Utah Genomics Plan

2006-2010

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Utah Genomics Plan

Section 1: Utah is the Place!
Utah Genomics Plan

Utah truly is "the place" for genetics, genomics, and family health history!

On July 24, 1847 a group of pioneers belonging to the Church of Jesus Christ of Latter-day Saints (LDS or commonly called "Mormons") led by church President Brigham Young, entered the Salt Lake Valley. It is recorded that when President Young saw the valley for the first time he said, "This is the right place," later abbreviated to simply "This is the place."

Utah truly is "the place" for genetics, genomics, and family health history! Utah has been – and must continue to be – a leader in using genetics to improve health. Why? The state's many unique resources, including:

- A rich genealogical heritage. The state's pioneer heritage has had a major impact on citizens' beliefs and interest in genealogy. The religious background of over 60% of the population encourages the recording of detailed family histories and access to these records is available in the Family History Library. Utah is also home to organizations like the Sorenson Molecular Genealogy Foundation that are interested in using DNA to trace family histories.
- Family History Library (FHL). Founded in 1894, the FHL is the largest library of its kind in the world and contains genealogical information on more than eight billion individuals. An estimated 1,900 people from around the world visit the library each day.
- International renown in genetics research. The University of Utah, Huntsman Cancer Institute, and Myriad Genetics attract some of the brightest genetic researchers in the world. In fact, more human disease genes have been discovered in Utah than any other place in the world.
- Utah Population Database (UPDB). By the 1950s geneticists began to take notice of Utah's gold mine of family history data. Several researchers formed an agreement with the LDS Church and created the UPDB in the 1970s. Today the UPDB contains genealogical information on 1.6 million individuals as well as annual updates on Utah births, deaths, cancer records, and driver license records.
- Twenty-plus years of using family health history to improve population health. From 1983-2002, the Utah Department of Health, University of Utah, local health departments, school districts, and the Baylor College of Medicine implemented the Health Family Tree (HFT)

program in Utah high schools. The HFT was a population-based project that successfully identified families at risk for chronic diseases that could be prevented, delayed, or treated effectively with early interventions. More than 151,000 families participated and follow-up showed the HFT motivated behavior change in both high and average-risk families.

- Characteristics of Utah citizens. Utah families are typically larger than other states and have children at relatively young ages. Many families reside in the same communities for generations and tend to live longer, healthier lives – all ideal factors for genetic research.
- Generous contributions to medicine. Utah citizens are extremely cooperative in participating in genetics research. It isn't uncommon for researchers to be invited to huge family reunions to collect DNA samples and family histories. Utahns truly take an interest in their families and in the future of medicine.

Section 2: Program Background
Chronic Disease Genomics Program

Utah received funding in July 2003 and created the UDOH Chronic Disease Genomics Program.

Recognizing the potential impact advancements in genetics would have on public health, the Utah Department of Health (UDOH) applied for funding from the Centers for Disease Control and Prevention. The funding was to develop infrastructure and leadership capacity to integrate genomics into public health, with a focus on chronic disease. Utah received funding in July 2003 and created the UDOH Chronic Disease Genomics Program. The program is one of only four similar programs in the nation.

Goals:

- Create an infrastructure to integrate genomics into public health practice.
- Develop community and public health leadership in genomics and chronic disease.
- Integrate genomics information into existing data collection systems.
- Educate public health professionals, health care providers, policymakers, and the public about the role of genomics in health.
- Develop and assess family history interventions.

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The Chronic Disease Genomics Committee is responsible for assuring that public health systems are in place to reduce the burden of chronic disease caused by genetic conditions.

Genetics Advisory Committee, Chronic Disease Genomics Committee

In May 2002, the Utah State Genetics Plan was written under the direction of the Utah Genetics Advisory Committee (GAC). The GAC advises the Utah Department of Health on genetics-related issues. One of the major outcomes of the Utah State Genetics Plan was the identification of a significant need to educate public health professionals about the genetic components of chronic disease.

In order to address this need, an objective was written calling for the establishment of a Chronic Disease Genomics Committee that would serve as an expert panel under the aegis of the GAC. The Committee's mission would be to "Provide recommendations to assure that public health systems are in place to reduce the burden of chronic disease caused by genetic conditions."

The UDOH Chronic Disease Genomics Program was charged with the task of establishing the Chronic Disease Genomics Committee. In the fall of 2003, program staff began recruiting genetics and chronic disease experts to participate on the Committee and develop a set of goals and objectives to accomplish their mission. The Committee met quarterly until development of these goals and objectives was complete in early 2006. Currently, the Committee meets twice a year to review progress and provide recommendations to the Family Health History Task Force on implementation of the Utah Genomics Plan.

Chronic Disease Genomics Committee Members

James Metherall
University of Utah

Jeffrey Botkin
University of Utah

Joseph Jarvis
University of Utah

Kara Thompson
American Heart Association

Section 3: Plan Development
Genetics Advisory Committee (continued)

Nicola Camp
University of Utah

Paul Hopkins
University of Utah

Sancy Leachman
Huntsman Cancer Institute

Saundra Buys
Huntsman Cancer Institute

Steven Hunt
University of Utah

Catherine Staes
University of Utah

Susan Morelli
Intermountain Healthcare

Ted Adams
Intermountain Healthcare

Vickie Venne
Huntsman Cancer Institute

Utah Department of Health Staff

Rebecca Giles

Jenny Johnson

LaDene Larsen

The Family Health History Task Force is responsible for implementation of the Utah Genomics Plan.

Family Health History Task Force

Recognizing the increasing number of organizations in Utah with an interest in family health history, the Chronic Disease Genomics Program formed the Family Health History Task Force in February 2006. Members of the Task Force include consumers, genealogists, genetic researchers, academia, public health professionals, genetic counselors, private business owners, scouting, clinicians, and health plans.

An initial planning meeting was held to develop vision and mission statements as well as a set of strategies to guide the promotion of family health history in Utah. These strategies overlapped with several of the goals and objectives developed previously by the Chronic Disease Genomics Committee. As such, the Chronic Disease Genomics Committee and the Task Force decided to combine these and create the Utah Genomics Plan.

The Task Force is responsible for implementation of the Utah Genomics Plan. Members of the Chronic Disease Genomics Committee provide leadership support and oversee Task Force activities. The Chronic Disease Genomics Committee also provides updates on the Task Force's activities to the GAC. The Task Force meets quarterly and on an as-needed basis in four subcommittees (Public Awareness, Clinical Applications, Research and Methodology, and Ethical Issues).

Vision Statement: Family health history – Utah's way!

Mission Statement: Utilize family health history to improve the health of all Utahns, through partnership development, clinical and community applications, public awareness, developing appropriate methodology, and incorporating policy and ethical considerations.

Family Health History Task Force Members

Anna Swayne
Sorenson Molecular Genealogy Foundation

Angela Schwab
Huntsman Cancer Institute

Brett McIff
Utah Department of Health

Section 3: Plan Development
Family Health History Task Force (continued)

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Doug Arnett
GenealogyFound

Doug Fogg
Sorenson Genomics

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Family Health History Task Force (continued)

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Louisa Stark
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Marcie Johnson
Davis County Health Department

Marie Godfrey
GeneForum

Mark Allen
Scoutmedia

Michael Barnes
Brigham Young University

Nicola Camp
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Patrick Lee
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Paul Clark
Educators Mutual Insurance Company

Ruthann Adams
Southwest Utah Public Health Department

Sacha Masek
Sorenson Molecular Genealogy Foundation

Sancy Leachman
Huntsman Cancer Institute

Sally Patrick
Eccles Health Science Library

Starr Campbell
Federation of Genealogical Societies

Steve McDonald
March of Dimes, Utah chapter

Section 3: Plan Development
Family Health History Task Force (continued)

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American Academy of Family Physicians, Utah Chapter

Ted Adams
Intermountain Healthcare

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Ugo Perego
Sorenson Molecular Genealogy Foundation

Warren Bittner
Utah Genealogical Association

Goal 1

Assess current understanding of the influence of genetics and chronic disease in the public sector and among primary care providers.

