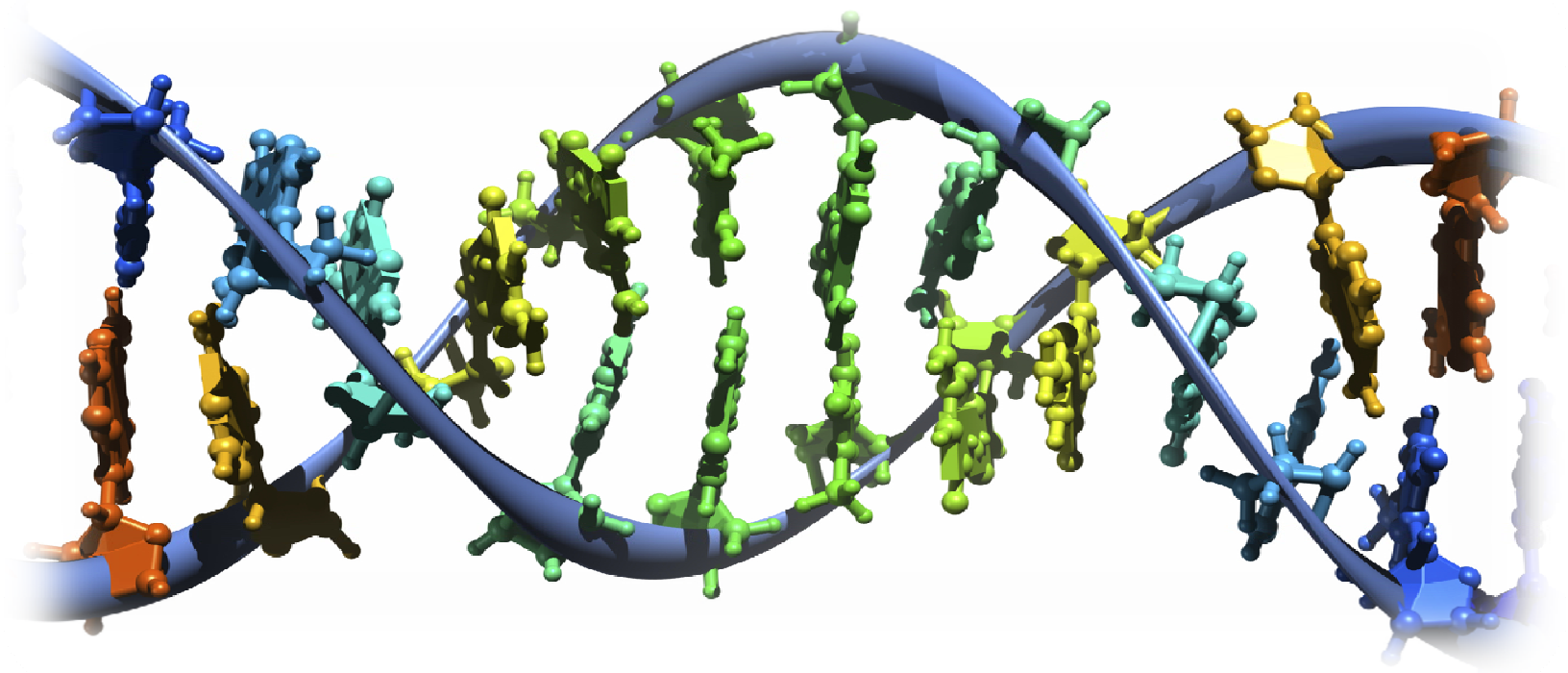
State of Kansas Genetics Plan

2010



KANSAS
OFFICE OF THE GOVERNOR

Mark Parkinson, Governor

www.governor.ks.gov

August 19, 2010

Dear Fellow Kansans:

Genetics and genetic disorders impact the lives and health of all Kansans. Along with healthy behaviors and environmental conditions, genetics plays an important role in our health. Today almost everyone knows someone whose health has been affected by genetic conditions.

Given the increased prominence of genetics for private and public health practice, KDHE convened a group of stakeholders with specific expertise to assess our service systems and our readiness to meet the challenges that lie ahead. The product of many hours of work by this group has resulted in the first Kansas State Genetics Plan.

Secretary Roderick Bremby joins me in recognizing the efforts of the individuals who have contributed to this effort. They have developed a plan to guide us through our future advances in genetics. Through the work of this group, we can continue to be on the forefront of new knowledge and technologies as we advance our goals of good public health.

I encourage you to read this plan, become informed, and consider how genetics plays a part in your life.

Sincerely,

Mark Parkinson
Governor of the State of Kansas

Capitol Building, Room 212S, Topeka, KS 66612-1590 • (785) 296-3232 • Fax: (785) 296-7973
e-mail: governor@ks.gov

State of Kansas Genetics Plan

2010

Kansas Department of Health and Environment
Bureau of Family Health
1000 SW Jackson, Suite 220
Topeka, Kansas 66612-1274
(785) 291-3363

Acknowledgements

Development of the State Genetics Plan was made possible through a grant from the Heartland Regional Genetics Center. The Kansas Department of Health and Environment was the convener of this process and worked in conjunction with DNAXPRT Consulting, LLC (Lenna M. Levitch, MS, CGC; Molly M. Lund, MS, CGC) on creating the original draft and EnVisage Consulting, Inc. in convening experts for a final review of the plan.

Contributors to the process include:

- Kansas Department of Health and Environment
  - Elizabeth Abbey, Newborn Hearing Screening Coordinator
  - Paula Clayton, Director, Bureau of Health Promotion
  - Rita Davenport, Cancer Control and Prevention Program
  - Garry Kelley, Maternal and Child Health Epidemiologist
  - Jamey Kendall, Newborn Screening Follow-Up
  - Linda Kenney, Director, Bureau of Family Health
  - Jamie Kim, Maternal and Child Health Epidemiologist
  - Ileen Meyer, Director, Children and Families Section
  - Richard Morrissey, Deputy Director, Division of Health
  - Carolyn Nelson, Director, Children's Developmental Services
  - Janet Neff, Director, Cancer Control and Prevention Program
  - Pati O'Hara, Cancer Program Manager
  - Stacey Sandstrom, Health Chemistry Director, Kansas Health & Environment Labs
  - Marc Shiff, Director, Children and Youth with Special Health Care Needs Section
  - Linda Williams, Newborn Screening Follow-Up

- Center for Practical Bioethics
  - Glenn Edwards McGee, PhD, John B. Francis Chair in Bioethics
  - Myra Christopher, President and CEO

- Families Together, Inc.
  - Darla Nelson-Metzger, Education Advocate Co-Coordinator

- Fort Hays State University
  - Liane Connelly, PhD, Professor and Chair, Department of Nursing

- Informed Medical Decisions, Inc.
  - Kelly Rogel, Genetic Counselor

- Kansas Advisory Council on Newborn Screening

- Kansas Commission for the Deaf and Hard of Hearing
  - Rebecca Rosenthal, Executive Director

- Kansas Health Policy Authority
  - Becky Ross, Acting Deputy Policy Director

- Kansas Hospital Association
  - Deborah Stern, Vice President, Clinical Services and General Counsel

- Kansas Insurance Department
  - Linda Sheppard, Director, Accident & Health Division

- Kansas School for the Deaf
  - Robert Maile, PhD, Superintendent

- Kansas State Department of Education
  - Carol Ayers, Early Childhood Special Education Consultant
  - Robin Harris, Assistant Director, Career, Standards & Assessment Services

- University of Kansas Medical Center
  - Julie Broski, Consumer Health Project Manager, Dykes Library Outreach
  - Merlin Butler, MD, PhD, Psychiatry and Behavioral Sciences
  - Lisa Butterfield, MS, CGC, Genetic Counselor, Maternal Fetal Medicine, Ob/Gyn
  - Deborah Collins, MS, CGC, Genetic Counselor, Medicine Department
  - Roy Jensen, MD, Director, Cancer Center
  - Diane Persons, MD, Resident Program Director/Director of Cytogenetics
  - Moya Peterson, PhD, Clinical Associate Director, School of Nursing
  - Paw Shaw, MD, Professor of Pediatrics

- University of Kansas School of Medicine-Wichita
  - Shobana Kubendran, MS, CGC, Genetic Counselor, Pediatrics

- Sickle Cell Disease Association of America
  - Ruby Bruce, Board Member
  - Linda Golson, Executive Director

- Wichita State University
  - Betty Elder, PhD, Associate Professor, Department of Nursing

Table of Contents

Introduction 1

Kansas Public Health: Past and Present 2

Kansas Demographic Overview 3

Kansas Racial, Ethnic, and Ancestral Diversity 4

Genetic Contribution to Chronic Diseases 8

Genetic Services in Kansas 9

Other Genetic-Related Resources in Kansas 14

2007 State Genetics Survey 16

Challenges 17

Goals and Objectives 18

Next Steps: Implementation Plan 25

Considerations from Other States' Genetics Program 28

Evaluation and Conclusion 29

Glossary 30

References 32

Resources 33

Appendix A: Historical Summary of Genetic Services and Leaders in Kansas A.1

Appendix B: Goal Action Plans B.1.1

Appendix C: Crosswalk Between Implementation Plan Steps and Goals/Objectives C.1

Appendix D: Other States' Genetics Programs D.1

State of Kansas Genetics Plan

Mission: **Improve availability and accessibility of genetic services in Kansas**

Introduction

Genetic and genetic-related health conditions have a significant impact on the health of the general population. Each year, there are approximately 40,000 live births in Kansas. Over 1,000 of these infants will have a genetic disease or major birth defect(1). Further, approximately 10% of all adults and 30% of children in hospitals are there due to genetically-related problems(1).

Genetics plays a role in the susceptibility to many diseases, either specifically inherited or due to the interaction between an individual's genetics and their environment. Currently, here are more than 6,000 known genetic disorders(1). It has been almost 150 years since Gregor Mendel published his theories on inheritance in pea plants and our knowledge of the field has expanded rapidly since that time. Advanced genetic and genomic technologies will further increase our understanding of the pathophysiology of common diseases, increase opportunities to prevent diseases, and allow for earlier and more effective treatments and therapies.

Healthy People 2010 is a comprehensive, nationwide health promotion and disease prevention agenda designed to achieve two overarching goals:

- Increase quality and years of healthy life
- Eliminate health disparities

Healthy Kansans 2010 subsequently identified three issues common to multiple health focus areas:

- Reducing and Eliminating Health and Disease Disparities
- System Interventions to Address Social Determinants of Health
- Early Disease Prevention, Risk Identification, and Intervention for Women, Children and Adolescents (2).

The State of Kansas Genetics plan mirrors these goals and will improve the health and quality of life for Kansans through integration of quality genetic services and technology into public health and reduce morbidity and mortality associated with genetic disorders. This plan is developed through the Kansas Department of Health and Environment in partnership with the genetics stakeholders across the state. The purpose of this document is to provide Kansas with direction over the next three to five years to optimize the potential benefits of new technologies and more effectively provide genetic services to residents. This plan includes a demographic overview of the State, a description of genetic and genetic-related services, a summary of the 2007 State Genetics Survey, and goals and objectives to improve the health and quality of life for Kansans as related to genetic disorders as a result of interviewing and convening stakeholders.

Kansas Public Health: Past and Present

In March, 1885 the Kansas Department of Health and Environment was formed. A number of organizational changes occurred during the past century, leading from a Board of Health appointed by the governor with a part-time executive secretary and a budget of less than $5000 to a Department of Health and Environment with a cabinet level secretary appointed by the governor with more than 500 employees and a budget of more than 40 million dollars[(2)].

The early board, and the present department, relied upon legislative backup and direction, public support and understanding, and consultation and advice from diverse professional groups, especially the medical community.

The most dramatic changes in the pattern of public health today, in contrast to that of a century ago, are in the areas of maternal care, infant survival, chronic diseases, care of the aging, and changing environmental problems caused by our high-tech economy.

As public health continues to mature, issues such as social determinants, the life course perspective, and systems infrastructure are receiving increased focus. Social determinants are the conditions in which people are born, grow, live, work and age, including the health system. Income level and neighborhood conditions are two common examples of social determinants. The life course perspective is a growing awareness in public health research of the long-term impact various events and exposures earlier in life have on health.

Genomics is the study of all the genes in a person, as well as interactions of those genes with each other a person's physical and social environment. Public health genomics, an emerging field, is a multidisciplinary field focused on the effective and responsible translation of genome-based knowledge and technologies into public health and clinic practice to improve public health.

Considering how genetics and genomics fits in the larger public health infrastructure in Kansas, developing the capacity to respond to advances in genomic research and technology, and planning to increase the availability and accessibility of genetics services in Kansas fits well with the emerging public health focus on social determinants, life course perspective, and systems issues.

Kansas Demographic Overview[2], [3]

As the face of disease has changed over the past century, so has the demographic and social fabric of our state. Just as Kansas was a destination for immigrants in the late 1800s, today it is home to an increasing minority of new immigrants as well as multigenerational Kansans. Since 1885, the population of Kansas has grown and Kansans represent a myriad of cultures, races, ethnicities and backgrounds.

Kansas was admitted as a state in 1861. Between 1860 and 1880, the population of Kansas exploded, increasing by a factor of nine. In 1880, Kansas was the 20th most populous of 47 states and territories, outranking California by 130,000 people. Since 1880, Kansas' population has steadily increased, though now it ranks 33rd in size.

Throughout the last century, Kansas' population has become more concentrated in metropolitan areas (e.g., Kansas City, Wichita) and regional centers (e.g., Salina, Hays, Garden City).

Not only has the population distribution in Kansas changed over the past 100 years, but the makeup of the population has also evolved. A constant factor in this change is the role health plays in a population's number and years of healthy life from infancy through old age. According to the 1880 Census, less than 2% of the population was 65 years or older compared to 13% in 2009. An even smaller fraction of the population, 0.04%, was 85 years or older versus 2.1% in 2009.

Today's Kansas population was more evenly distributed across the age groups, indicating increased longevity. Longevity is a function of advances in health, nutrition, and sanitation. In 2030, the population will be even more flatly distributed across the age groups with projected increases in life expectancies and the Baby Boomer generation well into their senior years. An estimated one in five Kansans will be aged 65 years or older, and one in ten will be 75 or older. The population of women of childbearing age is also increasing and it is projected that over 2.9 million people will reside in the State of Kansas by July 2030 [3].

In 1880, Kansas was a land of immigrants. Twelve percent were foreign-born, compared to 6% of the population in 2009. Most of 1880-Kansas was White (96%). Over the past 120 years, Kansas has become increasingly racially and ethnically diverse. In 2000, 13.9% of Kansans were a racial/ethnic minority; this has increased to nearly one in five Kansans (19.4%) for 2009.

In both Kansas and the United States, Hispanics surpassed Blacks in the 2000 Census as the largest minority group. From 1980 to 2009, Hispanics in Kansas increased nearly fourfold from 63,339 to 245,318. The 2000 Census was also the first time residents could select multiple races to describe themselves.

In addition to becoming more racially and ethnically diverse, the population of the U.S. and Kansas is becoming more economically disparate. Thirty-five years ago, the lowest earning households earned 8 times less than the highest earning households; today they earn 15 times less.

Kansas Racial, Ethnic, and Ancestral Diversity[2], [3]

Although Kansas may appear to be racially and ethnically homogenous at first glance, there is considerable diversity. There are sizable populations representing dozens of racial, ethnic and ancestral groups within Kansas' borders.

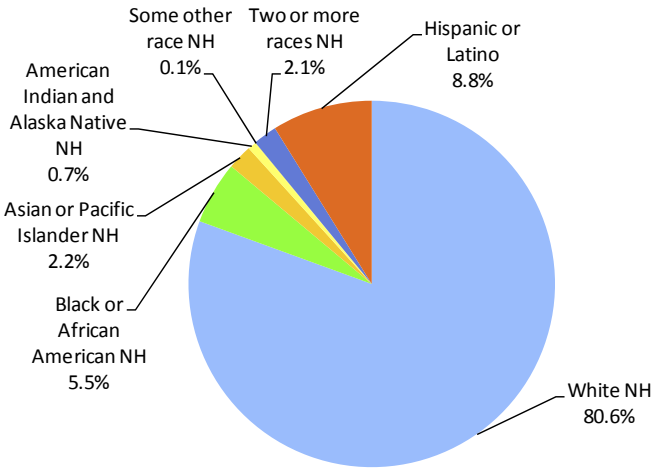
Race and Ethnicity

Nearly 20% of Kansans are of a racial or ethnic minority (2009). This includes 8.8% Hispanic or Latino; 5.5% Black or African American; 2.2% Asian, Native Hawaiian or Other Pacific Islander; and 2.1% of two or more racial groups.

