

# THE UTAH STATE GENETICS PLAN

**MAY 2002**

## **HISTORY**

The Utah Department of Health (UDOH) has provided statewide genetic services for several decades. Until the 1970's, public health genetic services in Utah were limited to newborn blood screening, a population-based method to identify babies with selected congenital conditions and bring them to treatment before symptoms of severe illness can develop. Utah babies are currently screened for phenylketonuria (PKU), congenital hypothyroidism (CH), galactosemia, and hemoglobinopathies such as sickle cell anemia. During the decade ending 1999 more than 400,000 babies received genetic screening in Utah; 148 children were identified who were born with conditions which, if untreated, can cause severe mental retardation. Table 1 summarizes data for the Utah Newborn Blood Screening program for the years 1996-2000. Well over 95% of births occurring in Utah are to mothers who reside in the state. Virtually all babies born in Utah receive a blood screen before discharge from the birth facility (first screen). Utah has required a second screen (i.e., a second blood sample during the baby's first month) for more than 20 years, and 90% or more of babies born in the state receive this service. Abnormalities found on screening far outnumber actual cases of disease diagnosed, and false positive screening results are much more common on the first screen than on the second.

TABLE 1  
UTAH NEWBORN BLOOD SCREENING 1996-2000

	1996	1997	1998	1999	2000
RESIDENT BIRTHS	42,056	43,009	45,128	46,243	47,331
OCCURENT BIRTHS	42,943	43,871	46,127	47,261	48,454
TOTAL 1 <sup>ST</sup> SCREENS	42,281	44,116	46,127	47,261	48,454
ABN.PHENYL-ALANINE	165	69	50	31	36
ABNORMAL GALT	39	65	44	63	55
ABNORMAL T4/TSH	231	335	288	424	220
TOTAL 2 <sup>ND</sup> SCREENS	37,964	41,505	43,771	43,975	45,377
ABN.PHENYL-ALANINE	3	44	21	19	10
ABNORMAL T4/TSH	52	78	65	103	72
CLASSICAL PKU	2	5	4	2	0
CLASSICAL GALACTOSEMIA	1	1	0	0	0
PRIMARY HYPOTHYROIDISM	18	9	10	15	23

UDOH staff successfully bring virtually all newborns in Utah to screening and provide diagnostic services to all newborns with screening abnormalities.

Since September 2001 newborns in Utah also receive screening for hemoglobinopathies, such as sickle cell anemia. During the last quarter of calendar year 2001, 68 infants had

abnormal hemoglobin screening results; two infants were subsequently identified with sickle cell disease.

The statute mandating newborn blood screening in Utah (except where parents object due to membership in a “specified, well-recognized religious organization” with teachings contrary to medical tests) provides for testing of infants for phenylketonuria and “other metabolic diseases which may result in mental retardation or brain damage”, as long as a “preventive measure or treatment is available” and “there exists a reliable laboratory diagnostic test method,” which are criteria generally recognized in all 50 state newborn blood screening programs in the United States (Cunningham, G: NEJM 346(14):1084-1085). According to the Utah statute, the UDOH may “charge fees” for materials, tests, laboratory analyses, and administrative costs for follow-up. By practice, the Utah Legislature sets an allowable range for newborn screening fees while UDOH fixes the actual fee charged for the test kit. Specifications for the test kit and other aspects of the newborn blood screening program are detailed in regulations promulgated by UDOH. These regulations state, in part: “The department (UDOH), after consulting with the Genetic Advisory Committee, may make additions or changes to the Newborn Screening battery of tests.”

