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Illinois State Genetics Plan

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Acronyms

ACMG = American College of Medical Genetics

AMA = American Medical Association

APORS = Adverse Pregnancy Outcomes Reporting System

ASHG = American Society of Human Genetics

CCJGD = Chicago Center for Jewish Genetic Disorders

CDC = U.S. Centers for Disease Control and Prevention

CEU = Continuing Education Units

CME = Continuing Medical Education

CPT = Current Procedural Terminology

DHS = Illinois Department of Human Services

DSCC = Division of Specialized Care for Children

ELSI = Ethical, Legal and Social Issues

GTFI = Genetic Task Force of Illinois

GMDAC = Genetic and Metabolic Disease Advisory Committee

HRSA = Health Resources and Services Administration

IAFP = Illinois Academy of Family Physicians

IAPA = Illinois Academy of Physician Assistants

IAPHA = Illinois Association of Public Health Administrators

ICAAP = Illinois Chapter, American Academy of Pediatrics

IDFPR = Illinois Department of Financial and Professional Regulation

IDPH = Illinois Department of Public Health

IMCHC = Illinois Maternal and Child Health Coalition

IL NAPNAP = Illinois chapter of the National Association of Pediatric Nurse Practitioners

IPHA = Illinois Public Health Association

IPLAN = Illinois Project for Local Assessment of Needs

IRHA = Illinois Rural Health Association

ISGNA = Illinois State Genetics Needs Assessment

ISMS = Illinois State Medical Society

LHD = Local Health Department

MLHRC = Midwest Latino Health Research, Training at Policy Center at UIC

NCHPEG = National Coalition for Health Professional Education in Genetics

NIPHC = Northern Illinois Public Health Consortium

NSGC = National Society of Genetic Counselors

NU = Northwestern University

SACGHS = Secretary's Advisory Committee on Genetics, Health, and Society

UIC-SPH = University of Illinois at Chicago – School of Public Health

Definitions

Genetics	The study of single genes and their effects.
Genetic counseling	The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the following: • Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; • Education about inheritance, testing, management, prevention, resources and research; and • Counseling to promote informed choices and adaptation to the risk or condition.
Genetic screening	Testing an individual or group of people to see if they carry a particular gene or genes associated with an inherited condition.
Genetic services	Health services that focus on the genetic or inherited components of health and disease across the lifecycle. Services include genetic evaluations, testing, counseling, treatment management, educational activities, family support and follow-up care.
Genetic testing	Analyzing genetic material to determine predisposition to, or confirm a diagnosis of, a genetic condition.
Genome	All of the genetic material (DNA) belonging to an organism.
Genomic competencies	The minimum knowledge, skills, and attitudes necessary for health professionals from all disciplines to provide patient care that incorporates genomic perspectives and reflects sensitivity to related ethical, legal, and social concerns.
Genomics	The study of the functions and interactions of all the genes in the genome, including their interactions with each other and environmental factors.
Human Genome Project	An international research project to map each human gene and to completely sequence human DNA.
Newborn screening	A preventive public health program for early identification of conditions in newborns that can affect their long-term health. Early detection, diagnosis, and treatment of certain genetic, metabolic, or infectious congenital conditions can lead to significant reductions of death, disease, and associated disabilities.
Public health genomics	The inclusion and application of genomic information and tools in public health planning, policy and programs.

Executive Summary

Genetic conditions, and diseases with a genetic component, significantly contribute to morbidity and mortality in the United States. These conditions can affect human health at any stage of life, whether prenatally, or in childhood, adolescence or adulthood. They also can have an impact on reproductive decision-making. In this country, 3 percent to 5 percent of all newborns have some type of birth defect and approximately 20 percent to 30 percent of all infant deaths are due to a genetic condition. In one U.S. study (McCandless), an underlying condition with a significant genetic component was found in 71 percent of pediatric inpatient admissions. Estimates report that among adults, approximately 10 percent of hospital admissions are for genetic conditions and 15 percent of all cancers have an inherited susceptibility. Other chronic illnesses, such as heart disease and stroke, diabetes, and arthritis, also have significant genetic contributions. Although clinical genetic research regarding the bases of these conditions is ongoing, it is currently estimated that 10 percent of these chronic illnesses are familial. In addition, nine of the 10 leading causes of death in the United States and in Illinois have a genetic component.

As more information becomes known about the importance of genetics and genomics for individual and population health, there is an increasing need to plan for the future of genetic health care and services in Illinois. In response to this need, the Illinois Department of Public Health initiated and supported a process to develop the first Illinois State Genetics Plan (ISGP). The plan was developed based on data collected in the Illinois Genetic Services Needs Assessment, which was conducted from 2003 through 2005; review of other state genetic services plans and other available resources; and the knowledge and expertise of many diverse participants and stakeholders. The plan development process involved the guidance of a steering committee and input from seven work groups, Planning conference participants, and statewide community forum attendees.

The Illinois State Genetics Plan is intended to serve as a guide document to facilitate implementation of seven key goals that were identified through the state needs assessment process and broad stakeholder input.

The seven goals for the Illinois State Genetics Plan are to:

1. Promote high quality, comprehensive, and accessible genetic services for all Illinois residents

2. Reduce barriers to access to genetic health care services in Illinois

3. Improve public health data collection and infrastructure to support and advance genomics activities in Illinois

4. Increase genomic awareness and literacy in the general public

5. Promote integration of genomics into Illinois' health care delivery system through education of health professionals and the health care work force

6. Address genetic services financing and reimbursement issues that impact individuals, families, and/or genetic service providers

7. Identify and examine the ethical, legal and social issues (ELSI) relevant to clinical genetic services, genetic research and related applications for the state of Illinois

These goals helped frame the development of specific objectives and action items to examine current and emerging genomic issues that address the core public health functions of assessment, policy development and assurance.

As a strategic plan, this five-year plan can be used to mobilize individuals, organizations, institutions, communities, and policy makers interested in improving access to, and outcomes of, genetic health care. Efforts to implement the ISGP will require collaborations with multiple partners as well as additional funding. Effective implementation, however, also will require ongoing, coordinated efforts and periodic review by invested stakeholders and partners.

Introduction

A. Purpose of the Plan

As more information becomes known about the importance of genomics for individual and population health, there is an increasing need to plan for the future of genetic health care services in Illinois. The ISGP is intended to serve as a guidance document to facilitate implementation of recommendations that were derived and prioritized by a variety of stakeholders. The plan will serve as a catalyst for further discussion of state genetic service needs.

The ISGP addresses the complete lifecycle and proposes a five-year perspective. The plan is intended to be a working document and includes seven key goals with prioritized objectives and action items. The goals include issues that can be addressed at the state level and will require the collaboration of multiple partners and additional funding for implementation. The plan was developed based on the data collected in the Illinois Genetic Services Needs Assessment, which was conducted from 2003 through 2005; review of other state genetic services plans and other available resources; and the knowledge and expertise of the many diverse participants and stakeholders in the state plan development process. The development of the ISGP was initiated and funded by the Illinois Department of Public Health.

B. Impact of Genetic Conditions and Genomics

Genetic conditions, and diseases with an inherited component, significantly contribute to morbidity and mortality in the United States. These conditions can affect human health at any stage of life: prenatally, in childhood, adolescence and in adulthood. They also can have an impact on reproductive decision-making. In this country, 3 percent to 5 percent of all newborns have some type of birth defect and approximately 20 percent to 30 percent of all infant deaths are due to a genetic condition. Nearly half of all post-neonatal deaths are also due to congenital malformations. In one U.S. study (McCandless), an underlying condition with a significant genetic component was found in 71 percent of pediatric inpatient admissions. These admissions accounted for 80 percent ($50 million) of total hospital charges. Among adults, it is estimated that approximately 10 percent of hospital admissions are for genetic conditions and up to 15 percent of all cancers have an inherited susceptibility. Other chronic illnesses, such as heart disease and stroke, diabetes, and arthritis, also have significant genetic contributions. Although clinical genetic research regarding the bases of these conditions is ongoing, it is currently estimated that 10 percent of these chronic illnesses are familial. In addition, nine of the ten leading causes of death in the United States, and in Illinois, have a genetic component (see table 1).

Table 1. Genetic Factors Contribute
to the Leading Causes of Mortality in Illinois

- Heart disease
- Cancer
- Stroke (cerebrovascular diseases)
- Chronic lower respiratory diseases
- Accidents/unintentional injuries
- Diabetes
- Influenza/Pneumonia
- Alzheimer's disease
- Kidney disease
- Septicemia

Clinical genetic service programs play a critical role in providing health care for individuals with, or at risk for, genetic conditions. More recently, genetics, public health, and primary health care providers are becoming involved in *genomics*: the study of all the genes in a person, the interactions of these genes with each other, and the interactions of these genes with a person’s environment resulting in health or disease. It is now well recognized that, although individuals inherit genes that increase risk or susceptibility of adult chronic illnesses, such as cardiovascular disease, cancer, and diabetes, the onset of these conditions can be significantly influenced by the individual’s lifestyle choices. The knowledge that positive lifestyle changes will improve the overall health of individuals, especially those with a family history of such diseases, should encourage public health efforts at all levels (national, state and local) to raise public awareness in this important area. Ultimately, the overall impact of genomics integration into health care will be to improve health by reducing morbidity and mortality through coordinated disease prevention and health promotion efforts.

C. Illinois State Profile

The state of Illinois covers 56,400 square miles and is more than 385 miles long and 218 miles wide. Bordering Illinois are six states and Lake Michigan. Nearly 80 percent of this area is farmland, covering more than 45,000 square miles.