Hispanic/Latino

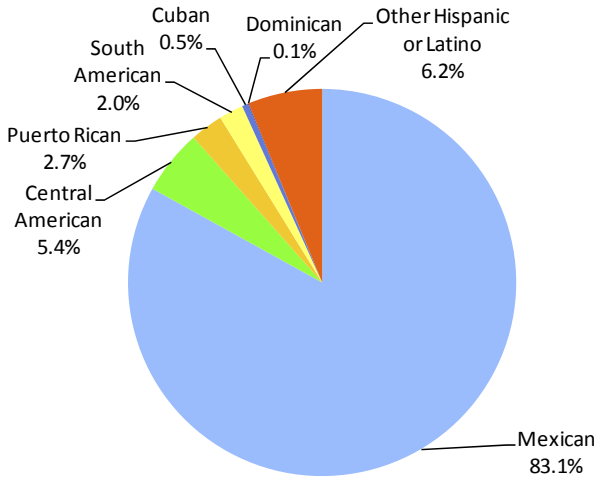
There are an estimated 245,318 Hispanics living in Kansas (2009). Over four in five of these are Mexican, though there are sizable populations of other Hispanic/Latino groups, including Central American, Puerto Rican, and South American. The largest Central American groups are Salvadoran (population 4,285), Guatemalan (3,743), and Honduran (3,398). The largest South American groups are Colombian (1,271), Ecuadorian (1,189), and Argentinean (768). The largest "other" Hispanic/Latino group is Spanish or Spaniard (4,162).

Kansas Population by Race and Ethnicity



NH: Non-Hispanic
Source: U.S. Census Bureau, 2006-2008 American Community Survey

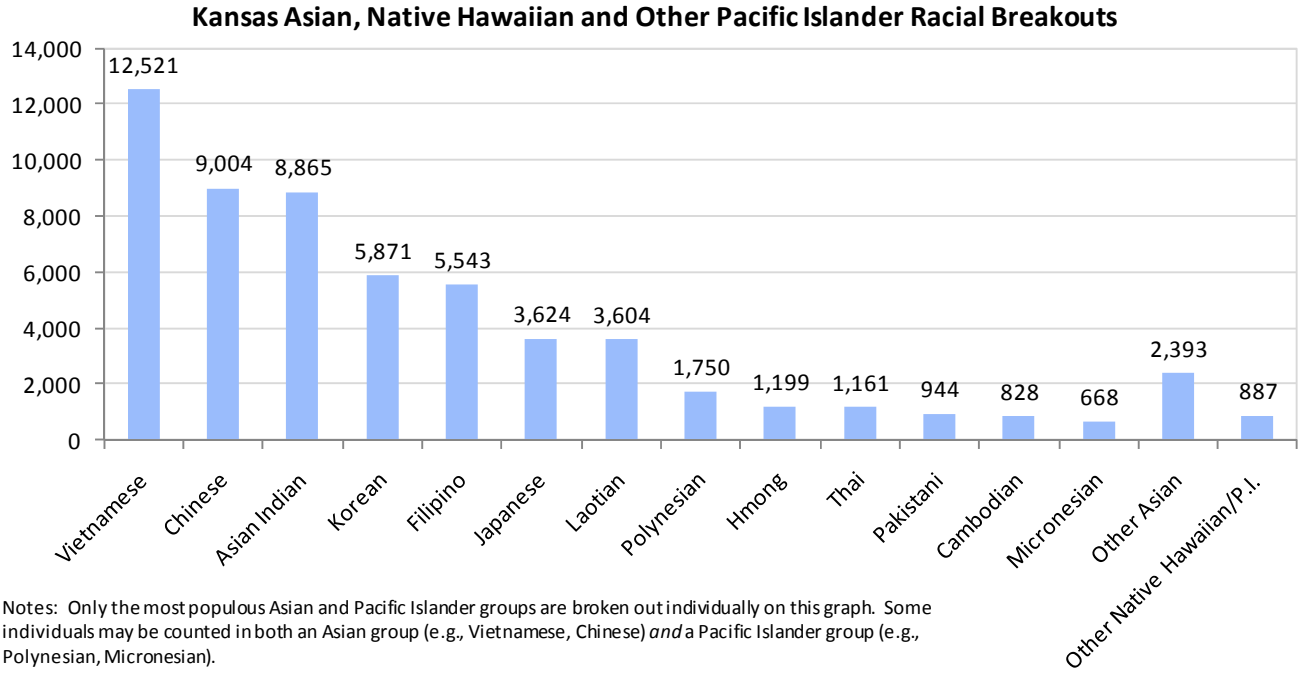
Kansas Hispanic or Latino Population by Origin



Source: U.S. Census Bureau, 2006-2008 American Community Survey

Asian, Native Hawaiian and Other Pacific Islander Racial Groups

According to the latest Census estimates, there are over 60,000 Asians, Native Hawaiians or Other Pacific Islanders living in Kansas. In the 2000 Census, multiple Asian and Pacific Islander racial groups were represented, the largest being Vietnamese. Those most populous Asian and Pacific Islander groups are broken out in the graph below.



Notes: Only the most populous Asian and Pacific Islander groups are broken out individually on this graph. Some individuals may be counted in both an Asian group (e.g., Vietnamese, Chinese) *and* a Pacific Islander group (e.g., Polynesian, Micronesian).

Source: U.S. Census Bureau, Census 2000 P.I.: Pacific Islander

American Indian and Alaska Native Tribes

In the 2000 Census, dozens of tribes were represented by Kansas residents, through Cherokee was by far the largest tribe represented. Tribes/tribal nations are listed in the table below; some individuals may be counted in more than one tribe.

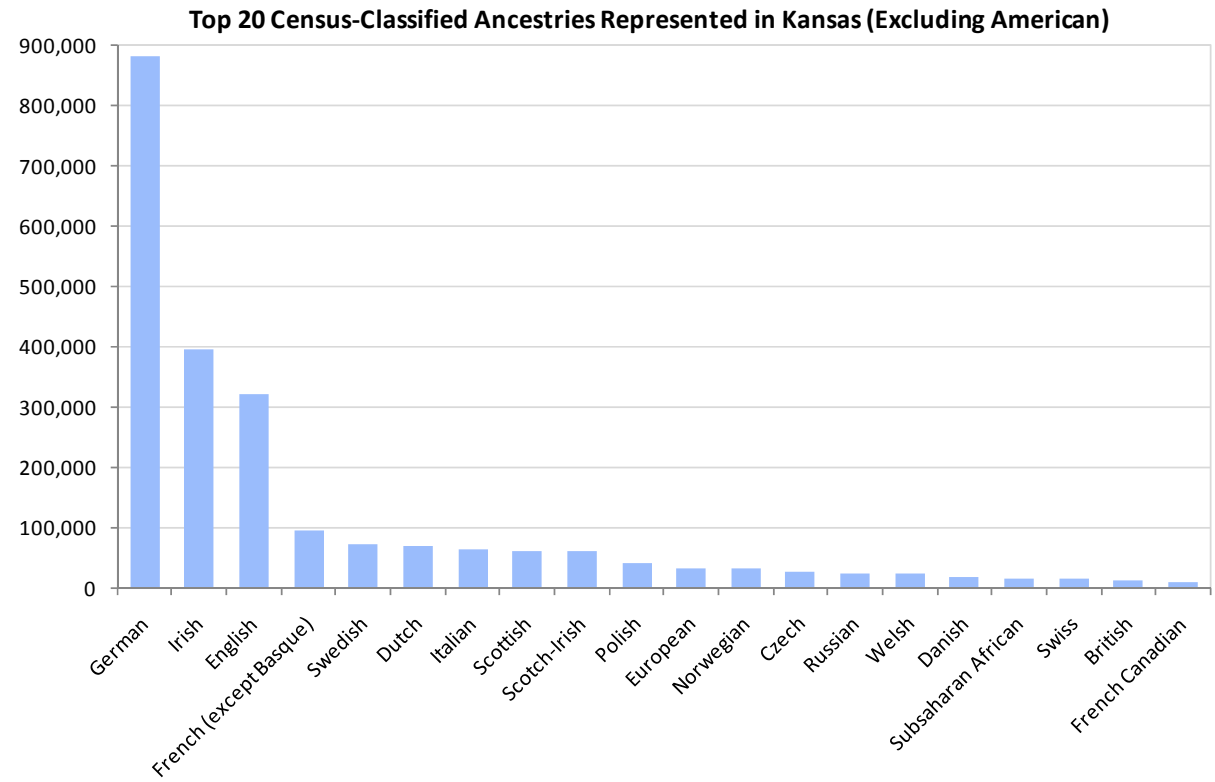
Cherokee	14,215
Potawatomi	2,922
Choctaw	2,076
Sioux	1,523
Creek	1,252
Latin American Indians	941
Blackfeet	927
Navajo	898
Apache	861
Iroquois	718
Osage	711
Delaware	616
Chippewa	540
Chickasaw	517

Seminole	435
Kiowa	378
Cheyenne	358
Comanche	354
Pueblo	226
Crow	106
Ottawa	104
Eskimo	98
Cree	82
Shoshone	72
Lumbee	68
Yaqui	67
Tlingit-Haida	65
Paiute	58

Menominee	56
Aleut	52
Alaskan Athabascan	43
Ute	35
Tohono O'Odham	30
Yuman	27
Pima	26
Yakama	20
Puget Sound Salish	15
Colville	11
Houma	6
Other specified tribes	4,784
Tribe not specified	12,826
Total tallied	**49,119**

Ancestries

The graph below lists the top 20 Census-classified ancestries for Kansans from the 2006-2008 American Community Survey. German is by far the most common ancestry, with 881,083 individuals, and Irish and English each represent more than 300,000 Kansans.



Source: U.S. Census Bureau, 2006-2008 American Community Survey

The following table includes a more complete listing of ancestries; individuals may be counted in more than one ancestry. These ancestries were collapsed within the table:

- "Subsaharan African" includes ancestries such as Kenyan, Ethiopian, Sudanese, Nigerian, and Somalian.
- "Arab" includes ancestries such as Lebanese, Egyptian, Syrian, Palestinian, Jordanian, and Moroccan.
- "West Indian (except Hispanic groups)" includes Dutch West Indian, Haitian, Barbadian, Jamaican, and Trinidadian and Tobagonian, among other ancestries.

Ancestry	Count	Ancestry	Count
German	881,083	Northern European	2,227
Irish	395,524	Finnish	1,929
English	321,511	German Russian	1,874
French (except Basque)	95,297	Iranian	1,833
Swedish	72,383	Slovak	1,646
Dutch	69,513	Romanian	1,322
Italian	64,426	Slovene	1,260
Scottish	61,721	Yugoslavian	1,210
Scotch-Irish	60,380	Eastern European	1,199
Polish	41,607	Slavic	1,101
European	33,241	Serbian	1,003
Norwegian	31,450	Brazilian	924
Czech	26,668	Armenian	754
Russian	23,677	Turkish	700
Welsh	23,591	Luxemburger	577
Danish	16,303	Australian	534
Subsaharan African	15,661	Latvian	505
Swiss	15,406	Icelander	461
British	10,543	Cajun	373
French Canadian	9,973	Bulgarian	293
Arab	7,902	Guyanese	188
Austrian	6,452	Macedonian	188
Croatian	5,446	Celtic	157
Belgian	4,886	Israeli	151
Hungarian	4,866	Basque	119
Czechoslovakian	4,188	Afghan	99
Scandinavian	3,951	New Zealander	97
Canadian	3,868	Albanian	96
Pennsylvania German	3,814	Maltese	39
Greek	3,675	Estonian	38
West Indian (except Hispanic groups)	2,993	Alsatian	36
Ukrainian	2,937	Cypriot	25
Portuguese	2,587	American	177,474
Lithuanian	2,500	Other groups	739,129

Source: U.S. Census, American Community Survey (2006-2008), Ancestry categories tallied for Kansans with one or more ancestries.

Genetic Contribution to Chronic Diseases

The important role of genes in the etiology of common, usually adult-onset, chronic disease is now being recognized. As the nation's population demographics shift, diseases of the elderly will become proportionately more significant and costly to the public health care system over the next 20 years. The use of pharmacogenetics to personalize medicine – by reducing adverse drug reactions, for instance – will become an important tool for reducing morbidity and mortality and has the potential to reduce health care costs.

Leading Causes of Death* Among Kansans
1. Heart Disease
2. Malignant Neoplasms (Cancer)
3. Chronic Lower Respiratory Disease
4. Cerebrovascular Disease (Stroke)
5. Unintentional Injuries
6. Alzheimer's Disease
7. Pneumonia and Influenza
8. Diabetes Mellitus
9. Nephritis, Nephrotic Syndrome and Nephrosis (Kidney Disease)
10. Suicide

**KS Vital Statistics Data for Year 2008*(4)*

Of the ten leading causes of death in Kansas, at least seven are known to have a genetic component. For instance, genetic factors are important in the development of cardiovascular disease. As the leading cause of death in Kansas and the United States, heart disease is estimated to incur annual health care costs of nearly $300 billion nationwide. About 10 percent of all cancers result from an inherited susceptibility - and multiple genetic predisposition syndromes have already been described for breast, ovarian, colorectal, and prostate cancer. Numerous others - including pancreatic, bladder and lung cancers - are currently under investigation.

Stroke, a complex condition involving a combination of genetic and environmental factors, is a leading cause of long-term disability today. Respiratory disease is the result of a number of factors: lifestyle choices such as smoking and environmental exposures, along with an underlying genetic susceptibility. Genetic factors account for about 30 percent of the risk for developing diabetes, which can lead to significant disability including blindness, heart disease, kidney failure and amputation.

Although more knowledge is still needed in the area of infectious disease, genetically mediated host susceptibility is an important

factor in a person's response to infectious organisms. Several genes for Alzheimer's disease, the most common cause of dementia in older individuals, have now been discovered. Finally, genetic diseases such as polycystic kidney disease and Alport syndrome contribute to illness and deaths from renal failure.

Genetic Services in Kansas

Genetic activities in the State of Kansas date back to 1965 with the establishment of newborn screening (NBS) for phenylketonuria (PKU). Additional tests were added to the newborn screening panel over the years, including: congenital hypothyroidism in 1977, galactosemia in 1984, sickle cell and other hemoglobinopathies in 1990/1993, universal newborn hearing screening in 1999. In July 2008, using tandem mass technology Kansas expanded screen conditions to include: cystic fibrosis, congenital adrenal hyperplasia, biotinidase deficiency, and other conditions in the American College of Medical Genetics (ACMG) core panel.

The State of Kansas has not had a formal genetics program in place with full-time dedicated staff. However, genetic-related activities have been managed by the Bureau of Family Health as part of the Kansas Department of Health and Environment.

Currently, there are four practicing medical geneticists and six full-time certified genetic counselors working in Kansas. Additionally, Children's Mercy Hospital provides genetic services part-time at their Overland Park location, and a University of Arkansas medical geneticist provides services part-time through a telemedicine program at KU School of Medicine - Wichita.

A summary of the types of genetic services is provided in this section, and a more comprehensive list of genetic services and providers is available in Appendix A.

Genetic Centers

Currently, the University of Kansas Medical Center (KUMC) offers a complete range of diagnostic and consultative medical services essential for delivery of effective genetic services. Board certified medical geneticists, genetic counselors, and cytogeneticists provide genetic diagnostic evaluations and counseling, genetic screening and genetic education, through regularly scheduled genetic clinics, prenatal clinics, and a variety of other specialty genetic disease clinics. Current specialty clinics offered at the University of Kansas Medical Center include: Cleft Lip and Palate Clinic, Craniofacial Clinic, Cystic Fibrosis Clinic, Developmental Disabilities Clinic, Muscular Dystrophy Clinic, Neurofibromatosis Clinic, Spina Bifida Management Clinic, and von Hippel Lindau Clinic (5).

