GENOMICS & CHRONIC DISEASE SUMMIT

A Report from the Association of State and Territorial Chronic Disease Directors

CHRONIC DISEASE DIRECTORS

March 2002

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Background

The Human Genome Project and other recent genetics advances present unique opportunities for public health. We now know that certain identifiable gene mutations increase risk for cancer, cardiovascular disease, diabetes and other chronic diseases. The challenge facing state health departments is to find optimal ways of integrating these genetic discoveries into broad disease prevention and management strategies.

The Association of State and Territorial Chronic Disease Program Directors (CDD) has been a leader in this arena. In September 2000, the CDD hosted a retreat for its members to recommend actions for both state and federal agencies. One of the recommendations called for "*CDD and CDC, in collaboration with others, [to] develop and disseminate a white paper regarding the importance of genetics in public health and chronic disease.*" Thus, the Association's Genetics Planning Group (see Appendix A), in collaboration with CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and Office of Genetics and Disease Prevention in the National Center for Environmental Health (OGDP/NCEH), convened the Genomics and Chronic Disease Summit at the Sheraton Atlanta Hotel, Atlanta, Georgia on January 31 - February 1, 2002.

This report summarizes the Summit proceedings and recommendations.

Summit Purpose and Agenda

The Summit's primary purpose was to engage genetics and public health experts in an exchange of information about the state of genomic science in relation to five chronic diseases – asthma, cancer, cardiovascular disease, diabetes, obesity – and the implications for public health over the next 3-5 years. **Jean Chabut, BSN, MPH, President, CDD**, served as Summit moderator. Participants included invited representatives of the CDD, NCCDPHP, NCEH, Council of State and Territorial Epidemiologists, Association of Public Health Laboratories, Coalition of State Genetics Coordinators, and the newly established Centers for Genomics and Public Health.

During the first morning, selected genetics experts delivered brief presentations on the science of genomics in general and compelling recent developments for each of the five specific chronic diseases. The information shared in these presentations was supplemented by written background material provided in participants' packets:

- Framework for Public Health Genetics Policies and Practices in State and Local Public Health Agencies (ASTHO)
- Brochures on Genomic Competencies for Public Health Professionals (CDC)
- Integrating Genetics Into State Chronic Disease Programs, Recommendations for Action FY 2000-2001 (CDD)
- Concept Papers on potential opportunities for integrating genomics into public health (CDC).

Following the presentations, participants divided into smaller breakout sessions for the afternoon, with each small group focused on one chronic disease. They were assigned to groups based on their area of expertise and a conscious attempt to ensure equal representation from CDC, state chronic disease programs, genetics experts, state epidemiology experts, state laboratory experts,

and directors of the newly funded Centers for Genomics and Public Health (see Appendix B for a complete participant roster). Groups were asked to focus on six questions:

Think genomically– act locally.

1. What genomic developments may or should influence national and states program delivery in the next 3-5 years?
2. What areas should or may be influenced – epidemiology/surveillance, family history, gene/environment, genetic testing, and public/professional literacy?
3. What actions are recommended for further group discussion, and in which core public health areas (e.g., assessment, policy development or assurance) do the actions fit?
4. What opportunities are there for integrating genomics into ongoing chronic disease programs?
5. What barriers are there for integrating genomics into ongoing chronic disease programs?
6. What kind of capacity or resources will be needed to accomplish this integration?

Each group had an assigned leader and recorder to help assure focus and document the discussion. The leaders then presented a summary of their groups' recommendations on the second morning of the Summit. The closing session was a general discussion of common themes and issues, facilitated by Ms. Chabut. (A detailed agenda can be found in Appendix C.)

This white paper summarizes Summit presentations and resulting recommendations, setting the stage for further planning towards the integration of genomics into public health programs and policies.

Presentations

Current Issues Confronting Chronic Disease Programs Related to Genomics

Jim Marks, MD, MPH, Director, National Center for Chronic Disease Prevention and Health Promotion, CDC, delivered the keynote address. Acknowledging the rapid expansion of genetic knowledge and public awareness in the past decade, Dr. Marks used a recent article on genetic testing for breast cancer in *USA Today* to highlight several critical issues for public health. These issues included: personal reactions to test results, the value of test results for family members, the high price of the test and the potential for exacerbating disparities in health care between rich and poor, fear of discrimination, physicians' ability to interpret and use test results for patient care, the impact of test results on family relationships, and the effect of test results on individual health behaviors.

Dr. Marks charged the Summit participants to "get practical," and to help public health take advantage of this tremendously exciting opportunity. He concluded by framing the public health role in genetics within the context of societal responsibility and four guiding principles of public health:

- Prevention as the primary focus.
- Reliance on a strong science base.
- Responsibility for serving the underserved.
- Need for interdependence among multiple sectors.

