CT Department of Public Health

Genomics Action Plan

Recommendations & Status Update

In 2005, the Connecticut Department of Public Health (DPH) published the *Genomics Action Plan* with the goal to integrate *genomics* into public health strategy and programs in Connecticut. The Plan's Recommendations & Action Steps have undergone a two- year review and revision based upon input from DPH's Expert Genomics Advisory Panel and Virtual Office of Genomics.

A compelling picture shows the necessity to create a significant and functional genomics presence within the Connecticut public health arena. The *Genomics Action Plan*'s vision ensures that an active genomics infrastructure is able to respond to the needs of Connecticut's citizens by the year 2010.

This November, 2007 update provides the status of activities completed or in progress intended to achieve each recommendation, goal and objective. It is anticipated that short-term objectives will be targeted for completion within the next two years while the long-term objectives may require additional time to accomplish.

In addition, new recommendations were developed and are summarized below.

- ❒ Continue to engage the public health and health care community in dialogue and activities that increase the awareness, knowledge and skilled delivery of genetic services and which promote genetic literacy among the citizens of Connecticut.
- ❒ Continue to guide and inform policies on genetics and genomics, and research and respond to opportunities for advocacy of such policy.
- ❒ Continue to bridge public health with emerging clinical genetics and health care and genetics and genomics research
- ❒ DPH review and consider the results of the survey efforts that may yield useful information for future planning efforts and in identifying barriers to access.
- ❒ Continue to detect, assess and address barriers that may prevent individuals with limited genetics literacy from accessing, comprehending, and taking advantage of genetics related health information and services.
- ❒ Define the process for sharing information about availability/access to culturally competent genetic services.
- ❒ Expand existing partnerships with regional, community-based organizations and providers to develop and disseminate culturally competent genetic information.
- ❒ Assure necessary services are provided for genetic testing, treatment and follow-up services. Continue to identify or create opportunities for networking with providers, affected families, advocates and other stakeholders to ensure quality of and access to needed genetic services
- ❒ Assess transition services from pediatric to adult primary care and specialty care services.
- ❒ DPH continue to monitor the effects of direct-to-consumer (DTC) marketing of genetic tests.

Priority I – Infrastructure

Establish a formal, stable, and sustainable infrastructure that promotes the integration of genomics into all relevant areas of public health across the lifespan.

Goal I.1

Create an Office of Genomics within DPH that has agency-wide reach and experienced Directorship.

Short-Term Objectives	**Status**
I.1.a. Continue the Department's commitment to genomics through the creation of an interim Virtual Office of Genomics (VOG).	DPH VOG continues to meet monthly, maintains the genomics website, and involving cross-program commitment.
I.1.b. Establish position, and recruit a Director of Genomics, with broad-based experience in genetics to direct DPH genomics policy and activities.	
I.1.c. Seek funding sources to fully implement the Connecticut Genomics Action Plan.	Submitted grant proposal to: 1)acquire perinatal genetic and environmental data with a postpartum survey (PRAMS) linked to birth records, and study the genetic and environmental determinants of adverse birth outcomes (IV.2 & V.1); 2)evaluate perceptions of genetics testing among minority women (I.3); and 3)incorporate family history into a pilot preconception training tool (V.2). Successful Involvement in HRSA-funded New England Genetics Collaborative that provides support for regional genetics activities.

Long -Term Objective	**Status**
I.1.d. By year 2010, have developed an active, fully functioning Office of Genomics, operating across units to serve as a clearinghouse and central site for genomics within DPH.	Submitted Budget Option, denied.

Goal I.2 **Establish internal and external interdisciplinary genomics advisory capacity within DPH.**	
Short-Term Objectives	**Status**
1.2.a. Formalize the ongoing internal Gene Team for the purposes of internal genomic development, information dissemination and advocacy within DPH, and expanding the genetic competencies among Departmental staff.	Maintaining DPH Gene Team, meets two - three times yearly, members invited to attend annual VOG genomics seminar. Announcements, articles, and other genomics related items are sent to Gene Team members for distribution to their respective program areas.
1.2.b. Identify, recruit and formalize a multidisciplinary external Expert Genomics Advisory Panel with the capability of guiding DPH genomic integration and ongoing efforts. The Panel should consist of researchers, scientists, educators, health professionals and providers, consumers and affected families, payers, community leaders, legal experts, ethicists, and representatives from advocacy groups and appropriate governmental agencies.	Established EGAP in 2006. Meets three times annually. Four Workgroups established: Education; Services; Science; and Ethical, Legal, & Social Impact.