Objective 1

Determine how well the public is informed regarding chronic disease and genetics.

Objective 2

Determine how knowledgeable primary care providers are regarding chronic disease and genetics.

Activities:

1. Identify or develop questions for inclusion in the Behavioral Risk Factor Surveillance System (BRFSS) questionnaire to assess public knowledge, attitude, and behaviors.
2. Initiate process of adding questions to the Youth Risk Behavior Survey (YRBS).
3. Identify and implement tools for assessing primary care provider knowledge and practices.
4. Assess primary care providers through focus groups or key informant interviews.
5. Assess use of the American Medical Association family history booklet.
6. Summarize literature regarding provider practices.

Desired Outcomes

- Increased understanding of how the public views genomics.
- Increased understanding of the barriers for collecting family history in primary care settings.
- Identification of strategies for overcoming barriers in primary care.

Section 4: The Plan
Goal 2

2 Goal 2

Improve understanding of genetics' influence on chronic disease in the public sector and among primary care providers.

Objective 1

Develop, implement, and evaluate a comprehensive and coordinated social marketing campaign designed to educate and increase utilization of family health history by the public and primary care providers.

Objective 2

Assure all activities are culturally appropriate and meet the needs of underserved populations.

Activities:

1. Define the target populations for the social marketing campaign.
2. Develop appropriate messages for the chosen target audiences.
3. Conduct formative research to determine best communication channels and messages.
4. Develop an evaluation plan for all activities.
5. Gather personal stories of Utah families to use in messages, media activities, etc.
6. Identify available resources, tools, and materials and adapt to meet the needs of the target audience(s).
7. Identify appropriate funding sources for the social marketing campaign (United Way, Eccles, Comcast, pharmaceutical companies, etc).
8. Identify and engage "champions" and appropriate partners for the social marketing campaign and to push messages.
9. Partner with agencies to develop, test, and distribute materials (such as the Genetic Science Learning Center, Cancer Learning Center, etc).
10. Identify appropriate avenues for distribution. Distribution should encompass the following community education settings:
    a. Schools
    b. Youth activities (scouting, FGS Youth Initiative, national youth Websites)
    c. Mass media (newspaper, radio, TV, magazine, PSAs)
    d. Community organizations and events (Healthy Communities, civic/volunteer organizations)
    e. Genealogists
    f. Libraries (Eccles Health Sciences Library, book clubs)
    g. Health departments
    h. Museum exhibits
    i. Faith based groups/churches
    j. Senior centers, housing, senior expo
    k. Oral histories/interviews

2 Goal 2
(continued)

l. Hospitals or clinic settings/offices

11. Address various age groups with activities (aging, adult, school age).
12. Partner with the Public Broadcasting System to develop a documentary program.
13. Partner with policymakers (e.g., legislators, city/community councils) to integrate messages into initiatives, proclamations, legislative resolutions, etc.
14. Integrate family health history into genealogical software programs.
15. Partner with genealogy organizations to develop specific messages and distribution methods to reach this target population.
    a. National Genealogical Society
    b. Federation of Genealogical Societies
    c. Ancestry broadcasts and radio segments
16. Explore ways to utilize technology to promote messages.
    a. Internet
    b. Blogs
    c. Podcasting
    d. Web-based materials
17. Review core curriculum for opportunities to collaborate with public schools.
18. Explore use of continuing medical education for primary care providers.
    a. Partner with Utah Medical Association, Academy of Family Physicians, etc. for educational efforts.
19. Incorporate messages into current and future professional development trainings. Trainings may include:
    a. Teacher development workshops
    b. Booths or presentations at professional conferences
    c. Professional listservs or newsletters
    d. Public health and health education programs
    e. Provider trainings/medical symposiums
20. Identify key decision makers/gatekeepers of underserved

2 Goal 2
(continued)

and ethnic populations and engage them in this process.

21. Explore integration of family health history into Utah Department of Health programs targeted to the public (such as the Women, Infants, and Children nutrition consultation visits).
22. Work with the Clinical Applications Committee to develop patient resources (hospitals, doctor offices, etc.) promoting messages.

Desired Outcomes

- 60% of Utahns will recognize and appreciate the importance of their family health history.
- Increased collection of family health history by individuals, families, and health care providers.
- Creation of culturally appropriate materials and messages.

3 Goal 3

Improve the method and subsequent use of family history collection in primary care and community settings.

Objective 1

Evaluate the current standard of care among primary care providers.

Objective 2

Explore currently available family history tools.

Objective 3

Develop, test, and evaluate a model plan to increase use of family history data collection tools in primary care and community settings.

Activities:

1. Review medical school curriculums for family history collection.
   a. Identify and utilize opportunities to enhance curriculum.
2. Identify role of staff in primary care provider offices/clinics.
   a. Intake evaluations
   b. Nurses collecting family history
3. Develop a plan to address the use of family history and education by allied health professionals.
4. Utilize the electronic Utah Health Family Tree in clinical, school, and other community settings.
5. Conduct a comparison study of CDC family history tool and the electronic Utah Health Family Tree.
6. Conduct a pilot project in a clinical setting.
7. Utilize or adapt currently available protocols and identify the family health history tool(s) for use in the pilot project.
8. Involve genetic counselors in the project development.
9. Identify, develop, or adapt standard guidance messages for providers.
10. Conduct pre-assessment with providers to determine knowledge, attitudes, and beliefs or use of family health history information.
11. Develop clinical outcomes desired and integrate into pilot test.
12. Identify case and control populations or clinics that will participate in pilot test and obtain necessary IRB approvals.
13. Develop resources for primary care providers.
14. Develop provider training such as risk messages, referral guidelines, etc.
15. Develop patient materials.
16. Evaluate the tools effectiveness, provider and patient knowledge, and clinical and behavioral outcomes.

3 Goal 3
(continued)

17. Assess public response to use of family history tools and quality of data collected.
    a. In various applications (self-administered, staff assisted).

Desired Outcomes

- 50% of Utah health care providers will appropriately utilize family health history in their clinical practice.
- Development of risk messages and clinical guidelines based on family history.
- Implementation of the electronic Utah Health Family Tree in various settings.

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Goal 4

Identify interventions and guidelines based on family history or genetic information that might reduce the burden of chronic disease in Utah.

Objective 1

Conduct a review to identify all known interventions (evidence-based) for clinical, public health, and other groups (industries, etc).

Objective 2

Disseminate findings.

Objective 3

Identify how primary and secondary prevention efforts that utilize family history change provider practices.

Activities:

1. Create a database of known interventions.
   a. Rank interventions by whether they are proven/unproven and strength of evidence.
   b. Convene a subcommittee and recruit graduate students to develop the project scope.
   c. Distribute results of findings through appropriate channels to the public and primary care providers.
2. Assess how primary and secondary prevention efforts change in the presence of positive family history.
   a. Among those with positive family history.
   b. Among primary care providers who diagnose and treat those with a positive family history.

Desired Outcomes

- Implementation of evidence-based family history interventions in public health and clinical practice.
- Increased understanding of how family history information changes provider practice.