Illinois is the fifth largest state in the United States by population, with a 2006 population of 12.8 million residents. There are 102 counties in Illinois, with Cook County having the largest population of any county, at more than 5.3 million.

The city of Chicago, located in Cook County, is the most populated city in Illinois. It is located in the northeast part of the state and covers more than 220 square miles. With a population of about 2.9 million residents, Chicago makes up nearly 25 percent of the total population of the state. The state capital of Springfield, located in the central part of the state, is the sixth most populous city.

According to the Census Bureau, of the 12.8 million Illinois residents, approximately 73 percent are Caucasian, 15 percent are African-American, and 12 percent are Asian and other races. Approximately one in seven residents is of Hispanic/Latino origin; the Hispanic population has increased nearly 70 percent in the last 10 years. Similarly, the Asian population has grown by about 60 percent during that time.

The median age of Illinois residents is 34.7 years. Females outnumber males by 51 percent to 49 percent, or 250,000. Nearly 74 percent of Illinoisans are aged 18 and older, and people older than age 65 represent 12.1 percent of the population. The median household income in 2003-2005 was $47,978.

Nearly 1.8 million, or 16.2 percent, of nonelderly Illinois residents are uninsured, and 1.3 million, or 10.2 percent, are on public insurance. Of these uninsured individuals, 62 percent were in families with at least one full-time worker. With the cost of health insurance premiums continuing to rise, estimates for the average premiums of annual employee sponsored family health coverage in 2007 are expected to be more than twice the average premium in 2001. A disproportionately large number of racial and ethnic minorities are without health insurance.

D. Genetic Services and Programs in Illinois

The genetic health care delivery system in Illinois consists of more than 20 organizations that serve as primary providers of clinical genetic services. These organizations include academic medical centers, private health systems/hospitals, a county hospital, and a state funded teratogen information service (see Appendix A). Services are provided at multiple primary and outreach sites throughout the state, but remain concentrated in the Chicago metropolitan area. Outside of the Chicago metropolitan area, clinical genetic centers are located in Rockford, Peoria, Urbana, Springfield and St. Louis (serving Illinois residents in the southern part of the state). *It should be noted that this list may not be comprehensive.*

Training in clinical genetics is available through one active residency program, jointly sponsored by the University of Chicago and Northwestern University, and one masters-level genetic counseling graduate program, located at Northwestern University.

Illinois Department of Public Health Genetics Section

The Illinois Department of Public Health's (IDPH) Genetics and Newborn Screening Program is the key coordinator of public health genetics in the state. The program has the following responsibilities: administration of the state's mandated universal newborn screening program; coordinating and overseeing a statewide network of public/private clinical genetic centers and local health departments; and providing educational programs to the public and health care providers. In addition to IDPH, the Illinois Department of Human Services (IDHS), the administrator of the Title V Maternal and Child Health Block Grant, and the Division of Specialized Care for Children (DSCC), the state's Title V Children with Special Health Care Needs Agency, provide case management, clinical care, and support services to women and children with reproductive and special health care needs, including those associated with certain types of genetic conditions and/or indications associated with genetic components or risk factors.

The Genetics and Newborn Screening Program currently administers two core programs: the Newborn Screening Program and the Genetics Program. The Newborn Screening Program, established in 1965, includes 37 conditions in its 2007 screening panel. More than 180,000 infants are screened annually in Illinois through this program. Follow-up services, including diagnostic testing, clinical care, and treatment services (e.g., medical products for newborns diagnosed with certain metabolic disorders and prophylactic medications for clients), are coordinated through and provided by the Newborn Screening Program, in conjunction with local health departments and other public health agencies (e.g., DSCC). The Newborn Screening Program also maintains a database of information of all individuals with positive newborn screens, tracks follow-up services, and includes diagnostic and developmental information on all newborns/children with a confirmed diagnosis, through age 15 years.

Since 1983, IDPH's Genetics Program also has supported a statewide network of clinical genetic centers through the administration of a clinical genetics grant program, with the intent of assuring community level access to genetic services throughout the state. In 2007, this network of clinical genetic care includes 16 university-based clinical genetic centers (Appendix A), 38 local health departments (Appendix B), and 11 pediatric hematology centers (Appendix C). The funded genetic centers represent the majority of the primary genetic centers serving Illinois residents.

Grants to clinical genetic centers provide a full range of prenatal/reproductive, pediatric, and adult/cancer genetics services, although individual centers differ in the types of services they provide. The sixteen funded centers also provide outreach services at 28 satellite clinics across the state; 10 of these outreach sites are located at local health departments. In addition to providing services, IDPH-funded clinical genetics centers work closely with IDPH-funded local health departments and provide educational presentations to health care providers and consumers.

Through *grants to local health departments*, IDPH's Genetics and Newborn Screening program seeks to increase local access to clinical genetic information and services through a coordinated community-based system of screening, case finding, referral and education. In 2007, 38 local health departments (Appendix B) were funded to: (a) provide follow up, referral, tracking, and educational services to the parents of infants with a confirmed diagnosis of a condition initially identified by a positive newborn screening result, (b) identify individuals and families who may benefit from genetic counseling and/or genetic services utilizing a genetic screening tool and referring all appropriate clients for such services, and (c) provide consumer and professional education. Ten of the IDPH-funded local health departments refer clients to on-site genetics clinics staffed by genetic counselors and MD geneticists from the funded clinical genetic centers. These clinics operate with varying frequencies, depending upon the need and location. Some of the 38 funded health departments also serve as lead agencies and subcontract to fund smaller health departments to provide genetic screening, referral, and follow up services. Through this two-tiered system, it is estimated that genetic services are being offered in local health departments in a majority of Illinois' counties.

The Genomics and Chronic Disease Prevention Program was formed in 2004 by the IDPH Genetics and Newborn Screening Program. This program is committed to the CDC's efforts to encourage genomics activity at the state level. Efforts have been made to integrate genomics information into existing chronic disease programs in the state. Cooperative activity between the various chronic illness prevention groups and the genomics program has been an ongoing priority, especially through each groups' partnerships.

Other IDPH projects and programs include an annual, three-day, educational program in clinical genetics for public health nurses. This educational program is offered in conjunction with the Illinois Chapter of the March of Dimes' Annual Perinatal Conference. The IDPH also participates in the Department of Health and Human Services, Health Resources and Services Administration funded Region 4 Genetics Collaborative Project, which is charged with increasing and improving interstate genetics communication and collaboration among Region 4 states, (IL, MI, IN, KY, WI, MN) so that shared efforts will benefit each individual state's genetics program, as well as genetic services in the region.

More information about genetic services, programs, data, and the genetic service provider workforce in Illinois can be found in the *Illinois Genetic Services Needs Assessment* at http://www.uic.edu/sph/irhwc/Illinoisgeneticservicesneedsassessment.pdf.

E. Key Findings from the Illinois Genetics Needs Assessment

Prior to the development of the ISGP, a needs assessment was conducted. The purpose of the needs assessment was to identify and document the role and function of the state health department with regard to the current and future needs for genetic policy, service provision, workforce and community education, research and surveillance in Illinois. The needs assessment process involved the review of key documents and program literature, as well as the administration of surveys and interviews with key stakeholders throughout the state. Stakeholders included genetic service providers, other health care providers, local health department personnel, state agency staff, and representatives of advocacy groups.

Below is a brief summary of the key findings of the Illinois Genetic Services Needs Assessment. (The IGSNA executive summary is included in Appendix D.) The findings emphasize the need, in Illinois, to:

- educate, inform, and raise awareness about genomics for the following stakeholders: primary care providers, other non-genetic health care providers, local health department staff, the general public and consumers, state agency personnel, and genetic service providers;

- examine the current and future supply of genetic service providers, their geographic distribution and cultural diversity, and their availability;

- address reimbursement policies for genetic services, including Medicaid, which may impact equitable service provision;

- address geographical, financial, and cultural disparities that may create access barriers for underserved populations;

- examine ethical, legal, and social issues related to genetics, and assure adequate protections for individuals and communities; and

- evaluate the completeness, usefulness, quality, and accessibility of state agency datasets, as well as linkages among datasets.

II. Methods and Stakeholder Involvement

Multiple strategies were utilized to engage a variety of stakeholders in the planning and development of the Illinois State Genetics Plan. The plan development process involved the guidance of a steering committee and input from work groups, planning conference participants, and community forum attendees. Participants involved in these efforts were from diverse backgrounds and varied geographic areas. Stakeholders included public health professionals, genetic service providers, non-genetic health care providers, health care administrators, policy makers, educators, consumers, and advocates.

Steering Committee

The steering committee was composed of approximately 30 individuals from various backgrounds with knowledge and interest in genetics, public health, and health care. The goal of the ISGP steering committee was to provide direction and leadership for the work groups and assist in the development of the planning conference and community forums. The steering committee met regularly and provided guidance in the overall prioritization of recommendations for the Illinois State Genetics Plan. A complete list of steering committee members is included in Appendix E.

Work Groups

Another key component of the ISGSP development process was the involvement of stakeholders who served on work groups. Seven work groups were formed to address specific priority areas including: genetic services, barriers to access to care, data/public health infrastructure, public education, professional education, financing and reimbursement, and ethical legal and social issues (ELSI).

The goal of each work group was to develop and prioritize goals, objectives and action items using the data collected in the needs assessment and other available resources. Additionally, each work group developed a list of potential partners and resources for implementation of action items in the state plan. Prioritized recommendations were shared with the steering committee and all work group members for discussion and comments. A list of the 47 work group members is included in Appendix F.