Goal I.3 **Promote genomic public health interests by engaging the public and mobilizing partnerships at the state and local levels to identify those communities that could benefit from genetic services and provide feedback about related needs and attitudes within the state, and by looking to key players at the national level for guidance and support.**	
Short-Term Objectives	**Status**
I.3.a. Establish partnerships with local health departments, community groups and health service providers.	Linked with CT Nurses Assoc., started Jan.2007. Biobank feasibility study resulted in strengthened networks with 1) genetics researchers at Yale & Uconn, 2) officers in state ACOG and Medical Society and 3) federal representatives in CDC, NHGRI,SACGHS, and national MOD. Participated in founding of Genomics Forum within APHA.
1.3.b. Identify and examine priority workforce groups for targeted genomics education efforts: ie, nurses, social workers, educators (including 8th – 12th grade science teachers, nursing educators, special education) and MPH students (including those working to obtain a CHES -Community Health Education Service- certification).	Outreach begun to CT schools of social work via online survey and invitation extended to DPH hosted seminar on genetic testing in May '07. CT State Department of Education representative sits on Education Workgroup.

I.3.c. Outreach to other state agencies, national/federal agencies and organizations, and community providers to clarify and establish appropriate roles for each regarding genomic issues. I.3.d. Explore the extent to which various national exams, certificates, and other educational standards require or include genomic components, or test for genomic knowledge or competencies. I.3.e. Develop targeted approaches for genomic education outreach, geared to address the particular functions and needs of each audience as well as the optimal vehicle for reaching them. I.3.f. Examine the options and various venues currently available for disseminating genomic training, including emerging technologies -i.e., the utilization of an online approach for nursing continuing education.	Strengthened partnership with UCHC TRIPP (Translating Research into Practice & Policy) Center. Assessment of genomics content taught within schools of nursing in CT conducted during summer of 2006, results distributed. Education Workgroup member has developed genomics content in online course geared for nurses' education. Further expanding the availability of this course is being examined by the workgroup. Linkage with Ct Nurses Assoc. resulting in joint collaborative activities aimed at greater genomic awareness and education among CT nurses. Participating in Round Table discussion of Genomics and Public Health, by invitation and hosted by the SACGHS (1115/07). Article drafted for CT Nursing News, with May, 2007 deadline; genetics breakout session planned for annual Nurses Convention on October 29, 2007.
Long-Term Objective I.3.g. Monitor community attitudes about genomics and genetic services, and facilitate consensus-building for genetic policy development. **NEW Recommendation** **Continue to engage the public health and health care community in dialogue and activities that increase the awareness, knowledge and skilled delivery of genetic services and which promote genetic literacy among the citizens of Connecticut**.	**Status** 2004 BRFSS included genomics question: "How likely do you think family history helps cause health conditions?" The analyzed data was presented at the 2006 APHA annual meeting. A question has been submitted for 2008 BRFSS to assess the general public's awareness of breast cancer and genetic testing.

Goal I.4 **Develop policies and practices and support legislation that ensure quality genomics programs throughout the state, and that address the ethical, legal and social implications of the expanding use of genetic testing and genetic information.**	
Short-Term Objectives	**Status**
I.4.a. Facilitate regular, ongoing review and discussion of ethical, legal and social implications for genomic policy development.	VOG sponsored genetic seminars in 7/2006 on Bridging PH Genomics and 5/07 on Genetic Testing. Monthly meetings of ELSI workgroup have membership from UCONN and Yale as well as internal DPH legal staff discuss access issues, direct-to-consumer testing, and gaps in education. Concurrent membership exists with other ELSI workgroups in CT, including the Stem Cell Research Advisory Ethics and Law Subcommittee and the Biobank Feasibility Study ELSI advisors.
I.4.b. Establish a process for coordinating state genomic policy issues pertaining to genetic testing, disclosure and use of genetic information, guided by reviews of national/state privacy, discrimination, and informed consent policies.	Recommend the inclusion of representatives from other stakeholders as such as Departments of Insurance and Social Services
Long-Term Objectives	**Status**
I.4.c. Foster policies and support legislation that improves reimbursement for comprehensive genetic services and coordinated care.	Being developed. As federal non-discrimination legislation is almost certain to pass this year. ELSI's focus is on remaining legislative gaps.
I.4.d. Ensure regular, periodic dissemination of pertinent privacy regulations and policies to public health and other healthcare professionals who are impacted by them (cross referenced with Priority II/Education).	
NEW Recommendation	
Continue to guide and inform policies on genetics and genomics, and research and respond to opportunities for advocacy of such policy.	