Goal 5

5

Goal 5

Educate the public and providers regarding genetic screening and testing.

Objective 1

Identify current issues among the public and/or health care providers.

Objective 2

Determine how health care providers are using genetic screening and/or testing.

Activities:

1. Develop a database of information on genetic tests that includes information such as:
   a. Available tests
   b. Web sources that offer tests
   c. Other resources
2. Develop guidelines for how to assess genetic tests.
   a. Utility
   b. Costs
   c. Identify other appropriate criteria
3. Invite interested partners to participate in discussions and development of the guidelines.
4. Identify appropriate resources for educational efforts.
   a. Consumer awareness
   b. Provider guidance
5. Explore relevant policy issues such as:
   a. How genetic information and/or test results are used by the health insurance industry.
   b. Gaps in current state and federal laws.

Desired Outcomes

- Increased understanding of the appropriate use of genetic screening/testing among the public and health care providers.
- Development and dissemination of guidelines for using genetic screening/testing.

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Goal 6

Gain a clearer understanding of the clustering of chronic diseases and the degree of genetic impact on these clusters in Utah.

Objective 1

Use epidemiologic methods to identify family and regional clustering of disease.

Objective 2

Compile informational listings of identified clusters with impact on suffering.

Activities:

1. Continue project with Lisa Cannon-Albright and medical informatics students to utilize the Utah Population Database.
2. Use familial clustering methods to rank all disease endpoints in the Utah Population Database by strength of clustering.
   a. Starting with disease with greatest burden in population
   b. Population-attributable risk
3. Apply findings to public health through population strategies.

Desired Outcomes

- Application of the Utah Population Database to public health practice.
- Increased understanding of the impact genetics has on chronic diseases in Utah families.

Section 4: The Plan
Goal 7

7

Goal 7

Utilize all available resources to develop a statewide family health history database.

Objective 1

Assure appropriate methodology so that as datasets are developed they can work together.

Objective 2

Identify and engage appropriate stakeholders to discuss solutions for the following issues:

- Funding
- Maintenance of the database
- Sources of data
- Commitments from stakeholders
- Appropriate model(s) to manage the database
- Privacy and confidentiality concerns

Activities:

1. Identify the tools that currently exist for family health history collection which are available to the public and used by health care providers and researchers.
2. Identify existing sources of data.
3. Determine the best model for the database to be developed.
4. Determine what Internet tools are required to provide education to the public and health care providers.
5. Involve all Family Health History Task Force committees in the planning and development process.

Desired Outcomes

- Identification of barriers impeding the development of a family health history database.
- Stakeholders have agreed to work together to overcome barriers.
- Development of a non-research family health history database for public health and clinical practice.

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Goal 8

All efforts in the Utah Genomics Plan will address appropriate policy and ethical issues.

Objective 1

Understand and identify gaps of current national and state legislation concerning genetic discrimination.

Objective 2

Assure that privacy and confidentiality are included in all methods and protocols developed.

Activities:

1. Review the current Utah Genetic Testing Privacy Act and other applicable state laws.
2. Review current national laws, such as HIPAA.
3. Identify specific issues of concern for the public and underserved populations.
4. Identify genetic policy and ethics experts to serve on appropriate Family Health History Task Force committees during the development of protocols and activities.

Desired Outcomes

- Appropriate components of legislation to protect against genetic discrimination are identified.
- Increased understanding of the potential harms genomics may have on the population.
- Ethical and policy issues are addressed in all state genomics activities.

Section 5: Implementation
Highlights of Accomplishments

The Chronic Disease Genomics Program and its partners began implementing strategies from the Utah Genomics Plan in 2004. The following are highlights of their accomplishments:

Data and Surveillance	Public Awareness	Health Systems and Professionals	Communities	Other
Collected genomics data on the 2005, 2006, and 2007 Behavioral Risk Factor Surveillance System.	Implemented a national, award-winning public awareness project to promote the importance of family health history.	Reviewed the University of Utah School of Medicine curriculum requirements regarding genetics.	Provided three community mini-grants throughout the state.	Integrated genomics into chronic disease and maternal and child health state plans and funding applications.
Collected family history data on the 2005 and 2007 Youth Risk Behavior Survey.	Distributed over 7,000 Family Health History Toolkits to educate families on how to collect a family health history.	Held a first-in-the -nation Asthma Genomics conference for health professionals.	Developed high school curriculum materials on family health history.	Published a peer-reviewed journal article on the Utah Family High Risk Program.
Analyzed data from the Utah Cancer Control Program breast and cervical cancer enrollment forms.	Distributed family health history messages to more than 945, 000 Utah households (TV, radio, and print).	Trained more than 1,200 health professionals on genomics and family health history.	Conducted a pilot test of the Web-based Health Family Tree tool in an employee worksite wellness program.	Partnered with agencies to determine usefulness of the Utah Population Database for public health.
Conducted a review of 407 medical charts to assess the extent to which physicians record and use family history in patient care.	Collected stories from Utah families on how family health history has impacted their lives.	Summarized literature regarding primary care provider practices in regard to family health history.	Trained more than 600 teachers, genealogists, and community members on the importance of family health history.	Adapted genetics education materials for Hispanic/Latino students and their families.

Section 5: Implementation
Public Awareness Campaign

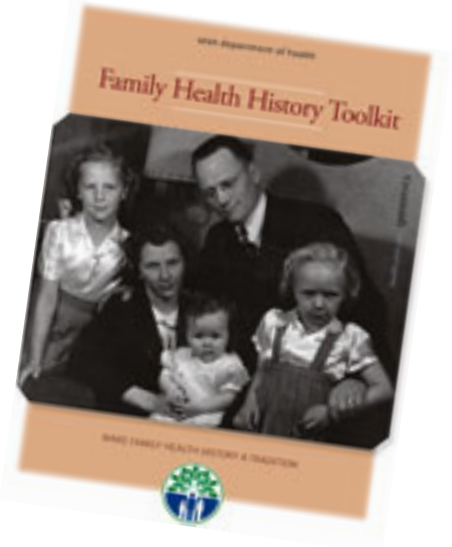
The entire collection of success stories is available at www.health.utah.gov/genomics.

Making Family Health History a Tradition in Utah

In 2004, the U.S. Surgeon General launched a Family History Initiative and encouraged Americans to collect their family health history. But few used this to promote the importance of family history at state and local levels.

In response, the Genomics Program adapted the initiative for Utah communities. The goal was to increase awareness about the importance of family health history. The "Make Family Health History a Tradition" campaign ran from November to December 2005. A free booklet called the "Family Health History Toolkit" was given to families to help them learn about their family health history. Materials were distributed using:

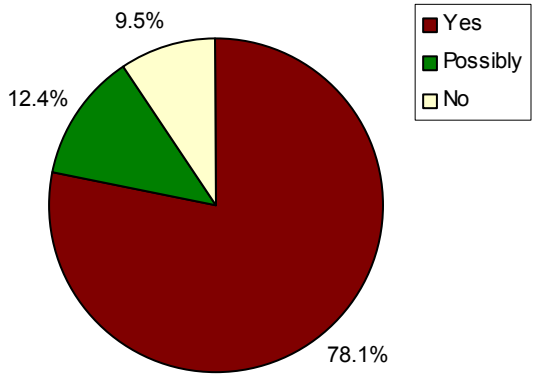
- Internet
- Telephone hotline number
- Libraries
- Community newsletters
- Newspapers and magazines
- TV
- Radio
- In-person classes taught at senior centers and the Family History Library