Genomics 101

Maren Scheuner, MD, MPH, GenRISK Program, Cedars-Sinai Medical Center, began by distinguishing genetics (the study of genetic variation) from genomics (the study of the entire genome). She reviewed basic information about genetics, provided a common understanding of genomics, and explored such topics as DNA and the double helix as the "code of life," variation in

the DNA sequence, deleterious mutations, cell reproduction, inherited genetic disease, and different transmission patterns. Dr. Scheuner stressed that the most common chronic diseases have a multifactorial etiology, and noted that chronic disease is typically due to an interaction of genetic and environmental factors.

Dr. Scheuner cautioned against using genetic tests on a population basis until more data are available, but noted their utility for selected patients and families. She stressed the value of family histories in identifying individuals most likely to be at high genetic risk. She explained pedigrees – what they are, how to interpret them, and how best to use them to identify patterns of disease susceptibility and risks associated with family history of specific conditions. The ultimate benefit of family history collection and interpretation (pedigree analysis) is to allow individualized prevention strategies, more frequent and comprehensive screening, chemoprevention, targeted lifestyle changes, and improved patient compliance.

Diabetes Mellitus

Toni Pollin, MS, Division of Endocrinology, Diabetes & Nutrition, University of Maryland School of Medicine, reviewed the genetics of diabetes and the role of family history in predicting risk. She characterized diabetes as a group of metabolic diseases defined by high blood sugar (or hyperglycemia). It is caused by defects in insulin secretion and/or response to insulin, and its primary consequences are damage to organs, especially eyes, kidneys, nerves, heart and blood vessels. Diabetes currently affects 5-8% of the U.S. population and its prevalence is rising. Influenced by both genes and environmental factors, Type 2 diabetes is a complex disease, is more common in the general population, and also has a higher rate of familial aggregation. Ms. Pollin enumerated diabetes screening criteria and noted other genetic conditions and syndromes with diabetes as a feature: genetic diseases affecting the exocrine pancreas (cystic fibrosis, hemochromatosis), Wolfram syndrome, and other genetic syndromes sometimes associated with diabetes (Down syndrome, Klinefelter syndrome, Turner syndrome, Prader-Willi syndrome, etc.)

Obesity

Molly Bray, PhD, Human Genetics Center, University of Texas Health Sciences Center, defined obesity as the state of being extremely fat, corpulent, and overweight. The disease may affect the whole body or any of its parts, and its etiology, pathology and prognosis may be known or unknown. Factors commonly known to contribute to obesity include a lack of physical activity, abundance of food, bacterial and viral insults, and changes in environment (e.g., increasing temperatures causing one to stay indoors). Family studies have provided evidence that gene mutations are important risk factors. The growing prevalence of obesity makes it a serious public health issue; 61% of Americans are either overweight or obese, with a disproportionate burden on women and children.

Dr. Bray noted that nearly everyone is at risk of obesity. She reviewed several recent genetic studies of mice and their implications for intervention. Of note is growing evidence of the multiplicity of genes involved in obesity. Answering the question of how genes interact with the environment to cause obesity requires a sufficiently large sample size. This question is being examined in several studies, including an ongoing study funded by CDC's Office of Genetics and Disease Prevention.

Cancer

Katherine Schneider, MPH, Dana-Farber Cancer Institute, spoke on cancer genetics. Hereditary Cancer Syndromes account for about 5-10% of total cancer cases. Ms. Schneider noted the major risk factors for two common forms of cancer: colon and breast cancer. She explored such issues as when clinicians should make a genetic counseling referral, how to find a genetic counselor, what a genetic counselor does, what a pedigree features, and what emotional

impact knowledge of cancer risk can have on an individual and his/her family. Important functions of a genetic counselor are to review personal medical history, assess family history of cancer, provide risk assessments, present surveillance and prevention options, and discuss genetic testing options. A variety of techniques are currently available which may reduce the risk of breast, ovarian and colorectal cancer in genetically predisposed individuals. Ms. Schneider suggested that a genetic test should be offered when: the patient has a reasonable likelihood of having a gene mutation; the genetic test is feasible and reliable; the result will influence medical decisions; and the patient wants the information for him- or herself or for family members. Genetic testing programs, typically staffed by multidisciplinary teams, involve multiple visits for pre-test counseling, results disclosure and follow-up. Individuals typically express a variety of reasons for wanting (or not wanting) to be tested, and have a similarly wide array of reactions to both positive and negative test results.

Ms. Schneider concluded that because cancer is such a widespread disease, the implications for public health are significant. Better education of the public is needed to allay fears and misinformation. Barriers to genetic counseling, including concerns about cost and privacy, need to be overcome; and greater support for genetics research is essential to develop more effective treatment and prevention methods.