The Genetics Advisory Committee was first established in 1990 by the UDOH and was intended to assist with policy development regarding genetic services, including but not limited to newborn blood screening. As early as 1977 UDOH had secured a public health funding stream for clinical genetic services, including genetic counseling. These funds have financed a contract between UDOH and the University of Utah School of Medicine’s Division of Clinical Genetics in the Department of Pediatrics, and have

grown to support the provision of 728 genetics outpatient clinic visits and 289 metabolic outpatient visits. With the growth of demand for clinical genetic services effectively capturing whatever increases in funding became available, and analyses of proposed changes in newborn blood screening occupying actual committee deliberations, the Genetics Advisory Committee throughout the 1990's was unable to fulfill its promise as a source of statewide genetics policy discussion and proposals. In part, the suboptimal productivity of the Genetics Advisory Committee can be traced to a dearth of UDOH staff support. The staff time that has been available has come from the major existing public health genetics program—Newborn Blood Screening. It is not surprising, therefore, that the Genetics Advisory Committee's deliberations have emphasized newborn screening issues and that the sole reference to the Genetics Advisory Committee in Utah law is found in the newborn screening regulations. The recent change in the newborn blood screening panel enabling the inclusion of hemoglobinopathies among the conditions for which newborns in Utah will be screened occurred only after an Ad Hoc Committee on Newborn Screening recommended the change to UDOH. The early indications are that the change has been a service delivery success, which demonstrates that an advisory committee can have an impact that construes Utah law broadly.

In addition to the recent success in the newborn blood screening program, the potential for policy advice from the Genetics Advisory Committee in Utah has been primed by two grants from the Health Resources and Services Administration (HRSA) in the US Public Health Service:

- 1) UDOH is the recipient of a three year grant from HRSA to develop resources and policies that will foster an approach to the care of children with special health care

needs that is high quality and cost effective. The goal of this approach to care, known by the title 'medical home', is to have primary care physicians, families, and allied health professionals act as partners to identify and access all the medical and other services needed to help children and their families achieve their maximum potential. Utah primary care pediatricians who partner in the care of children with special health needs have indicated that they would be most helped in maximizing the potential of their patients' medical home if assisted in three ways: a) having a case manager based in the pediatrician's office; b) having information about community resources more readily available; and c) having easy access to disease specific practice guidelines. In response, UDOH has developed three components of the Utah Collaborative Medical Home Project: a) a web based medical home resource; b) paid medical home facilitators and family advocates in five disparate pediatric offices across the state; and c) with Utah Medicaid (a division of UDOH) as a partner, identification and implementation of mechanisms for reimbursing medical home services. Through this project, and the resources and training developed within Utah during its completion, families with children with special health care needs, including children with genetic conditions, should enjoy the benefits of a medical home, including improved coordination of care, efficient use of limited resources, and increased wellness because of comprehensive care.

- 2) UDOH has also received federal funds to support the Utah Genetics Implementation Project. (The planning phase has been completed by May 2002 and application has been made for the implementation phase, to continue for three

years.) These grant funds have enabled UDOH to examine the needs of Utah's population for genetic services, as is outlined in the Needs Assessment section of this document below. Among the expected products of this funding will be enhanced integration of child health records, which will include use of a single shared birth record number for newborn blood screening, newborn hearing screening, and birth certificates. Ultimately, data integration is expected to include all aspects of child health records within Utah's public health programs.

During the most recent session of the Utah legislature, the Genetic Testing Privacy Act was passed; Utah's governor later signed the act into law. (See appendices for a complete copy of the act.) The act defines a genetic test as "analysis of an identifiable individual's DNA that results in information that is derived from the presence, absence, alteration, or mutation of an inherited gene(s)" or the "presence or absence of a specific DNA marker(s)". By definition of the act, information accrued through routine physical examination; routine chemical, blood, or urine analysis; testing for drugs or HIV infection; or testing performed due to manifestations of disease cannot be considered a "genetic test". Private genetic information is defined by the act as any information derived by personal testing of an individual or his/her blood relative. Under the act employers and health insurers are restricted in their access to and use of private genetic information. Employers may not take private genetic information into account when making decisions about "hiring, promotion, or retention" except in specific circumstances detailed in the statute. Likewise, health insurers may not "access or otherwise take into

consideration private genetic information” when offering, renewing, or underwriting insurance products, except in specified circumstances.