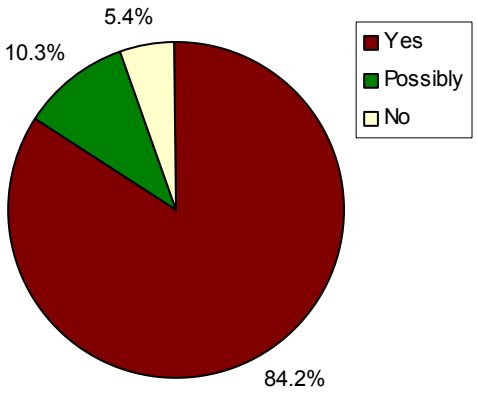
Section 5: Implementation
Public Awareness Campaign (continued)

A four-question survey was given to more than 400 class participants to evaluate the key messages. Results showed:

Percentage of participants who reported they would COLLECT their family health history



Percentage of participants who reported they would SHARE their family health history with their family and/or doctor



Section 5: Implementation
Health Family Tree Program

Health Family Tree Program

From 1983-1999, the Utah Department of Health collaborated with local health departments, school districts, the Baylor College of Medicine, and the University of Utah Cardiovascular Genetics Research Clinic to implement the Health Family Tree (HFT) program. The HFT identified families at an increased risk of suffering from chronic diseases that could be prevented, delayed, or treated with early interventions.

The HFT was used in 10th grade health education classes. Students collected health and lifestyle information from their family. Algorithms were used to analyze the family health history data recorded by the student and to assign a disease risk estimate. Personalized reports describing the family's disease risk and recommendations to prevent disease were sent to consenting families. Those considered "high-risk" were offered tailored interventions from public health nurses.

Highlights of the HFT program:

- 151,188 Utah families participated.
- 80,611 usable HFT were collected.
- 284 teachers in 55 Utah high schools participated.
- 8,546 high-risk families were offered interventions.
- Both high and average risk families reported an increase in healthy lifestyle behaviors, such as getting yearly medical exams and blood pressure checks, as a result of participating in the HFT.

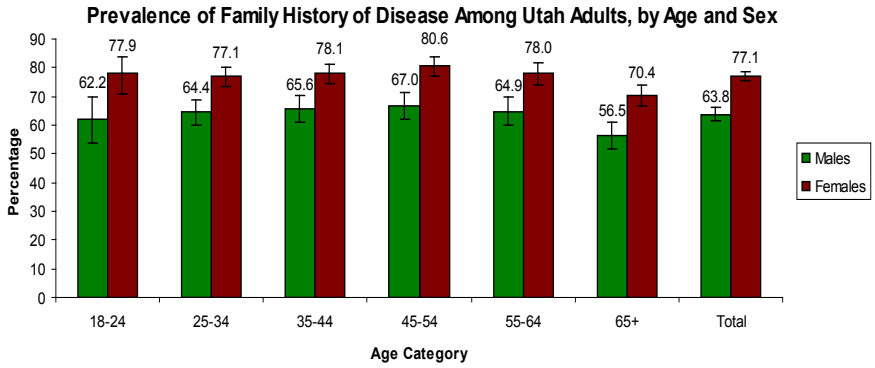
In 2004, the UDOH conducted an assessment of the HFT program to identify essential components for "new" family history projects. Eight recommendations were made, including the conversion of the original paper-based HFT into a Web-based tool. The Web-based HFT is currently under development. In addition, an updated high school curriculum has been developed and field-tested for use with it. The Web-based HFT has the potential to be used in schools, public health, worksite, and clinical settings.

Appendix A
BRFSS Data

Adult Family History Knowledge
Behavioral Risk Factor Surveillance System (BRFSS)

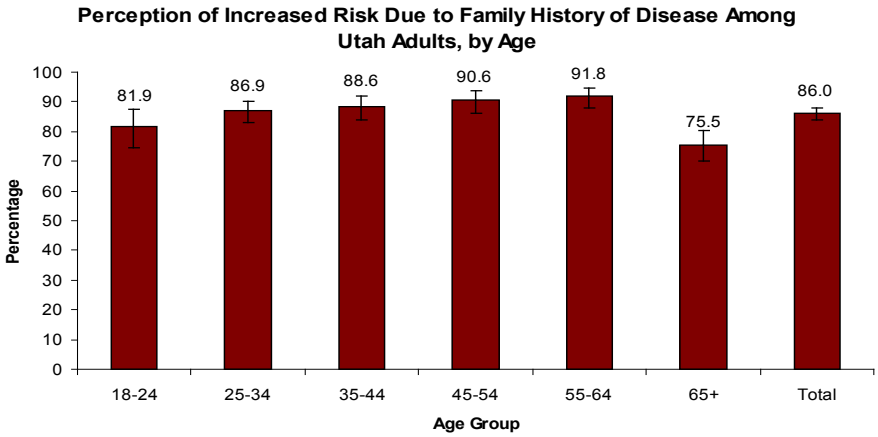
Family history of chronic disease has been recognized as a risk factor for the development of many common, chronic diseases. However, the collection and interpretation of family health history information has rarely been applied in public health to assess disease risk and influence behavior change. Since its inception in 2003, the Utah Department of Health Chronic Disease Genomics Program (CDGP) has worked to integrate family health history into public health, with a focus on chronic disease. Efforts have included surveillance activities to assess the public's knowledge of family health history and its link with the development of certain chronic diseases. Information gathered was used to develop appropriate interventions designed to raise awareness among Utah adults.

Genomics-related questions were included on the statewide BRFSS survey beginning in 2005 to assess the general public's knowledge of family health history. Specific goals of the genomics questions included: assessment of the public's knowledge, attitudes, and beliefs about family health history; assessment of the public's awareness of the link between disease and genetics; determination of how provider practices surrounding family history have influenced the public's actions toward their own health; and the determination of the number of people who have been seen by a provider who has asked about their family health history. Survey results were used to develop and evaluate interventions, which have included the development and dissemination of educational packets, state- and nationwide genomics presentations, work-site interventions, publications, and the development of family health history tools.



Source: Behavioral Risk Factor Surveillance System, 2005-2007 combined, crude rates.

70.5% of Utah adults reported that, when thinking about their immediate family members (grandparents, parents, siblings and children, both living and deceased), one or more of the following diseases such as heart disease, stroke, diabetes, or cancer tend to run in their family. A significantly higher percent of females (77.1%) reported family history for disease when compared to males (63.8%). This trend was observed for all age groups.

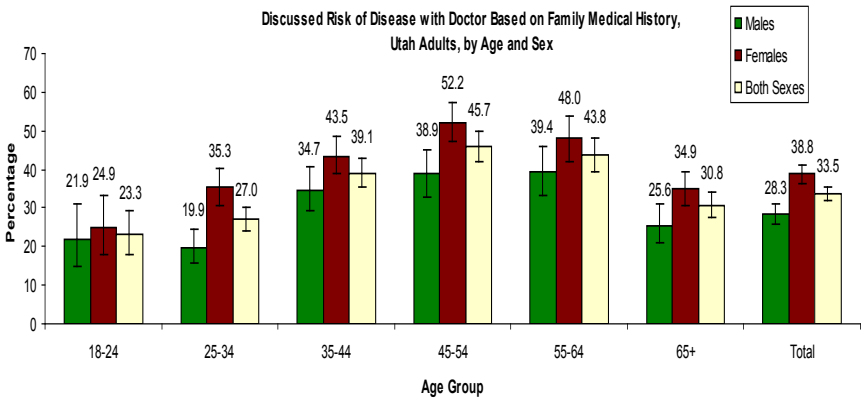


Source: Behavioral Risk Factor Surveillance System, 2005, crude rates

In 2005, Utah adults were asked if they thought having a family history of chronic disease, such as heart disease, stroke, diabetes, or cancer would increase their risk for developing the disease. 86% of the adult population responded that a positive family history of disease would increase their risk. There appears to be a trend of increasing perception of risk with increase in age for all age groups except among those aged 65 and older. Only 75.5% of adults aged 65 and older responded