The KU School of Medicine - Wichita provides comprehensive genetic evaluation and management for a variety of indications such as developmental delay, birth defects

and dysmorphology, heritable conditions including familial cancers, and newborn

screening follow-up through an arrangement with a medical geneticist at the University of Arkansas Medical School to provide telemedicine consultation. The Wichita-based genetic counselor is facilitating the administration of the clinic and assists the geneticist in case evaluation, management, and follow-up.

Genetic counseling is also available through Stormont-Vail, Topeka, and Menorah Medical Center, Overland Park.

Outreach Services

Medical genetic services are located in Kansas City and Wichita. Some outreach clinics have been offered in the past to reach geographically and/or culturally remote areas of the State. These clinics are not currently operational due to lack of service providers, though Wichita is planning to provide an outreach clinic in Garden City via telemedicine.

Newborn Bloodspot Screening

State law(6) mandates that all infants born in Kansas be screened for PKU, galactosemia, congenital hypothyroidism, and abnormal hemoglobinopathies. In July 2008, congenital adrenal hyperplasia, cystic fibrosis, biotinidase deficiency and an additional five amino acid disorders, five fatty acid oxidation disorders, and nine organic acid disorders were added to the newborn screening panel. Kansas screens for the 29 conditions recommended by the American College of Medical Genetics and the March of Dimes, including hearing screening. The complete list of disorders covered by the current metabolic screening panel may be found on the Kansas Newborn Screening Program website: www.kdheks.gov/newborn_screening

The Kansas program encompasses all components of a comprehensive state system: (7)

- Screening - About 40,000 KS births/initial tests each year, with 47,495 total tests in 2009 with nearly 4,000 requiring follow-up work.
- Follow-up - Appropriate health care providers are notified and staff track to assure retesting.
- Diagnosis - Newborns with positive screens see medical specialists for a final determination.
- Management - Families and their infants receive ongoing care through a medical team.

- Education - Information and education are available to families and to providers.
- Evaluation - Advisory council oversees program/systems to ensure effectiveness/efficiency.

The Neonatal Chemistry Laboratory is located in Topeka and conducts initial tests for each of the ACMG metabolic disorders. Infants with positive newborn screens for a particular condition are followed-up to assure that a repeat newborn screen or confirmatory testing has been done. Those infants confirmed to be positive are linked to appropriate services.

Kansas Advisory Council on Newborn Screening

The Kansas Advisory Council on Newborn Screening (KACNS) was established to advise the Kansas Department of Health and Environment (KDHE) on the establishment of a comprehensive, quality system for screening, follow-up and treatment of all newborns. Members of the Council are appointed by the Secretary of KDHE and are representative of stakeholders with interest in and concern for screening of newborns for congenital and inherited diseases/disorders and inborn errors of metabolism.

Optimum membership consists of at least one representative from each of the following categories:

- pediatric specialist relevant to each disorder screened (e.g., pediatric hematologist for hemoglobinopathies
- pediatric metabolic specialist for metabolic diseases such as PKU, MCAD, biotinidase deficiency and galactosemia, a pediatric endocrinologist for diseases such as congenital primary hypothyroidism)
- pediatrician practicing in a Kansas community
- family physician practicing in a Kansas community
- neonatologist
- pathologist
- laboratory Ph.D. level or above chemist
- hospital representative
- nutritionist practicing at a Kansas metabolic clinic
- geneticist
- nurse practitioner practicing at a Kansas metabolic clinic
- parent or consumer representatives
- bioethicist
- others as the Council determines necessary

The Council members are responsible for:

1. Providing input on ideas and participating in discussions

2. Reviewing and commenting on research, reports and other background information
3. Attending quarterly meetings
4. Recommending strategies for program improvement
5. Voting on issues requiring a vote
6. Providing to KDHE nominations of candidates to fill vacant member positions

Sub-committees are utilized by the KACNS as deemed appropriate by the Council. Sub-committees include: Education, Parent/Advocacy, Program Administration, Hemoglobinopathies, Endocrine Conditions, Cystic Fibrosis, Metabolic Conditions, and Evaluation. New subcommittees are added as needed.

Metabolic Formula Program

Metabolic formula and treatment products are provided to some Kansas residents through the Children and Youth with Special Health Care Needs (CYSHCN) Program (5). The program is funded with state and federal MCH funds. Each application is individually reviewed, and medical and financial eligibility is determined according to established guidelines. The guidelines assure that Kansas residents of any age who have a condition identified through the newborn screening program are covered as of 7/1/08 when they meet the financial guidelines (subject to funding availability).

Sound Beginnings (9)

Kansas legislation authorized mandatory newborn hearing screening in 1999. The goal is to identify congenital hearing loss in children before three months of age with appropriate intervention no later than six months of age. Statistics show that three newborns per 1,000 have some degree of permanent hearing loss. Congenital hearing loss is more common than cleft lip or Down syndrome. Early identification of hearing loss and enrollment in appropriate intervention services during the first six months of life allows children who are deaf or hard of hearing to take advantage of the critical first few years of life, when language, whether spoken or signed, is acquired and allows children to develop language at a level equal to that of their hearing peers.

In 2008, there were 42,587 occurrent births, and 98.1% of those were screened. The biggest obstacle for Sound Beginnings Early Hearing Detection and Intervention (EHDI) is the percentage of Loss-to-Follow-up (LFU) and Loss- to-Documentation (LTD). Loss-to-Follow-up (LFU) is defined as any infant who did not receive or complete the recommended birth admissions screen, diagnostic or early intervention process. This includes infants who are in process, parent declined services, infants who have moved out of jurisdiction, infants who are

nonresidents, parents who cannot be contacted and parents who are unresponsive or unknown. Loss-to-Documentation (LTD) is defined as infants who did not pass their hearing screening and whose diagnostic or intervention status has not been reported to the state EHDI program following screening, following diagnosis or following referral to early intervention. Contributors to LFU and LTD are diagnostic providers not scheduling appointments, parents not scheduling or not keeping appointments, providers not submitting results, delayed diagnostic authorization and a small number of qualified pediatric audiologists in Kansas.

Many approaches are taken in following up with families to ensure that they receive follow-up screenings and/or diagnostic evaluations. Daily downloads from the vital records management system identify infants who were not screened prior to hospital discharge and those infants who did not pass the initial hearing screen. Letters are sent to the out-of-hospital birth families indicating the importance of the hearing screen and supporting financial assistance programs. A phone call is made to the infant's primary care physician indicating that their patient has not passed the newborn hearing screen and requesting assistance in educating the family on the importance of having the rescreen completed and also requesting any additional screening reports that Sound Beginnings has not yet received. Monthly hospital pending reports are emailed to the Newborn Hearing Screening Coordinator. These reports show which follow-up reports Sound Beginnings has not yet received on babies that did not pass the initial hearing screen or who were not tested. Based on these reports, audiologists and transferring hospitals are contacted. Physician pending reports are generated asking for additional information such as screening or audiologic evaluation reports and/or parent phone number. When Sound Beginnings receives a report that a child has been identified with hearing loss, the physicians, parents and early intervention programs are contacted to ensure that services and resources are available.

Birth Defects Registry (10)

Congenital anomalies have been reported on the Kansas birth certificate since 1979. The current version of the Kansas Birth Certificate details 13 specific conditions. Kansas has conducted limited passive surveillance activities under congenital malformations reporting under Kansas administrative regulations (KAR 28-1-4) since 1982 with fetal alcohol syndrome added in 1986. In 2004, Kansas statutes annotated (KSA 65-1241 through 65-1246) provided statutory reporting of all patients under 5 years of age with a primary diagnosis of a congenital anomaly or

abnormal condition and establishing a birth defects surveillance system. No funding was appropriated to implement the new law.

Congenital anomalies reported through two data sources (birth certificates and the birth defects prevention program reporting form) have been used to provide baseline rates of morbidity and mortality from different congenital defects, monitor secular and temporal trends, and identify unusual changes in disease patterns. The system is internally managed by KDHE. Data is reported in aggregate and conforms to state laws for confidentiality.

Birth defect export files (live and still birth) from the Vital Statistics Integrated Information System have been utilized for notifying of the availability of services and supports through Children and Youth with Special Health Care Needs, early intervention, and other programs.

Other Genetic-Related Resources in Kansas

Children and Youth with Special Health Care Needs (CYSHCN) (5)
Children and Youth with Special Health Care Needs promotes the functional skills of young persons in Kansas who have or are at risk for a disability or chronic disease by providing or supporting a system of specialty health care. The program is responsible for the planning, development and promotion of the parameters and quality of specialty health care for children and youth with disabilities in Kansas in accordance with state and federal funding and direction. CYSHCN is funded by state and federal Title V funds. Services are provided by physicians and health care professionals in specialty clinics in Kansas City, Wichita and outlying communities. Many of the conditions covered by CYSHCN have either a genetic origin or genetic implications that would benefit from genetic counseling and evaluation services. Referral between CYSHCN and the genetic service system is necessary to assure that families are receiving needed services.

Bureau of Health Promotion (11)
The mission of the Bureau of Health Promotion (BHP) is to improve the quality of life and reduce the incidence of death and disability from chronic disease and injury, which supports KDHE's mission of protecting the health and environment of all Kansans by promoting responsible choices. The Bureau is responsible for the core public health functions related to reducing the preventable burden of chronic diseases and injuries. Program activities are supported by state, federal and private grant funds, which have been obtained through competitive processes and through collaboration with partner organizations to leverage funds from existing resources.

Programs include: the Kansas Arthritis Program, the Kansas Heart Disease and Stroke Prevention Program, the Kansas Diabetes Prevention and Control Program, the Injury Prevention Program, Kansas Coordinated School Health, the Physical Activity and Nutrition Program, the Kansas Behavioral Risk Factor Surveillance System, and the Tobacco Use Prevention Program.

The Kansas Cancer Control and Prevention Plan (11, 12)

The Kansas Cancer Control and Prevention Plan was published in March 2005 and more than 3,000 copies have been distributed statewide. The 175 members of the Cancer Partnership have been working on the goals and objectives outlined in the Plan. The Partnership has the following six workgroups: Patient Navigation, Policy Issues, Professional Education, Public Education, Research and Data, and Survivorship/End-of-Life. These groups target activities in the continuum of care for breast, cervical, colorectal, lung, prostate and skin cancers. Issues such as access to care, patient navigation and screening, and survivorship also are being addressed.

The Breast and Cervical Cancer Screening Program (Early Detection Works) provides screening to women statewide who meet income/age guidelines and are uninsured. The program is funded by the CDC and the National Breast and Cervical Cancer Screening and Early Detection Program. This is the only BHP program that contracts for direct medical services. Women ages 50-64 who meet income guidelines are eligible for all screening and diagnostic services; women 40-49 are eligible for Pap tests, clinical breast exams (CBE), and mammograms only if there is an abnormal finding on the CBE, the woman has had cancer or has a close family member with breast cancer. Uninsured women who are diagnosed with cancer through the program are referred to Medicaid and receive a medical card for the duration of their cancer treatment. The woman returns to the program upon completion of treatment.

The Kansas Cancer Registry collects statewide data on cancer incidence and deaths and is contracted to the University of Kansas Medical Center. BHP submits the supporting grant to CDC. State general funds also support the Registry. The only Kansas law affecting a BHP program relates to the establishment and reporting requirements for the Cancer Registry.

Nutritional Health (13)

The mission of Nutrition & WIC Services is to improve the health status and nutritional well-being of Kansans through access to: quality nutrition intervention services by a

registered/licensed dietitian; breastfeeding promotion and support; and substance abuse identification, nutrition education, and integration with and referral to other health services. Nutrition & WIC Services contracts with local agencies to provide services in Kansas.

The Nutrition & WIC Services Section administers the USDA – funded Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). This program provides nutrition education and supplemental foods to income eligible Kansas women who are pregnant, postpartum or are breastfeeding. Services are also provided to infants and children. The Nutrition & WIC Services Section also provides nutrition support for all programs within the Bureau of Family Health. WIC may provide treatment formula to eligible infants and young children.

2007 State Genetics Survey (14)

To address the growing need for genetics information and assure adequate continuing education opportunities are available to physicians, a study was undertaken in 2007 to determine current status and perceived need. KDHE sponsored the project in collaboration with the University of Kansas Medical Center (KUMC). Funding for the project was obtained through a federal grant to the eight state Heartland Genetics Consortium at the University of Oklahoma Health Science Center. The Office of Health Assessment conducted a survey of primary care physicians. They were asked to complete and return a questionnaire about the demand for genetics services and the need for continuing education either by mail or Internet.

The report was prepared because the role of the physician in providing basic genetic medicine is growing and genetics issues are becoming increasingly important to practices. Although there are specialists in medical genetics, it is reported that there are not enough specialists to meet the growing demand for genetic guidance. Physicians recognize that they have a role in explaining medical genetics to patients and discussing the impact of genetics on health outcomes, but physicians need current information in order to carry out their role.

Survey findings show respondents were experienced and mainly clinical primary care medical doctors licensed by the Kansas State Board of Healing Arts. Most of the physicians reported that they do not see patients with identified genetics problems or make genetically related referrals. Of those who do, an average number of three patients were referred to other medical practices by clinical primary care physicians over a period of 12 months. Surveys showed that most clinical physicians are aware of genetics referral resources.

Policy implications from this study include:

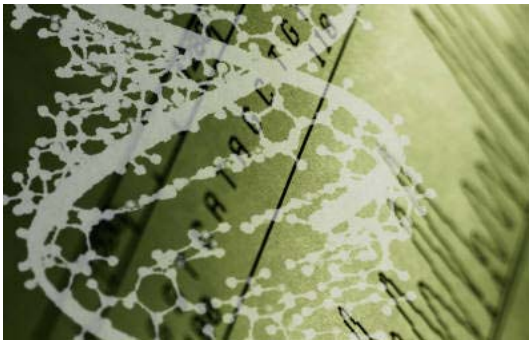
- Genetics resource information should be made available to the general public and to all primary care physicians, counselors or other medical providers via circulars, program materials and on the Internet.
- Coordinated assistance should be made available to physicians so that they can include genetics service planning in their medical practices.
- Information about available services should be distributed that can be provided by genetics counselors to physicians, providers and the public via circulars, program materials and on the Internet.
- Information should be prepared on cord blood banking and made available via circulars and the Internet for physicians, providers and the public.
- Continuing education courses should be provided on "Genetics of Specific Conditions", "Basic Genetics 101", and "Ethical and Legal Issues of Genetics" via self-study training manuals, interactive CDROM, conveniently located one-day weekend conferences and via the Internet.

Challenges

Several current and future challenges to improving the availability and accessibility of genetic services in Kansas were identified during the development of this plan:

- No dedicated state-level resources have been made available for genetics infrastructure and systems development (other than related resources directly supporting the newborn screening program).
- There is a lack of coordinated, genetics infrastructure in the State that could provide centralized capacity for expertise and drawing in outside funding. Examples include
  - No Clinical and Transitional Science Award (CTSA) Institution in Kansas
  - No for-profit genetics companies in Kansas
  - University of Kansas does not have one centralized genetics department or program, although there are many genetics-related activities taking place. (Note: This decentralized approach to genetics could also be seen as a strength.)
- Genetics expertise in the state is currently insufficient to meet clinical and patient needs, program development, and policy/planning demand across the state, even though the interest is high.
- Career opportunities in genetics are not well-established, and the Midwest offers limited educational and workforce development opportunities in genetics.

- Potential partners and stakeholders in related areas, while interested, may not see immediate linkages and are hesitant to engage.