## **NEEDS ASSESSMENT**

According to the Year 2000 US Census, Utah’s population currently stands at 2.2 million persons. Seventy percent of this population resides along a 200-mile series of mountain valleys called the Wasatch Front. Since all of Utah’s urban areas are found there, Utah’s population is more urbanized than those of most other states, including eastern seaboard states such as New Jersey. The 75% of Utah’s landmass other than the Wasatch Front is sparsely inhabited, classified as rural or frontier, and characterized by geographically challenged health service delivery.

In 1998, Utah was one of 20 states involved in the Family Voices “Your Voice Counts” survey performed in partnership with Brandeis University. One hundred and three families with children with special health care needs were surveyed in Utah (2200 nationwide). Utah data did not differ significantly from the national results. Sixty-two percent of Utah respondents identified their primary care physician as their child’s “most important doctor”, but only 70% were “sure” that their physician had the needed skill and expertise to care for their child. Among the dissatisfactions with the “most important doctor” were: giving information on medical research (39% rated poor or okay); communicating with the child’s school or Early Intervention Program (27%); and communicating with other health care professionals (23%).

A detailed Utah Child Health Survey, completed in February 2000, identified 13% of children in surveyed households as meeting the definition of children with special health care needs. Though 97% of families of children with special health care needs reported having a usual place of care for routine or acute health care needs, a physician's office was the most common source for only 70%. Over 97% of families were "always" or "frequently" satisfied with the respect and treatment they received from their physicians. Ninety percent of families were "satisfied" with the information provided for decision-making about their child's health care needs and 90% felt their provider had a thorough understanding of the services their child was receiving. However, 30% did not understand certain discussions with their provider about specialty care and 41% had not communicated with their providers about plans for their child's transition into adulthood. Each of the 718 families surveyed was asked the diagnosis of their child with special health care needs. Nearly five percent of the families reported a diagnosis of "syndromes"; 1% reported "developmental disability/mental retardation"; 3% reported a "nutritional or metabolic" problem and 0.4% reported an "oral/facial abnormality." These estimates indicate that as many as 8000 children in Utah have genetic conditions leading to special health needs.

A recent study of 123 families of children with chronic conditions in Central Massachusetts compared the perceptions of unmet needs among fathers, mothers, and their pediatricians. A key message of the study was that pediatricians often misjudge the needs of families and should develop methods of accurately assessing those needs. Over half of the parents identified information as one of their major needs. Specifically, they wanted information about the child's condition, treatment, behavior and development,

and planning for the future. A recent survey of young adults (ages 14-21) with special health needs and their parents has been conducted in Utah to ascertain what barriers existed to transitioning from pediatric to adult health care. Parents most often stated the following barriers to transitioning for their young adult children: a) restrictions in the health care programs or insurance plans (66%); b) lack of doctors familiar with the needs of disabled young adults (47%); and c) lack of money to pay for adult health care (39%). Staff of health programs serving youth with special health needs universally stated that the most common barriers to transition from pediatric to adult health care for young adults with special health needs were a lack of physicians familiar with the care of these patients and lack of funding for their health care once they became adults.

During the year of genetics services planning just concluded, UDOH staff were able to conduct focus groups sessions with attendees drawn from UDOH program staff, children's and community advocacy groups, local providers, and an ethicist from the Human Genome Ethical, Legal and Social Implications Branch of the US Genome project. The major findings of this assessment were:

- 1) A very strong need was delineated among the Genetics Advisory Committee and focus group invitees to develop a mechanism for systematically adding to the newborn or population-based screening, evaluating the effectiveness of new and existing screening activities and deleting screening for conditions where no clear benefit is demonstrated. Members of the Genetics Advisory Committee have determined that a Screening Subcommittee will be necessary to undertake the task of developing, piloting, and evaluating a Population Screening Management System (PSMS).