Planning Conference

In July 2006, an ISGP planning conference was held in Lisle, Illinois (Appendix G). The purpose of the conference was to raise awareness about public health genomics, build partnerships with key stakeholders, and begin the development of goals and objectives for the Illinois State Genetics Plan. There were approximately 80 attendees, including professional and lay participants. The planning conference included an update on state genetics plan accomplishments and a review of identified needs in Illinois. Breakout sessions for the work groups were held to discuss specific priority issues. Following the breakout sessions, each work group submitted an informal report of key issues identified, availability of and gaps in resources, and follow-up action items. This process set the groundwork for the subsequent work group activities.

Community Forums

In the fall of 2006, community forums were held in diverse geographic areas including Mt. Vernon, Champaign-Urbana, Rockford, and Chicago. In addition, videoconferencing available at the Urbana site allowed for participation from Springfield and Peoria. The purpose of the community forums was to raise awareness about key issues in genetic services in Illinois, inform participants about the state genetics plan development process, and allow health professionals, consumers, advocates, and the public an opportunity to provide input into the genetics state plan process. More than 75 participants representing local health departments, hospitals, health centers, private foundations, and other groups participated in the public forums. Each community forum agenda included a presentation of the key findings from the Illinois Genetic Services Needs Assessment, an overview of the state plan development process, and key issues and local perspectives on genetic services. Open dialogue sessions from the community forums were summarized and shared with the work groups and steering committee for consideration and integration into the state plan. A community forum agenda is included in Appendix H.

III. Priority Issues: Goals and Objectives

The Illinois State Genetics Plan addresses seven key priority areas that were identified through the state needs assessment process and broad stakeholder input. The following goals, objectives, and action items provide the foundation for the state genetic services plan. The order of the objectives and action items for each goal are prioritized.

A. Genetic Services

Genetic services are available to help individuals and families understand their specific genetic condition, or risk of a genetic condition, and ultimately improve health by reducing morbidity and mortality associated with these conditions. Due to advances in genetic technology and increasing clinical applications for more common conditions, the need for genetic services is growing. Comprehensive genetic services include evaluations, testing, counseling, treatment, management, educational activities, family support, and follow-up for all members of the population. Assuring the quality and accessibility of genetic services to the public is a fundamental component of the state genetics plan.

GOAL: Promote high quality, comprehensive, and accessible genetic services for all Illinois residents

Objective 1. Evaluate and improve the availability and accessibility of genetic services in Illinois

Action Items

1. Regularly review select components (includes locations, referral patterns, numbers of patients seen) of IDPH genetics grantees
2. Evaluate genetic services delivery in Illinois (Action Item 1 components and other) and identify gaps *(collaborate with Data and Public Health Infrastructure efforts, Objective 1, Action Item 1)*
3. Monitor the IDPH Newborn Screening Program in order to identify, evaluate, and incorporate, when appropriate, new technologies to facilitate screening and follow-up
4. Expand IDPH laboratory and follow-up program capacity to support comprehensive and emerging testing, tracking, and treatment options for genetic conditions

<u>Potential Resources/Partners:</u>
IDPH Genetics, IDPH genetics grantees reporting form data, IDPH Data Release and Research Committee, IDPH epidemiology and infectious disease, ISGNA, GTFI, Child and Family Connections, Ounce of Prevention, GMDAC (Newborn Screening Subcommittee), health service providers, advocacy groups

Objective 2. Create and support a Genetic Services Network to share strategies for providing quality, accessible, and comprehensive services to all Illinois residents

Action Items

1. Recruit network members, including representatives from IDPH genetic grantee sites
2. Develop a mission, goals, structure, desired outcomes, and administration of the Genetic Services Network
3. Identify existing protocols or develop guidelines describing appropriate genetic/genomic services
4. Develop strategies for providing accessible and comprehensive services (*see Barriers to Access to Care Objectives 1, 2, 3, and 4*)
5. Adapt or develop quality indicators for genetic services in Illinois
6. Publicize the network and the availability of genetic services and related support services to all residents in Illinois
7. Evaluate the network outcomes

Potential Resources/Partners:
IDPH Genetics, IDPH genetics grantees, IDPH data monitoring committee, ASHG, ACMG, GTFI, NSGC, Midwest Latino Health Research Center, Illinois Chapter March of Dimes, genetic service centers, genetic support groups, Illinois genetic service providers, outreach specialists, Illinois hospitals, Web links, evaluation funding sources

B. Barriers to Access to Care

Advances in genetic technology and genomics have led to the development of primary, secondary and tertiary prevention strategies. However, access to genetic services is not equally available and utilized by all segments of the population, particularly in underserved rural, low-income, and minority communities. Understanding and reducing potential barriers limiting access to genetic services is key in providing equal opportunities for disease prevention and health promotion.

GOAL: Reduce barriers to access to genetic health care services in Illinois

Objective 1. Improve access for medically underserved individuals in Illinois by addressing economic barriers

Action Items

1. Raise public and professional awareness of available sources of reimbursement for and coverage of genetic services *(collaborate with Financing and Reimbursement efforts, Objectives 1 and 2)*
2. Link clients to available genetics advocacy and consumer support groups

Potential Resources/Partners:
All Kids Program, Early Intervention, DSCC, Genetic Alliance, government sponsored programs, privately funded programs, other existing groups

Objective 2. Improve access for medically underserved individuals in Illinois by addressing geographic barriers

Action Items

1. Evaluate genetic services delivery in Illinois and identify gaps (*collaborate with Genetic Services efforts, Objective 1, Action Item 2)*
2. Examine the need for establishing additional genetics outreach clinics in underserved areas
3. Identify and increase funding opportunities for providing genetic services in underserved areas
4. Review existing genetics telemedicine efforts and conduct a study to assess the feasibility of telemedicine for genetic services in rural Illinois
5. Link clients to health departments for assistance with transportation to nearest genetics clinics

Potential Resources/Partners:

IDPH, IRHA, DSCC, HRSA Region 4 Genetics Collaborative, LHDs, consumer and advocacy organizations

Objective 3. Improve access for medically underserved individuals in Illinois by addressing language and cultural barriers

Action Items

1. Assess cultural barriers to receiving genetic services in Illinois
2. Identify groups in Illinois who would benefit from interpreter services
3. Determine methods of providing interpreter services to those in need, including raising awareness of existing services and costs of those services
4. Evaluate current genetics education literature for cultural competence and develop resources where there is a gap in existing materials *(collaborate with Public Education efforts, Objective 2, Action Item 2)*

Potential Resources/Partners:

Midwest Latino Health Research Center, Governor's Office of Asian Affairs, Salud Latina, Ethnic advocacy and health organizations, including African American, Polish, Russian, migrant, deaf, and other communities, DHS Interpreter services, AT&T Translation Services, Genetic Alliance

Objective 4. Improve access for medically underserved individuals in Illinois by addressing educational barriers

Action Items

1. Collaborate with Public Education efforts, Objectives 1, 2, and 3
2. Collaborate with Professional Education efforts, Objectives 1 and 2

C. Data and Public Health Infrastructure

Developing a state genomics infrastructure requires invested leadership, genomics expertise and accessible genetics data. This infrastructure is critical to the successful integration of genomics and related technologies into health promotion and prevention activities, disease management, and other areas throughout the public and private health care systems.

GOAL: Improve public health data and infrastructure to support and advance genomics activities in Illinois

Objective 1. Develop a public health infrastructure to support genomics activities in Illinois

Action Items

1. Examine the effectiveness of grants to genetic service providers and local health departments for genetic screening and outreach *(collaborate with Genetic Services efforts, Objective 1, Action Item 2)*
2. Continue efforts to integrate genomics into other program areas (e.g., chronic disease, cancer, infectious disease) and across the lifespan
3. Educate and raise awareness of public health policymakers and agency leaders about the importance of genomics *(collaborate with Public Education efforts, Objective 3)*
4. Justify and identify funding for additional staff for data/epidemiology, education and incorporating genomics into chronic disease programming
5. Identify and develop partnerships and resources that may support the implementation of the State Genetic Plan

Potential Resources/Partners:

IDPH Genetics, IDPH genetics grantees, specific program areas within IDPH and DHS, IPHA, IAPHA, NIPHC, Midwest Latino Health Research Center, Illinois Chapter March of Dimes, GTFI, IMCHC, HRSA, NSGC, state chapters of professional associations, legislators, General Assembly, coalitions, non-government funding opportunities, outside evaluators

Objective 2. Improve the accuracy and availability of data regarding genetic conditions and services in Illinois

Action Items

1. Inventory existing databases and archived data, and assess ability for linkage or sharing
2. Increase awareness of public health program staff and partners regarding the types and quality of data currently collected by and available from state agencies
3. Improve the accuracy and completeness of the data currently collected by state agencies
4. Make available aggregate genomics data to the public via Internet capable systems as well as to individuals without Internet access (hard copies)

5. Make individual, de-identified public use data sets available to public health researchers and other interested individuals via internet capable systems
6. Incorporate IDPH Genetic Screening Tool into the Cornerstone data system

Potential Resources/Partners:

IDPH resources: Newborn Screening Laboratory, Genetics Grantees, Newborn Genetic Screening and Newborn Hearing Screening follow-up programs, APORS, Vital records, Cancer Registry, Immunization Registry, IPLAN, Specific IDPH program areas, Communications – Governor's Office, Public Use Data Committees; DHS sources: Cornerstone

D. Public Education

A genomics-literate population is more likely to apply genomic information to health and lifestyle decisions and related ethical, legal and social issues. To increase genomics literacy in the population, education efforts should begin early in student education. Efforts targeted at specific community groups also can be implemented. Educators, policymakers, health care providers, spiritual leaders, and the media are all key partners in public genomics education efforts.