Asthma

Lanny Rosenwasser, MD, Allergy and Immunology, National Jewish Medical and Research Center, defined asthma as the narrowing of airways, airway obstruction and inflammation, and increased airway responsiveness. Asthma is not a purely physiologic disease, but a disease of the autoimmune system. The variety of risk factors includes: genetics, bronchial hyperresponsiveness, skin test reactivity, allergen exposures (indoor air quality), geographic location (air pollution, pollen, molds), and demographic factors (air, gender, race/ethnic group, and socioeconomic status). Since the 1960's, the prevalence has been steadily increasing; about 15 million Americans have diagnosed asthma and 5,500 individuals die from asthma each year.

Dr. Rosenwasser reviewed factors contributing to asthma severity, the pathology of asthma, and other genetic aspects of this complex disease. Family studies can only ascribe relative risk; thus, genomics research is needed to further study the impact. While primary prevention is not yet possible, genetics can be used for improved secondary prevention and targeted treatment. Genetic factors impact the efficacy, cost-benefit and safety of such strategies.

Carol Greene, MD, Office of Science Policy, Office of the Assistant Secretary for Planning and Evaluation, focused on the prevention of asthma. For primary prevention, genes that predispose to or cause asthma are being identified including:

- Genes that influence or mediate response to environmental toxins;
- Genes that contribute to control of respiratory physiology; and
- Genes involved in allergic and immunologic responses.

This knowledge may lead to strategies to prevent the development of asthma in at-risk individuals and populations. For secondary prevention and targeted treatment, Dr. Greene noted that genes play a significant role in response to environmental triggers and to medications used to treat asthma. Thus, genetic factors impact the efficacy, cost-benefit and safety of strategies to prevent and treat asthma attacks. Public health strategies, including treatment guidelines and protocols, should be based on all available information that bears on efficacy, cost effectiveness and safety.

Cardiovascular Disease

Maren Scheuner, MD, MPH, Cedars-Sinai Medical Center, limited her presentation to coronary artery disease (CAD), since it accounts for most of the morbidity and mortality due to cardiovascular disease. She reviewed the risk factors and the clinical process that results in CAD. She indicated that 20% of the time, sudden death may be an individual's first symptom. CAD is a complex metabolic disorder influenced by multiple factors, including: lipids, insulin sensitivity, thrombosis, fibrinolysis, platelet function, homocysteine, inflammatory response, blood pressure, endothelial function, and others. Dr. Scheuner reviewed the evidence for genetic contribution to CAD from animal model, familial aggregation, twin, gene association, and linkage studies. She described a range of prevention strategies for genetically susceptible high-risk individuals – early detection of subclinical CAD, modification of all risk factors, avoidance of aggravating factors – and assessed each strategy and its relative value. In conclusion, Dr. Scheuner cited four potential public health roles:

- Educate consumers and health care professionals about genetic aspects of CAD.
- Create a family history tool for identifying genetically susceptible individuals.
- Facilitate referrals for evaluation of genetically susceptible individuals.
- Study the efficacy, utility and cost-effectiveness of risk stratification and prevention strategies for individuals with genetic susceptibility.

Overview of CDC's Office of Genetics and Disease Prevention

Marta Gwinn, MD, MPH, Office of Genetics and Disease Prevention, provided an overview of current and future activities of the Office of Genetics and Disease Prevention (OGDP). The mission of the Office is to integrate advances in human genetics into public health research, policy and programs. To accomplish this mission, the Office's four goals are to:

- Promote leadership in genetic policy development
- Develop science for public health action
- Communicate and distribute information
- Train and educate the public health workforce.

Dr. Gwinn noted the funding of three new university-based Centers of Genomics and Public Health as one of the Office's newest ventures. Established through a Cooperative Agreement with the Association of Schools of Public Health, the Centers are housed at the University of Michigan, University of North Carolina, and the University of Washington. They are charged with three major functions to help translate advances in genomics into public health:

- Improve the knowledge base by assembling "working groups" to assess key questions, synthesize information, and identify critical research gaps.
- Provide training by evaluating existing needs assessments, identifying and developing targeted training materials, making strategic use of training channels, and considering training needs of various groups of practitioners.
- Offer technical assistance by identifying opportunities and supplying appropriate expertise.

Dr. Gwinn felt that the schools are ideally suited to these tasks since all three are leaders in epidemiologic research, innovators in academic and workforce training, and public institutions with close ties to local, state, and regional public health communities. While each adopted a specific disease focus (cardiovascular disease in Michigan, cancer in North Carolina, and diabetes and asthma in Washington), the Centers plan to matrix and coordinate their efforts wherever possible. CDC's ultimate vision is to create a broad network of such centers and generate a synergy that brings relevant sectors together to improve the nation's health.