- 2) The Genetics Advisory Committee has also identified a substantial need to educate UDOH program staff about the genetic components of chronic disease as well as about genetic contributions to adverse pregnancy outcomes (e.g., maternal PKU, factor V Leiden, etc.). This need has been refined through meetings with leadership in UDOH's MCH and Health Promotion (Chronic Disease) Bureaus. These two Bureaus are part of the UDOH Community and Family Health Services Division, which provides continuing education opportunities for staff on a quarterly basis. These educational opportunities were selected as the best settings for ongoing training of UDOH staff regarding genetic components of disease and adverse pregnancy outcomes.
- 3) Problems with transition from pediatric to adult medical care for individuals with genetic disorders was also identified as a significant need in Utah. Working with the Utah Medical Home Advisory Committee in the CSHCN Bureau to educate medical care providers about needs of people with genetic disorders was seen as a way of refining the focus of this need, as well as of determining the best way to meet the need.

Finally, Utahns enjoy the lowest tobacco use rate and one of the lowest alcohol abuse rates in the nation. Chronic disease causation is consequently shifted slightly away from behavioral risk factors and towards inherited risk. Educating UDOH staff responsible for prevention of chronic diseases about the genetic contribution to these disorders is seen as a considerable need in Utah. Another need is for better characterization of the knowledge of health care providers and the public about the genomics of some chronic diseases.

## GOALS

- A) The Utah Department of Health will become better organized to promote healthier populations in Utah through responsible use of genetic knowledge.

Rationale: UDOH is committed in statute and by virtue of its public health mission to devise systems for the early identification of individuals at risk for genetic conditions and to assist these individuals to receive comprehensive care. Coordination of these services will require better communication between various programs within UDOH. And UDOH needs more consistent advice and support from genetics professionals and citizens from the community.

- B) The Utah Department of Health will ensure that all Utah children are screened for appropriate newborn conditions.

Rationale: UDOH has already received requests to consider adding a number of conditions to the newborn blood screening program, including congenital adrenal hyperplasia, biotinidase deficiency, cystic fibrosis, and disorders of fatty acid metabolism. UDOH also requires advice about newborn screening including follow up

of abnormal screens and treatment of children who receive a diagnosis on an ongoing basis.

- C) The Utah Department of Health will establish a system to ensure appropriate transition from pediatric to adult care for individuals with genetic conditions.

Rationale: Young adults with genetic conditions face significant barriers as they approach the age of majority and begin to become responsible for their own health care.

- D) The Utah Department of Health will increase the effectiveness of public health systems in reducing the burden of chronic disease caused by genetic conditions.

Rationale: Chronic diseases such as cancer and cardiovascular disorders are increasingly recognized as heritable problems. Utahns have a relatively low rate of some behavioral risk factors for chronic disease. Therefore, persons with some chronic diseases in Utah may have inherited higher risk for these disorders, making recognition of heritable patterns of chronic disease among Utahns a high priority.

## **SPECIFIC OBJECTIVES**

A1: UDOH staff will form a genomics working group.

Activities: All program directors in UDOH will be invited to participate with the UDOH Genomics Work Group, either personally or by representation. Those program directors

with interests in population screening, chronic disease, special health needs, or health care financing will be strongly encouraged to join the work group. The work group will meet regularly, not more often than monthly, and receive rotating presentations about public health genetics programs within UDOH.

**Timelines:** The UDOH Genomics Work Group will begin meeting during the first year of implementation grant funding.

**Responsible Agency:** Lynn Martinez will initially convene and chair the work group.

**Expected Outcome:** Program directors in UDOH will become better informed about genomics activities with the department.

**Evaluation Strategy:** Lynn Martinez will arrange an annual informal survey of program directors.

**A2:** The Utah Genetics Advisory Committee will be reorganized as a five-person executive board, staffed by UDOH, with at least three expert panels from which to draw recommendations.