GOAL: Increase genomic awareness and literacy in the general public in Illinois

Objective 1. Improve genomics knowledge and education in the primary and secondary school systems

Action Items

1. Identify and educate stakeholders (e.g., legislators and administrators) in the state education system
2. Partner with the Illinois State Board of Education to review and enhance existing genetics/genomics components of the Illinois Learning Standards
3. Identify existing genomics curriculum materials, adapt or develop necessary materials, and make them easily available to educators
4. Provide genomics education for educators, both existing and currently in training programs

Potential Resources/Partners:

Illinois State Board of Education, NCHPEG, ASHG, Illinois School Health Association, Illinois Science Teachers Association, Illinois Parent Teacher Associations, University of Kansas Genetics Education Center, genetics organizations, family support groups, local universities, local science foundations, local museums

Objective 2. Increase genetic awareness and knowledge in all segments of the Illinois population

Action Items

1. Develop a comprehensive, culturally sensitive Web site to provide information and resources about genomics to the public
2. Identify leaders in underserved and minority communities for the purpose of building relationships and disseminating information about genomics and public health
3. Identify and develop appropriate written materials for individuals without Internet access
4. Develop and coordinate a statewide Genetics Awareness Day, in coordination with existing national DNA and family history days
5. Identify existing genetic and family history awareness programs/materials and replicate successful models and projects
6. Identify religious professionals/spiritual leaders for the purpose of building relationships and disseminating information about genomics and public health
7. Identify "mass media" mechanism for promoting family history
8. Develop relationships with media contacts

Potential Resources/Partners:

IDPH, UIC-SPH, NU graduate program in genetic counseling, Midwest Latino Health Research Center, CCJGD, Illinois Chapter March of Dimes, CDC, NSGC, HRSA Region 4 Genetics Collaborative, GTFI, Surgeon General's Family History Initiative, CDC National Office of Genomics, IAFP, ICAAP, community outreach educators, LHD's, other states, faith-based organizations, local universities, family support groups

Objective 3. Increase genetic awareness and knowledge among state policymakers, including legislators, other elected officials, and public health leadership

Action Items

1. Form a coalition of partner organizations
2. Develop a strategy for approaching state policymakers

Potential Resources/Partners:

Illinois Chapter March of Dimes, CCJGD, GTFI, state chapters of health professional organizations

E. Professional Education

As new strategies and services evolve from genomic technologies, it will become increasingly important to provide education and training to health care professionals and the health care work force to enhance awareness, build competencies, and ensure integration of genomics in the health care delivery system. Health care providers' current level of awareness and understanding of genetic conditions and genomics has not kept pace with the current increase in genomic knowledge. Therefore, by increasing provider awareness and knowledge of genomics, health care professionals may make more informed decisions regarding delivery of genetic services.

GOAL: Promote integration of genomics into Illinois' health care delivery system through education of health professionals and the health care work force

Objective 1. Identify the educational needs and assess the current state of genomics knowledge of the public health and health care work force in Illinois

Action Items

1. Identify existing genomics competencies for health professionals
2. Identify liaisons and develop relationships with state professional organizations
3. Review published studies assessing health professional needs and knowledge in genomics to provide direction for educational efforts in Illinois
4. Pending results of Action Item 3, conduct a formal research study to assess genomic knowledge and integration of genomics into medical practice among Illinois health professionals and the health care work force

Potential Resources/Partners:
NCHPEG, ACMG, ICAAP, IAFP, IAPA, ISMS, IL NAPNAP, IDFPR, NSGC, GTFI, NU graduate program in genetic counseling, Midwest Latino Health Research Center, Illinois Chapter March of Dimes, Nursing genomics competencies, public health genomics competencies, other genomics competencies, professional accreditation documents, health provider organizations, external funders.

Objective 2. Increase Illinois health professionals' genomics knowledge through identification, development and dissemination of educational resources

Action Items

1. Identify existing genomics educational resources for health care providers
2. Assess and evaluate the quality of available genomics resources for health care providers and identify gaps in educational materials
3. Create a clearinghouse of genetics educational resources for health care professionals, accessible via the IDPH genetics program Web site, which would include curricular materials, referral resources and guidance, a speaker's bureau with list of speaker topics, and other pertinent information
4. Disseminate and raise awareness about clearinghouse materials (Action Item 3) to the Illinois health care work force through relationships developed under Objective 1

5. Develop regular and ongoing statewide CME/CEU opportunities for continuing genomics education and updates
6. Develop genomics curricular materials where there is a gap in available educational resources

Potential Resources/Partners:
ASHG, ACMG, NSGC, NCHPEG, CDC National Office of Public Health Genomics, Midwest Latino Health Research Center, Illinois Chapter March of Dimes, AMA, University of Kansas Genetics Education Center, Illinois genetic service providers, state health professional associations, external funders

Objective 3. Evaluate the effectiveness of Objectives 1 and 2

Action Items

1. Assess referral patterns of primary care providers to genetic service providers, including the appropriateness of referrals and "missed opportunities" for referrals
2. Monitor usage ("hits") of the IDPH clearinghouse Web site
3. Survey Illinois health care professionals regarding changes in their genomics knowledge (baseline is Objective 1, Action Items 3 and 4)
4. Identify other appropriate outcomes and measures to evaluate Objectives 1 and 2

Objective 4. Assess and assure an adequate work force supply and access to genetic providers in Illinois

Action Items

1. Conduct ongoing surveys, or obtain existing data from the Illinois Genetic Services Needs Assessment, to determine supply and distribution of qualified genetic providers in Illinois
2. Develop and support undergraduate pipeline programs and graduate medical education programs that will lead to an adequate and diverse genetic provider workforce in Illinois
3. Assure board certification and recertification as appropriate for genetic providers
4. Partner with genetic professionals and health systems to investigate opportunities for providing genetic consultation and counseling through electronic communications networks, thus extending genetic clinical services to areas in Illinois currently without such access
5. Convene a study group to investigate alternative genetic service delivery models, including use of other types of health care providers

Potential Resources/Partners:
Educational institutions (secondary education, community colleges, colleges, universities) and health professional organizations

F. Financing and Reimbursement

Adequate financing and reimbursement for genetic services by public and private sources can significantly impact the genetic services delivery system. Limited insurance coverage and reimbursement may reduce access to and availability of genetic evaluations, counseling, tests and treatments. As many public and private financing decisions are made at the state level, it is important to have the necessary data to improve coverage and reimbursement for genetic services in Illinois.

GOAL: Address genetic services financing and reimbursement issues that impact individuals, families, and/or genetic service providers in Illinois

Objective 1. Assess current status of reimbursement for clinical genetic services in Illinois

Action Items

1. Identifying existing efforts to study and gather data on reimbursement for genetic services, nationally or in other states
2. Survey genetic service providers regarding reimbursement for genetic services in Illinois, to gather data on the following:

    a. Clinical genetic services activities that are part of evaluation, testing, management and counseling

    b. CPT and other codes used for the above activities

    c. Proportion of patients by payer type (such as Medicaid, Medicare, private insurance) and service category (including preconception, prenatal, pediatric, adolescent, adult)

    d. Reimbursement for different activities/CPT codes by payer type

    e. Reasons for non-payment by different payers

    f. Identify gaps in services provided, billed for, and reimbursement

3. Examine existing public and private insurance policies regarding coverage and reimbursement for genetic testing, screening, and services in Illinois
4. Obtain reimbursement rates and policies regarding genetic services from the Illinois Medicaid program
5. Conduct cost-effectiveness studies regarding coverage for genetic health services in Illinois, including estimates of changes in state and private expenses if additional services are covered

Potential Resources/Partners:

ACMG, NSGC, regional genetics collaboratives, external funders

Objective 2. Based on the results of Objective 1, explore strategies for improving third-party coverage and reimbursement for genetic health services in Illinois

Action Items

1. Identify liaisons with third-party payers and the Illinois Medicaid program
2. Based on data gathered in Objective 1, advocate for improved private insurance coverage of genetic services by identifying or developing a presentation or other materials to educate private health insurers about the value, financing, delivery, and organization of genetic services in Illinois
3. Based on data gathered in Objective 1, advocate for improved Medicaid coverage of genetic services by identifying existing models and developing materials to educate Illinois Medicaid policy makers about the value, financing, delivery, and organization of genetic services in Illinois
4. Educate genetic and other specialty providers about optimal billing and coding practices, using existing educational resources when available, and developing new materials as needed

Potential Resources/Partners:
NSGC, ACMG, ASHG, GTFI, state chapters of health professional organizations

Objective 3. Examine billing by Illinois genetic counselors for the provision of genetic services

Action Items

1. Conduct study to assess how genetic counselors are currently billing in Illinois
2. Examine genetic counselor billing practices in other states
3. Identify the necessary steps, as well as the advantages and disadvantages, regarding implementation of genetic counselor billing
4. Coordinate state efforts with national organizations

Potential Resources/Partners:
NSGC, ACMG, GTFI, SACGHS report

G. Ethical, Legal and Social Issues

Ethical, legal and social issues (ELSI) are critical to all facets of the Illinois State Genetics Plan. The ELSI goal aims to address existing and anticipated issues that likely will develop as a result of technological advancements in genomics. Consideration of ELSI in the plan is necessary to establish ethical and legal standards that will protect and promote the interests of individuals, families, and communities throughout Illinois.