Priority II - Genomics Education

Educate the public about genomics, and ensure a public health and healthcare workforce that is competent in genomics, including the associated ethical, legal and social implications.

Goal II.1

Inform the general public and policymakers about genetics and its impact on health.

Short-Term Objectives	Status
II.1.a. Create a DPH Genomics Speaker's Bureau to reach a variety of audiences.	
II.2.a. Create/enhance Family Health History outreach efforts.	Joint family health history and chronic disease outreach effort currently under development.
II.3.a. Examine the degree to which genomics education is included in key workforce curricula: nursing, medical providers, social work, public high school science education, special education, and so on.	Social Work schools surveyed in 2006 for genomics content in curricula, follow-up required due to low response. Completed review of basic science curricula, determined that genetics education is lacking.
II 4. a. Examine the degree to which various national exams, certificates and other educational standards require/include genomic components or test for genomic knowledge and/or competencies.	Nursing competencies are being reviewed to identify areas for enhanced genomics education and in response to new NCLEX exam questions pertaining to genetics.
II 5.a. Develop targeted approaches for genomic education outreach.	Completed of available online resources for health professionals, posted on DPH webpage.
11.5.b. Examine options and venues currently available for disseminating genomic training – (i.e., an online approach for nursing continuing education in genomics).	Possible adaptation of online genomics course for nurses being examined for cost and availability.

Long-Term Objectives	Status
II.1.b. Assess community needs for genetic information/education services.	Set workplan & actionable strategies.
II.1.c. Develop and offer educational programs for school age youth that increase genetic awareness.	Education Workgroup Invited Project to Increase Mastery in Mathematics and Science representative.
II.1.d. Develop and offer educational programs for the general public and disadvantaged groups that increase genetic awareness, including ethical and social implications.	Need to focus on public education surrounding issues such as informed consent, awareness of genetic tests, access issues.

Goal II.2

Develop, maintain, and assure availability of a public health and healthcare workforce that is competent in genetics.

Short-Term Objectives	Status
II.2.a. Identify opportunities for including genetic information in the breadth of existing programs within DPH, having to do with chronic and infectious diseases, environmental and occupational health, family health and epidemiology.	Developed/delivered Family History presentation to chronic disease units at DPH from Jan – April '07. Outreach expanded to additional DPH units.
II.2.b. Create and offer educational opportunities for workforce development among public health and healthcare workers, and build genomics literacy training into ongoing public health training.	"Genomics" unit developed as DPH PH introductory course for new staff; information booth has been staffed for each of the past three years at the CT Public Health Association Annual Conference; annual genetics presentations have been offered to all public and local health staff.
II.2.c. Assess priority workforce groups i.e., nurses, social workers, educators, nursing educators, special education, and so on, for genomic education needs and examine methods for addressing them such as developing guidelines for the integration of genomics into nursing curricula.	Letter from EGAP supporting genomics content in CT MPH programs sent to DPH Commissioner, who in turn advocated for genomic education to the two public MPH programs in state. New NBS/Hearing training released 3/07.
Long-Term Objectives	**Status**
II.2.d. Prepare students of public health and other healthcare areas for the role of genetics in professional practice	Genetic resources/ issue briefs posted on DPH Genomics webpage. Two MPH students interned with the DPH VOG. VOG staff presented on genomics at MPH intern orientation sessions, and graduate MPH courses. ELSI workgroup is exploring the possibility of genetic specialty licensure.
II.2.e. Seek data from current workforce of nurses and other health professionals as to their perceived needs for genomic education. Identify existing resources and promote broadened genomic education.	Assessment of genomics content taught within schools of nursing in CT conducted during summer of 2006, results distributed.
II.2.f. Promote continuing education programs available online, many of which are free, to current registered nurses toward enhanced expertise in genomics.	Developed web-based training program "Newborn Screening in CT" for Pediatricians, Family Practitioners, Advanced practice Nurses and Physician Assistants. CME credits, nursing contact hours provided. Genetic information for nurses posted on DPH webpage.