Appendix A
BRFSS Data (continued)

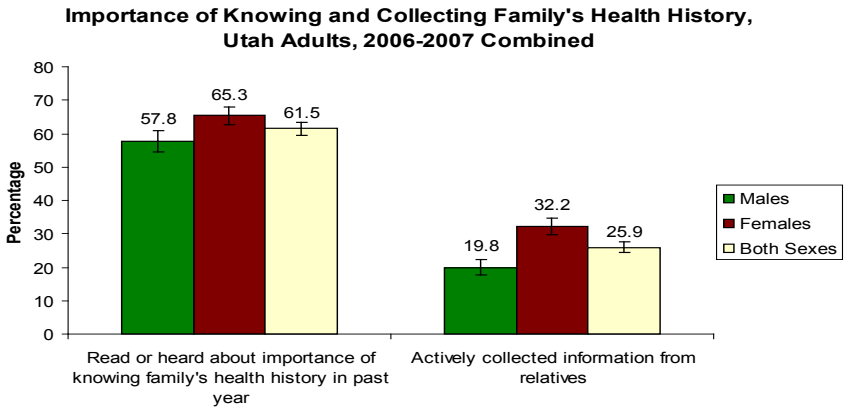
that family history of disease would increase their risk of contracting disease, which is significantly lower than the overall prevalence and all other age groups except 18-24. Significant differences were not found between males and females regarding their perceived risk of disease based on family history.



Source: Behavioral Risk Factor Surveillance System, 2005-2006 combined, crude rates.

Only 33.5% of adults reported that their doctor or another health care professional had ever discussed with them their risk for certain diseases or other health problems based on their family medical history. Adults in age groups 35-44, 45-54, and 55-64 were more likely to report that a doctor or other health care professional had ever discussed with them their risk for certain diseases when compared to all other age groups. Overall, females (38.8%) were more likely to report that their doctor or another health professional had discussed with them their risk for disease based on family history than males (28.3%). This trend was observed among all age groups.

Of those who reported that their doctor or other health professional had discussed their risk of disease based on family history, 71% said that their health care provider had also made recommendations based on their family history. 27% of all adults said that their doctor or other health professional had ever made recommendations to them based on their family history of disease.

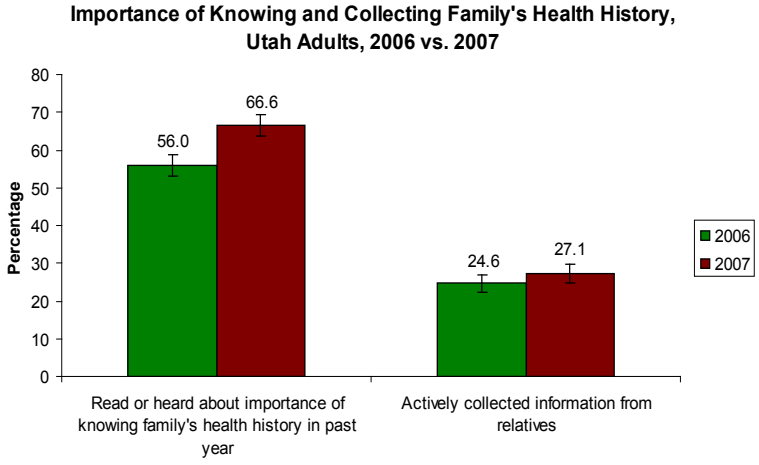


Source: Behavioral Risk Factor Surveillance System, 2006-2007 combined, crude rates.

In 2006 and 2007, 61.5% of adults responded that they had heard about the importance of knowing their family's health history within the past year. Females (65.3%) were more likely to have heard about the importance of knowing their family's health history than males (57.8%).

Only 25.9% of adults reported having ever actively collected information from their relatives for the purpose of developing a family health history. The percentage of females who reported having actively collected family health history information (32.2%) was one and a half times greater than the percentage of males (19.8%).

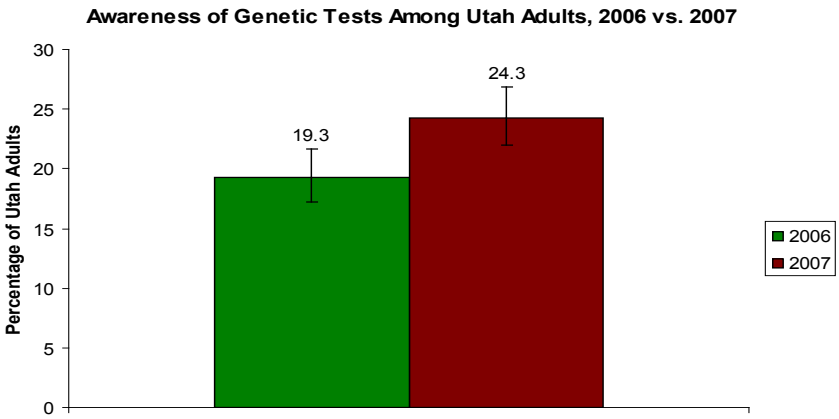
Of those respondents who said they had actively collected family health history information, 84% said they had shared that information with a doctor, nurse, or other health care professional (data not shown).



Source: Behavioral Risk Factor Surveillance System, 2006 and 2007, crude rates.

Appendix A
BRFSS Data (continued)

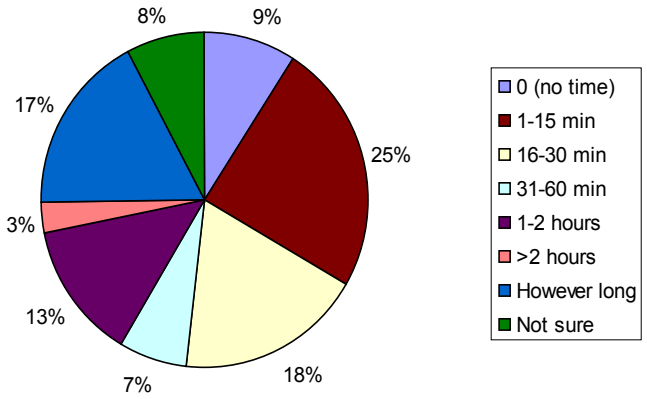
Responses for years 2006 and 2007 were compared to determine if educational efforts among Utah's adult population had an impact by increasing the prevalence of Utah adults who had recently heard about and who had actively collected family health history information. The prevalence of adults who had heard or read about the importance of knowing one's family health history within the past year increased by more than 10% between 2006 (56.0%) and 2007 (66.6%), which represented a statistically significant increase. While the percentage of adults who had actively collected health information from relatives appears to have increased slightly (from 24.6% in 2006 to 27.1% in 2007), the observed increase was not statistically significant.



Source: Behavioral Risk Factor Surveillance System, 2006 and 2007, crude rates.

In 2006 and 2007, Utah adults were surveyed to assess their awareness of genetic tests of DNA advertised by companies to improve health and prevent disease. Direct-to-consumer marketing of genetics has become an increasingly scrutinized area of research by public health professionals over the past few years. Between 2006 and 2007, there was a 5% increase in the percentage of adults who reported having heard about these tests, increasing from 19.3% to 24.3%. This increase was statistically significant.