GOAL: Identify and examine the ethical, legal and social issues (ELSI) relevant to clinical genetic services, genetic research and related applications for the state of Illinois

Objective. Establish an Illinois ELSI advisory group, consisting of diverse professional and public members, to advise the Illinois Department of Public Health regarding ethical, legal and social issues relevant to clinical genetics and genetic research

Action Items

1. Review and document other states' legislation and policies related to informed consent for newborn screening
2. Identify informed consent issues related to prenatal, preimplantation, and preconception genetic diagnosis, genetic testing of children, genetic testing for competent adults, and population-based genetic screening
3. Identify informed consent and other issues related to genetic research
4. Review and develop access and usage guidelines related to stored tissue samples, including biobanks, in Illinois
5. Review and document genetic privacy legislation and regulations in Illinois, and identify any Illinois cases of genetic discrimination in employment or insurance
6. Develop a Genetic Bill of Rights for the citizens of Illinois
7. Serve as a resource to review pending state legislation related to clinical genetics and genetic research
8. Address social justice issues related to advances in genetics, particularly issues related to health disparities, religious concerns, cultural differences, and vulnerable populations

Potential Resources/Partners:

Medical ethics programs at area universities, advisory groups, faith-based organizations, genetic and non-genetic health care providers, ACMG, family support groups, consumer advocacy groups, GMDAC Ethics Subcommittee.

IV. Evaluation

Evaluation is an important component in implementing and monitoring the results of the ISGP. Ultimately, an evaluation will provide a comprehensive overview of the impact of genetic service-related activities in Illinois. The Illinois Department of Public Health and designated collaborators will be involved in the implementation of ISGP activities and will share the responsibility for collecting and reporting data to verify the process, progress and outcomes of the state plan goals, objectives, and action items.

The U.S. Centers for Disease Control (CDC) recommends a framework for evaluating public health programs. The CDC evaluation framework includes the following six steps, which are recommended as a guide in the evaluation of the ISGP: (1) continue to engage stakeholders; (2) develop goal attainment measures; (3) focus the evaluation design; (4) gather credible evidence; (5) justify conclusions; and (6) ensure dissemination and use. By using the principles of this framework as a guide in ISGP implementation, the state will be better positioned to effectively document and demonstrate the effects of the state plan. Through this type of evaluation strategy, it is anticipated that the ISGP recommendations will be more clearly defined; stronger partnerships will allow collaborators to focus on achieving identified goals, objectives, and action items; and lessons learned from evaluations will be used more effectively to guide improvements in genetic health services and to demonstrate results of resource investments.

Specific details of the monitoring and evaluation process will be developed to track methods, outcomes, and outputs for each goal, objective and action item in the ISGP. Based on the CDC framework, standard reporting methods will be used to describe the effects and outcomes for the target population. An annual assessment evaluation of state plan activities will be conducted, and the findings will be reported back to stakeholders. Similarly, periodic input will be sought from consumers to develop additional strategies to improve state plan outcomes. Ultimately, the evaluation will provide IDPH with the information needed to plan for policy changes that directly affect genetic service delivery and related outcomes.

V. Implementation

In order to achieve the goals outlined in the ISGP, it is important that the objectives and action items are implemented. The state plan efforts can be used to mobilize individuals, organizations, institutions, communities, and policy makers interested in improving access to, and outcomes of, genetic health care. Effective implementation, however, will require ongoing, coordinated collaboration of invested stakeholders and partners.

The following are anticipated activities for implementation of the ISGSP:

- Disseminate the plan widely throughout the state
- Begin plans to implement specific action items within three months of state plan publication
- Identify individuals and/or organizations to conduct activities that will carry out the mission of the state plan goals, objectives and action items
- Identify, coordinate, and secure funding opportunities for implementation efforts
- Facilitate new and existing partnerships and collaborations
- Develop and administer an annual evaluation to review goal attainment
- Report evaluation and progress to stakeholders and seek continued input

The ISGP will be made accessible and disseminated widely throughout the state via the IDPH Web site and other organizations interested in genetic service-related activities. An electronic announcement will be sent to various organizations announcing the completion of the state plan and how to access it. The state plan will also be sent to all steering committee members, work group members, planning conference and community forum attendees, as well as to any individuals requesting a written copy.

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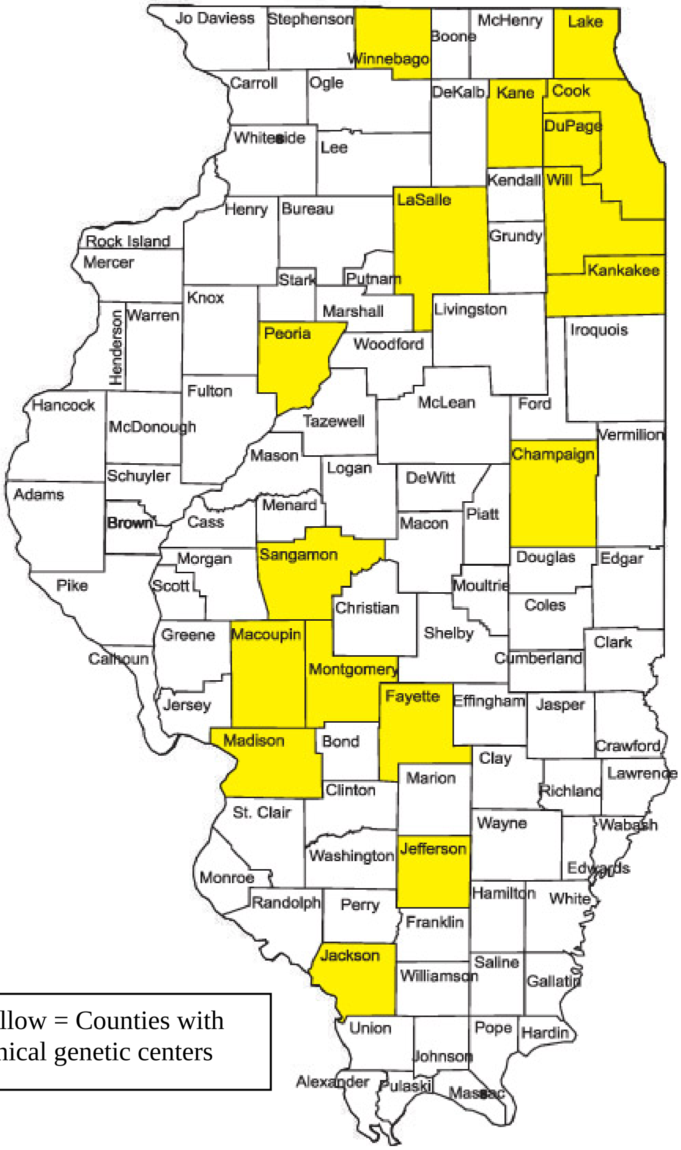
Appendix A: Clinical Genetic Centers in Illinois

Northern Illinois

Advocate Christ Medical Center-Oak Lawn*
  +Will County Health Department - Joliet
Adventist Hinsdale Hospital - Hinsdale
Advocate Illinois Masonic Medical Center - Chicago
Advocate Lutheran General Medical Center – Park Ridge*
  +Central DuPage Hospital –Winfield
  +Provena Mercy Medical Center – Aurora
  +Good Samaritan Hospital - Downers Grove.
Children's Memorial Hospital - Chicago*- +Winchester
Delnor-Community Hospital - Geneva
Evanston Northwestern Healthcare - Evanston
  +Glenbrook Hospital
  +Highland Park Hospital
Illinois Teratogen Information Service*
John H. Stroger Jr. Hospital, Cook County – Chicago*
Loyola University Medical Center – Maywood*
  +Elmhurst
  +Glendale Heights
  +Homer Glen
Northwestern University/Northwestern Memorial Hospital/
  Northwestern Medical Faculty Foundation - Chicago
OSF St. Anthony Medical Center-Rockford
Regional Metabolic Diseases Treatment Network*
  +Advocate Christ Medical Center
  +Rockford Memorial Hospital
  +Springfield Department of Public Health
  +St. Francis Medical Center
  +Hinsdale Hospital
Reproductive Genetics Institute-Chicago
Rockford Memorial Hospital-Rockford*
Rush University Medical Center-Chicago*
  +Poplar Creek Health South, Hoffman Estates
  +Riverside Hospital and Medical Center- Kankakee
  +Rush-Copley Hospital-Aurora
  +St. Joseph Hospital-Joliet
St. Alexius Medical Center -Hoffman Estates
University of Chicago*
  +LaRabida Children's Hospital
  +Friends and Family
University of Illinois College of Medicine at Chicago*
  +Chicago Department of Public Health Uptown Clinic
  +Mercy Hospital and Medical Center
University of Illinois-Chicago*

Central Illinois

Southern Illinois University Medical Center at Springfield*
  +Macoupin County Health Department
  +Montgomery County Health Department
University of Illinois Urbana Champaign College of
  Medicine* -Carle Clinic
University of Illinois College of Medicine at Peoria* -
OSF St. Francis Medical Center/Children's Hospital of
Illinois
  +LaSalle County Health Department-Ottawa



Yellow = Counties with
clinical genetic centers

Southern Illinois

St. Louis University (Cardinal Glennon Hospital–St Louis)*
  +Fayette County Health Department
  +Jackson County Health Department
  +Jefferson County Health Department
  +Madison County Health Department
Washington University School of Medicine-St. Louis*