II.2.g. Assure availability of a competent genetics workforce particularly genetic counselors and medical geneticists. II.2.h. Survey of the CGCs in state is needed to ascertain the number of and optimal ratio of CGCs to general population.	CGC's identified as a priority by Educ. Workgroup, initial inquiries conducted to the National Society of Genetic Counselors for data results in a response that there are no published target ratios.
II.2.i. Partner with health departments in other states to develop educational materials that could be shared regionally.	Regional genetics effort underway with NE Public Health Genetics Education Collaborative – which has resulted in: a regional resource directory; NBS brochure translated in over ten priority languages; a new "Understanding Genetics: A NE Guide for Patients & Health Professionals"'.
II.2..j. Review licensing requirements of health professionals, both generalists and specialists, to consider incorporating genetic competencies. **NEW Recommendation** **Continue to bridge public health with emerging clinical genetics and health care and genetics and genomics research**	Nursing requirements under review. A review of the genetics requirements for physicians re licensure via CMEs needs to be conducted. A review of the potential application of genomics for optometric practitioners is recommended.
Goal II-3 **Develop and implement a regional strategic plan that addresses educational needs.**	
Short-Term Objective	**Status**
II.3.a. Identify needed partners, and educational areas of common need.	A survey will be distributed in 2007 to Residency Directors in Pediatrics, Obstetrics, Family Practice and Internal Medicine in New England to assess exposure to genetics in their programs and the core competencies imparted.
NEW Recommendation **DPH review and consider the results of the survey efforts that may yield useful information for future planning efforts and in identifying barriers to access.**	DPH ELSI workgroup reviewed and provided input into a survey being conducted by Dr. A. Chapman/UCHC to be sent to approximately 9,000 physicians in CT. An additional survey of laboratory directors is being developed to assess the impact of insurance issues and patents on access to genetic testing and genetic services.

Long-Term Objective	Status
II.3.b. Develop regional response to areas of shared genetic education needs.	Regional genetics effort underway with NE Public Health Genetics Education Collaborative Completed "Understanding Genetics Guide for Patients & Health Professionals" in collaboration with the Genetic Alliance and the NE Public Health Genetic Education Collaborative
NEW Recommendation **Continue to detect, assess and address barriers that may prevent individuals with limited genetics literacy from accessing, comprehending, and taking advantage of genetics related health information and services.**	Dissemination and utilization feedback strategies needed.

Priority III - Services

Assure equal access to and appropriate use of genomic services across the lifespan.

Goal III.1

Assure high-quality, culturally competent genetic services, and help provide linkages for those needing services.

Long-Term Objectives	Status
III.1.a Continue to assess the need for specific genomic services (public and private), identify ways to assess testing and other genetic services provided in state, and evaluate such services on an ongoing basis to identify and eliminate gaps.	Holding joint ELSI and Science workgroup meetings to look at barriers to access.
III.1.b. Develop a strategic plan for ensuring high quality genetic services across the lifespan. *Pending: The Services Workgroup will draft and submit a letter to EGAP Workgroups for comment. A final letter will be submitted to the EGAP requesting consideration and endorsement of the National Human Genome Research Institute and the National Institutes of Health Task Force framework for ensuring that new genetic tests meet criteria for safety and effectiveness before they are implemented.*	Services workgroup recommends that genetic tests not be implemented unless national recommendations of criteria for testing are approved for each genetic test. Services Workgroup reviewed National Genetic Testing Report "Promoting Safe and Effective Genetic Testing in the United States" and endorse the recommendations made by the Task Force to ensure safe and effective genetic testing. This criteria assures that all necessary components are in place prior to testing (testing, tracking and treatment services).

Goal III.2

Assure access to genetic services across the lifespan and across a broad range of conditions including infectious and chronic diseases.