- The technology, science, and practice guidelines of genetics and genomics are advancing rapidly and becoming increasingly complex. It is challenging for genetics experts to keep abreast of the latest recommendations, and even more difficult to ensure this information is disseminated to others (e.g., health care providers, educators, insurance companies, etc.) in a timely manner.
- Bioethics is a growing field of increasing importance, especially in light of the rapid advances in genetics and genomics. Although the Center for Practical Bioethics in Kansas City, Missouri is a nearby, valuable resource, there is a need to significantly increase knowledge and expertise among providers, stakeholders, and the public related to bioethics issues.

Goals and Objectives

As stated, our mission is to improve the availability and accessibility of genetic services in Kansas. The following goals and objectives provide guidelines for ways to guarantee the continuation of quality services in the face of evolving genetic technologies. This plan is based on the premise that current systems of care must be evaluated continuously and updated to be responsive to the constantly changing field of genetics. As a next step, stakeholders drafted Action Plans to begin outlining the implementation of these goals and objectives in Kansas. (See Appendix B.) These will continue to be expanded and updated as this State Plan is implemented.

The four core goals of the genetics plan for Kansas are to

1. **Improve the state's capacity to respond to advances in genomic medicine and technology**
2. **Promote collaborative partnerships in support of genetic services in Kansas**
3. **Develop a genetics literacy agenda for the public and policymakers**
4. **Assess the impact of heritable conditions on public health and sustain a statewide partnership of genetic services**

Goal 1: Improve the state's capacity to respond to advances in genomic medicine and technology

Objectives

1. Ensure an adequate workforce by promoting awareness of careers in genetics for interested individuals
   a. Increase collaboration with existing organizations, career counselors, and training grants to promote awareness of clinical, laboratory, public health and research careers, and generate support for existing and future training programs
   b. Identify ways to increase career opportunities in genetics for underrepresented populations

2. Promote the integration of public health genomics within KDHE and other relevant state and local agencies
   a. Facilitate activities necessary to achieve the goals of the state genetics plan through collaboration with partner agencies, organizations and programs
   b. Establish and maintain a state genetics advisory committee and relevant subcommittees
   c. Employ a full-time State Genetics Coordinator
   d. Establish and maintain partnerships with relevant local, state and national projects
   e. Increase visibility of the current state genetics / newborn screening unit
   f. Identify marketing strategies to create a program image that encompasses the expanding role of genetics in public health

3. Identify funding opportunities to increase state and local public health capacity to respond to current and emerging technical and administrative needs relative to a comprehensive statewide genetics and newborn screening program
   a. Pursue relevant funding opportunities including federal grants and cooperative agreements
   b. Explore other possible funding sources such as private foundation grants
   c. Increase collaborative partnerships with state and local agencies and institutions to facilitate successful grant applications

4. Promote / enhance / improve availability of comprehensive genetics clinics throughout Kansas

a. Maintain a network of outreach genetics clinics to underserved geographic regions
b. Identify outcome measures to demonstrate the effectiveness of genetic services
c. Assure continued viability of statewide clinical services by providing supplemental financial support as needed

5. Promote / enhance / improve availability of DNA testing for children with heritable disorders and their relatives

6. Promote / enhance / improve quality of genetic laboratory testing in Kansas
   a. Explore the need for and ways to enhance communication among genetic laboratory personnel to increase collaboration and maintain competencies

Goal 2: Promote collaborative partnerships in support of genetic services in Kansas

Objectives

1. Promote collaborative partnerships between hospitals, educational institutions and health care professionals to support genetic services and education
   a. Identify professionals and organizations in Kansas that are interested in participating and supporting genetic services
   b. Assess interest and need for connecting clinics/ organizations/ institutions providing genetic services and education in Kansas
   c. Identify cost effective modalities for linking stakeholders
   d. Conduct annual genetics update symposium in Kansas to update local health care professionals and educational institutions

2. Increase utilization of telegenetics for clinical and educational purposes
   a. Assess telemedicine capability of hospitals and organizations participating in genetic services in Kansas
   b. Survey organizations and professionals about their perception, acceptance and need for telemedicine
   c. Encourage setting up telemedicine in rural hospitals to increase access to genetics services

3. Identify and pursue use of telemedicine as a tool for improving accessibility and dissemination of information and resources
    a. Improve accessibility and dissemination of information about resources and services to families of children with or at risk for birth defects and heritable disorders
    b. Provide resources for uniform information for all families of children with a genetic diagnosis
    c. Disseminate resources and services information to all pediatricians, family physicians, pediatric and family nurse practitioners, nurse midwives, and registered nurses and interpretive services
    d. Assess unmet informational and resource needs and utilization of existing brochures by hospital social workers and neonatal intensive care units
    e. Include translators and interpreters in the development and dissemination of information about resources and services. Provide information and/or training so they are familiar with genetics terminology

4. Promote / enhance / improve / standardize quality and availability of clinical reproductive genetic services statewide and disseminate consensus guidelines for reproductive genetic health care

    a. Promote use of the guidelines by primary and specialty health care providers serving women of reproductive age, in order to increase utilization of birth defect prevention strategies and appropriate reproductive genetic screening techniques statewide
    b. Identify best practice guidelines for medical management of common genetic conditions and birth defects diagnosed prenatally
    c. Assist primary care providers in assuring appropriate follow-up of abnormal prenatal tests
    d. Provide genetics training for obstetric/gynecological professionals, including physicians, nurses, and/or administrative staff
    e. Disseminate standardized resource materials

Goal 3: Develop a genetics literacy agenda for the public and policymakers

Objectives

1. Expand provider knowledge regarding the impact of genetics on health
   a. Explore cost-effective methods of providing genetics education to health care providers
   b. Make genetics resource information available to all primary care physicians and other medical providers via circulars, program materials, and on the established State Genetics webpage
   c. Coordinate assistance to physicians so that they can include genetics service planning in their medical practices
   d. Identify educational tool(s) regarding public and/or private cord blood banking for healthcare professionals
   e. Provide resources on continuing education courses that cover topics such as Genetics of Specific Conditions, Basic Genetics/101, and Ethical and Legal Issues of Genetics via self-study training manuals, interactive CD-ROM, conveniently located one-day weekend conferences and via the established State Genetics webpage
   f. Assess nursing, PA and medical school programs for genetic content and competencies

2. Develop avenues for communication about gene-environment issues between academia, public health, primary care professionals, and the public
   - Identify stakeholders for gene-environment issues, such as union health and safety committees and occupational health workers
   - Develop methods of linking stakeholders with sources of specialized information pertaining to genetics and various environmental exposures

3. Create a State Genetics webpage

4. Expand public knowledge regarding the impact of genetics on health
   a. Make information on underlying genetic causes of common chronic diseases and the importance of early detection more readily available to providers, including those who care for adults with developmental disabilities of genetic origin
   b. Distribute information about services that can be provided by genetic professionals to physicians and other medical providers via circulars, program materials and on the established State Genetics webpage, including the process for referrals

c. Create a genetic literacy campaign targeting the general public to dispel myths and misconceptions, as well as increase recognition of the role of genetics in health and the benefits of genetic services
d. Distribute information about services that can be provided by genetic professionals via circulars and on the established State Genetics webpage
e. Make information on underlying genetic causes of common chronic diseases and the importance of early detection more readily available to consumers
f. Promote the Surgeon General's Family History tool and other tools and updated website to Kansas citizens and encourage them to share this with their healthcare providers
g. Identify resources for information on cord blood banking for expectant parents and parents of newborns

5. Facilitate trainings for service coordinators of children with special health care needs, consumers, and genetic health care providers to improve collaboration between agencies and families

Goal 4: Assess the impact of heritable conditions on public health and sustain a statewide partnership of genetic services

Objectives

1. Improve financing of genetic health care and support services
   a. Explore avenues for improving third party coverage and reimbursement
   b. Identify liaisons with major third party payers and Medicaid
   c. Educate health insurance plans and providers about the value of genetic services
   d. Educate genetic and specialty clinic providers about the billing and reimbursement process
   e. Evaluate current reimbursement practices for genetic laboratory tests and establish a schedule for periodic review
   f. Identify new strategies for public and private funding of genetic services and related needs for individuals and families

2. Improve the utilization of existing data sources for planning, implementing, and evaluating program activities

a. Strengthen infrastructure and capacity for data analysis
b. Use existing databases to improve care and evaluate progress made in outcomes of children and adults with selected genetic and health conditions

3. Develop a statewide surveillance system for genetics
   a. Establish data linkages among genetic counselors and evaluation centers

4. Develop and maintain systems to improve the accuracy and completeness of newborn screening data.
   a. Establish efficient and effective linkages with vital records and other databases in order to identify health services needed or received by high risk populations
   b. Track specific health care services received by high risk populations such as infants diagnosed with metabolic disorders

5. Improve the assessment and understanding of birth defects as a public health problem
   a. Use the Kansas Birth Defects Registry for epidemiological analyses of selected birth defects including incidence by socioeconomic status, trends over time, a map of selected conditions by county and recurrence to the same mother
   b. Strengthen local interest and investment in birth defects surveillance, prevention and intervention issues through connections with community health departments, community assessment advisory groups, and tribal leaders

6. Develop methods to assess the public health burden of genetic/familial disease in the adult population
   a. Design pilot studies to examine mortality related to specific genetic conditions and assess the costs of medical care for selected genetic conditions and related disorders
   b. Examine issues related to transition from pediatric to adult health care systems for young adults with developmental disabilities, heritable disorders and birth defects and address barriers to continuity of care for this population

7. Conduct annual reviews of all genetic service components

8. Create mechanisms to routinely assess evolving genetic issues

Next Steps: Implementation Plan

Many of the goals and objectives have a more long-term view of strengthening and expanding the State's genetics resources and expertise. Thus, the stakeholders also identified specific steps of a more limited scope for short-term action. These directly complement the overall plan's goals and objectives. (See Appendix C for a crosswalk between implementation plan steps and related objectives.)

Year One Implementation Steps

1. **Hire a Full-Time State Genetics Coordinator.** A full-time, dedicated State-level genetics coordinator position is central to developing and sustaining the genetics infrastructure in Kansas. The successful implementation of most goals and objectives identified in the state plan depend upon a State Coordinator.
   As a first step, identify potential funding resources and/or KDHE staff and section reorganization options for creating the position.

2. **Form a Kansas Genetics Advisory Council.** Establish a statewide advisory council that meets regularly and can provide guidance on implementing other portions of the State Genetics Plan. Form additional subcommittees or task forces to address specific genetics goals or issues, as needed.

   As a first step, the Genetics Advisory Council may start as a Subcommittee of the Newborn Screening Advisory Council, before splitting into an independent advisory group after the first year, or as deemed appropriate by members. Identify additional, key stakeholders outside of the Newborn Screening Advisory Council to help charter this Kansas Genetics Advisory Council.

3. **Develop a Website and Resource Clearinghouse.** Develop a central, State of Kansas website to disseminate information to the public and stakeholders, communicate best practices and consensus guidelines, report data, and link services. Other than providing information on Kansas-specific services, the initial focus will be linking to respected and proven resources rather than creating new ones. Oversight for the website project would be provided by the State Coordinator, based on guidance provided by the Statewide Genetics Advisory Council.

   As a first step, identify individuals to serve on a Genetics Website Committee to determine the website's specifications and identify resources to share.

4. **Catalog Data Resources and Pilot Genetics Services Survey.** Although the long-term goal is a comprehensive, web-based system, initial steps are to catalog current genetics-related data resources, inventory services, and disseminate this information. It may be helpful to conduct an annual genetics services survey to establish a baseline for demand and how well that demand is being met.

   For first steps, (1) use this plan as a guide to develop a list of data, resources, services, and related contact information that can be posted online or disseminated and (2) make a list of key data elements not readily available that could be gathered through an annual survey to providers (e.g., number of patients served by genetics counselors last year).

5. **Accessibility through Telemedicine and/or Outreach Clinics.** Improve accessibility of services and networking of providers/stakeholders through telemedicine and other approaches. Western Kansas and Southeast Kansas are priority outreach areas.

   As a first step, support and share information on the telemedicine efforts currently underway at KU School of Medicine – Wichita

6. **Workforce Development.** Continue conversations with Kansas State Department of Education. Identify first steps for reaching out to secondary school students, universities, and health professional and technician programs.

7. **Insurance Reimbursement.** Improve reimbursement for genetic services and promote reimbursement policies consistent with best practices through working collaboratively with Kansas Insurance Department and insurers**.**

   As a first step, ask Kansas Insurance Department to facilitate conversations between genetics services providers and insurance companies. Research successful reimbursement practices and policies across the country.

Year Two Implementation Steps

1. **Kansas Genetics Advisory Council.** The Kansas Genetics Advisory Council is functioning independently. They may wish to consider the Kansas Cancer Partnership model when finalizing their structure. Possible standing subcommittees for the Kansas Genetics Advisory Council are

a. Resource Clearinghouse: Including website, resource dissemination, updating with best-practice information.

b. Data and Research: Including data, surveys.

c. Workforce: Including current and future workforce development, partnerships with educational stakeholders on all levels.

d. Funding and Policy: Including grants and other funding sources, insurance reimbursement.

e. Access: Including outreach clinics and telemedicine.

2. **Website**. Website is launched. Procedures are in place for stakeholders to submit new information/resources for dissemination and the website to be updated regularly.

3. **Genetics Survey**. First annual genetics survey piloted and conducted. Tweak survey, as needed, and/or identify specifications of web-based system for collecting information on ongoing basis.

4. **Insurance Reimbursement.** Research potential impact of health reform on insurance reimbursement. Conclude KID-facilitated negotiations with insurance companies and assist with implementation of policy changes.

5. **Funding.** Identify and pursue funding options to further develop and sustain state genetics infrastructure.

6. **Workforce Development.** Implement action steps identified with the Department of Education, universities, and health professional programs in the secondary school system, junior colleges, universities, and continuing education programs. Disseminate information through website and resource clearinghouse.

7. **Outreach Clinics.** Build on successes and lessons-learned from the first year of the KU School of Medicine – Wichita experience with telemedicine. Continue to build relationships with information technology partners, support collaborative development of technology infrastructure, and take steps necessary to promote successful implementation of telemedicine and other technology solutions promoting genetic outreach services.

Considerations from Other State Genetics Plans and Programs

Many other states have already gone through the process of developing a genetics plan and genetics services delivery system similar to what Kansas is currently engaged. In an effort to strengthen Kansas' genetics initiatives and build on the lessons learned by others as we move forward, an informal survey of neighboring states' genetics plans was conducted, as well as conversations with other State Genetics Coordinators and Newborn Screening Program Managers. In particular, an effort was made to survey states participating in the Heartland Regional Genetics and Newborn Screening Collaborative. Additional state-specific detail can be found in Appendix D.

Some common themes among genetics programs surveyed include

- A State Genetics Coordinator administering the genetics program.
    - Some states have a full-time State Genetics Coordinator.
    - In other states, the State Genetics Coordinator is not a position but a title, with the role's responsibilities usually being fulfilled by a newborn screening program manager.
- An Advisory Group(s) providing guidance to genetic specific issues. Membership is diverse, including licensed physicians, specialists, geneticists, families and parents, attorneys, representatives from hospitals, insurance commissions, community-based organizations, the field of ethics/bioethics, and public health.
- Secure avenues of program funding. Sources of funding for genetics programs consisted of revenue from newborn screening test fees, MCH Title V Block Grant monies, state appropriated funds, and federal grants.
- All states generated revenue from the collection of newborn screening test fees. In all states surveyed, except Missouri, a portion of the revenue generated supported the genetics program.
- No two states employed the same model for public health genetics and the scope of program activities, services, and initiatives also varied greatly.

Heartland Regional Genetics & Newborn Screening Collaborative

Evaluation and Conclusion

The major form of evaluation for this plan will be determining if the implementation and action plan objectives have been met by the target dates. KDHE staff and the Kansas Genetics Advisory Council will continue to monitor progress, update the plan, and work collaboratively with other stakeholders.

Successful implementation of the plan – and fulfillment of the vision for genetics in public health – will depend not only on KDHE but also on many new partners at the local, state and national levels. Key players, in addition to state and local public health programs, include other state and federal agencies, medical care providers and hospitals, consumers, advocacy groups and organizations, educators, industry, media, schools and training programs, and healthcare payers, to name just a few. These partners will each play a vital role in helping to improve health outcomes for the people of Kansas - at all stages of the life cycle - through the informed use of genetic knowledge in medicine and public health.