Group Recommendations

Six questions were posed to the five disease-specific groups:

1. What genomic developments may or should influence national and state program delivery in the next 3-5 years?
2. What areas should or may be influenced – epidemiology/surveillance, family history, gene/environment, genetic testing, and public/professional literacy?
3. What actions are recommended for further group discussion, and in which core public health areas (e.g., assessment, policy development or assurance) do the actions fit?
4. What opportunities are there for integrating genomics into ongoing chronic disease programs?
5. What barriers are there for integrating genomics into ongoing chronic disease programs?
6. What kind of capacity or resources will be needed to accomplish this integration?

The groups' responses to Questions 1, 5, and 6 were highly compatible – and in many cases duplicative. Thus, they are presented as one overall set of recommendations. The responses to the remaining questions are itemized by the respective chronic diseases. They are listed in no particular order of priority.

Question 1:
What genomic developments may or should influence national and state program delivery in the next 3-5 years?

Summit participants predicted the following developments in genomics research.

- Population-specific mutations will be identified, allowing more precise screening for groups who possess these mutations.
- With new technologies, we will be able to identify high-risk individuals before they develop clinical disease – as well as those with borderline risk factors who are at high risk and need immediate intervention.
- Family history assessments will grow in popularity and use, as will the need for a reliable, standardized screening tool.
- A systematic evidence-based review of genetic testing will be conducted to identify what is known and can be translated into action, what gaps in knowledge remain, and what research is needed.
- There will be more scientific information regarding gene-environment interaction.
- Criteria for assessing the effectiveness and value of genetic tests will become more controversial.
- We will learn more about the genetic interactions and variations that can impact outcomes (i.e., for treatment, prevention and markers of disease).
- New techniques and tools for geno/phenotyping will help us better describe the prevalence of chronic disease (especially asthma) in the population.

These research advances may in turn lead to related social development in the next few years.

- New legal issues around genetic testing will surface and the need for consistent legal protections across states will increase.
- Genetic information will increasingly be used for therapeutic decisions, and the pressure will mount to keep drugs in circulation that are effective only for certain specific groups.
- Commercial laboratories and pharmaceutical manufacturers will aggressively market new genetic tests directly to consumers.
- The public will be increasingly reluctant to share personal information and data.

- Public health educational messages will address the issue of susceptibility to chronic disease.
- State policymakers will question whether they can justify paying for genetic screening without also supporting sufficient treatment budgets.
- Knowledge of genetics will influence/pressure insurance and managed care companies to cover new types of services such as lifestyle interventions, weight loss strategies for obesity, etc.

Question 2:
What areas should or may be influenced – epidemiology/ surveillance, family history, gene/environment, genetic testing, and public/professional literacy?

Each group's thoughts about areas that can and should be influenced are presented separately by disease. Some are itemized in specific categories; others are shared in a general listing.

Asthma

- ***Epi/surveillance***
  - More complete case definition
  - Better identification of high risk populations
  - Deeper understanding of the genetic links in common with other diseases
- ***Family History***
  - Validation of family histories, with more specifics, as a surrogate for genetic testing
  - Value of family histories in asthma as a prevention, rather than treatment, tool
- ***Gene/environment***
  - Gene-environmental interactions that can modify risk and therefore affect exposure practices
  - Educational implications of gene-environmental research
  - Genotype prevalence data using existing blood spot samples
  - Genotype/phenotype correlation and relationship to other conditions
  - Stronger science base to guide development of testing/treatment
- ***Genetic Testing***
  - Genetic testing for targeted therapies/stratified therapies
  - Stronger basic science/technology to find markers, etc. to guide development of tests
  - More funding of and greater access to tests (related to the ethical, legal and social implications of disparities)
  - Genetic testing for occupational exposures and job selection
  - Design of the "perfect test"
- ***Public/professional Literacy***
  - Demystification of genetics
  - Significance of genetic variations
  - Improved specificity of patient education
  - Commercial role in education through pharmaceuticals and genetic testing a la Myriad
- ***Public Health Home and Role***
  - Funding, leadership and infrastructure
  - Development of updated guidelines that include genetics
  - Access to screening/treatment for underserved populations
  - Convening of relevant partners

Cancer

- More complete family history information incorporated into program intake forms
- Consideration of pilot projects in Healthy Women Partnerships
- Modified Cancer Registry data collection forms
- Clinical guidelines on cancer genetics

- Outcomes research on prevention and early detection strategies to document reduction of morbidity and mortality in high risk populations (i.e., justify costs of genetic testing)
- Consideration of non-traditional outcomes important to patients and families
- Knowledge base on the prevalence and disease risk associated with specific gene mutations
- Public health provider education based on Public Health Genomics competencies
- Incorporation of genetics concepts into educational materials for public and professionals
- Standards of care for specific types of cancer that incorporate cancer risk assessment and gene testing where appropriate