Short-Term Objectives	Status
III.2.a. Assure access to genetic information that is culturally competent and effective in improving health.	CT Newborn Screening met with ELSI and Science Workgroups re: barriers to genetic testing and services and to identify barriers. Will conduct reviews of current Treatment Center Services. Newborn Screening brochures developed in ten+ high-priority languages, posted on the NERGG Website.
III.2.b. Assure awareness and promote utilization of the Family Health History Tool that would help identify risk factors.	VOG includes chronic disease participation in a efforts focused on preventative via promoting the importance of family health history and prevention of chronic diseases
NEW Recommendations	
Define the process for sharing information about availability/access to culturally competent genetic services.	
Expand existing partnerships with regional, community-based organizations and providers to develop and disseminate culturally competent genetic information.	DPH will establish and maintain a list of partnerships of community-based organization and providers for information exchange.

Long-Term Objectives	Status
III.2.c. Assure that all persons with genetic conditions have adequate public/private insurance to pay for needed services.	DPH continues to provide fiscal support for Regional Treatment Centers through contractual agreements. The ELSI & Science workgroups continue to meet with CT Regional Treatment Centers to assess and identify gaps and barriers to confirmation testing and follow up care and services for newborns identified with genetic disorders.
III.2.d. Assure seamless transition throughout the lifespan for children with genetic conditions to appropriate adult services.	DPH will continue to address transitional services to adult primary care and specialty services

NEW Recommendation	
Assure necessary services are provided for genetic testing, treatment and follow-up services. Continue to identify or create opportunities for networking with providers, affected families, advocates and other stakeholders to ensure quality of and access to needed genetic services	DPH appropriated funding for the development of centers for excellence for sickle cell care. Established stakeholders workgroup to discuss barriers to care and services and to assure quality care and services to young adults transitioning from pediatric to adult primary care and sickle cell specialty services. Development and education on the standards of care for individuals with sickle cells in the hospital emergency departments will be explored. DPH & community advocacy groups met with hospital ED Directors to discuss and improve management of patients with sickle cell disease.
Assess transition services from pediatric to adult primary care and specialty care services.	DPH participated with parent community organizations and collaborative grants to address the gaps and barriers to transition individuals with sickle cell from pediatric to adult primary care and specialty care services.
Goal III.3 **Ensure that an adequate capacity is in place to support the DPH newborn screening program and to address future needed capacity.**	
Short-Term Objectives	**Status**
III.3.a. For the optimal provision of services, continue the implementation of the integration of all child health data.	DPH will continue to enhance the NSS, NBS, EDHI, and Birth Defects Tracking Systems to include necessary field to meet emerging needs. Birthing facilities demographic and screening data is shared with DPH Hearing & Birth Defects Programs via the electronic reporting system (NSS). The Genetic Newborn Screening Program's Child Health Profile and genetic significant results are populated and maintained in the NBS Tracking System (NBTS) and Early Hearing Detection & Intervention (EDHI) Tracking System through confirmatory results. Statistical data and reports are provided for state, regional, and national requirements/QA reviews.
III.3.b. Expand newborn screening resources to support comprehensive testing,	The DPH budget for Genetic NBS Laboratory Services was increased to address Laboratory Newborn Screening needs.

tracking, and treatment options.	DPH will continue to assess the fees for newborn screening to cover all components of Testing, Tracking & Treatment.
Long-Term Objective III.3.c. Assure that all children with genetic conditions receive coordinated, ongoing, comprehensive care within a medical home.	**Status** Currently, families consider their PCP's and Treatment Center Specialists as their medical homes. The two providers coordinate care and services and provide ongoing counseling, education, and multi-disciplinary services. DPH continues to develop partnerships with community organizations to address the transition of young adults from pediatric to adult primary care and specialty services. CT continues to partner with New England Regional Genetics Group and New England Public Health Genetic Education Collaborative on HRSA-funded activities resulting in educational products such as the translation of Newborn Screening Brochures in 15 languages, NE Genetic Resource Directory, Understanding Genetics Guide.
Goal III.4 **Expand DPH laboratory capacity to support comprehensive testing, tracking and treatment options for genetic conditions.**	
	Status The Genetic NBS Tracking staff was relocated to the State Public Health Laboratory in July, 07 to streamline and enhance communication of results and collaborative efforts. The Tracking Unit will be included in the construction plans for the new State Laboratory. DPH continues to review disorders for potential expansion of the screening panel. In 2006 and 2007, legislation was proposed to add Cystic Fibrosis to the screening panel. DPH will continue to monitor current disorders on the testing panel and explore other opportunities for expansion.