**Activities:** The chairs of each of three expert panels (see Specific Objectives B1, C1, and D1 below) will serve as members of the Genetics Advisory Committee. A family advocate, preferably the parent of a child with a genetic condition, will also be a member of the Genetics Advisory Committee. The Chair of the Genetics Advisory Committee will be an individual with doctoral level (PhD or MD) training and experience in either bioethics or public health. The Genetics Advisory Committee will meet at least quarterly and as often as monthly, and will assist UDOH with advice about and oversight for all programs and functions within the UDOH having to do with genetic services. The

Genetics Advisory Committee will have responsibility for coordination of public health genetics programs in Utah with national efforts (such as coordinating the Utah Newborn Blood Screening program with the National Newborn Screening and Genetics Resource Center.) The advice of the Utah Genetics Advisory Committee is not binding on UDOH.

Timelines: The reorganization of the Utah Genetics Advisory Committee will be accomplished within the first half year of implementation grant funding.

Responsible Agency: Utah Department of Health Director Rod Betit, with counsel from Dr. George Delavan, Division Director of the Family and Community Health Services Division, will invite selected individuals to participate on the Genetics Advisory Committee. Selected UDOH personnel will be delegated to staff and support the functions of the Genetics Advisory Committee.

Expected Outcome: All genetics related programs and functions within UDOH will receive the benefit of review and advice from members of Utah's professional and lay communities with interests in policy and services in the field of genetics. Thereby public health efforts in genetics will improve in quality and in stature in the community.

Evaluation Strategy: An annual review of Genetics Advisory Committee minutes will be conducted.

B1: The Utah Department of Health will organize the Population Screening Standing Committee as an expert panel under the aegis of the Utah Genetics Advisory Committee.

Activities: Membership of the Population Screening Standing Committee will represent both professional and lay organizations with an interest in newborn blood screening in Utah. Participation on the committee will be voluntary and will require attendance at

meetings (perhaps as often as monthly) as well as preparation time before meetings. At a minimum, the committee will include parents of children identified with each disease targeted for screening in Utah; two primary care physicians (family practice and pediatrics); physician specialists in metabolic disease, pediatric endocrinology, hematology, and clinical genetics; a hospital administrator; a genetic counselor; a representative of the Utah Public Health Association; a representative of a non-profit agency with an interest in genetic or congenital disease, such as the March of Dimes; a representative of the Governor's Council for People with Disabilities; a representative of the Utah Birth Defects Registry; and a director of a clinical laboratory. Staff and facilities for the committee will be provided by the UDOH. Mr. Rod Betit will select the committee chair. Within the realm of population based screening for genetic conditions, and utilizing nationally established and recommended guidelines for screening, the committee shall advise UDOH (through the Genetics Advisory Committee) concerning the three primary functions of public health agencies: assessment, policy formation, and assurance. A) Assessment: What diseases fit statutory criteria for population based screening in Utah (including but not limited to congenital diseases of infants)? What laboratory methods are best suited for population based screening in Utah? How effective are follow-up diagnostic tests? Are effective treatments available? Is the follow-up of screening tests in Utah bringing infants with genetic conditions to diagnosis and treatment efficiently and in a timely manner? Is the treatment of infants with these conditions optimally effective? What national objectives for newborn blood screening have been established? B) Policy formation: Are the statutes, regulations, and financing of population based screening in Utah adequate and appropriate? What role do private

sector agencies have in providing population based screening services, follow-up, and treatment? C) Assurance: What information and training about genetic conditions is available to primary care and public health providers? Are genetic counseling services needed by families with infants having conditions identified through newborn screening sufficient?