Glossary and Acronyms

AAFP:	American Academy of Family Physicians
AAP:	American Academy of Pediatrics
ABMG:	American Board of Medical Genetics
AHEC:	Area Health Education Centers
BHP:	Bureau of Health Promotion
bioethics:	branch of applied ethics studying the philosophical, social, and legal issues arising in medicine and the life sciences
CBE:	Clinical Breast Exam
CDC:	Centers for Disease Control and Prevention
CGC:	Certified Genetic Counselor
CMH:	Children's Mercy Hospital
congenital:	relating to a condition that is present at birth, as a result of either heredity or environmental influences
CSHCN:	Children with Special Health Care Needs
CYSHCN:	Children and Youth with Special Health Care Needs
cytogenetics:	a branch of biology that deals with the study of heredity and cellular components, particularly chromosomes, associated with heredity
DNA:	deoxyribonucleic acid; the main component of chromosomes and the material that transfers genetic characteristics in all life forms
dysmorphology:	a branch of clinical genetics concerned with the study of structural defects, especially congenital malformations
EHDI:	Early Hearing Detection and Intervention
etiology:	the study of the causes of diseases
genetic:	affected or determined by genes
genetic counseling:	provides patients and their families with education and information about genetic-related conditions and helps them make informed decisions
genome:	all the genetic material in the chromosomes of a particular organism
genomics:	the study of all the genes in a person, as well as the interactions of those genes with each other and a person's environment

hemoglobinopathy:	a blood disorder caused by a genetically determined change in the molecular structure of hemoglobin
KACNS:	Kansas Advisory Council on Newborn Screening
KDHE:	Kansas Department of Health and Environment
KDHE-BDIS:	KDHE-Birth Defects Information System
KGAC:	Kansas Genetics Advisory Council
KHEL:	Kansas Health and Environment Laboratories
KID:	Kansas Insurance Department
KSDE:	Kansas State Department of Education
KUMC:	University of Kansas Medical Center
KUSM Wichita:	Kansas University School of Medicine - Wichita
LFU:	Loss-to-Follow-up
LTD:	Loss-to Documentation
MCH:	Maternal and Child Health
NBS:	Newborn Screening
NIH:	National Institutes of Health
NSAC:	Newborn Screening Advisory Council
pathophysiology:	the functional changes associated with or resulting from disease or injury
pharmacogenetics:	the study of the interaction of an individual's genetic makeup and response to a drug
PKU:	phenylketonuria; an enzyme deficiency genetic condition that can cause brain damage and progressive mental retardation

References

1. Nussbau, RL, McInnes RR, Willard HF. Tompson & Tompson's Genetics in Medicine, 7th ed. 2007, WB Saunders Company, Philadelphia, PA

2. Healthy Kansans 2010: www.healthykansans2010.org

3. U.S. Census 2000 and American Community Survey: www.census.gov

4. 2008 Kansas Annual Summary of Vital Statistics: www.kdheks.gov/hci/as/2008/AS2008.html

5. Children with Special Health Care Needs: www.kdheks.gov/cshcn/

6. Statute 65-180: www.kslegislature.org

7. The Kansas Department of Health and Environment: Newborn Screening: www.kdheks.gov/newborn_screening/

8. Charter of the Advisory Council on Newborn Screening: www.kdheks.gov/newborn_screening/download/advisory_council_charter.pdf

9. Sound Beginnings: www.soundbeginnings.org

10. Conversation with KDHE Epidemiologist, Jamie Kim

11. KDHE Bureau of Health Promotion: www.kdheks.gov/bhp/

12. KDHE Nutrition and WIC Services: www.kdheks.gov/nws-wic/index.html

13. KDHE Cancer Control and Prevention: www.cancerkansas.org

14. Kansas Maternal and Child Health 2008 Biennial Summary (pp.72-73): www.kdheks.gov/bcyf/download/MCH_2008_Summary.pdf

Resources

American Board of Genetic Counseling: www.abgc.net

American College of Medical Genetics: www.acmg.net

Centers for Disease Control and Prevention Public Health Genomics: www.cdc.gov/genomics

GeneTests at NCBI: www.ncbi.nlm.nih.gov/sites/GeneTests

Genetic Science Learning Center: learn.genetics.utah.edu

Kansas Cancer Partnership: www.cancerkansas.org

National Human Genome Research Institute: www.genome.gov

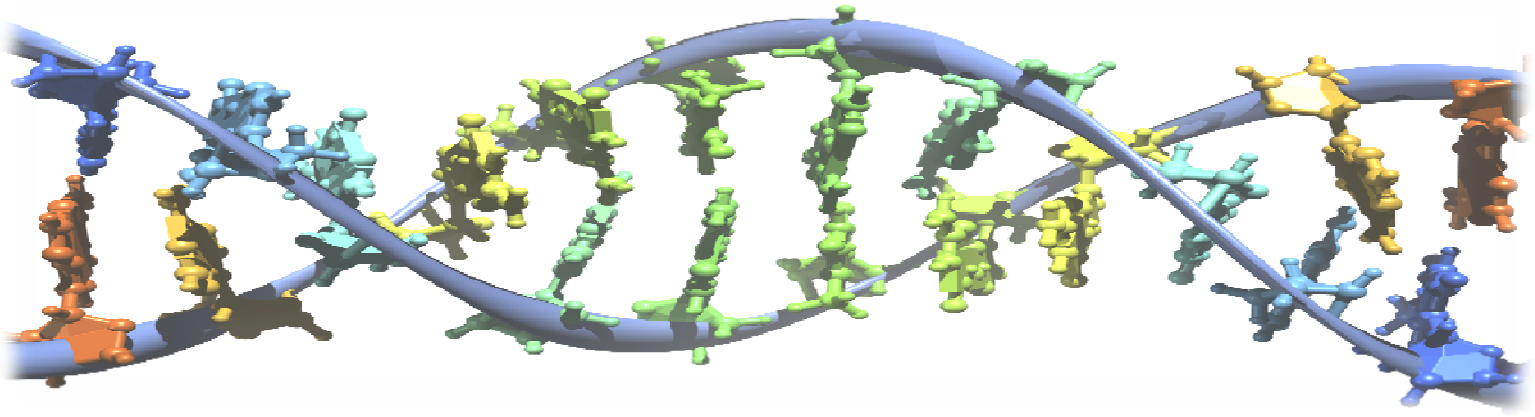
Newborn Screening Program: www.kdheks.gov/newborn_screening

Online Mendelian Inheritance of Man: www.ncbi.nlm.nih.gov/omim

University of Kansas Genetics Education Center: http://www.kumc.edu/gec/

Appendix A

Historical Summary of Genetic Services in Kansas



Appendix A.

Historical Summary of Kansas Genetic Services Providers and Leaders

Genetic activities in the State of Kansas date back to 1965 with the establishment of newborn screening (NBS) for phenylketonuria (PKU). Additional tests were added to the newborn screening panel over the years, including: congenital hypothyroidism in 1977, galactosemia in 1984, sickle cell and other hemoglobinopathies in 1990/1993, universal newborn hearing screening in 1999, and cystic fibrosis, congenital adrenal hyperplasia and biotinidase deficiency and the American College of Medical Genetics core panel using tandem mass technology in July 2008.

The State of Kansas has not had a formal genetics program in place with full-time dedicated staff. However, genetic-related activities have been managed by the Bureau of Family Health as part of the Kansas Department of Health and Environment, and Jamey Kendall serves as the State Genetics Coordinator.

University of Kansas Medical Center

Throughout the last several decades, the University of Kansas Medical Center has been the primary provider of genetics services in Kansas.

1967 - Current
Genetic Services have been available at KUMC since the early 1960's when R. Neil Schimke, MD returned to Kansas following his completion of a genetics fellowship with Dr. Victor McKusick, at Johns Hopkins University. Dr. Schimke has provided genetic and endocrinology services in the Internal Medicine Department, as well as pediatric genetics services, at KU since 1967 where he is a Professor of Medicine and a Professor of Pediatrics.

1979 - Current
Debra Collins, MS, CGC, has worked with Dr. Schimke since 1979 in providing genetic services to outpatients and inpatients. She has provided services at various times to the Cleft Lip / Palate / Craniofacial Clinics, Cystic Fibrosis Clinics, Huntington Disease Center, and Muscular Dystrophy Clinics. In the past, she coordinated the outreach clinics to Topeka, Salina, and Hays. She has received several large national grants for teacher education, and currently maintains a large web site with clinical genetics, as well as educational material.

1982 – 1985

Laura Thomson, MS, CGC, provided general genetics services, as well as services to the Muscular Dystrophy and Spina Bifida clinics. She also coordinated the outreach clinics in Colby, Parsons/Pittsburg.

1977 - 1983

William Horton, MD completed a fellowship in medical genetics at UCLA-Harbor General Hospital under Dr. David Rimoin, MD, PhD and returned to Kansas in 1977, providing clinical genetics services (especially for children and adults with dwarfism and other connective tissue disorders) at KU and investigating the molecular and genetic basis of the chondrodysplasias through his laboratory. He began work in 1983 at the University of Texas in Houston, and he is now a Professor of Molecular & Medical Genetics at Oregon Health & Science University and Director of Research at the Shriners Hospital for Children in Portland, Oregon. He has returned to KU frequently to provide lectures and updates on his research.

1978 - 1991

Charles King, MD, completed his OB/GYN training and genetics fellowship at the University of Washington and provided genetics services at KU from 1978 to 1991, including the introduction of amniocentesis and chorionic villus sampling for prenatal diagnosis. He also directed the Cytogenetic Laboratory.

1991 - 2003

Holly Ardinger, MD, is a board certified clinical geneticist who completed a genetics / dysmorphology genetics fellowship at the University of Iowa Hospitals and Clinics in 1984 and provided genetics services in the KU Pediatrics Clinics, oversaw in-patient consults at KU, and Overland Park Regional Genetics Center. Her specialty is in dysmorphology. Her publications and research involve the complex diagnosis and management of children with these rare conditions.

1993 - 1994

Tracy Cowles, MD, served as director of the Cytogenetics Laboratory from 1993 to 1994. She is ABMG board certified in clinical genetics; however, her primary interest is in Perinatology.

1994 - Current

Diane Persons, MD, is a board certified Cytogeneticist who completed her genetics fellowship at the Mayo Medical Center before returning to KU to direct the Cytogenetic Laboratory. She has expanded the clinical lab services at KU to include high resolution chromosome banding (750+ bands) as well as FISH (fluorescent in situ hybridization) and chromosome painting.

2007 - Current
Majed Dasouki, MD, is a board certified clinical geneticist who completed his pediatric residency at both Children's Hospital of Oklahoma and the University of Minnesota, Variety Club Children's Hospital in Minneapolis, Minnesota. He followed with a Fellowship in Biochemical Genetics, Department of Pediatrics, University of Missouri-Columbia, Columbia, Missouri. Dr. Dasouki is board certified in Pediatric Medicine, and in Medical Genetics (Clinical Biochemical Genetics, Clinical Cytogenetics, and Clinical Genetics).

2008 - Current
Merlin G Butler, MD, PhD is a board certified clinical geneticist who works within the Departments of Psychiatry and Behavioral Sciences and Pediatrics at KU. Dr. Butler has published extensively in the areas of phenotype-genotype correlations, clinical delineation and description of rare and common genetic syndromes, and principles of medical genetics and genetic mechanisms.

2009 - Current
Erin Youngs, MS, provides genetic counseling services in the departments of Pediatrics and Psychiatry & Behavioral Sciences.

Genetic Counselors who have served in the KUMC OBGYN Department include the following:

1989 - 2001
Lenna (Mallin) Levitch, MS, CGC

2002 - 2004
Elizabeth (Hellman) Varga, MS, CGC

2004 - Current
Lisa Butterfield, MS, CGC

KU School of Medicine - Wichita

Services that have been provided at the KU School of Medicine - Wichita clinics include the following:

2001 – Current
Drs. Brenda Issa, MD and Rebecca Reddy, MD are general pediatricians who direct KUSM Wichita Newborn Screening Services. Dr. Issa provides genetic counseling and clinical care for children and young adults with PKU and galactosemia. Dr. Reddy provides genetics counseling and clinical care services for children with sickle cell disease, thalassemias and other hemoglobinopathies. Julie Wellner, RN, is the clinical nurse coordinator.

2009 - Current
Kansas University School of Medicine in Wichita (KUSM Wichita) contracts with Dr. Bradley Schaefer from the University of Arkansas for Medical Sciences (UAMS) to provide consultation for genetic evaluation and management by telemedicine. The telemedicine clinic is located at Wesley Medical Center in Wichita. Shobana Kubendran, MS, CGC, Genetic Counselor at KU School of Medicine Wichita (KUSM Wichita), facilitates the administration of the clinic and assists the geneticist in case evaluation, management, and follow-up. A Garden City outreach clinic is planned.

1977 - 2002
Sechin Cho, MD is a primary clinical geneticist, who provided services from 1977 to the early 2000's, when he retired. He saw pediatric patients and oversaw prenatal genetic services for southern and western Kansas through that now defunct outreach clinic.

1981 - 2002
Paula Floyd, RN, CGC provided prenatal genetic services to patients in conjunction with Dr. Cho during this time period.

1990 - 1995
Richard Lutz, MD is an ABMG board certified geneticist who provided genetic services in Wichita during this timeframe.

Stormont-Vail Health Care

2007-Current
The Maternal Fetal Medicine Service at Stormont-Vail, Topeka, has provided genetic counseling services two days per week since 2007. They contract with DNAXPRT Consulting, LLC and services are provided by Certified Genetic Counselors Lenna Levitch and Molly Lund.

Menorah Medical Center

2007 - Current
Menorah Medical Center in Overland Park provides genetic counseling services through their Cancer Care program through an arrangement with Lenna Levitch, MS, CGC and Molly Lund, MS, CGC of DNAEXPRT Consulting, LLC.

Children's Mercy Hospitals and Clinics

There are four department medical genetics faculty who are associated with the University of Missouri - Kansas City School of Medicine as well as seven Certified Genetic Counselors who serve the Department.

Although their main facility is not located in Kansas, CMH has two Kansas facilities: CMH-South and CMH-West. Several of their patients are Kansas residents. Furthermore, Holly Ardinger, MD, Genetics Faculty Section Chief, and Bernarda Strauss, MD, along with one or two staff genetic counselors, provide services at Children's Mercy South in Overland Park once a week.

Midwest Perinatal Associates, PA

Genetic counseling services are available five days a week at their Overland Park facilities and are supplied for by genetic counselors from Children's Mercy Hospital. Tracy Cowles, MD, also provides prenatal genetics services as a Maternal Fetal Medical specialist. Dr. Cowles was an ABMG board certified geneticist from years 1993-2003.

Kansas Department of Health and Environment, Funding and Coordination Efforts

From 1979 to 1986, the Kansas Department of Health and Environment (KDHE) coordinated outreach genetic services in Kansas through funding from the federal Genetics Disease Act. Kansas City geneticists provided services to Topeka, Salina, Hays, Colby, and Parsons / Pittsburg in conjunction with local pediatricians and the Area Health Education Centers (AHEC). Wichita geneticists provided genetic services to Garden City and Parsons.

In addition, this federal funding provided community educational programs to local physicians and health care providers. After the funding was rolled into a large general appropriation, KDHE reallocated these funds for other services.