Priority IV - Information Systems Development & Integration

Develop a system of linked health databases that enables the monitoring of health status, and that could be enhanced with genetic information.

Goal IV.1

Develop a child health informatics profile (HIP-Kids) of child health databases within DPH.

Short-Term Objectives	Status
IV.1.a Identify genetics information currently available within the HIP-Kids data system.	Information in the DPH Birth Defects Registry will be a core component of the information to be included in the HIP-Kids data warehouse. In light of the importance of genetics for a number of birth defects, DPH has undertaken a collaborative project with UCONN to consider ways to improve the completeness and accuracy of information reported to the registry.

Goal IV.2

Expand the HIP-Kids initiative to link with databases external to DPH and to incorporate health information across the lifespan.

Short-Term Objectives	Status
IV.2.a. Develop a strategy to expand the HIP-Kids Project.	With support from the Environmental Public Health Tracking grant, DPH is working to build a data warehouse that would enhance access to child health information (HIP-KIDS). The first phase of this requires updating the IT infrastructure supporting the core component databases. When implemented, ELSI will review privacy issues.

Goal IV.3 **Seek ways to collect new genetic information from existing data sources for inclusion into HIP-Kids.**	
Short-Term Objective	**Status**
IV.3.a. Incorporate genetics awareness questions into BRFSS.	BRFSS 2004 included "How likely do you think family history helps cause health conditions?" Results presented at 2006 APHA annual meeting. BRFSS 2006 included "Do you have a blood relative who has been diagnosed with heart disease?" and "Has a health care provider collected family history from you?" BRFSS 2008 to assess the general public's awareness of breast cancer and genetic testing.
Long-Term Objectives	**Status**
IV.3.b. Analyze SLAITS data specific to Connecticut to assess needs of children with genetic conditions.	Various survey modules related to Asthma, Early Childhood Health, Adult Transition and Health, and Children with Special Health Care Needs were developed as part of State and Local Area Integrated Telephone Survey (SLAITS), a survey-type data collection mechanism developed by NCHS.
IV.3.c. Identify new ways to use existing infectious disease, chronic disease, and environmental health data systems to help quantify the genetic basis of disease and to identify populations at risk of developing a genetic-related condition.	The 2005-2006 National Survey of CSHCN has been conducted, but the data are not available to date. Recommended that DPH develop a progress report for CSHCN comparing results from 2000-2002 to 2005-2006.
IV.3.d. Recommend revisions of the Connecticut birth and fetal death records to include relevant genetic information. The Vital Records form revision process is planned for 2008, which represents a unique opportunity to enhance the content of these forms.	The 2007 Birth Defects in CT Surveillance Report was produced in 2007 based on 2001-2004 data from hospital reporting, hospital discharge data, and vital records. The EGAP Science Workgroup will develop recommendation in early 2008.

Priority V - Improved Health Outcomes

Monitor health status to identify health problems linked to genomics.

Goal V.1

Use health data linked across divisions to identify genetic risk factors that can be incorporated into existing public health programs and that indicate needed development of new programs across the lifespan.

Short-Term Objectives	Status
V.1.a. Assess the annual occurrence of newborn metabolic disorders and hemoglobinopathies, hearing disorders, and birth defects.	DPH website has statistics on cumulative newborn screening disorders 1964-2005, newborn hearing disorders for 2006. Updated annually.
V.1.b. Analyze incidence, mortality, and morbidity data to support existing genetics-related programmatic activities aimed at early intervention, reduction of disease burden, and primary prevention of disease throughout the lifespan.	The EGAP Science work group is collaborating with Birth Defects researchers at DPH and UCHC to identify opportunities to improve the DPH Birth Defects surveillance system. Analyzed statewide incidence of preterm births, which has a strong genetic component, and which is proposed as a public health indicator in the Infant and Toddler workgroup of the Early Childhood Cabinet.

