood of families reading the toolkit, ease downloading the documents from the Internet, and to keep readability low. The total cost for printing and packaging the toolkits was approximately \$.80 – \$1. The following materials were packaged together in a 10”x13” white envelope and distributed as the Family Health History Toolkit:

- Family Health History Toolkit (six-page booklet)
- Turkey Talk health discussion fact sheet
- Questions and Answers fact sheet
- How to Talk with Your Family fact sheet
- When to Get a Genetic Consultation fact sheet
- Sources to Learn Your Family’s Health History fact sheet (designed for genealogists)
- Health Family Tree tool

The toolkits were available on the CDGP website, classes offered at the Family History Library (FHL) and senior centers, FHL main floor service desk, and by calling the UDOH Health Resource Line (HRL). However, several additional strategies were used to promote the availability of the toolkits including a display at the FHL, Public Pioneer/Utah’s Online Library website, listserv emails, and media placements. The HRL staff were trained by the CDGP in October 2005 to take calls from the public and handle requests for the toolkits. Toolkits were mailed free of charge to individuals if they called

the HRL. The following tables show the number of toolkits distributed, not including website downloads, from October 24 – November 30, 2005.

| <b>Distribution method</b> (website downloads not included) | <b># of Toolkits distributed</b>       |
|---|--|
| FHL classes   | 48                                     |
| FHL service desk  | 103                                    |
| Senior center classes                                       | 165                                    |
| HRL   | 175 (70 individual calls for toolkits) |
| Other classes   | 35                                     |
| Other requests  | 175                                    |
| <b>Total</b>  | <b>701</b>                             |

Downloads and requests for the toolkit were received from around the world. The total number of CDGP website downloads of all the toolkit materials as of December 4, 2005 was 2,892. The six-page toolkit was downloaded 1,865 times alone. *This approximates to a grand total of 2,566 toolkits distributed from October 24 – December 4, 2005. It is anticipated this number will continue to increase throughout the holiday season.*



Family History Library main floor display promoting the toolkit and classes

## **Classes**

Classes were also used as a strategy to accomplish the project goal. The CDGP and Healthy Aging Program developed a curriculum targeted to seniors to use in either a one-hour or 30 minute class. The main objectives of the classes were to help participants understand 1) why a family health history is important to their health as well as their family's health and 2) encourage them to share what they learned with family members. Emphasis was placed on sharing personal stories from Utah families to help illustrate the importance of learning about your family health history. Family Health History Toolkits were also distributed during the classes.

Four classes were held at the Family History Library (FHL) in Downtown Salt Lake City. A total of 19 participants attended the classes at the FHL. The CDGP coordinated and taught these in conjunction with the FHL staff. The CDGP also taught classes at the Smithfield International Lions Club meeting with 19 participants, Federation of Genealogical Societies/Utah Genealogical Association Conference with 75 participants, and the UDOH with 5 participants. Genealogists Starr Campbell and Mindi Stevens were recruited to present a family health history class to 30 participants during the Healthy Aging Day event on September 14, 2005. The Salt Lake County Aging Services, Healthy Aging Program chooses a topic each month for senior centers to focus on and develops classes and activities around the topic. Family Health History was chosen as the November topic. Eighteen classes were then organized and taught at senior centers in Salt Lake County. A total of 259 participants attended these classes. ***In total, 26 classes were offered in which 407 participants attended.***

## **Evaluation of Classes**

A four-question survey was developed to evaluate the FHL and senior center classes by the CDGP and Healthy Aging Program staff. Class participants were encouraged to complete the survey but not required to do so. Of the 58 participants in the classes taught by the CDGP, 43 (74%) completed surveys. Of the 259 participants in the classes taught at the senior centers, 159 (61%) completed surveys.