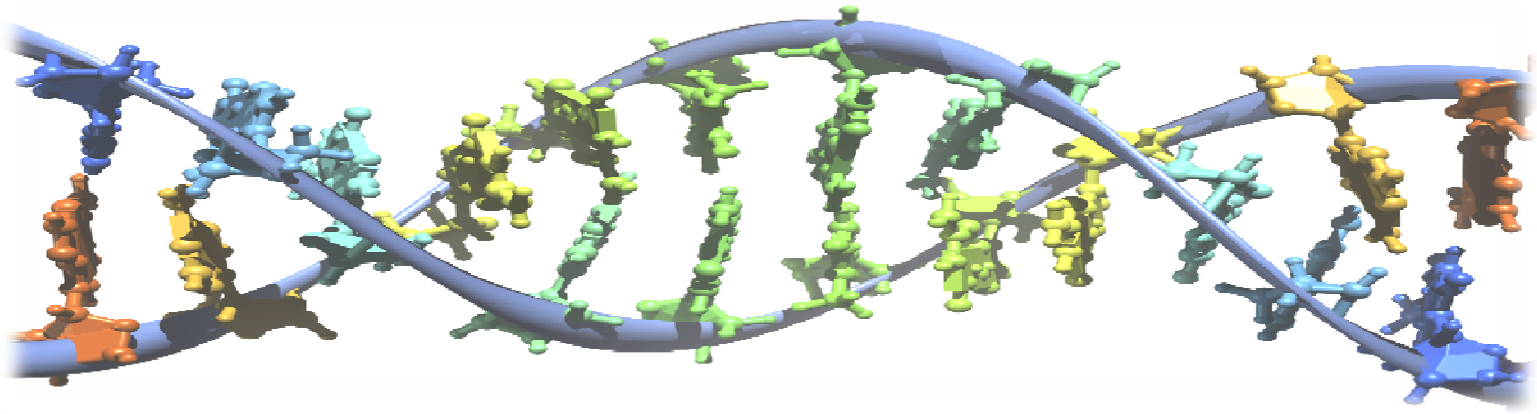
Additional support in the past has come from the March of Dimes, the Fraternal Order of the Eagles, and grants from the Department of Energy Human Genome Program, and the Department of Education.

In 2008, in conjunction with the expansion of the newborn screening panel, Kansas Department of Health and Environment provided two staff members with additional training in genetics, and Jamey Kendall, Newborn Screening Coordinator, was also designated the State's Genetic Coordinator. However, limited resources mean limited staff time is devoted to genetics.

In 2009, KDHE received a grant from the Heartland Regional Genetics and Newborn Screening Collaborative to complete a statewide planning process. This report is the culmination of that process.

Appendix B

Goal Action Plans



Action Plan for Goal #1:

Improve the state's capacity to respond to advances in genomic medicine and technology.

This goal focuses on developing baseline infrastructure and capacity. Successful implementation of other goals depends on the completion of two objectives, in particular, in Goal 1:

- Establishing and maintaining a statewide Kansas Genetics Advisory Council (Obj 2.b) and
- Employing a full-time, dedicated State Genetics Coordinator (Obj 2.c)

Once these objectives are completed, the State Genetics Coordinator and Kansas Genetics Advisory Council will finish identifying appropriate actions for the remaining objectives in this and the other action plans.

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1. Ensure an adequate workforce by promoting awareness of careers in genetics for interested individuals.	High	Create an Education Committee within the Kansas Genetics Advisory Council (KGAC) to address workforce and career development issues. Include representatives of higher education, secondary education, and business community. Committee should have broad geographic and professional representation.	Because implementing into curriculums will be difficult, start by targeting career days. Potential audiences: • Middle and high school students • Biology majors • Nursing students • Laboratory technology and technician programs First steps: • Work with KSDE to identify competencies in K-12 standards related to careers in genetics. • Identify instructional resources to incorporate into teaching strategies. • Develop brochures, displays or other resources for schools. • Incorporate resources into genetics website. • Work with stakeholders to disseminate information electronically to students and teachers. • Establish virtual mentoring. *Long-term outcome: More genetics experts / resources in the state.*	Kansas State Department of Education Kansas Department of Commerce Kansas Postsecondary Technical Education Kansas Board of Regents Colleges and Universities Resources/Initiatives: - National DNA Day - National Society of Genetics Counselors - Work with high school science educators - Exposure in colleges also important - Education Day at KU in Kansas City (could also educate general public) - National Family History Day over Thanksgiving (sponsored by U.S. Surgeon General) - American Society of Human Genetics: www.ashg.org - National Human Genome Research Institute: www.genome.gov - National Coalition for Health Professional Education in Genetics, www.nchpeg.org - Phpartners.org genomics list: http://phpartners.org/public_health_genomics.html - University of Utah Learn Genetics: http://learn.genetics.utah.edu	*Initial:* Newborn Screening Advisory Council (NSAC) *Once created:* Kansas Genetics Advisory Council (KGAC) In collaboration with KDHE and KSDE	Identify small group to work on this by Fall 2010 Materials ready for high school and junior college career days (if determined to be best method for dissemination) by Spring 2011

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1.a. Increase collaboration with existing organizations, career counselors, and training grants to promote awareness of clinical, laboratory, public health and research careers, and generate support for existing and future training programs.		Promote internships, clinical, job shadowing, etc. through experience-based opportunities. Identify multiple pathways to careers in genetics.		Kansas Department of Health and Environment Kansas State Department of Education University of Kansas Medical Center	KGAC Education Committee	
1.b. Identify ways to increase career opportunities in genetics for underrepresented populations.		Establish mentors in genetics for underrepresented populations.		Medical geneticists and genetic counselors		
2. Promote the integration of public health genomics within KDHE and other relevant state and local agencies.						
2.a. Facilitate activities necessary to achieve the goals of the state genetics plan through collaboration with partner agencies, organizations and programs.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2.b. Establish and maintain a Kansas Genetics Advisory Council and relevant subcommittees.	Very High - #1 Priority	Form a Statewide Kansas Genetics Advisory Council with relevant subcommittees. The advisory group should be comprised of members at a high enough level to make changes in their organization. Possible Committees under this group could include. • Education/ Workforce Development education and business • Funding • Policy • Website/ Communications	Hold an initial meeting of charter stakeholders in conjunction with a Newborn Screening Advisory Council (NSAC) meeting. Identify and invite stakeholders outside the NASC.	Start by establishing under or in conjunction with the Newborn Screening Advisory Council (NSAC). Continue doing this until it is established enough to warrant a separate meeting. *Other suggestions* • Research statute that covers NBS Advisory Council to determine how much leeway in subcommittees, number of meetings per year, etc. • Utilize phone and electronic meeting formats to maximize stakeholder time and involvement. • Consider holding NSAC twice/year and the Kansas Genetics Advisory Council twice/year.	KDHE	August 2010: Additional meeting of genetics stakeholder group following Newborn Screening Advisory Council Meeting
2.c. Employ a full-time State Genetics Coordinator.	Very High	Within the next five years, have a dedicated State Genetics Coordinator	(1) Explore funding opportunities (2) Procure funding within KDHE or through grant source to hire full-time coordinator	Jamey Kendall, Genetics Coordinator, KDHE *(Note: Ms. Kendall functions in this role part-time; majority of position's duties are related to Newborn Screening*)	KDHE and Policymakers	July 1, 2012

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2.d. Establish and maintain partnerships with relevant local, state and national projects to help maintain awareness of latest issues.				Heartland Regional Genetics and Newborn Screening Collaborative		
2.e. Increase visibility of the current state genetics/newborn screening unit.						
2.f. Identify marketing strategies to create a program image that encompasses the expanding role of genetics in public health.						

3. Identify funding opportunities to increase state and local public health capacity to respond to current and emerging technical and administrative needs relative to a comprehensive statewide genetics and newborn screening program.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
3.a. Pursue relevant funding opportunities including federal grants and cooperative agreements.						
3.b. Explore other possible funding sources such as private foundation grants.						
3.c. Increase collaborative partnerships with state and local agencies and institutions to facilitate successful grant applications.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4. Promote / enhance / improve availability of comprehensive genetics clinics throughout Kansas.	High	(1) Continue to develop strategies to promote genetics careers to those from Kansas/Midwest (e.g., Arkansas program), with the long-term objective of bringing them back to Kansas after they finish their training. (2) Continue to develop telemedicine system to improve outreach services. Maximize reimbursement strategies for telemedicine services.				
4.a. Maintain a network of outreach genetic s clinics to undeserved geographic regions.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4.b. Identify outcome measures to demonstrate the effectiveness of genetic services.						
4.c. Assure continued viability of statewide clinical services by providing supplemental financial support as needed.						
5. Promote / enhance / improve availability of DNA testing for children with heritable disorders and their relatives.		Maximize insurance reimbursement policies to improve availability of DNA testing for children with heritable disorders and their relatives.	Evaluate insurance plans to determine barriers to genetic testing, particularly blanket exclusions that prevent best-practice genetic testing.			
6. Promote / enhance / improve quality of genetic laboratory testing in Kansas.	High	Maintain core screening based on the recommendations of ACMG and remain proficient in each of these disorders.	Catalog current laboratory resources within the State.	State Lab	KHEL	Ongoing, with annual reviews

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
6.a. Explore the need for and ways to enhance communication among genetic laboratory personnel to increase collaboration and maintain competencies.	Med	Make improvements to the current laboratory database system to minimize manual errors that occur with submission, analysis, reporting, and follow-up.	Share laboratory resources list with partners; request updates and corrections from laboratory partners; determine potential gaps.	State Lab	KDHE/KHEL	

Action Plan for Goal #2: Promote collaborative partnerships in support of genetic services in Kansas.

This goal focuses on developing the processes and infrastructure to link patients with services for improved accessibility and availability, providers with each other for standardized care, and providers with partners and resources for dissemination of the latest information on practice guidelines and quality care. Key steps to the successful implementation of this goal include

- Having the Statewide Kansas Genetics Advisory Council and genetics website in place to support this Goal
- Identify and linking stakeholders – both professionals and organizations
- Evaluating the infrastructure available for connectivity among stakeholders, including telemedicine, listservs, etc. and building upon that baseline

Once these steps are completed, the Kansas Genetics Advisory Council will finish identifying appropriate actions for the remaining objectives in this action plan.

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1. Promote collaborative partnerships between hospitals, educational institutions and health care professionals to support genetic services and education.	High				KDHE & Genetics Stakeholders	
1.a. Identify professionals and organizations in Kansas that are interested in participating and supporting genetic services.	High	Survey both clinical and educational institutions.		Similar survey done by KDHE in 2007. Consider updating it.		1 year

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1.b. Assess interest and need for connecting clinics / organizations / institutions providing genetic services and education in Kansas.	High	Survey both clinical and educational institutions.		None		
1.c. Identify cost effective modalities for linking stakeholders.	High	Evaluate effective communication methods such as listserv or televideo calls.		Currently no listserv exists that is specific to genetics in Kansas.		
1.d. Conduct annual genetics update symposium in Kansas to update local health care professionals and educational institutions.	Low	Small symposium or conference annually or every two years to bring together genetics experts in Kansas. Consider partnering with AAP or AAFP.				
2. Increase utilization of telegenetics for clinical and educational purposes.	High					
2.a. Assess telemedicine capability of hospitals and organizations participating in genetic services in Kansas.				Heartland conducted a telegenetics survey in 2007 but it was incomplete / needs updating.		
2.b. Survey organizations and professionals about their perception, acceptance and need for telemedicine.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2.c. Encourage setting up telemedicine in rural hospitals to increase access to genetics services.				Heartland grant funding		
3. Identify and pursue use of telemedicine as a tool for improving accessibility and dissemination of information and resources.						
3.a. Improve accessibility and dissemination of information about resources and services to families of children with or at risk for birth defects and heritable disorders.		Create genetics website. (See also Goal 3.)	Compile information. Develop Website. Post online.			
3.b. Provide resources for uniform information for all families of children with a genetic diagnosis.		Create genetics website. (See also Goal 3.)	Compile information. Develop Website. Post online.			
3.c. Disseminate resources and services information to all pediatricians, family physicians, pediatric and family nurse practitioners, nurse midwives, and registered nurses and interpretive services.		Create genetics website. (See also Goal 3.)	Compile information. Develop Website. Post online.			

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
3.d. Assess unmet informational and resource needs and utilization of existing brochures by hospital social workers and neonatal intensive care units.						
3.e. Include translators and interpreters in the development and dissemination of information about resources and services. Provide information and/or training so they are familiar with genetics terminology.						

4. Promote / enhance / improve / standardize quality and availability of clinical reproductive genetic services statewide and disseminate consensus guidelines for reproductive genetic health care.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4.a. Promote use of the guidelines by primary and specialty health care providers serving women of reproductive age, in order to increase utilization of birth defect prevention strategies and appropriate reproductive genetic screening techniques statewide.						
4.b. Identify best practice guidelines for medical management of common genetic conditions and birth defects diagnosed prenatally.						
4.c. Assist primary care providers in assuring appropriate follow-up of abnormal prenatal tests.						
4.d. Provide genetics training for obstetric/gynecological professionals, including physicians, nurses, and/or administrative staff.						
4.e. Disseminate standardized resource materials.						

Action Plan for Goal #3: Develop a genetics literacy agenda for the public and policymakers.

This goal focuses on developing the means and processes for disseminating information to improve genetics literacy among the public, policymakers, and genetics stakeholders. Key steps to the successful implementation of this goal include

- Creating and deploying a state genetics website as soon as possible
- Having a full-time, dedicated State Genetics Coordinator in place, who can serve as a point-of-contact for linking stakeholders, reviewing and disseminating information, and deciding what to post online
- Establishing the statewide Kansas Genetics Advisory Council, who can develop general guidelines for disseminating and posting information
- Developing and strengthening links with the educational community to

Once these steps are completed, the State Genetics Coordinator and Kansas Genetics Advisory Council, in collaboration with relevant stakeholders, will finish identifying appropriate actions for the remaining objectives in this action plan in collaboration.

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1. Expand provider knowledge regarding the impact of genetics on health.	Very High	Expand current knowledge of health care providers through existing resources while exploring opportunities to obtain additional funding.			KDHE & Kansas Genetics Advisory Council (KGAC)	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1.a. Explore cost-effective methods of providing genetics education to health care providers.	High	(1) Develop a resource center that can identify existing genetic resources and screen for providers. (2) Support development of genetic awareness at state and local professional meetings for providers through advertising and circulars.	Assist educational institutions to seek resource grants for educational opportunities. Post grant information on website.	Health Literacy Grants Betty Elder is currently writing grants.	KDHE, Educators, and Kansas Genetics Advisory Council (KGAC)	1 year
1.b. Make genetics resource information available to all primary care physicians and other medical providers via circulars, program materials, and on the established State Genetics website.	High / Med	(1) Establish links to services via State Genetics website. (2) Develop circulars and program materials to inform providers of resources available.	Link to: Human Genome website (additional links to many resources available here).	Human Genome Project Website, University of Utah, University of Cincinnati	State Genetics Coordinator Educators can develop then link through State Website	2 years
1.c. Coordinate assistance to physicians so that they can include genetics service planning in their medical practices.	High	(1) Identify key resources for health care providers and link on State Genetics website. (2) Support development of on-line CEU opportunities through Newsletters from licensing organizations.	Create a central source for dissemination (resource clearinghouse) of information to health providers via State Genetics website.	Human Genome Project, CDC, NIH, etc.	State Genetics Coordinator KGAC	(1) Ongoing Resource

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1.d. Identify educational tool(s) regarding public and/or private cord blood banking for healthcare professionals.	High / Med	(1) Link to existing web resources. (2) Create a cord blood resource on State Genetics website.	Verify CDC guidelines regarding generic banking of cord blood.	NHLBI & CDC 4-year project starting 2010 National Cord Blood Stem Cell Bank Program National Marrow Donor Program	State Genetics Coordinator KGAC	2+ years
1.e. Provide resources on continuing education courses that cover topics such as Genetics of Specific Conditions, Basic Genetics/101, and Ethical and Legal Issues of Genetics via self-study training manuals, interactive CD-ROM, conveniently located one-day weekend conferences and via the established State Genetics website.	Med	(1) Locate conferences that provide updates on genetics through websites and webinars. (2) Provide email updates to registered clinicians through the websites. (3) Create a location where genetics updates can be posted by clinicians so that other clinicians can access.	Create a place on the State Genetics website that would allow for listings of genetics courses, updates and CEU offerings.	Providers are already taking genetics in their current programs of study & have to meet competencies. Updates for existing providers should be covered through 1a-d.	State Genetics Coordinator KGAC	3 – 6 months Website: Begin work by August 2010
1.f. Assess nursing, PA and medical school programs for genetic content and competencies.	High	Provide copies of competency documents to appropriate state review boards.	Send notices to schools for all programs regarding availability of genetics links and resources.	Essentials documents already exist from accrediting organizations.	Board of Healing Arts, Pharmacy, and Nursing	3 months

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2. Develop avenues for communication about gene-environment issues between academia, public health, primary care professionals, and the public.	High / Med	(1) Create separate links on the State Genetics Website for professionals and for the public. (2) Create educational links for K-12 educators.		Many links are available for educational purposes through Human Genome Project.		
2.a. Identify stakeholders for gene-environment issues, such as union health and safety committees and occupational health workers.	Low	(1) Identification of disease states that have high priority. (2) Review and identification of resources for environmental exposure risk.		Limited resources available at this time.		2 + years
2.b. Develop methods of linking stakeholders with sources of specialized information pertaining to genetics and various environmental exposures.	Low	Identification of specific exposure risks with documented association with genetic disease.		Information is available for specific exposures such as asbestos, nothing available that is a generic resource at this time.		1 – 2 years (existing linkages between genetic and environmental exposures have only limited resources)

3. Create a State Genetics website.	High (1st priority)	(1) Create a State Genetics website. (2) Section the website for healthcare professionals, general public, educators, and other special groups (See Cancer website).	Once established create a list of links for genetics that are provided through genetics stakeholders.	Create a separate State Genetics website.	KDHE Webmaster State Genetics Coordinator KGAC	1 – 2 months

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4. Expand public knowledge regarding the impact of genetics on health.	Medium	Develop relationships with K-12 biology educators to establish genetics competencies for high school education.	Link the State Genetics website to resources available to K-12 educators through the education web access.		State Genetics Coordinator KGAC KSDE	6 months – 1 year
4.a. Make information on underlying genetic causes of common chronic diseases and the importance of early detection more readily available to providers, including those who care for adults with developmental disabilities of genetic origin.	Medium	(1) Maintain a chronic disease section on the State Genetics website. (2) Develop an information system for high school educators to access genetics resources.		Individual disorders have programs available.		1 – 2 years
4.b. Distribute information about services that can be provided by genetic professionals to physicians and other medical providers via circulars, program materials and on the established State Genetics website, including the process for referrals.		Covered in 1.a – 1.f above.				