Long-Term Objectives	Status
V.1.c. Monitor ongoing demographic trends such as: the aging population and its impact on chronic disease prevalence; growing racial and ethnic diversity; and the impact of delayed childbearing.	Completed 2006 Population Estimates for Connecticut Counties and Towns, 2000 Census Population by Town by Sex by Age Cohort, 2000 Census Population by Town by Race.
V.1.d. Encourage the use of genetic information in epidemiological analyses to associate genetics with disease and to support the development of novel genetics-related programs that reach across DPH divisions.	
V.1.e. Analyze incidence, mortality, and morbidity data to identify environmental factors that may interact with genes to cause disease.	Completed DPH reports on Tobacco Usage Behaviors and Attitudes, Oct 2005 and Youth Behavioral components of the School Health Survey, 2007.

Goal V.2 **Develop new strategies for linking genetics with adverse health outcomes within the state.**	
Long-Term Objectives	**Status**
V.2.a. Assess the use of family history and other genetics programs in public health.	Development of a Family Health History promotion module underway during 2007. Funding required for outreach, delivery and expansion into additional mediums partially provided via collaborative effort with cardiovascular program grant.
V.2.b. Develop a program that links adverse health outcomes with genetics that can be used to advise on the design of a needed response or intervention	An issue brief on population-based biobanks and genetics research was prepared by VOG members in 2007, and is based on a more detailed paper [Swede et. al. Genetics in Medicine, 9 (3), 2007] posted on the VOG website.
V.2.c. Assure the effectiveness of programs targeted at the prevention and reduction of disease burden of genetics-related diseases, particularly among racial and ethnic minorities.	Legislative proposal developed, entitled An Act Concerning the Establishment of a Statewide Population-based Biobank, for a formalized feasibility study of a biobank to study preterm births and birth defects, for consideration in 2008 Legislature.
V.2.d. Assure identification of genetic risk factors to increase opportunities for early intervention, treatment and primary prevention throughout the lifespan; and assure access to genetic services across the lifespan and across a broad range of conditions including infectious and chronic diseases.	Encouraging local and statewide FIMS (Fetal Infant Mortality) programs to advocate for use of family history of preterm births to assess high-risk status of pregnancies.
Goal V.3 **Review and monitor the scientific merit and adverse health outcomes of genetic tests across the lifespan.**	
Long-Term Objectives	**Status**
V.3.a Establish models for evaluating adult genetic tests.	ELSI workgroup providing ongoing monitoring of federal legislation regarding scientific merit of genetic tests.
V.3.b. Review promising genetics tests to support related legislative considerations.	Issue Brief “Universal Newborn Screening for Cystic Fibrosis in CT” posted on DPH website.
V.3.c. Establish a model for ensuring informed consent for genetics tests.	ELSI Workgroup has reviewed legal issues regarding direct to consumer genetic testing, will continue to monitor.

Goal V.4 **Ensure scientific accuracy of genetics materials.**	
Short-Term Objectives V.4.a. Assess research findings for appropriate use in public health. V.4.b. Ensure availability of updated genetics materials. **New Recommendation** **Continue to review and seek opportunities to link genetics with adverse health outcomes within the state, and to ensure the scientific accuracy of materials produced and promoted by CT DPH.**	**Status** VOG and EGAP members raise issues, share research findings and provide feedback to the degree possible given time constraints and voluntary status. Updates presented on DPH VOG website section "What's New", materials updated and links maintained.
Long-term Objective V.4.c. Become a resource for balanced information that tempers commercial marketing. V.4.d. Become a resource for information about the public health implications of personalized medicine. **New Recommendation** DPH continue to monitor the effects of DTC marketing of genetic tests.	**Status** ELSI reviewed issues regarding "recreational" genetic testing. Posted Federal Trade Commission Consumer Alert on home genetic tests to VOG website. Developed and posted new breast cancer and genetic testing materials in response to a New England direct to consumer marketing campaign. Documents include: an overview on breast and ovarian cancer; a Q & A document on genetic testing (including links to additional resources), a list of cancer genetics counselors in New England; and a document outlining the burden of disease in Connecticut. A press release and other communication from DPH announced the availability of the new on line resources for the public and health professionals.