Cardiovascular Disease

- ***Epi/surveillance***
  - To determine which populations are at particular risk
  - To determine prevalence of genetic variants, gene penetrance, and gene-environment interactions
  - Usefulness of CVD registries
  - Self-reporting on family history through the BRFSS
  - Public reactions to genetics, testing and receiving genetic information
  - Information on who is being tested
- ***Family history – as a surrogate for genetic information***
- ***Public/professional literacy – to deliver the "right" messages***
- ***Genetic testing***
  - Validation
  - Assurance
- ***Ethical, social, legal issues***
  - For research
  - For clinical practice

Diabetes

- ***Legislation***
  - Changes to facilitate genetic testing, data collection, surveillance and intervention
- ***Family History***
  - Significance for predictive value and targeting interventions
  - Unintended consequences: obligation to share information with other family members
  - Assurance of confidentiality
- ***Genetic Testing***
  - Distinguishing genetic testing from screening
  - Using screening appropriately in investigations and research
  - Role of public health in screening specific populations
- ***Public/professional Literacy***
  - Influencing system changes among other health professionals (family practice, nurses, diabetes educators, etc.)
  - Documentation of family history in medical charts and registries
  - Evidence-based public education to counter marketing information from commercial labs, local newspapers, etc.
  - Debunking policy makers' misconceptions about genetics and testing

Obesity

- ***Epi/surveillance***
  - Quality of estimates of BMI by relatives
  - Validity of assessments of apple or pear shapes and fat distributions in relatives
- ***Family History***
  - Implications of screening with family history or genetic variants on interventions

- ***Gene/environment***
  - Gene-environment interaction
- ***Genetic Testing***
  - Impact of family based screening and targeted interventions on outcome
- ***Public/professional Literacy***
  - Public education that genetic susceptibility is not health destiny

Question 3:
What actions are recommended for further group discussion, and in which core public health areas (e.g., assessment, policy development or assurance) do the actions fit?

Asthma

- ***Assessment***
  - Surveillance – case definition
  - Family history – usefulness
  - The perfect test
- ***Policy Development***
  - Partnerships – academic/public health/pharmacology/genetic counselors
  - Funding, access and other ethical, legal and social issues
  - Public health "home"
  - Preparation for what is to come
- ***Assurance***
  - Demystification of genomics/asthma: education
  - Screening/treatment guidelines
  - Financing
  - Skilled public health workforce

Cancer

- ***Assessment***
  - Opportunities for collecting genetic information from existing programs
  - Evidence-based report from credible source on current state of genomics science in relation to chronic disease (e.g., Preventive Health Services Task Force)
  - Collection of electronic data on cancer genetics from hospitals, clinics, gene testing laboratories, and other providers of cancer diagnostic and treatment services for cancer registries or other public health programs
  - Information on prevalence among newborns of BRCA1 and BRCA2
  - Enhancements of cancer registries to incorporate genetics/family history
  - Standard data sets for family histories
  - Use of genetic information to target prevention among high risk populations
- ***Policy Development***
  - Identifying who's in charge within state health departments
  - More interaction and "talking" between genetic and chronic disease programs
  - Policies and regulations to protect privacy and avoid discrimination
  - Policies to prevent overmarketing of tests for inappropriate situations
- ***Assurance***
  - Professional standards for those providing genetic counseling, testing, services and programs
  - Public/professional education
  - Pilot projects in breast cancer and other public health programs
  - Incorporation of genetics into comprehensive cancer programs
  - Keeping abreast of knowledge and disseminating via educational material
  - Balance between waiting for definitive evidence-based science to implement population-based approaches – and proceeding cautiously with current information to assure equal access of interventions to all population groups

Cardiovascular Disease

- ***Assessment***
  - Employers' knowledge of genetics and risk
- ***Policy Development***
  - Impact of genetic information on insurance coverage
  - State variation in risk-based insurance practices and laws
- ***Assurance***
  - Educating consumers and employers on genetics and risk issues
  - Role of social marketing in conveying messages about genetics
  - Key messages to convey to public

Diabetes

- ***Assessment***
  - Standards for family histories
- ***Policy Development***
  - Third party coverage of physical activity programs for those most likely to benefit
- ***Assurance***
  - Practical education for public health staff working in diabetes control programs
  - Educational sessions in conjunction with other national partners (e.g., American Public Health Association, American Diabetes Association, CDD, Agency on Aging, ASTHO)
  - Communication response system in every state health department to explain to the public and media what new discoveries mean for public health

Obesity

- ***Assessment***
  - Accuracy of family history assessments
  - Validity of genetic tests
  - Algorithm to determine best use of genetic information
- ***Policy Development***
  - Determining how to approach testing for a disease that affects 60% of the population
- ***Assurance***
  - Effect of genetic risk factors on choice of interventions
  - Testing of family-level interventions

Question 4:
What opportunities are there for integrating genomics into ongoing chronic disease programs?