Amount of Time Willing to Spend Completing a Family Medical History, Utah Adults



Source: Behavioral Risk Factor Surveillance System, 2005, crude rates.

In 2005, Utah adults were asked how much time they would be willing to spend completing a family medical history, either on their own or in their doctor's office. Nearly half (43%) said that they would only be willing to spend less than 30 minutes, 9% said they would be willing to spend no time, and 17% responded that they would be willing to spend any amount of time necessary to complete a family medical history.

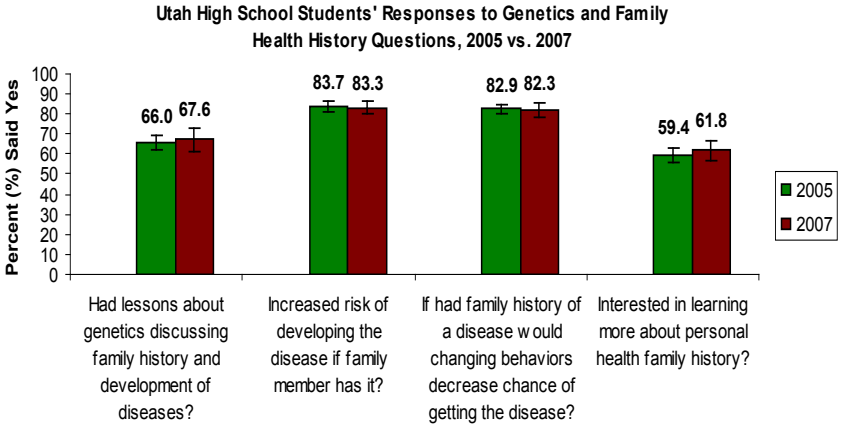
Appendix B
YRBS Data

Family History and Youth
Youth Risk Behavioral Survey (YRBS)

One of the goals of the CDGP has been to increase awareness of the importance of family health history and its relationship to the development of certain chronic diseases among Utah youth. Surveillance activities have been conducted as part of this effort and have provided important information regarding their knowledge of and interest in family health history. The information has been used to develop and evaluate appropriate interventions targeted toward this population.

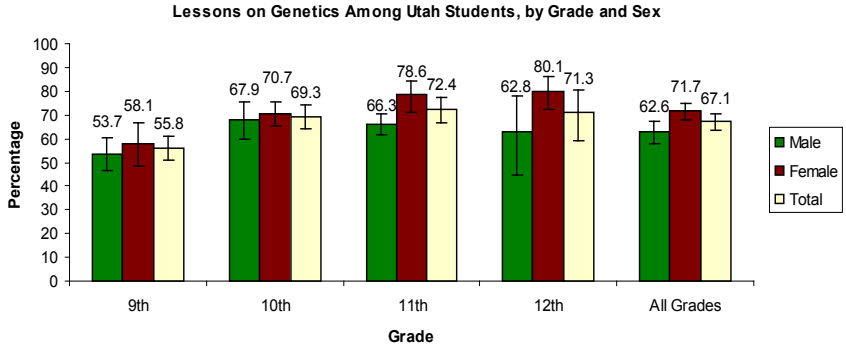
The YRBS is a survey that is administered to a representative sample of Utah high school students every two years which contains a variety of questions regarding health risk behaviors. Four survey questions regarding genetics and family health history were asked as part of the YRBS in 2005 and 2007 to assess students' knowledge of and interest in genetics and family health history. In 2006, the CDGP and Genetic Science Learning Center used the YRBS results to develop the *Using Family History to Improve Your Health* curriculum module (available at http://learn.genetics.utah.edu) and to gain support from the Utah State Office of Education for use of the curriculum in Utah schools. The module is designed to teach high school students that chronic diseases have both a hereditary and lifestyle/environmental component and to help them understand what it means to be at risk for a disease. Future survey results may indicate whether or not the curriculum was effective in reaching these objectives.

Appendix B
YRBS Data (continued)



Source: Youth Risk Behavior Survey, 2005 and 2007.

Survey responses for 2005 and 2007 were compared to determine if an increase had occurred in students' knowledge of and interest in family history and health due to the addition of the family history module to high school curriculums. Survey results for those two years were comparable and reflect no significant difference between responses. However, lack of a difference may be due to the fact that revisions were still being made to the module during 2007, and it is uncertain whether or not the module was implemented in high school curriculums statewide.



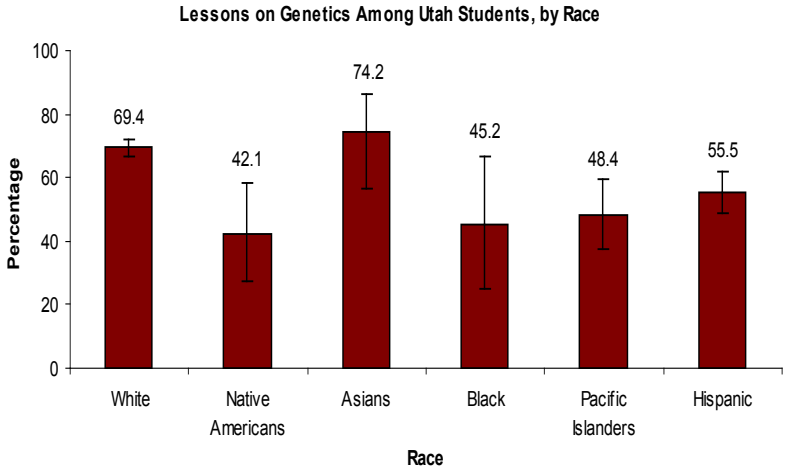
Source: Youth Risk Behavior Survey, 2005 and 2007 combined.

67.1% of Utah high school students reported that they had received lessons about genetics that discussed the relationship between family history and the development of certain diseases such as heart disease, diabetes, asthma, or cancer.

Appendix B
YRBS Data (continued)

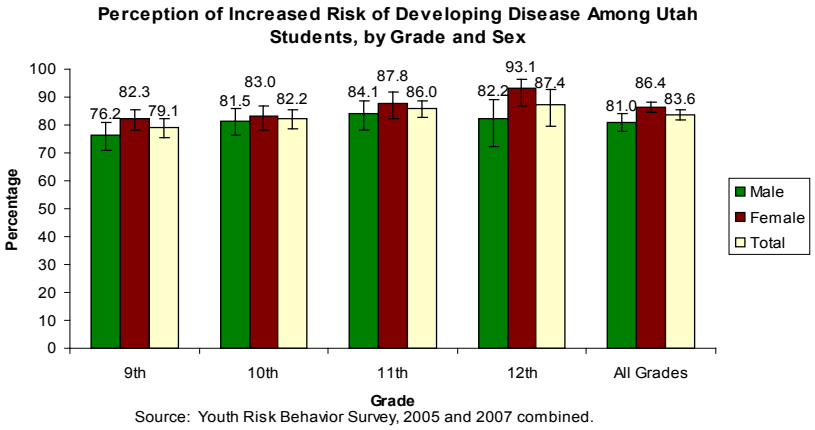
9th graders reported a significantly lower prevalence (55.8%) for lessons on genetics compared to the prevalence for 10th (69.3%) and 11th (72.4%) grades and all grades combined (67.1%). No significant difference was found between other grades.

Among all high school students, a significantly higher percentage of females (71.7%) than males (62.6%) reported having received lessons on genetics and the relationship between family history and the development of certain diseases. Within individual grades, the prevalence between sexes was similar for most grades, and a significant difference between males and females was found only among students in the 11th grade.