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4.c. Create a genetic literacy campaign targeting the general public to dispel myths and misconceptions, as well as increase recognition of the role of genetics in health and the benefits of genetic services.	Med / Low		Create State Genetics website with links to genetics services.			
4.d. Distribute information about services that can be provided by genetic professionals via circulars and on the established State Genetics website.	High	(1) Create a link on State Genetics website for health professionals. (2) Establish a link for State Genetics Resources.		KDHE services Genetic Counseling through KUMC	State Genetics Coordinator	3 – 6 months
4.e. Identify sources of information for underlying genetic causes of common chronic diseases and the importance of early detection more readily available to consumers.	Low	Link to major genetic disorders locations.	Information for State Genetics needs development and review process	Links through Human Genome Project (Genetic Stakeholders could request TA on links, information)	State Genetics Coordinator	Up to 1 year
4.f. Promote the Surgeon General's Family History tool and other tools and updated website to Kansas citizens and encourage them to share this with their healthcare providers.	High	(1) Add Family History Tool Link to State Genetics website. (2) Create Link through Kansas Department of Education for K-12 Biology Instructors.		Surgeon General's website CDC, NIH websites	State Genetics Coordinator	3 months

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4.g. Identify resources for information on cord blood banking for expectant parents and parents of newborns.	Medium	(1) Create links from State Genetics website to existing national resources. (2) Develop a state resource page for banking services that can be privately accessed.		CDC information via web Private blood banking resources have established educational links	State Genetics Coordinator KGAC	2 + years

5. Facilitate trainings for service coordinators of children with special health care needs, consumers, and genetic health care providers to improve collaboration between agencies and families.	Medium		Expand State Genetics website to include newborn screening; post current information, resources, and training dates (when available).		State Genetics Coordinator KGAC	1 year

Action Plan for Goal #4: Assess the impact of heritable conditions on public health and sustain a statewide partnership of genetic services.

Once the baseline statewide genetics capacity and infrastructure has been developed (Goal #1), linkages among providers are established and services are accessible to patients (Goal #2), and a means for disseminating information and educating the public and stakeholders is available (Goal #3), this goal focuses on evaluating and sustaining capacity and services.

Overarching issues related to this goal are

- Data is a key need. Without more standardized, regular data collection, it will be difficult to move genetics forward in Kansas. A first step is documenting the data that does exist and making this information available to others in the State.
- There is a sufficient *need* for genetic services in Kansas. Sustainability is an issue due to funding challenges. The state must determine how to better support genetics staff long-term.

The remainder of the actions in this plan will be determined after initial implementation of key steps in other goals.

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1. Improve financing of genetic health care and support services.						
1.a. Explore avenues for improving third party coverage and reimbursement.		Provide information to insurance companies.	Identify information important to insurance companies. Collect and/or compile information, including consumer perspective. Work with Kansas Insurance Department (KID) to facilitate negotiations with insurers. Involve consumers in discussions.		State Genetics Coordinator Kansas Genetics Advisory Council (KGAC) Kansas Insurance Department (KID)	
1.b. Identify liaisons with major third party payers and Medicaid.						
1.c. Educate health insurance plans and providers about the value of genetic services.		Work with KID to present relevant resources, best practices, and scientific advances to insurers.				
1.d. Educate genetic and specialty clinic providers about the billing and reimbursement process.						

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
1.e. Evaluate current reimbursement practices for genetic laboratory tests and establish a schedule for periodic review.	Very High	(1) Identify the codes being used for reimbursement. (2) Assist in posting codes for reimbursement.	Survey providers			
1.f. Identify new strategies for public and private funding of genetic services and related needs for individuals and families.		(1) Once priorities and strategies are identified, consider hiring a grant writer. (2) Explore funding opportunities through private foundations.				

2. Improve the utilization of existing data sources for planning, implementing and evaluating program activities.			Compile a list of the existing data resources. Share with genetics providers, and ask for feedback.	KDHE MCH Epidemiologists Kansas Health Data Consortium	KDHE MCH Epidemiologist	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2.a. Strengthen infrastructure and capacity for data analysis.		(1) Create a written plan to assess, identify, and evaluate issues regarding data, planning, and evaluation of program activities. (2) Establish memorandums of understanding with neighboring states and Heartland Consortium for data exchange. (3) Determine feasibility/desirability of increasing genetic or family history information in existing disease registries and surveillance systems: • Cancer Registry • Diabetes Surveillance • Asthma Surveillance Include consumers in these discussions. (4) Increase awareness of and promote the use of special congenital malformations reporting form.	Identify and assess existing MOUs.		KDHE KDHE KDHE-BDIS	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
2.b. Use existing databases to improve care and evaluate progress made in outcomes of children and adults with selected genetic and health conditions.		(1) Promote the awareness and utilization of data for existing intervention service planning and provision. (2) Determine feasibility to link with other databases that have not used genetic tools in the past, such as acute disease and environmental health. (3) Provide regular reports from newborn screening and birth defects information system (BDIS). (4) Link with existing programs to identify and increase awareness of service gaps.	Develop reports		KDHE KDHE KDHE	

3. Develop a statewide surveillance system for genetics.		Long-term: State-wide, internet-based genetics tracking system, which allows providers to login and view/edit/add data.				

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
3.a. Establish data linkages among genetic counselors and evaluation centers.		(1) Assess and strengthen existing linkages. (2) Promote the use of uniform case standards.	Survey			
4. Develop and maintain systems to improve the accuracy and completeness of newborn screening data.			Share information on current capacity and activities related to newborn screening data with genetics providers. Ask for their input.			
4a. Establish efficient and effective linkages with vital records and other databases in order to identify health services needed or received by high-risk populations.		(1) Establish memorandums of understanding with screening/intervention programs. (2) Support efforts to improve the accuracy of information collected on birth certificates about inherited conditions and congenital anomalies.			KDHE KDHE	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
4b. Track specific health care services received by high risk populations such as infants diagnosed with metabolic disorders.		(1) Promote use of single patient identifier in intervention/treatment services. (2) Strengthen working partnerships with intervention services. (3) Provide better access to resources and information to parents about services that their child may be eligible in receiving. (4) Support studies to evaluate interventions and health outcomes for specific inherited conditions or birth defects. (5) Work with wellness and prevention programs to identify strategies for wellness promotion in persons with genetic conditions.			KDHE KGAC	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
5. Improve the assessment and understanding of birth defects as a public health problem.		Work with partners to develop public education campaign that can help increase awareness of public health genetics. (Example: Incorporate genetics information into folic acid campaign).		March of Dimes		
5.a. Use the Kansas Birth Defects Registry for epidemiological analyses of selected birth defects including incidence by socioeconomic status, trends over time, a map of selected conditions by county and recurrence to the same mother.		(1) Develop mechanisms for KDHE to assure timely collection and birth defects surveillance data, including financial support for record abstraction or in-kind support for report compilation. (2) Determine how programs want aggregate birth defects surveillance data reported and by what mechanisms. (3) Improve quality and quantity of data reported of BDIS.			KDHE-BDIS KDHE-BDIS KDHE-BDIS	

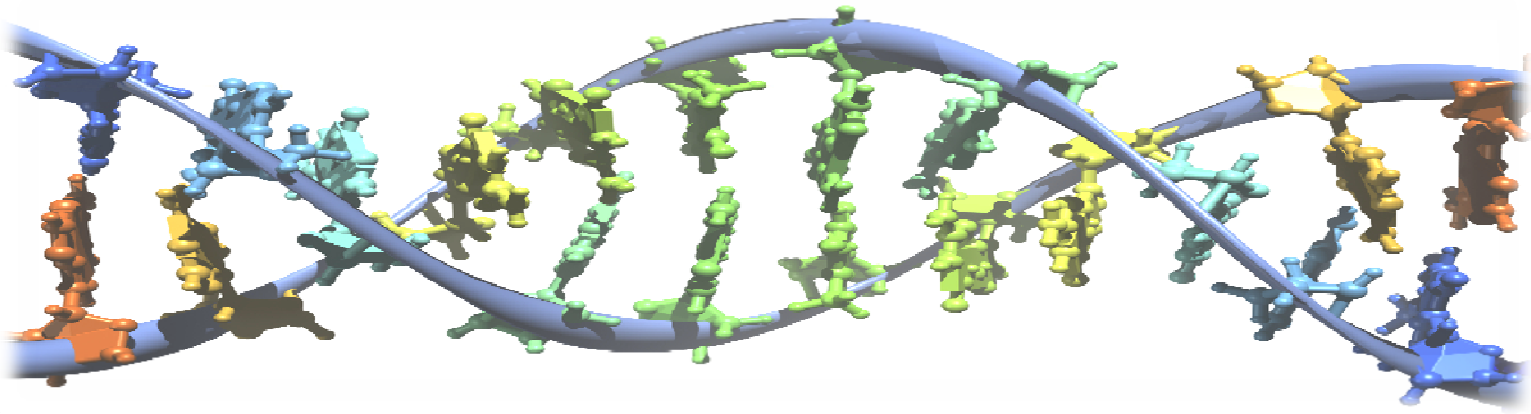
Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
5.b. Strengthen local interest and investment in birth defects surveillance, prevention and intervention issues through connections with community health departments, community assessment advisory groups, and tribal leaders.		(1) Assist in securing short and long term funding for staff and activities. (2) Promote the creation of community cross-program work group to identify opportunities for incorporating genetics into existing programs and services. (3) Identify opportunities to bring genetics-related information to interested community groups (e.g., incorporating genetics information into presentations about health topics that are relevant to a particular community or population). (4) Involve community and tribal leaders in designing education and information programs that are community-based, and accessible.		Other groups that may be interested include • Families Together • Public Libraries • Medical and Academic Libraries • Health Career Pathways Program at KU Med	KDHE KGAC	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
6. Develop methods to assess the public health burden of genetic/familial disease in the adult population.	Low because long-term		Must develop data first			
6.a. Design pilot studies to examine mortality related to specific genetic conditions and assess the costs of medical care for selected genetic conditions and related disorders.		First, further develop statewide genetics infrastructure, data.	KDHE contracts out to qualified programs Data must be available before pilot studies can be implemented			
6.b. Examine issues related to transition from pediatric to adult health care systems for young adults with developmental disabilities, heritable disorders and birth defects and address barriers to continuity of care for this population.		Identify barriers for children aging out in regard to access multispecialty, interdisciplinary care and services for genetic disorders (e.g., geography, personnel, cost, space and transportation).		Resources may also include • KU Life Span Institute (Beach Center) • KSDE • Disability groups • Individuals and families	KDHE KGAC	

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
7. Conduct annual reviews of all genetic service components.		(1) Assist in developing a core set of questions and issues regarding genetic services data, such as information regarding genetic risk assessment, genetic education, and utilization reporting. (2) Assist in creating a minimum data set of genetic services information, including a data dictionary (outlines definitions for data elements).	Survey or questionnaire of genetics services in Kansas		KGAC	Announce 2010 Begin 2011

Objective/Step	Priority (High, Med, Low)	Action Recommended	First Step (if different from Action Recommended)	Current Resources Available	Responsible Person or Org.	Implementation Timeline (By When?)
8. Create mechanisms to routinely assess evolving genetic issues.		(1) Establish and maintain an advisory council (KGAC) that meets regularly to promote awareness, disseminate information, provide advice on ways to improve surveillance and outreach for genetic conditions. (2) Identify and promote an entity for public to report incidents of employee and insurance discrimination related to genetics. (3) Establish full-time, dedicated State Genetics Coordinator position. (4) Include consumers on statewide Kansas Genetics Advisory Council.	Central point-of-contact at State	KS Insurance Department	KGAC	

Appendix C
Crosswalk Between Implementation Plan Steps and Goals/Objectives



Appendix C.

Crosswalk Between Implementation Plan Steps and Goals/Objectives

I. State Genetics Coordinator

Creating a full-time position dedicated to state genetics coordination is central to ensuring other goals and objectives are completed.

- Goal 1. Obj 2c. Employ dedicated State Genetics Coordinator
- Goal 4. Obj 8. Mechanisms to routinely assess evolving genetics issues - state genetics coordinator is central point-of-contact

II. Statewide Kansas Genetics Advisory Council

Establishing a statewide advisory council that meets regularly, with subcommittees or task forces, is central to providing guidance and implementing other portions of the State Genetics Plan.

- Goal 1. Obj 1. Workforce: Form Education Committee
- Goal 1. Obj 2b. Form Statewide Advisory Council
- Goal 4. Obj 8. Establish and maintain advisory council to routinely assess evolving genetics issues

III. Website and Resource Clearinghouse

Most of the other recommended action steps depend upon a central website or clearinghouse to disseminate information to the public and stakeholders, communicate best practices and consensus guidelines, report data, and link services.

- Goal 2. Obj 3a-3c. Provide and disseminate resources through website
- Goal 3. Obj 1a. Develop resource center/central clearinghouse
- Goal 3. Obj 1b-1e. Develop website. Identify and link to existing resources through website
- Goal 3. Obj 2, 2a-2b. Create links on webpage specific to public, professionals, K-12 educators, diseases, risks/environmental exposures, etc.
- Goal 3. Obj 3. Create State Genetics Webpage
- Goal 3. Obj 2, 4. Add educational links on website for K-12 educators
- Goal 3. Obj 4, 4a-g. Make materials available to public, professionals, and educators through website (increase genetic literacy)
- Goal 3. Obj 5. Make information, resources and training dates available on website

IV. Data Resources and Survey

Although the long-term goal is a comprehensive, web-based system, several objectives suggest initial steps related to inventorying current services, cataloging data resources, and disseminating this information.