Asthma

- Use newborn blood spots for multiple purposes.
- Employ other diseases as models.
- Piggy back on other programs that collect surveillance and/or clinical data.
- Rethink existing asthma surveillance systems.
- Reassess data already collected.
- Expand partnerships to genetics, pharmacies, and genetic counselors.
- Put "generic" genomic chronic disease strategies in state plans.

Cancer

- Determine prevalence of specific mutations influencing cancer risk by genotyping newborn blood spots.
- Identify gaps in information that impede policymaking.
- Modify intake forms for Cancer Registry, Healthy Women Partnerships, etc.
- Identify relevant clinical guidelines and distribute to providers.
- Assess and work to modify public health laws relevant to genetics

- Conduct pilot projects for outreach to individuals at high-risk due to family history.
- Incorporate genetics into Comprehensive Cancer Control planning.
- Explore efficient yet effective ways to integrate collection of basic family history information in primary care settings.

Cardiovascular Disease

- Include key partners at the table.
- Build on past experience of public health labs to define their future role in assuring validity of genetic tests.
- Establish an information clearinghouse on genetic testing technology.
- Conduct an annual meeting to share developments and lessons learned.
- Rely on Centers for Genomics and Public Health for technical assistance and training.
- Use genetics to re-emphasize the need to intervene on traditional risk factors.
- Identify best practice models and program prototypes.
- Glean information from blood spots that have already been collected.

Diabetes

- Avoid relying on expensive tests to identify risks; use family histories instead.
- Develop model standards for patient education regarding family history.
- Remember that different ethnic groups view disease differently, and incorporate this into messages, programs and research.
- Debunk myths.
- Integrate genomics concepts across the chronic disease spectrum including family history tools.

Obesity

- Use family-level interventions for addressing childhood obesity.
- Influence family behavior/culture by targeting interventions to children in school.
- Focus on policy and developing recommendations for reimbursement issues.
- Urge policies to implement interventions in client populations (e.g., WIC) that foster and encourage participation in genomics and interventions research.
- Incorporate family history information into programs, and include informed consent.

Question 5:
What barriers are there for integrating genomics into ongoing chronic disease programs?

All five groups identified barriers in the areas of research and surveillance, communication and education, public health infrastructure, policy and advocacy, and health systems.

Research and Surveillance

- Lack of sufficient scientific evidence to support interventions (e.g., regarding cost-effectiveness, value added, outcomes, and effect of genetic testing information on health behaviors).
- Lack of knowledge about the prevalence of gene mutations in order to establish baselines and monitor changes/trends over time.
- Lack of widespread access to newborn screening bloodspots.
- Difficulty in meeting IRB criteria and getting approval for studies.

Communication and Education

- Public misperceptions and fears about genetics.
- Lack of clarity of messages.
- Resistance among certain population groups to participate in research studies due to perceived stigma, mistrust and lack of feedback on study outcomes.
- Perception that prevention of a genetic disease equates with eugenics.
- Inherent difficulties in explaining the complexity of genetics and chronic diseases.
- Perception among public health professionals that emphasizing genetics and family history will absolve people who are not in the target audience from adopting healthy behaviors and lifestyles.
- Reservations among stakeholders about implementing programs that seem "esoteric," without a clear understanding of what genomics is, why it is important, and what difference it can make.

Public Health Infrastructure

- General reluctance in the public health community to take advantage of and act on what is now known.
- Insufficient funding for research, program interventions, and staffing.
- Lack of vision among key leaders of the role of genetics in public health.
- No consistently identified leader or "home" for integrating genomics and public health within state health agencies.
- Lack of understanding among public health staff of the role and relationship of genomics to their jobs.
- Lack of knowledge of and competence in genomics among public health practitioners.
- Resistance among public health professionals to adding one more responsibility to an already overworked agenda.
- Lack of integration of chronic disease program elements within state health departments, resulting in programmatic silos with different cultures, approaches and languages/terminologies.

Policy and Advocacy

- Ethical issues surrounding use of genetic information.
- Potential disparities in access to and use of genetic tests and treatments.
- Lack of a sense of urgency or crisis in genomics.
- Genomics not viewed by state governments as a priority.

Health Systems

- Lack of information on the potential impact of genetic testing and treatment on reimbursement.
- Difficulties in engaging private providers in using new technologies.
- Impact of the changing nature of families over time (e.g., mixed and transient families) on the effectiveness of interventions.
- View by some scientific leaders that genetics will lead to disease cure, thus rendering lifestyle interventions less important.
- Consent issues.
- Fear of stigmatization associated with genetic susceptibility.
- Lack of models for using existing providers or integrating other providers (genetic counselors) into multidisciplinary centers.
- Potential influence of new HIPAA rules (and our current knowledge of HIPAA) on integrating genomics.

Question 6:
What kind of capacity or resources will be needed to accomplish this integration?