+designates satellite clinic
*** designates FY07 IDPH grantees**

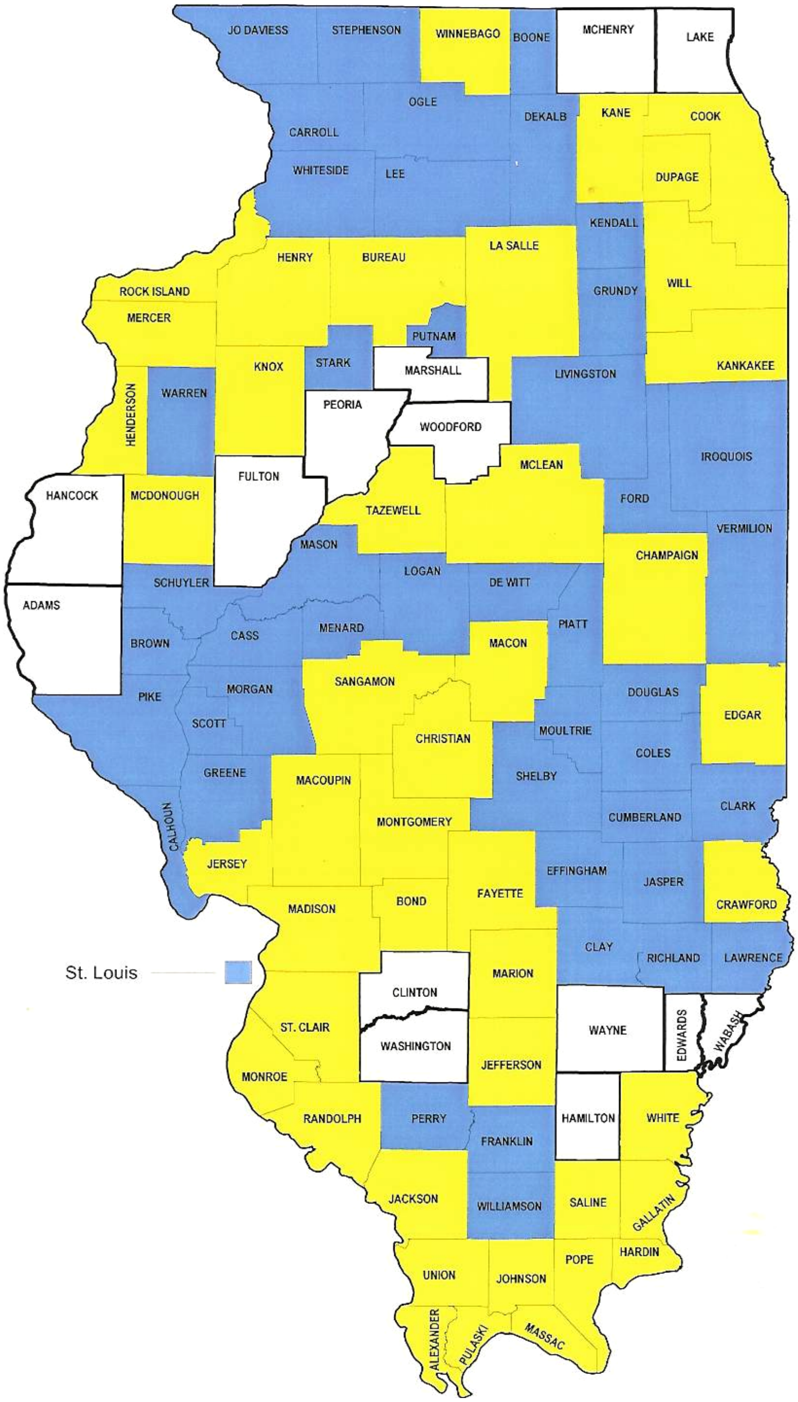
Appendix B: Illinois Local Health Departments Participating in IDPH Genetics Program (FY07)

Bond County Health Department
Bureau County Health Department (Putnam)
Champaign County Public Health Department
(Clark, Coles, Cumberland, Douglas, Ford,
Iroquois, Vermilion, City of Champaign & Urbana)
Chicago Department of Public Health (City of Chicago)

Cook County Health Department (Suburban
Cook County)
Crawford County Health Department
DuPage County Health Department
East Side Health District (Portions of St. Clair Co.)
Edgar County Health Department
Egyptian County Health Department (Gallatin,
Saline, White)
Evanston City Health Department
Fayette County Health Department (Clay,
Effingham, Jasper, Lawrence)*
Henderson County Health Department (Warren)
Henry County Health Department (Stark)
Jackson County Health Department (Perry,
Jefferson County Health Department
Jersey County Health Department
(Calhoun, Greene, Jersey)
Kane County Health Department
Kankakee County Health Department
Knox County Health Department
LaSalle County Health Department
(Livingston)
Macon County Health Department (DeWitt,
Moultrie, Piatt, Shelby)
Macoupin County Health Department
Madison County Health Department
Marion County Health Department
McDonough County Health Department
McLean County Health Department
Mercer County Health Department
Montgomery County Health Department
Rock Island County Health Department
Sangamon County Health Department (Brown,
Cass, Logan, Mason, Menard, Morgan, Pike,
Schuyler, Scott)
Southern Seven Health Department (Alexander,
Hardin, Johnson, Massac, Pope, Pulaski,
Union)
Springfield Department of Public Health
St. Clair County Health Department
Tazewell County Health Department
Will County Health Department (Grundy, Kendall)

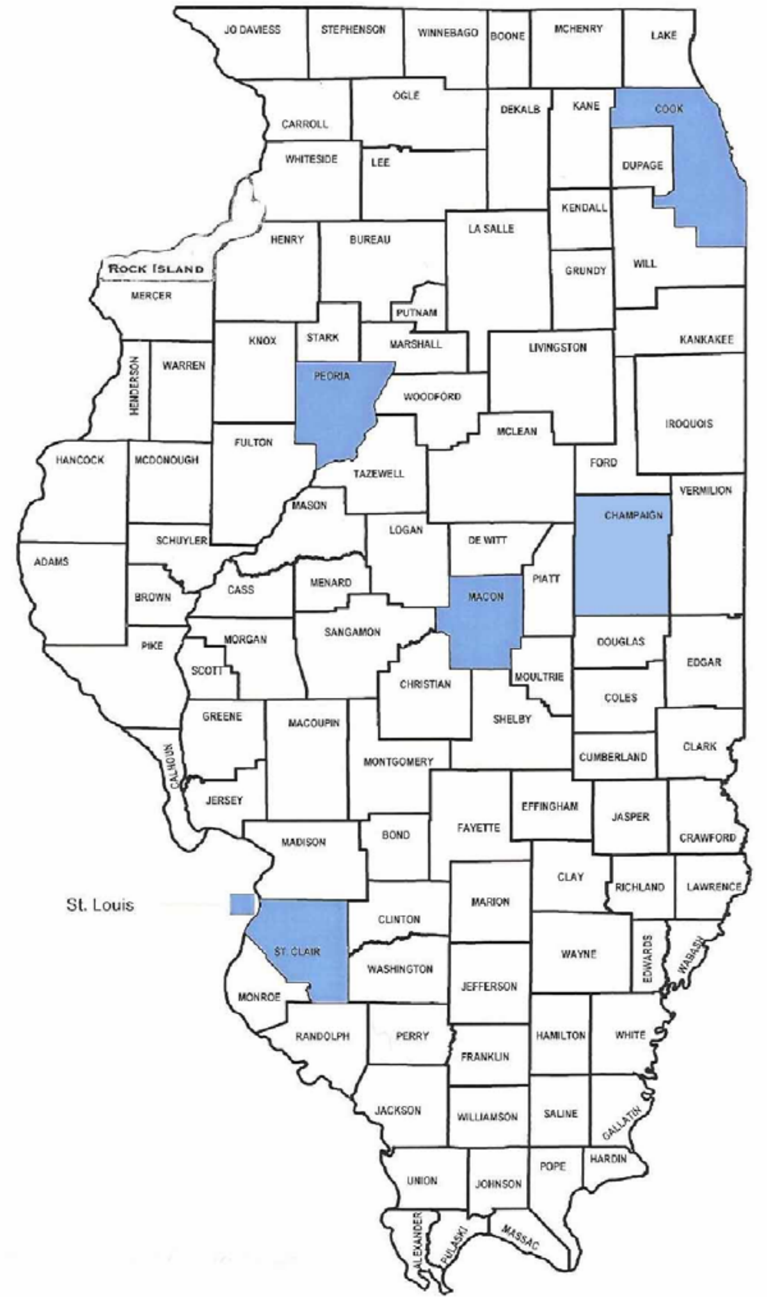
Winnebago County Health Department (Boone, Carroll, DeKalb
JoDaviess, Lee, Ogle, Stephenson, Whiteside)

Genetic clinic sites in bold



LHD Grantees (38) in yellow (46 counties)
Covered Areas by Grantees (44 counties in blue)
Areas not covered in white (15)

Appendix C: Pediatric Hematology Centers and Outreach Sites (FY07)



<u>Chicago Area</u>

Children's Memorial Hospital
John H. Stroger, Jr. Hospital of Cook County
Mt. Sinai Hospital
Rush University Medical Center
University of Chicago
University of Illinois at Chicago

<u>Peoria Area</u>

OSF St. Francis Medical Center
+Macon County Health Department
+Rock Island County Health Department

<u>Champaign Area</u>

Carle Clinic

<u>Southern Illinois Area & St. Louis, MO</u>

Southern Illinois Health Care – Centreville (Mother Child Center)

St. Louis University – Cardinal Glennon Hospital
Washington University – St. Louis Children's Hospital

+Genetic satellite clinic site

Appendix D: Illinois Genetic Services Needs Assessment
Executive Summary

The U.S. Centers for Disease Control and Prevention has articulated a vision of public health in the 21st century that emphasizes the integration of genetics/genomics into public health practice. As a part of this vision, the CDC has encouraged every state to develop a genetics plan identifying the specific ways in which states will address their current and future genetic service and policy needs. Planning in this arena is crucial at this time because of the rapid development of genetic science and technology, the actual and potential consequent changes in the medical care delivery system, the impact the field will have on population health, and associated broad social and policy implications.