- Goal 2. Obj 1a-1b. Survey clinical and educational institutions about level of support for genetics, provision of services
- Goal 2. Obj 2b. Survey organizations and professionals about telemedicine
- Goal 4. Obj 2. Compile list of existing data resources, disseminate
- Goal 4. Obj 2a. Assess current capacity for data analysis, develop plan to increase capacity
- Goal 4. Obj 2b. Promote awareness and utilization of existing data, provide regular reports, promote linkages
- Goal 4. Obj 3a. Survey genetic counselors and evaluation centers, promote use of uniform case standards
- Goal 4. Obj 4. Share information on data capacity and resources with genetic service providers
- Goal 4. Obj 4a-4b. Establish linkages between population-based databases, steps towards tracking high-risk patients across multiple services
- Goal 4. Obj 5, 5a-5b. Link efforts with birth defects registry for reporting, public education, increased awareness
- Goal 4. Obj 7. Annual survey of genetics services, create minimum data set of genetics service information

V. Access through Telemedicine and Outreach Clinics

Improve accessibility of services and networking of providers/stakeholders through telemedine and other approaches.

- Goal 1. Obj 4. Outreach clinics: Network of outreach genetics clinics, develop telemedicine system
- Goal 2. Obj 1c. Link stakeholders: Evaluate effective communication methods such as listserv, televideo
- Goal 2. Obj 2, 2a-3c. Increase utilization of telegenetics for clinical and educational purposes
- Goal 2. Obj 3. Use telemedicine to improve accessibility and disseminate information

VI. Workforce Development

Related to workforce, three primary types of action steps have been identified:

- Develop career pathways and increase competencies through health professional programs and health professional continuing education and trainings (including laboratory).
- Increase awareness of careers in genetics by working with junior colleges and Kansas State Department of Education.

- Increase awareness of genetics among public via the website and by reaching students and their families through the K-12 school system.
    - Goal 1. Obj 1. Workforce: Target career days, high schools, and junior colleges
    - Goal 2. Obj 4d. Provide genetics training for obstetrics/gynecological professionals (physicians, nurses, and administrative staff)
    - Goal 3. Obj 1f. Provide copies of competency documents to state review boards; send notices to schools for all programs regarding genetic resources
    - Goal 3. Obj 2. Add educational links on website for K-12 educators
    - Goal 3. Obj 4. Develop relationships with K-12 biology educators to establish genetic competencies for high school education
    - Goal 3. Obj 4f. Educate families through connections with schools (e.g., Family History Tool)
    - Goal 3. Obj 5. Facilitate trainings for service coordinators, consumers, and care providers to improve collaboration
    - Goal 4. Obj 1, 1a-1e. Disseminate best practice information, relevant links to insurance companies through website

VII. Insurance Reimbursement

Improve reimbursement for genetics services and ensure insurance policies are consistent with best practices.

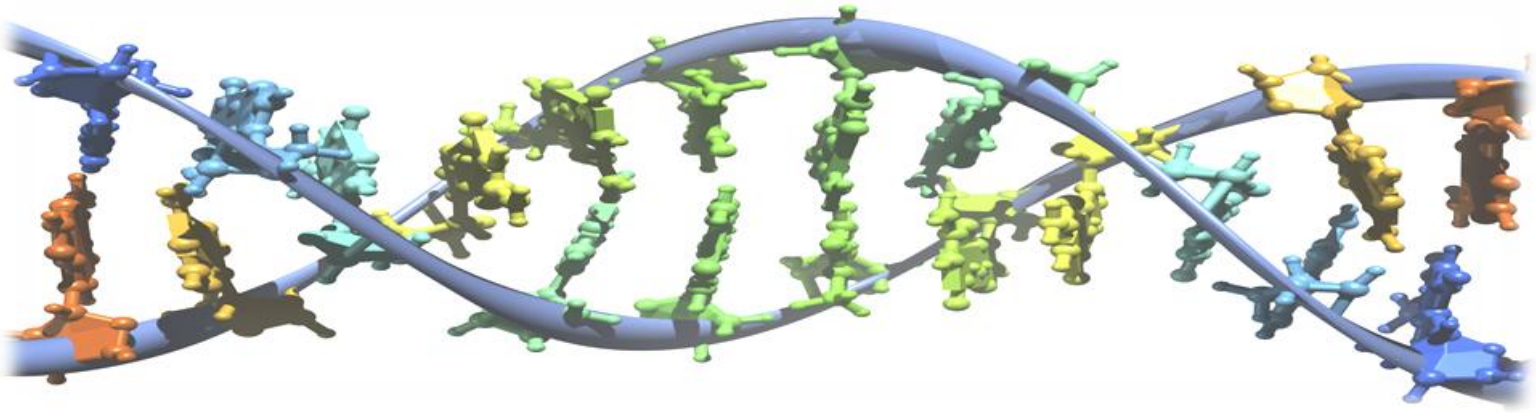
- Goal 1. Obj 5. Evaluate insurance plans/reimbursement, maximize reimbursement for testing
- Goal 4. Obj 1, 1a-1e. Explore strategies for financing, educate insurance providers about genetics, evaluate current reimbursement practices
- Goal 4. Obj 8. Method of reporting incidents of employee and insurance discrimination related to genetics

VIII. Funding

Identify and secure funding for state infrastructure in support of genetics as well as funding/improved reimbursements for the state to better meet the demand for genetics services.

- Goal 1. Obj 2c. Secure funding for State Genetics Coordinator
- Goal 1. Obj 3, 3a-3c. Identify/pursue funding opportunities
- Goal 3. Obj 1a. Submit grants for educational opportunities
- Goal 4. Obj 1, 1a-1f. Improve financing, educate/work with insurance companies to improve reimbursement, hire grant writer, explore funding through private foundations

Appendix D
Other States' Genetics Programs



Appendix D.
Other States' Genetics Programs

Note: Information was gathered through reviews of states' genetics plans and websites as well as conversations and emails with state genetics program personnel.

Illinois (State Genetics Plan written in 2007)

State Coordinator	Genetics Program	Advisory Committee	Funding
• No separate "Genetics Coordinator." • Duties fulfilled by Illinois Department of Public Health (IDPH) Genetics and Newborn Screening Administrator.	• IDPH Genetics/Newborn Screening Program coordinates public health genetics in the state. • Responsibilities include: administering state's mandated universal newborn screening program, coordinating and overseeing statewide network of public clinical genetics centers and local health departments, providing educational programs to the public and health care providers. • IDPH's Genetics Program supports statewide network of clinical genetics centers through administration of grant program. Network includes university-based centers, local health departments, and pediatric hematology centers. • Through grants to local health departments, the Genetics and Newborn Screening Program's intent is to assure community level access to genetic services throughout the state.	• Genetic & Metabolic Diseases Advisory Committee • Passes on recommendations to Public Health Genetics Program.	Newborn screening revenues fund all public sector genetic activities.

Additional information:

Genetics Program Budget Information: Funding

- $3 million appropriated from newborn screening fee revenue
- Newborn screening test cost = $78/test with approximately 180,000 births annually

Genetics Program Budget Information: Expenditures

- $1.3 million in grants for genetic counseling services
- $700,000 in grants to local health departments for genetic case finding and referral services
- $8,000 for educational efforts
- $225,000 in grants to pediatric hematologists supporting newborn screening follow-up
- Remainder of budget held in reserve

Competitive Grant Information

- First fiscal year: Five $35,000 grants awarded
- Second fiscal year: Five $75,000 grants awarded
- Third and Fourth fiscal years: Funding unavailable for grants

Grant Examples

- Efforts to include genetics in curricula
- Website development
- Reaching out to professionals

Iowa (State Genetics Plan written in 2001)

Note: State Plan is no longer referenced; it has been replaced by an annual work plan. The work plan is developed through a survey distributed by the State Genetics Coordinator to genetics program staff, Advisory Committee members, and other stakeholders. The plan is then based on survey results.

State Coordinator	Genetics Program	Advisory Committee	Funding
• Provides oversight to five programs 1. Iowa Registry for Congenital and Inherited Disorders 2. Iowa Neonatal Metabolic Screening Program 3. Neuromuscular and Related Genetic Disease Program 4. Regional Genetic Consultation Service 5. Iowa Stillbirth Surveillance Project and prevention programs • Management of grants and contracts	• The Iowa Department of Public Health (IDPH) has the authority to do screening. With their authority, they designated the University of Iowa's Hygienic Laboratory to conduct the testing. • Screening follow-up is done by University of Iowa's Department of Pediatrics.	• Congenital and Inherited Disorders Advisory Committee (CIDAC) • Formation mandated by Iowa state code. • Advises the director of the Iowa Department of Public Health. • Membership is made up of representatives of professional groups, agencies, consumers, and two state legislators. • Meetings are open to the public.	Recipients of four federal grants (two HRSA MCHB and two CDC grants). Appropriated state funds provide part of State Coordinator salary. Newborn Screening Test fees provide for remainder of the budget.

Additional information:

<u>Newborn Screening Fee Structure</u>

- Total cost = $112/test
- $3/test to metabolic food program
- $2/test to State Genetics Coordinator salary
- 10% to developmental fund (developing new tests, expanding databases…)
- No cost for rescreen, if necessary.

Michigan (State Genetics Plan last revised 08/04)			
State Coordinator	**Genetics Program**	**Advisory Committee**	**Funding**
• Manages contracts, grant applications, proposals, and reports. • Administers personnel. • Coordinates activities among Genomics Section programs.	• Genomics and Genetic Disorders Section is in the Division of Genomics, Perinatal Health and Chronic Disease Epidemiology within the Michigan Department of Community Health and is divided into three program areas: o Newborn Screening Follow-Up o Birth Defects Prevention and Follow-Up o Genomics Program • Genetics services network includes six pediatric genetics clinics, five pediatric outreach clinics, twelve cancer genetics sites, and adult cancer clinics.	• Genetics Advisory Committee no longer active. As genetics program expanded into increasing areas of interest, membership on the committee became difficult to maintain. Section-specific steering committees and several subcommittees have been formed to address genetics issues. • Newborn Screening General Advisory Committee most closely resembles the advisory committees of other states, as it has the widest stakeholder base. • Newborn Screening quality improvement subcommittees include: o Pediatric Endocrine o Cystic Fibrosis o Hemoglobinopathy o Metabolic • Mandated Newborn Screening Quality Assurance Committee meets annually to recommend additions to the panel and fee changes • Other main advisory organizations include: o Birth Defects Steering Committee o Cancer Genomics Steering Committee • The BioTrust for Health Initiative, dealing with issues surrounding residual dried blood spot specimens, has two advisory committees: o Community Values Advisory Board o Scientific Advisory Board	Newborn screening revenue covers all follow-up costs and supports designated medical management centers through contractual agreements. Revenue also contributes to pediatric outreach clinic sites and provides the salaries of some genetics program staff. Funding for remainder of genetics program and related activities comes from federal grants: Cooperative agreements with CDC for birth defects surveillance and cancer genomics; CDC/NIH cooperative agreement for hemoglobinopathy surveillance; and March of Dimes Chapter Community grants.

Missouri (State Plan first in 1997, updated in 2003, then as needed)			
State Coordinator	**Genetics Program**	**Advisory Committee**	**Funding**
• State Genetics Coordinator is a title and not a position. • Currently, Coordinator duties are filled by Bureau Chief in the Bureau of Genetics and Healthy Childhood. • Oversees all programs that assist in genetics services delivery.	• Bureau of Genetics and Healthy Childhood; Division of Missouri Department of Health and Senior Services. • Bureau serves as central clearinghouse for all genetic issues in the State, through the Genetics Advisory Committee. • Network of services include four genetic tertiary referral centers, outreach clinics, Cystic Fibrosis Centers, Hemoglobinopathy Resource Centers, and an adult genetics program administering a metabolic formula program. • The tertiary centers offer genetic screening, counseling, and education, as well as handling newborn screening follow-up.	• Missouri Genetic Advisory Committee • Governor-Appointed, Senate-Confirmed membership • Advises Department of Health and Senior Services on provision of genetic services • Has five standing committees: Newborn Screening, Cystic Fibrosis, Hemophilia, Sickle Cell, and Newborn Hearing Screening. • Advisory Committee and Standing Committees meet at least annually to monitor, review, and analyze programmatic activities.	Majority of program funding comes from state appropriated funds. Annual budget totals approx. 1.2 million. Portion of revenue generated from newborn screening fees goes toward newborn screening follow-up.

Nebraska (State Genetics Plan completed 03/03)			
State Coordinator	**Genetics Program**	**Advisory Committee**	**Funding**
• Designated "State Coordinator" is 1.0 FTE Newborn Screening Program Manager with less than 1% of time devoted to genetics beyond NBS. • Genetics program duties fulfilled by Newborn Screening Program Manager.	• Division of Nebraska Department of Health and Human Services (DHHS). • Statewide genetics services are coordinated by the University of Nebraska Medical Center's (UNMC) Munroe-Meyer Institute for Rehabilitation and Genetics (MMI). • MMI is primary location genetic services can be received.	• Newborn Screening Advisory Committee (NBSAC) is the long-term standing committee chartered by Nebraska DHHS. • Newborn Screening *and Genetics* Advisory Committee (NBSGAC) was in place for two years • NBSGAC carried out needs assessment and developed state plan	All of the lab costs and approximately half of the covered treatment (foods/formula) are covered by revenue generated from the Newborn Screening fees. The rest of foods formula are covered by $42K State General Fund, and $100-150K Title V Block Grant. All of the State Program Administrative costs (including follow-up) are covered by the Title V Block Grant. Funding for genetic services beyond newborn screening (e.g. neurodevelopmental clinics, etc.) – generally is done via the CYSHCN's program which is also Title V MCHB funding, billing, and other Medicaid and Medicaid Waiver programs but administered in different sections of the DHHS agency.

Additional information:

Newborn Screening Fee Information:

- $38.50 charged to hospitals for test. Fee covers all testing, cost of filter paper, shipping, data system, results reporting, and phone notification of abnormal screen results
- Laboratory retains $28.50/test, sending $10/test back to the State; totals approximately $270,000 per year.
- Part of revenue contributes to coverage of metabolic foods/formula program. *Remainder of program costs are covered by Title V MCH Block Grant monies ($100,000-$150,000) and a State General fund ($42,000).*

MCH Title V Block Grant Newborn Screening Program Allocation

- Total amount allocated = approximately $400,000
- Contributes to metabolic food/formula program
- Covers State Program administrative costs: 2 FTE follow-up staff, 1 program manager, 1 administrative assistant, and supports Newborn Screening Advisory Committee by reimbursing travel expenses for volunteer members.

Wisconsin (Genetic Services Plan completed 2001)

State Coordinator	Genetics Program	Advisory Committee	Funding
• Administers MCH contract for the Wisconsin Genetics System • Coordinates with Newborn Screening Coordinator • Responsible for "Genetics in Wisconsin" resource website. • Works for integration and collaboration among genetics service providers in ensure comprehensive genetics services across all phases of life.	• Wisconsin Genetics System • Funded entirely with Title V grant monies. • Current priorities: o Revitalizing Advisory Council o Supporting Wisconsin Genetics Listserv o Hosting Genetic Exchange annual conference o General genetics promotion within Wisconsin and educating primary care providers o Outreach clinics	• Members appointed by Deputy Administrator of the Department of Health • Current focus is on addressing genetics issues in general, beyond those of MCH target areas. • Recent high turnover at State Coordinator position has hurt Advisory Council membership and functionality.	Genetics System funded by MCH Title V Block Grant monies. State Coordinator salary funded through newborn screening program.

Additional information:

<u>Division of Public Health portion of newborn screening funds are for:</u>

- Subcontracts with 9 agencies providing follow-up services (confirmatory testing, counseling, care coordination and transition services, communication with primary healthcare providers)
- Special dietary treatment products for children with metabolic conditions or cystic fibrosis
- Supporting Newborn Screening Umbrella group and Subcommittee meetings
- Newborn Screening Coordinator and State Genetic Coordinator salaries

<u>Wisconsin Genetics System Budget</u>

- Last fiscal year, $225,000 was allocated to Genetics System from MCH Title V Block Grant monies (amount subject to change)

<u>Telemedicine Implementation Challenges</u>

- Lack of "buy-in" at potential sites
- Funding for necessary IT staff not available
- Necessary trainings not enacted
- Firewall issues between different institutions