As in Question 5, participants' responses about needed capacity are divided into five areas.

Research and Surveillance

- Applied research at the federal level, with links to national or regional databases for small states with insufficient population size for valid studies.
- Needs assessments of community-based providers and consumers to determine knowledge, attitudes and practices related to genetics and public health.
- Chronic disease representation in the Human Genome Project so that more resources are devoted to translational research.
- Improved research coordination between NIH and CDC.
- Design of prevalence and other data systems.
- Think tank modeling.
- Research to derive:
- Cost-benefit estimates to justify resources for state health agencies, health plans, and research organizations
- Process measures to evaluate the Centers of Genomics.
- Measures to evaluate lab capacity and knowledge of state health departments' workforce.

Communication and Education

- Consistent messages used to educate the public and health providers.
- Champions to "speak to" and spread key messages.
- Case examples that are population-based rather than clinical and individualized.
- Increased use of technology (e.g., videoconferencing) for education/information sharing.

Public Health Infrastructure

- Expanded national and state funding.
- Trained workforce in state health departments, including:

  –Genetics coordinators.

  –Genetic experts who, like epidemiologists, can relate to all programs.

  –Genetic counselors to develop information and educational programs.
- Updated job descriptions to reflect roles and responsibilities in genomics.
- Expanded training in genetics and public health through CME, CEU and other continuing education programs.
- New models for applied training programs through federal agencies (e.g., a new model of EIS officer training).
- Networking to build relationships between chronic disease staff and genetics working groups, maternal and child health staff, and others who have relevant experience with genetics issues.
- Participation and collaboration in ongoing related efforts such as:

  –CDC's initiatives to encourage interaction between sectors and disciplines (like this Summit).

  –HRSA's assistance to states in developing genetic advisory groups and plans.

  –Secretary of HHS's advisory group on genetics testing.

Policy and Advocacy

- Policies dealing with discrimination issues.
- Information sheets for legislators on key issues.
- Clarification of the state health departments' roles and responsibilities, and marketing to gain acceptance and support of that role.
- CDC policies and grant announcements that support the state health departments' role in genomics.

Health Systems

- Scientists to make genetic tests more widely available.
- Multidisciplinary approaches to counseling, testing and intervention.
- Appropriate services for individuals and populations seeking counseling and testing.
- Inclusion of genetic counseling, testing and treatment in managed care and insurance packages.
- Model programs.
- Links between health departments, medical centers and universities to gain access to certain populations for gathering information, targeting interventions and demonstrating success.

Conclusions and Next Steps

Recommendations

The Summit concluded with a discussion of the small group's presentations, moderated by **Ms. Chabut.** The following major recommendations emerged for furthering the integration of genomics into public health.

1. Assess the public's knowledge, attitudes and beliefs about genetics. "We need to learn more about what the public thinks and where they are before we can serve them well."
2. Learn more about family histories – how to collect information, how valid they are, how to use them for multiple chronic diseases, how to build them into surveillance, etc.
3. Identify best practices in each chronic disease from peer review literature and package this information so that states can take advantage of it (e.g., as a Guide to Community Preventive Health Services).
4. Encourage state-level change by incorporating genomics concepts and approaches into CDC grant announcements.
5. Include genetic workups as a standard component of epi-aid investigations.
6. Define the appropriate public health role in genetics, identify the proper home for genomics within state health departments, and market that role broadly.
7. Educate chronic disease staff about genetics, with help from the Centers for Genomics and Public Health.
8. Develop and strengthen partnerships between public health and genetics; share terminology and begin to develop common languages and perspectives.

9. Expand partnerships to include private providers, business and legislators.
10. Determine the role of newborn screening and blood spots for research and program, and negotiate effective ways of sharing this resource.
11. Pursue efforts to establish better prevalence estimates of gene mutations or polymorphisms.
12. Generate concrete evidence and examples of the effectiveness of incorporating genetic information into programs. "Pay attention to outcomes and whether genetic information makes a difference in modifying behavior, reducing disease, or saving money."
13. Determine how to best piggyback behavioral interventions onto genetic counseling – and vice versa.
14. Address access and disparity issues to ensure that genetics advances are equally available to all.
15. Examine existing and emerging public health laws, statutes and regulations to assess their implications.
16. Seek expanded and flexible funding for additional Centers for Genomics and Public Health, state health program staff, research and surveillance.
17. Enhance collaboration between CDC and other federal agencies (e.g., with HRSA for coordination in planning, grant making and program design; and with the Agency for Health Care Research and Quality Assurance for the development of guidance about genetic testing).
18. Address the public perception that cancer is primarily caused by environmental factors.
19. Continue to explore the balance between genetic and environmental risk factors.
20. Involve laboratories in national and state planning efforts to define their appropriate role.