One of the first steps in the process of developing a state plan was the completion of a needs assessment (2003-2005). The Illinois Department of Public Health contracted with the Midwest Center for Health Workforce Studies, located in the School of Public Health at the University of Illinois at Chicago to conduct a statewide genetics needs assessment.

The purpose of this needs assessment was to assess the role and function of the state health department with regard to the current and future needs for genetic policy, service provision, workforce and community education, as well as research and surveillance in Illinois. This was accomplished through:

- an assessment of the current provision of genetic services in Illinois; and,
- an assessment of the essential elements of a state genetics program, currently and in the coming years, defined through the perspectives of key stakeholders in Illinois.

The needs assessment process involved the review of key documents and program literature, as well as surveys and interviews conducted with key stakeholders throughout the state. Surveys were sent to genetic coordinators or maternal and child health coordinators at all 94 local health departments and to all 150 identified genetic service providers in Illinois, including medical and laboratory geneticists, genetic counselors, and genetic nurse coordinators. Responses were received from 71 (76%) local health departments and 78 (52%) genetic service providers. A total of 86 interviews were conducted with genetic service providers, other health care providers, local health department personnel, state agency staff, and representatives of advocacy groups.

This report provided an overview of Illinois' population characteristics, summarized the current genetic services system in Illinois, presented findings from the surveys and interviews, reviewed literature about public attitudes and perspectives of ethical, legal, and social issues (ELSI) in genetics, and summarized key legislation in Illinois relevant to genetic services. It included the information that was used to develop prioritized goals and objectives for a genetic services state plan for Illinois.

Overview of Current System

The needs assessment report included descriptive data about Illinois' population sociodemographics, health insurance, and health status, as well as the current genetic services system. The Illinois Department of Public Health's (IDPH) Genetics and Newborn Screening Program is the key coordinator of public health genetics in the state. The program has the following responsibilities: administering the state's legally mandated universal newborn screening program;

coordinating and overseeing a statewide public/private network of clinical genetic centers and local health departments; and providing educational programs to the public and health care providers on genetics and health promotion. In addition to IDPH, the Illinois Department of Human Services (IDHS), the administrator of the Title V Maternal and Child Health Block Grant, and the Division of Specialized Care for Children (DSCC), the state's Title V Children with Special Health Care Needs Agency, provide case management, clinical care, and support services to women and children with reproductive and special health care needs, including those associated with certain types of genetic conditions and/or indications associated with genetic components or risk factors.

Key Findings

Below are summaries of the key findings from: the surveys of genetic service providers and local health departments; the interviews with genetic service providers, non-genetic health care providers, local health department personnel, state agency personnel, and consumer/advocacy group representatives.

Genetic Service Providers

Survey Results. This section provided demographic and practice data for genetic service providers in Illinois. The results from these 78 survey respondents may not be generalizable to all genetic providers in Illinois, although the results were consistent with the recently published results of a national survey.

Almost all genetic providers were white and non-Hispanic. Over half of geneticists and all but two genetic counselors were women. The youngest geneticist respondent was 41 years of age, with 34 percent aged 55 years or older. In contrast, 60 percent of genetic counselors were younger than 35 years of age, and almost half (47%) had been at their current place of employment for less than five years. On average, geneticists worked 51 hours per week, while genetic counselors worked 40 hours. Only 8 percent reported that their practice was full.

Eighty percent of genetic service provider respondents worked either in an academic medical center/university or a hospital. Most providers discussed risks with clients when recommending susceptibility testing or pre-symptomatic testing. There was support for potential telemedicine use, but limited experience with it. Sixty-two percent of respondents reported being very familiar or familiar with IDPH's Genetics and Newborn Screening Program.

Genetic service provider respondents had the opportunity to provide comments on many topics. Some respondents expressed concern with insurance coverage and reimbursement issues, including constraints regarding payment for genetic services; lack of physician education regarding genetics; the size and distribution of the genetic provider workforce; and the need for public education. Concerns and uncertainties were described regarding the future of the field of genetics, notably questions about the roles and responsibilities of trained genetic specialists and other non-genetic health professionals. Some respondents indicated that IDPH should play a role in genetic services funding, coverage and reimbursement issues, and education.

Interview Findings. Thirty-four genetic service providers were interviewed. These participants identified a number of key issues affecting the current and future provision of genetic services in Illinois, including important needs and barriers with respect to genetic health care. These issues, which were identified repeatedly throughout the interviews, fell readily into the categories of finance/reimbursement, workforce adequacy, education, engagement, access, and a cluster of issues that have come to be known as ethical, legal, social issues or implications (ELSI). According to the genetic service providers interviewed, the issues that needed to be addressed in the state included:

1. an inadequate and uneven system of third-party reimbursement for genetic testing and clinical services

2. the discrepancies between what are considered essential components of clinical care in genetics and what third-party payers consider reimbursable services

3. an inadequacy in the current supply of genetic professionals, including medical geneticists and genetic counselors

4. a lack of effective integration between current systems of non-genetic primary and specialty care and genetics

5. knowledge, educational, and informational gaps and needs throughout the primary care and non-genetic health workforce

6. knowledge and informational gaps and needs among the public

7. access disparities, including (a) an uneven distribution of genetic service provision, and (b) a lack of linguistic and cultural diversity among genetic service providers

8. ethical, legal, and social concerns, including issues related to genetic discrimination and concerns that genetics may exacerbate existing or create new health disparities

The genetic service provider respondents suggested that the role for the state department of public health focus on education, direct service provision, assuring access, and assuring a stable and secure system of finance/reimbursement for genetics. While emphasizing important systemic issues, these genetic service providers also stressed the need for the state to continue to support public health's role in the provision of direct genetic services.

Local Health Departments

Survey Results. Of the 71 health departments that had a staff member respond to the survey, 50 provided some level of genetic services; 39 of those received genetic services grants from IDPH. Among the health departments that provided genetic services, there were differences between those that did and did not receive IDPH grant funding. A larger proportion of funded health departments used a questionnaire to screen clients for inherited risk factors, provided on-site genetic clinics, referrals to genetic providers, and public and professional genetics education; a larger proportion also reported that they were able to meet their clients' needs. None of the non-funded health departments had a genetic nurse coordinator on staff. When asked about the future impact of genetics on their public health programs, a greater proportion of funded than non-funded health departments predicted a significant impact, regardless of their provision of genetic services. IDPH-funded health departments were more comfortable with providing a variety of different services than were their non-funded counterparts. The large proportion of respondents who did not know what public health programs areas would need to incorporate genetics in the next three to five years also indicated a need and opportunity for educational interventions. When asked about key issues that providers in local health departments will face over the next five to 10 years, some respondents stressed the need for public education regarding genetic services. Other challenges included: incorporating genetics into chronic disease programs; program funding within the context of state budget constraints; inadequacies in insurance coverage; limited local access to genetic services; ethical, legal, and social issues, and non-genetic health care providers' limited knowledge about genetics. Local health department respondents indicated that IDPH should play a role in funding genetic services (counseling), health department staff education, and community/public education.

Interview Findings. The challenges and access barriers identified by the 15 interviewees from local health departments reflected the population served by local health departments (generally, poor and uninsured, often rural) as well as broader system issues: transportation problems; lack of client follow-up; lack of client education/awareness about genetics and genetic services; and financial/insurance constraints. Local health department interviewees also reported a need for more staff training in and awareness of genetics. The most frequently mentioned roles for IDPH were education (public, caregivers, health department staff) and funding (genetic testing, genetic services, transportation assistance).

Non-Genetic Health Care Providers

Obtaining the participation of non-genetic health care providers was challenging. The small, diverse group of 10 primary and specialty care providers who participated provided insight into their current involvement with the provision of genetic services in Illinois, the challenges they face, and their thoughts on IDPH's role in the genetic services system. While genetics has impacted their practices, these non-genetic health care providers reported uncertainty about their roles and responsibilities in the genetic services system. Some interviewees were concerned about insurance and reimbursement issues, education for themselves and the public, and the supply of genetic service providers. Recommendations for IDPH's role in the genetic service system included service provision, public and health provider education, and financial support.

State Agency Personnel

Excluding those participants from the state's genetic program, most of the 21 interviewees from state agency programs reported having only minimal genetic knowledge and training and reported that their program areas included genetics only in limited ways. Interviewees discussed the need for program and agency staff to have greater awareness and education about genetics. Some respondents noted that, in addition to staff education, organizational structure and funding streams were barriers to integrating genetics into their programs. Overall, state agency staff indicated that IDPH's role should be to coordinate and ensure access to genetic services, educate and provide information to health care providers and the public about genetics, and to assume various data and surveillance functions.

Consumer/Advocacy Organizations

Of the eight persons interviewed in this category, persons in the role of organizational leader or parent generally focused on personal issues and the need for support services; how well health care providers communicate with families about genetic issues; and concerns about the accuracy of the information provided by health care professionals. Advocacy professional, respondents tended to focus on education and training for themselves and for health professionals, as well as on the need for policies to protect the privacy of genetic information. Continuing education for clinicians and health care providers was already a service provided by two of the advocacy groups.