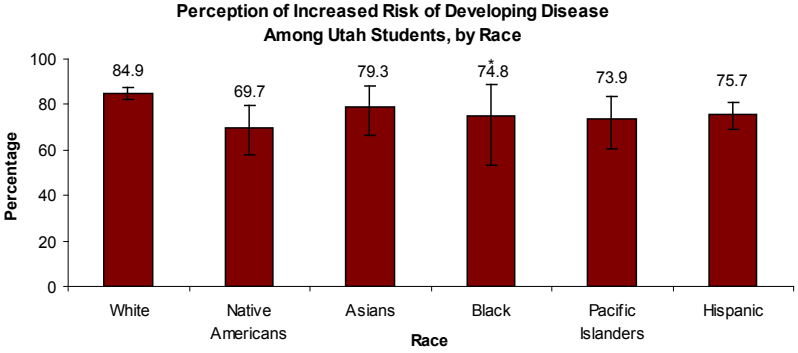
Source: Youth Risk Behavior Survey, 2005 and 2007 combined.

Disparities were found between students of different races regarding having received lessons on genetics. A significantly lower percentage of Native American (42.1%), Pacific Islander (48.4%), and Hispanic (55.5%) students reported having received lessons about genetics when compared to white students (69.4%). Significant differences were not found between students of other races.



Source: Youth Risk Behavior Survey, 2005 and 2007 combined.

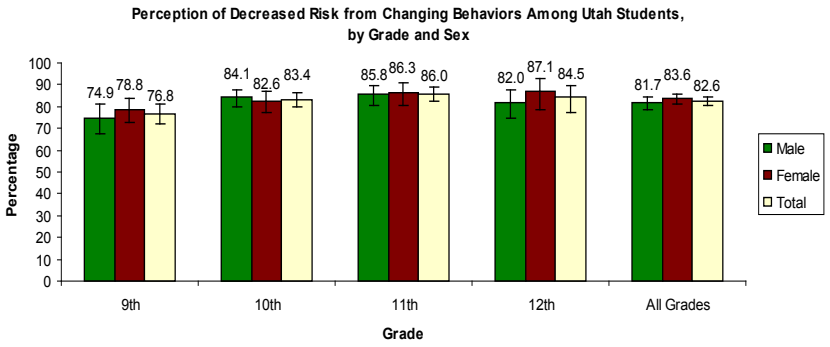
When asked if they would be at increased risk of developing the disease if a parent, grandparent, or sibling had heart disease, diabetes, asthma, or cancer, 83.6% of all high school students responded that they would consider themselves to be at increased risk. Responses were similar across grades and sex.



Source: Youth Risk Behavior Survey, 2005 and 2007 combined.
* The prevalence for race category Black has a coefficient of variance >30% and does not meet UDOH standards for reliability.

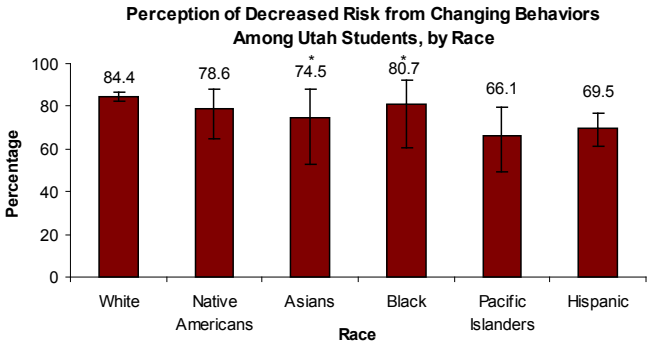
Differences were found between students of different races regarding perceived risk of developing a disease if a parent, grandparent, or sibling had the disease. A significantly lower percentage of Native American (69.7%) and Hispanic (75.7%) students felt they would be at increased risk for disease when compared to the percentage of white students (84.9%). Responses were comparable among students of other races.

Appendix B
YRBS Data (continued)



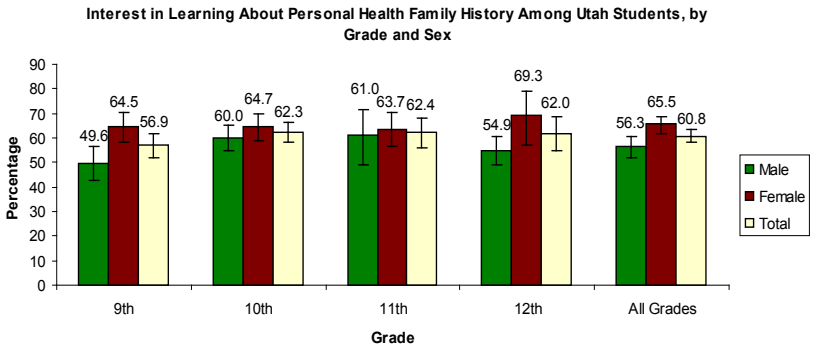
Source: Youth Risk Behavior Survey, 2005 and 2007 combined.

High school students were asked if they thought changing behaviors such as not smoking, exercising more, getting early or regular checkups for a disease, or eating a healthy diet would decrease their chances of getting certain chronic diseases if they also had a family history of it. 82.6% of students responded that their chances of developing disease would be decreased through the adoption of healthy behaviors. 17.4% of all high school students did not think healthy behaviors would decrease their risk of disease. No significant differences in responses were found between grades and sex.



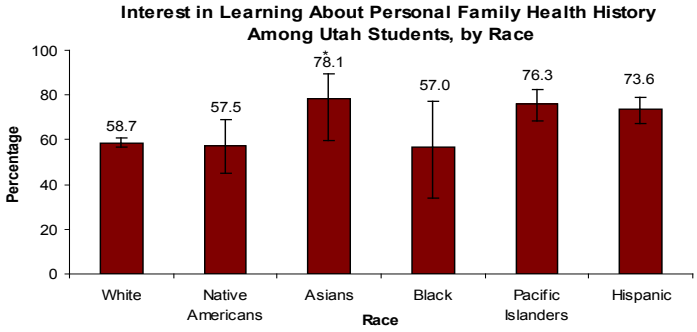
Source: Youth Risk Behavior Survey, 2005 and 2007 combined.
* The prevalences for race categories Black and Asians have a coefficient of variance >30% and do not meet UDOH standards for reliability.

Fewer Pacific Islander (66.1%) and Hispanic (69.5%) students felt that improving behaviors would decrease their risk of developing disease when compared to white students (84.4%). Responses were similar to whites among students of other races.



Source: Youth Risk Behavior Survey, 2005 and 2007 combined.

60.8% of high school students responded that they would be interested in learning more about their personal family health history. Among all students, a significantly higher percentage of females (65.5%) than males (56.3%) indicated interest. Females in the ninth grade showed a significantly higher interest (64.5%) compared to ninth grade males (49.6%). No difference between males and females was found within other grades, and no significant difference in the prevalence of interested students was found between grades.



Source: Youth Risk Behavior Survey, 2005 and 2007 combined.
* The prevalence for race category Asians has a coefficient of variance >30% and does not meet UDOH standards for reliability.

Differences were found between students of different races regarding their interest in learning more about their personal family health history. A significantly higher percentage of Pacific Islander (76.3%) and Hispanic (73.6%) students responded that they would be interested in learning additional information when compared to white students (58.7%). Interest levels were not significantly different among students of other races.