Closing Remarks

Ann Malarcher, PhD, speaking on behalf of NCCDPHP, reiterated the commitment of the Center to integrating genomics into chronic disease programs. She thanked the Genomics Planning Group, the speakers and the participants; and complimented the group on their significant accomplishments during the Summit. Dr. Malarcher asked Center staff to review the draft report and to disseminate the final version to key staff and external partners. She also anticipated a published summary of the Summit's recommendations in a widely read professional journal.

The Center plans to use the Summit recommendations to help shape guidance for future program grant announcements, support demonstration projects to foster translation of research into practice, sponsor research on family histories, conduct needs assessments at the program level, and provide educational sessions on genomics and family histories at national meetings. Dr. Malarcher encouraged each program-specific division to expand discussions with OGDP on relevant issues and to explore opportunities for using the existing chronic disease infrastructure to support genomics.

Muin Khoury, MD, MPH, Director, OGDP, closed the meeting by reinforcing the importance of public health leadership in assuring that genetics is placed appropriately within the context of population-based, community interventions for disease prevention and health promotion. Referring to Dr. Marks' opening address, he reiterated public health's unique responsibility to serve the underserved, and urged great creativity and flexibility in the days ahead. OGDP's priorities for the future include continuing support for the Centers of Genomics and Public Health, conducting applied public health research, building on existing national and state-based surveillance and data systems, packaging relevant findings in genomics and public health in an annual report and other publications, and developing state public health capacity to translate research into action.

Next Steps

Immediate priorities for ASTHO, CDC, the Centers of Genomics and Public Health, and other relevant organizations are the following:

1. Define the leadership role for public health in genomics and chronic disease, and develop policy statements as appropriate.
2. Explore the potential for the use of family histories as a public health tool.
3. Provide resources for development of technical assistance to states, and increase the flexibility of disease-specific funding to incorporate genomics into chronic disease prevention activities.
4. Design and conduct training for the public health community on genomics and chronic disease, and provide communications materials to improve knowledge and competence.
5. Develop and disseminate key guidelines and best practices models for integrating genomic science into cross-cutting and disease-specific programs.
6. Initiate targeted surveillance and research in key disease areas to fill gaps in disease prevention knowledge, beginning with bloodspots and family history.

The concepts raised in this white paper will be shared with Summit participants and a broader audience of public health practitioners and policymakers. It is the Association's hope that the ideas and recommendations contained herein will serve to stimulate a concerted, focused and evidence-based national effort for using genomics to advance chronic disease prevention.

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Appendix C: Summit Agenda

January 31, 2002

8:00 am Continental Breakfast

8:30 am **Jean Chabut** – Welcome and Introductions

8:45 am **Jim Marks** – Current Issues Confronting Chronic Disease Programs Related to Genomics

9:15 am **Maren Scheuner** – Genomics 101

9:45 am BREAK

10:00 am Introduction to Genomics - Hear from the Experts - Each expert presents compelling recent developments including use of case studies where possible. In addition, each speaker speaks on one cross-cutting issue and Q&A.

1. Diabetes .....**Toni Pollin**
2. Obesity.....**Molly Bray**
3. Cancer .....**Kathy Schneider**
4. Asthma.....**Lanny Rosenwasser and Carol Greene**
5. CVH .....**Maren Scheuner**

12:00 pm LUNCH

1:00 pm **Marta Gwinn** – Overview of current/future activities of the Office of Genetics and Disease Prevention/Discussion of 3 new Genomics Centers and their capacity to provide technical assistance to states.

Jim Marks - Genomics challenges and observations

Jean Chabut - Moderator

1:45 pm **Jean Chabut** – Wrap-up/Discussion of Afternoon Itinerary.

2:00 pm Break-Out Sessions – five groups will meet & discuss their issue - Asthma/Cancer/Cardiovascular/Diabetes /Obesity -

Format for group discussions:

1. What genomic developments may/should influence the National/States program delivery in the next 3-5 years?
2. What areas should/may be influenced - family history, epi./surveillance, gene/environment, genetic testing, and public/professional literacy?
3. What actions are recommended for further group discussion? Indicate which core public health areas the actions fit into (e.g. assessment, policy development or assurance), plus any brief rational that may be necessary.
4. What opportunities are there for integrating genomics into ongoing chronic disease programs.
5. What barriers are there for integrating genomics into ongoing chronic disease programs.
6. What kind of capacity/resources will be necessary/needed to accomplish this integration.

5:30 pm Adjourn For Dinner

February 1, 2002

8:30 am Continental Breakfast

9:00 am Group Leader Reports – Moderator – **Ann Malarcher** (15 minutes each – clarifying questions allowed at end of presentations)

10:15 am BREAK

10:45 am Group Consensus On Genomics Recommendations & Next Steps – **Jean Chabut/Ann Malarcher**

11:30 am Wrap-up and Remarks – **Muin Khoury**

12:00 pm Adjourn