Discussion and Next Steps

Four major themes were identified during the needs assessment process:

- limited genetic provider supply;
- low genetic literacy on the part of the general public;
- inadequate third- party reimbursement; and
- lack of integration between genetics and the overall health care system.

The findings discussed in this report served as a basis for the next phase, the development of a state genetic services plan for Illinois. That phase involved stakeholders in Illinois in a systematic process to develop a consensus about what needs and opportunities should be pursued, by IDPH and perhaps by other organizations, and how these should be prioritized.

Appendix E: ISGP Steering Committee

Chairperson:
Lynn D. Fleisher, Ph.D., J.D.
Sidley Austin LLP, Chicago

Members:
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Genetics and Newborn Screening Program
Illinois Department of Public Health

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Appendix F: ISGP Work Groups

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Southern Illinois University School of Medicine

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Spence & Elster, P.C.

Dan Greenberg, J.D.
National Tay Sachs & Allied Diseases
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University of Chicago Law School

Lainie Friedman Ross, M.D., Ph.D.
MacLean Center for Clinical Medical Ethics
University of Chicago

Appendix G: ISGSP Planning Conference Agenda

UIC UNIVERSITY OF ILLINOIS AT CHICAGO

Planning Conference for the Development of an Illinois State Genetic Services Plan

July 27, 2006

Conference Objectives

- Raise awareness about public health genetics/genomics
- Build partnerships with key stakeholders
- Begin to develop goals and objectives, via work groups, for the Illinois State Genetic Services Plan

9:30 a.m.-10 a.m. ***Registration***

Conference Moderator - Lynn Fleisher, Ph.D., J.D, Sidley Austin L.L.P.

10 a.m. ***Welcoming Remarks*** - Chandana Nandi, M.S., R.D., L.D.N., Chief, Division of Chronic Disease Prevention and Control Illinois Department of Public Health

10:15 a.m. ***The Future of Genomics and Population Health: Opportunities and Challenges*** - Jean Chabut, B.S.N., M.P.H., Chief Administrative Officer, Public Health Administration, Michigan Department of Community Health

11 a.m. ***Key Findings of the Illinois Genetic Services Needs Assessment and the Development of the Illinois State Genetic Services Plan*** - Gayle R. Byck, Ph.D., Institute for Health Research and Policy, University of Illinois at Chicago

11:30 a.m. ***Illinois State Genetic Services Plan Work Group Overview and Process*** - Amy A. Lemke, M.S., Ph.D., Institute for Health Research and Policy, University of Illinois at Chicago

11:45 a.m. ***Lunch***

12:30 p.m. ***Work Group Break-out Sessions***

2 p.m. ***Brief Work Group Reports***

2:40 p.m. ***Closing Remarks*** - Barbara K. Burton, M.D., Northwestern University Feinberg School of Medicine; Division of Genetics; Children's Memorial Hospital

Appendix H: ISGSP Community Forum Agenda

Community Forums: The Illinois State Genetic Services Plan

An Illinois State Genetic Services Plan is currently being developed for the Illinois Department of Public Health to address the future of genetic services delivery in Illinois. Four community forums have been scheduled to:

- raise awareness about key issues identified from the *Illinois Genetic Services Needs Assessment**, as well as about the current process of developing the Illinois State Genetic Services Plan.
  (*available at: www.uic.edu/sph/irhwc/Illinoisgeneticservicesneedsassessment.pdf)
- allow interested stakeholders an opportunity to provide their perspectives and input in the genetic state plan process.

The free forums are open to genetic and non-genetic health care professionals, consumers, educators, advocates, the public, and others with an interest in genetic issues or services.

Community Forum Sites:

Mount Vernon, ILL.
Thursday October 5, 2006
2 p.m. – 4 p.m.
Municipal West Building
200 Potomac Blvd.

Urbana, ILL.
Monday, October 23, 2006
4 p.m. – 6 p.m.
National Center for Supercomputing Applications
University of Illinois at Urbana-Champaign
1205 W. Clark St., Room 1030
*Videoconferencing locations in Springfield and Peoria

Rockford, ILL.
Tuesday, October 24, 2006
3:15 p.m. – 5:30 p.m.
UIC Medical College at Rockford
1601 Parkview Ave.

Chicago, ILL.
Thursday, November 2, 2006
5:45 p.m. – 8 p.m.
Feinberg School of Medicine
Hughes Auditorium
The Robert H. Lurie Medical Research Center
Northwestern University – Chicago Campus
303 E. Superior Ave.

General Forum Agenda:

I. Welcome and Introductions
II. Key findings from the *Illinois Genetic Services Needs Assessment*
III. The Development of the Illinois State Genetic Services Plan
IV. Preliminary Priority Issues
V. Public Comment Session
VI. Final Thoughts and Acknowledgements

For more information or to **RSVP**, please contact
Meagan Grant at 312-996-4246 or mgrant1@uic.edu

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Appendix I: Key Genetics-Related Legislation in Illinois

Genetic Information Privacy Act PA 90-0025, June 1997 (HB 8)	Genetic testing and information derived from genetic testing is confidential and may be released only to the individual tested or his/her authorized representative. Insurers cannot seek information derived from genetic testing for accident and health insurance. Individuals may submit genetic information to insurers, but it may only be used in policy decisions if the results are favorable to the individual. No one may disclose or be forced to disclose the identity of any person upon whom a genetic test has been performed or the result of a genetic test that permits identification of an individual except as provided in the act.
PA 91-0549, August 1999 (HB 1348)	Updates state insurance code to clarify when genetic information may be treated as a pre-existing condition for purposes of the Illinois Health Insurance Portability and Accountability Act; prohibits health insurers from imposing a preexisting condition exclusion relating to genetic information, under certain circumstances where there has been no diagnosis of a condition related to the genetic information.
PA 92-0701, July 2002 (HB 5870)	Amends Phenylketonuria Testing Act of 1965 to mandate expanded newborn screening for all infants through state NBS lab beginning July 1, 2002.
PA 92-0430, August 2001 (SB 42)	Amends Genetic Information Privacy Act such that insurers that receive information derived from genetic testing may not use that information for a nontherapeutic purpose "regardless of the source of that information."
Genetic Counselor Licensing Act PA 93-1041, September 2004 (HB 4200)	Requires all health professionals who advertise themselves as genetic counselors to be licensed by the state. Does not prevent others from engaging in this activity so long as they do not represent themselves as genetic counselors. Requires successful completion of the American Board of Medical Genetics or American Board of Genetic Counseling exam to be licensed. Regulates genetic counseling referral process. Genetic counseling information is designated as privileged and confidential.
HR 299, May 2005	Calls attention to sickle cell disease and urges all public and private entities to inform the public of the effects of sickle cell disease on Illinois citizens.
PA 094-0661, August 2005 (SB 2012)	Amends Genetic Counselor Licensing Act to allow that genetic counseling referrals be written or telecommunicated. Allows genetic counseling to be performed without referrals in some non-clinical research settings.
Executive Order 6 July 12, 2005	Establishes the Illinois Regenerative Medicine Institute within the Department of Public Health. Makes state research funds available for scientific research on therapeutic uses of stem cells.

Appendix J: General Resources

American College of Medical Genetics
9650 Rockville Pike
Bethesda, Maryland 20814-3998
301-634-7127
Email: acmg@acmg.net
http://www.acmg.net/

American Society of Human Genetics
9650 Rockville Pike
Bethesda, MD 20814
1-866-HUM-GENE
301-634-7300
Email: society@ashg.org
http://www.ashg.org

Centers for Disease Control and Prevention
National Office of Public Health Genomics
4770 Buford Highway Mailstop K-89
Atlanta, GA 30341
Email: genetics@cdc.gov
http://www.cdc.gov/genomics/

Genetic Alliance, Inc.
4301 Connecticut Ave. N.W.
Suite 404
Washington, DC 20008-2369
202-966-5557
Email: info@geneticalliance.org
http://www.geneticalliance.org/

Genetic Task Force of Illinois, Inc.
http://www.gtfi.us/

Genetics Home Reference:
Your Guide to Understanding Genetic Conditions
National Library of Medicine
888-FIND-NLM
http://ghr.nlm.nih.gov/

Illinois Department of Public Health
Genetics and Newborn Screening
500 E. Monroe St., First Floor
Springfield, Illinois 62701
217-524-4900
http://www.idph.state.il.us/HealthWellness/genetics.htm

March of Dimes Illinois Chapter
111 W. Jackson Blvd., Suite 2200
Chicago, IL 60604
Email: IL623@marchofdimes.com
http://www.marchofdimes.com/illinois/

National Coalition for Health Professional
Education in Genetics
2360 W. Joppa Road, Suite 320
Lutherville, MD 21093
410-583-0600
Email: info@nchpeg.org
http://www.nchpeg.org

National Human Genome Research Institute
National Institutes of Health
Building 31, Room 4B09
31 Center Drive, MSC 2152
9000 Rockville Pike
Bethesda, MD 20892-2152
301-402-0911
www.genome.gov

National Society of Genetic Counselors
401 N. Michigan Ave.
Chicago, IL 60611
312-321-6834
Email: nsgc@nsgc.org
http://www.nsgc.org/

Northwestern University
Center for Genetic Medicine
Graduate Program in Genetic Counseling
676 N. Saint Clair St., Suite 1280
Chicago, IL 60611
312-926-7467
http://www.cgm.northwestern.edu/gpgc.htm