Results from the FHL class surveys showed:

- 90% strongly agreed they had learned why a family health history is important
- 53% definitely would share the information with their family members and/or doctor (33% most likely would)
- 58% definitely would try to collect their family health history (28% most likely would)
- 86% felt the classes were useful to them

Results from the senior center classes showed:

- 65% strongly agreed they had learned why a family health history is important (15% somewhat agreed, 19% agreed)
- 52% definitely would share the information with their family members and/or doctor (31% most likely would)
- 45% definitely would try to collect their family health history (28% most likely would)
- 65% felt the classes were useful to them (28% felt the class was somewhat useful)

## **Media**

A media plan was developed by the committee and the UDOH Public Relations, Information, Marketing and Outreach (PRIMO) department from August to October 2005. The media plan was then implemented throughout November and into December 2005. The media was used to promote the availability of the Family Health History Toolkit and classes at the FHL. Personal stories from Utah families were collected and used as part of the media activities. A news release was distributed by the UDOH to all media contacts on November 1, 2005. Eight newspapers ran articles based on the UDOH news release. More articles could have been published but we were unable to track them. The articles are listed below:

- **Davis County Clipper** (November 3, 2005) – *Put family discussions to good use this season*
- **The Times Independent** (November 3, 2005) – *Tool helps Utahns collect family health histories*

- **Transcript Bulletin** (November 4, 2005) – *Tool helps Utahns collect family health history, save lives*
- **Uintah Basin Standard** (November 8, 2005) – *Knowing family health history can save lives, ‘toolkit’ will help*
- **Millard County Chronicle Progress** (November 9, 2005) – *Tool helps Utahns collect family health history: knowing family health history can save lives*
- **Ogden Standard Examiner** (November 15, 2005) – *Make health talk part of the holidays*
- **Salt Lake Tribune** (November 15, 2005) – *Health Findings Give thanks, discuss family’s health history*
- **Millcreek Journal** (November 2005 issue) – *Tool helps Utahns collect family health history*

In addition, newsletter and magazine articles were also written:

- **Rural Health Association Newsletter** (Summer 2005 issue) – *Make Family Health History a Tradition*
- **Salt Lake County Aging Services, Options and Opportunities Newsletter** (November 2005 issue) – *Make Family Health History a Tradition this Thanksgiving*
- **Utah Health Magazine** (November 2005 issue) – *Knowing your family health history could save your life*, featuring stroke survivor Arainna Forth and the 10 Questions to Ask Your Family at Thanksgiving.

Several TV stories were developed as part of the media plan. TV coverage was provided at no cost by the stations. Established relationships with three of Utah’s major TV stations were utilized to get the following TV coverage:

- **KUTV** (November 4, 2005) – *Check Your Health* segment on Family History and Diabetes, featuring the Jay Henderson family. Reached approximately 23,000 households.
- **ABC 4 News** (November 15, 2005) – *What’s Going Around?* segment, featuring stroke survivor, Arianna Forth and her mother.

- **KUTV** (November 17, 2005) – *Healthy Living: Genealogy and Health* segment, featuring cancer survivor and genealogist Starr Campbell and her family. Reached approximately 51,000 households.
- **KSL** (December 23, 2005) – *Our Town* segment, featuring Jenny Johnson. Reached approximately 150,000 viewers.

As a result of the KSL TV segment, KSL radio (FM 100) contacted the CDGP about producing a 23-minute radio show on family health history. The radio show will air in January 2006, date to be announced. It will be taped on January 19, 2006 at no cost to the CDGP. If available, the TV and radio segments will be posted online for future viewing.

### **Lessons Learned**

This was the first public awareness project conducted by the CDGP. It was difficult to estimate the amount of interest the public would have with the project and so the overall success of the project far exceeded any expectations held by the CDGP. The following is a brief summary of the lessons learned and recommendations for future projects.

- ***Family Health History Committee:*** The committee worked well together, was enthusiastic about the project, and represented a diverse range of experience. Committee members understood the expectations of the project early on, were engaged in the entire planning process, and provided timely feedback on materials and ideas. The genealogy organizations involved were a wonderful and unique resource to the project and represented the public’s knowledge and beliefs well. Future projects must continue to include diverse organizations that normally do not work in the public health setting. An understanding of the committee members’ personal expectations of the project as well as ensuring the committee understands their responsibility as a group is important to establish early on. The committee has agreed to continue working together on promoting the importance of knowing your family health history in the upcoming year. Already additional individuals have been recruited to join the committee and several ideas have been generated for projects in November 2006.