**Timelines:** During the first year of implementation grant funding, the Standing Committee on Population Screening will be constituted, convened, and review function of the current newborn screening program, with particular attention to the recent program addition: hemoglobinopathy screening. During the second year of grant funding the Population Screening Standing Committee will advise the UDOH (through the Genetics Advisory Committee) about implementation of newborn screening for congenital adrenal hyperplasia. During Years 2 and 3 of implementation grant funding, the Population Screening Standing Committee will evaluate other conditions as potential targets for newborn screening, including but not limited to cystic fibrosis, biotinidase deficiency, and disorders of fatty acid metabolism. Once constituted, the Standing Committee on Population Screening will, of course, set objectives for itself, and may well decide to examine more than one of the proposed target diseases or others simultaneously. In addition, the Committee may address population screening beyond the newborn period.

**Responsible Agency:** The chair of the Genetics Advisory Committee will recommend candidates for the Chair of the Population Screening Standing Committee to Mr. Rod Betit, who will make the final selection. The newly selected chair of the committee, along with Dr. V. Fan Tait, Bureau Director for Children With Special Health Needs, will

invite all other committee members to participate. Dr. Tait will arrange committee staffing and facilities.

Expected Outcomes: Evaluation of newborn blood screening conditions for inclusion in the program will become more efficient and consistent as the standing committee replaces an ad hoc committee used in the past. UDOH staff will be able to refer inquiries from the professional and lay communities about newborn screening to a standing committee for their review before taking action. Recommended changes in newborn blood screening will arise from lay and professional communities in the state, providing a more substantial basis for pursuing policy and funding changes through political processes.

Evaluation Strategy: the UDOH staff shall conduct an annual review of committee meeting minutes.

C1: UDOH will establish a Standing Committee on Transition as an expert panel under the aegis of the Utah Genetics Advisory Committee.

Activities: Membership of the Standing Committee on Transition will represent both professional and lay organizations with an interest in assisting young adults with genetic conditions to transition from pediatric to adult medical within a medical home context. Participation on the committee will be voluntary and will require attendance at monthly meetings as well as preparation time before meetings. At a minimum, the committee will include parents of children with genetic conditions identified as needing transition from pediatric to adult medical care; three primary care physicians (family practice, pediatrics, and internal medicine); physician specialists in clinical genetics and rehabilitative

medicine; a home health agency nurse or administrator; a genetic counselor; representatives of the insurance and managed care industries; a representative from the Social Security Administration; a representative of a non-profit agency with an interest in genetic disease such as the March of Dimes or ARC; a representative from the Department of Education; a representative from the Governor's Council for People with Disabilities; and a staff member from the Utah Legislature. The chair of the Genetics Advisory Committee will select the committee chair. The committee shall advise UDOH (through the Genetics Advisory Committee) concerning the following: A) Needs Assessment: What primary care physicians are currently performing a medical home function for young adults with genetic conditions who are transitioning through the years of reaching the age of majority? What knowledge and skills do these primary care physicians need? What needs do the young adults with genetic conditions have for medical and other services, such as genetic counseling?; B) Policy formation: What payment policies exist for the services needed by youth with genetic conditions transitioning into adulthood? What are the existing resources to meet the needs of these youth? What are the qualifications for receiving coverage through Social Security? What gaps in coverage exist and who is aware of these gaps?; and C) Assurance: The committee will work with the Utah Medical Home project to assure that education modules and best practice guidelines for genetic conditions are present on the medical home website.

Timelines: During the first year of implementation grant funding the Standing Committee on Transition will be constituted, convened, and begin needs assessment activities. During the second year of implementation grant funding, the committee will

carry out the activities under policy formation by identifying the resources currently available and the gaps of coverage that occur. During the second year of implementation grant funding, the committee, working with the medical home team, will assure that appropriate web based modules are available to primary care physicians in Utah concerning at least two genetic conditions. During the third and subsequent years after implementation grant funding, the committee will begin work to improve access to needed services for those youth transitioning to adulthood.