Appendix C
Data Sources

Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a state-based system of health surveys established by the Centers for Disease Control and Prevention (CDC) to assess the prevalence of and trends in health-related behaviors in the non-institutionalized adult population aged 18 years and older. Data are collected monthly from a random telephone sample of adults living in households with telephones. Currently, data are collected in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. More than 350,000 adults are interviewed each year, making the BRFSS the largest telephone health survey in the world.[1] Utah has participated continuously in the BRFSS since its inception in 1984.

The BRFSS questionnaire is modified each year by the CDC in collaboration with participating state agencies. The questionnaire has three parts. The first part is a core set of questions that is asked by all states. The second is a series of topical modules developed by the CDC. States have the option of adding modules as they wish. Utah has used several of the CDC modules. The final part of the questionnaire consists of questions designed and administered by individual states to address issues of local concern. These have been revised annually in Utah to maximize the survey's ability to address the needs of Utah's health programs. Participants in the Utah BRFSS are asked about a wide variety of behaviors such as seat belt use, exercise, tobacco and alcohol consumption, health services utilization, and basic demographic information. Participation in the BRFSS is completely anonymous and voluntary. Prior to analysis, BRFSS data are weighted so that the findings can be generalized to the Utah adult population.

Utah Youth Risk Behavior Survey (YRBS)

The YRBS is a state-based survey that collects uniform, state-specific data on priority health risk behaviors that contribute markedly to the leading causes of death, disability, and social problems among youth in the United States. These behaviors, often established during childhood and early adolescence, include: tobacco use, unhealthy dietary behaviors, inadequate physical activity, alcohol and other drug use, and sexual behaviors that contribute to unintended pregnancy and sexually

transmitted diseases, including HIV infection. Also included are behaviors that contribute to unintentional injuries and violence. The YRBS was designed to: determine the prevalence of health risk behaviors; assess whether health risk behaviors increase, decrease, or stay the same over time; examine the co-occurrence of health risk behaviors; provide comparable national, state, and local data; provide comparable data among subpopulations of youth; and monitor progress toward achieving the Healthy People 2010 objectives and other program indicators.

The YRBS includes national, state, and local school-based surveys of representative samples of 9th through 12th grade students. These surveys are conducted every two years, usually during the spring semester. The national survey, conducted by the Centers for Disease Control and Prevention (CDC), provides data representative of high school students in public and private schools in the United States. The state and local surveys, conducted by departments of health and education, provide data representative of public high school students in each state or local school district. Utah has participated in the YRBS since its inception in 1999. School and student participation in the survey project are voluntary and student responses on the questionnaire are confidential. Active consent is obtained from parents of participating students. Students who do not have parental consent do not participate in the survey.

Reference:

1. Centers for Disease Control and Prevention. About the BRFSS. Retrieved on August 26, 2008 from http://www.cdc.gov/brfss/about.htm.

Appendix D
Glossary

Attributable risk: The excess risk of a specified health effect assumed to result from a specified exposure. In the case of complex disease, one can speak of the attributable risk associated with the genetic or environmental contributions.

Base pair: Two bases, which form a "rung on the DNA ladder". Bases are the "letters" (Adenine, Thymine, Cytosine, Guanine) that spell out the genetic code. Normally, adenine pairs with thymine and cytosine pairs with guanine.

Candidate gene: A gene, located in a specific chromosomal region suspected of being associated with a disease, whose protein product is consistent with the known disease process.

Carrier testing: Type of genetic testing that can tell individuals if they are carriers of a mutated gene. Carriers rarely develop the disease, but can pass on the mutated gene or the normal gene to their children (Example: cystic fibrosis).

Chromosome: One of the threadlike "packages" of genes and other DNA in the nucleus of a cell. Humans have 23 pairs of chromosomes.

Complex trait: A trait that results from the interaction of one or more genes and environmental factors (Example: asthma).

Confidentiality: Acknowledgment that genetic information is sensitive and private and access should be limited to those authorized to receive it.

DNA (Deoxyribonucleic acid): The organic molecules inside the nucleus of a cell that carries the genetic instructions for making living organisms.

ELSI: An abbreviation for the ethical, legal, and social implications of human genome research.

Eugenics: An early twentieth century movement which aimed to improve the human race by preventing "unfit" people from reproducing (negative eugenics) and encouraging "fit" people to reproduce (positive eugenics). Eugenics was implemented in the United States, the Nordic countries, and Germany. The eugenic philosophy is most widely known for the association with Nazi abuses, "better baby" and "fittest family" contests.

Appendix D
Glossary (continued)

Family health history: Reflects a family's shared genetics, environment, culture, lifestyle, and behaviors that interact to affect a person's risk of developing disease.

First-degree relative: An immediate family member such as a parent, sibling, or child.

Gene: The basic unit of hereditary information passed from parent to offspring.

Gene-environment interaction: The effects of one or more genes interacting with environmental factors in determining the occurrence of disease.

Gene-gene interaction: The interaction of several different genes in the production of a disease.

Genetic counseling: Provides patients and their families with education and information about genetic-related conditions and helps them make informed decisions.

Genetic discrimination: Prejudice against those who have or are likely to develop an inherited disorder.

Genetic profile: The particular arrangement of genes and markers in the DNA, unique to each individual.

Genetics: The study of biological variation. Typically refers to a single gene and its effects.

Genetic screening: Testing a group of people to identify individuals at high risk of having or passing on a specific genetic disorder.

Genetic testing: Testing done by analyzing DNA to determine if an individual has certain mutations associated with an inherited condition.

Genome: All of the DNA contained in an organism or a cell.

Genomics: The study of all the genes and how they interact with each other and the environment.

Human Genome Project: An international research project to map each human gene and to completely sequence human DNA, completed in 2003.

Inherited: Traits transmitted from parents to offspring.

Multifactorial: A trait or disease resulting from interplay be-

Appendix D
Glossary (continued)

tween multiple genes and environmental factors.

Mutation: A permanent change in DNA. Some mutations can have no effect, can be beneficial, or cause harm to the organism.

Pedigree: Diagram of a family's genealogy that shows family members' relationships to each other and how a particular trait or disease has been inherited.

Personalized medicine: The development of drug therapies intended to treat people as individuals.

Pharmacogenetics: The study of how an individual's genetic makeup affects their response to drugs.

Pharmacogenomics: Combines pharmacogenetics with genomic studies. Uses large groups of people to evaluate how drugs interact with a range of genes.

Polymorphism: A variation in the sequence of DNA among individuals found in at least 1% of the population.

Predictive testing: Genetic testing to identify people who are at an increased risk for developing a certain type of disease or disorder.

Relative risk: The chance of developing a specific disease as compared to the risk for another individual or group.

Second-degree relative: A relative such as grandparent, grandchild, uncle, aunt, niece, nephew, or half-sibling.

Single gene disorder: A disorder caused by mutations within one particular gene (Example: Huntington's disease, Tay-Sachs).

Single Nucleotide Polymorphism (SNPs): Pronounced "snips". A DNA sequence variation that is one base long, and that occurs in at least one percent of the general population. SNPs account for much of the variety among humans.

Third-degree relative: A relative such as great-grandparent, great-uncle/aunt, or cousin.

Utah Genetic Testing Privacy Act: This law protects Utah citizens from genetic discrimination in employment and some health insurance settings (To read the law visit www.code-co.com/utah/code/03/26-45.htm).

Appendix D
Glossary (continued)

References:

- Human Genome Project Information, U.S. Department of Energy
- Lawrence Berkeley National Laboratory's ELSI Project
- National Coalition for Health Professional Education in Genetics
- National Human Genome Research Institute, National Institutes of Health
- University of Utah Genetic Science Learning Center

www.health.utah.gov/genomics