- **Classes:** Despite a good turnout at the senior center classes, the number attending the FHL classes was quite disappointing. As this is a somewhat new spin on family history for genealogists in general, this may have affected class attendance. Other possible reasons for low attendance included limited class dates and times, limited time of library patrons who are doing personal research at the library to attend the classes, and lack of media attention during the first two weeks in November to generate interest in the classes. However, the relationships formed with the FHL will be extremely beneficial in future projects. FHL staff generously donated their time to help teach the classes, develop a fact sheet, ensure approval from FHL administration for the classes and copyright permission to post the fact sheet on the CDGP website, and create the display that was on the main floor of the FHL. FHL staff also recommended a family health history class be taught at the Utah Genealogical Association spring seminar in March 2006 to continue to generate awareness about family health history and the resources available.

The Healthy Aging Program had already established protocols for working with senior centers that included teaching monthly classes at each senior center in Salt Lake County, providing one-on-one education to center patrons, and evaluating these education strategies. The Healthy Aging Program was also able to use these relationships to gain administrative support for the project and interest in future family health history projects.

Other strategies for advertising classes will need to be determined in the future, as being dependent only on the media to get the word out was not as effective as originally thought. Possible ideas may include putting a class schedule in the toolkits that are mailed to the public, adding class schedules to the news release or newsletter articles, and hanging posters in businesses or community centers.

- **Media:** The committee capitalized on relationships the UDOH had with local media to do all of the media events for the project at no cost. The UDOH has

contact information for all media throughout Utah, which was used in distributing the news release statewide. The PRIMO department recommended sending out the news release the first week of November to help promote the classes being offered at the FHL; however, the timing was not effective and generated no media contacts until the week prior to Thanksgiving. Possible reasons for the bad timing included the President's avian bird flu plan announcement the first week of November and the message of talking with your family during the holidays was more appropriate during the week prior to Thanksgiving. It was quite surprising that the media had kept the news release for two weeks before contacting the CDGP, as many times if the media hasn't responded within a couple of days after a news release the story won't be picked up. UDOH also has working contracts with KUTV that was utilized to schedule the Check Your Health and Healthy Living TV segments in August 2005. The PRIMO department provided the contact for KSL to schedule the Our Town TV segment and a possible radio segment in January. Local families were highlighted in each of the media events, all of whom were referred by committee members. Future projects will need to plan media events closer to Thanksgiving and be prepared for large requests for toolkits and materials.

- ***Family Health History Toolkit:*** The response for the toolkits was overwhelming and completely unexpected. With little funding for the project, it was anticipated that only 500 toolkits could be distributed. However, as reported earlier, an estimated 2,566 toolkits were distributed (via CDGP website, classes, and HRL requests). The cost of printing and mailing the toolkits was lower than expected because in-house printing was used which allowed a greater distribution than originally planned. Several genealogy organizations requested the toolkits for conferences and fairs, although due to the high demand we were unable to fill all of these large requests (however, these groups were given enough materials to make displays similar to the FHL display to promote family health history).

The University of Utah Cardiovascular Genetics Research Group generously donated the original paper-based HFT tools for the toolkits, although the number of them available for the project was only about 750. The committee felt it was important to include a tool that would collect family health history information in the toolkits, rather than just providing ideas for how to talk to one's family about this topic. The toolkits were also used to help generate interest and name recognition for the new Internet-based HFT tool that will be launched in 2006. Feedback from those who received toolkits indicated the HFT was the highlight of the materials and that most people only wanted the Health Family Tree tool (and several of them for their entire family). The logo from the original Health Family Tree program was used to develop the toolkit layout and color scheme.

The committee also felt it was important to include pictures of ethnically diverse families in the materials. Future plans include testing the materials with different populations to assess their effectiveness. Requests for Spanish materials were also received and will need to be taken into account for future projects. The CDGP will continue to explore ways to provide a paper-based HFT with the toolkits. It is anticipated the demand for a paper-based tool will continue to be high and even with an electronic version available, it will be important to have a paper-based tool included in the toolkit with reference to the Internet HFT website.