**Responsible Agency:** The chair of the Genetics Advisory Committee will recommend candidates for the Chair of the Standing Committee on Transition to Mr. Rod Betit, who will make the final selection. The newly selected chair of the committee, along with Dr. V. Fan Tait, Bureau Director for Children with Special Health Care Needs, will invite all other committee members to participate. Dr. Tait will arrange committee staffing and facilities.

**Expected Outcomes:** With consistent committee work over several years, medical homes for young adults with genetic conditions will become available throughout the state of Utah. The physicians who partner with these young adult patients within the context of these medical homes will have the requisite information and skills to serve these patients needs. And the policies of payers within the medical financing system will favor proper development of medical homes for this population.

**Evaluation Strategy:** the UDOH staff shall conduct an annual review of committee minutes.

D1: UDOH will establish a Standing Committee on Chronic Disease as an expert panel under the aegis of the Utah Genetics Advisory Committee.

Activities: Membership of the Standing Committee on Chronic Disease will represent both professional and lay organizations with an interest in the reduction of morbidity and mortality related to chronic disease in Utah. Participation on the committee will be voluntary and will require attendance at monthly meetings as well as preparation time before meetings. At a minimum, the committee will include family members of those with chronic diseases potentially caused by heritable risk factors; physician specialist in oncology genetics and cardiovascular disease genetics; a chronic disease genetics counselor; health promotion specialists from hospitals and local health departments; two representatives of non-profit agencies with an interest in chronic disease control, such as the Utah chapters of the American Heart Association and the American Cancer Society; an epidemiologist; and a representative of the Utah Public Health Association. The staff and facilities for the committee will be provided by UDOH. The chair of the Genetics Advisory Committee will select the committee chair. The committee shall advise UDOH (through the Genetics Advisory Committee) about the following: A) What does the general public know about heritable risk factors for chronic disease (to be assessed using the Behavioral Risk Factor Surveillance Survey)? What genomic clusters of chronic disease are evident within the Utah population (using Utah Population data bases such as the birth defects registry or the cancer registry)?; B) Based upon epidemiologic data, what genomic interventions may successfully reduce the burden of chronic disease in Utah? Will better attention to family histories in the medical setting improve early intervention? Can epidemiologic methods identify family or regional clustering of

disease while screening or other population based methods will still improve outcome?;

C) What educational interventions will improve primary care physician performance of family history as a screening tool for genetic risk factors for chronic disease? What modules on the Medical Home web pages are indicated for primary care physician practice guidelines for reducing the burden of genetic based chronic disease?

Timelines: During the first year of implementation grant funding, the Standing Committee on Chronic Disease will be constituted, convened, and will plan and execute the survey of the Utah population knowledge concerning genetic based disease. During the second year of grant funding, the Standing Committee on Chronic Disease will provide UDOH with advice (through the Genetics Advisory Committee) about an epidemiologic approach to genomic clusters of chronic disease. During the third and subsequent years after implementation grant funding, educational programs for public health officials, primary care physicians, and genetic counselors detailing the methods for reducing the burden of chronic disease through genetic interventions will be carried out and placed on the medical home website.

Responsible Agency: The chair of the Genetic Advisory Committee will recommend candidates for the Chair of the Standing Committee on Chronic Disease to Mr. Rod Betit, who will make the final selection. The newly selected chair, along with Ms. LaDene Larson, Bureau Chief of Health Promotion in UDOH, will invite all other committee members to participate. Ms. Larson will arrange committee staffing and facilities.

Expected Outcomes: UDOH will begin to approach chronic disease control not just through behavioral risk factor reduction but also through recognition of heritable risk factors for chronic disease. Persons within Utah communities at particular risk for

chronic disease because of heritable risk factors will receive earlier interventions targeted to reduce the eventual burden of these diseases on Utah communities.

Evaluation Strategies: An annual review of committee meeting minutes shall be conducted by the UDOH staff.

