From: Sarah.Patrick@state.sd.us
Sent: Sunday, September 09, 2001 3:14 PM
To: joannl@doh.state.ri.us; pquinlis@idph.state.ia.us;
tim.aldrich@palmettohealth.org; ursula_bauer@doh.state.fl.us;
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rstroube@vdh.state.va.us; rteclaw@isdh.state.in.us
Cc: sroohi@cste.org
Subject: ASTHO Genetics Toolkit Workgroup and Meeting

Dear Fellow CSTE Genetics Team Members:

It is a pleasure to serve with you and co-leader, Joann Lindenmayer, for the next few years on the CSTE Genetics Team. One task we will be working on is to assist ASTHO in the development of a genetics toolkit (http://www.astho.org/phiip/genetics.html <http://www.astho.org/phiip/genetics.html>). A small meeting with representation from each participating organization will be held this Tuesday in Washington, DC. The participating organizations will be NCSL, ASTCDPD, APHL, CDC, NACCHO, AMCHP, CSGC, CSTE, and ASTHO. The goal of the project is to provide resources on genetics and public health to health agencies, to assess genetics activities in the state and identify capacity building areas, and to articulate the need for infrastructure building resources. I will provide a full report of that meeting back to you for your thoughts and input. If you have suggestions about states for site visits (see below), I'd appreciate your feedback.

Thank you for volunteering your time to this CSTE team!

Sincerely,
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-----Original Message-----
From: Amy Klein [mailto:aklein@ASTHO.org]
Sent: Wednesday, September 05, 2001 1:52 PM
To: Tim Baker (Tim Baker); Ann Willey (Ann Willey); Cheye Calvo (Cheye Calvo); Janice Bach (Janice Bach); Jean Chabut (Jean Chabut); Jeff Goldhagen

(Jeff Goldhagen); Jeffrey Lobas (Jeffrey Lobas); Sarah Patrick (Sarah Patrick)
Subject: Profile of Selected State Genetics Program

Attached is a summary of state genetics programs to aid in the identification of states for site visits. Theses states were recommended by Sylvia Au, President, State Genetics Coordinators, as being more on the cutting edge. Our discussion regarding states for site visits will not necessarily be limited to the states in the document.

Amy

ARKANSAS

The Arkansas Department of Health administers the Newborn Screening Program, which collects and analyzes newborn screening specimens for phenylketonuria (PKU), congenital hypothyroidism, sickle cell diseases and galactosemia; reports test results; provides follow-up on abnormal test results including retesting; offers counseling for families of infants with positive trait results; and provides medical information on various genetic diseases. Arkansas also identifies the infants born in the State of Arkansas who are at high risk for hearing loss and refers them to their primary care physician for follow-up, coordinates efforts in establishing Universal Newborn Hearing Screening programs in the state's birthing hospitals, and maintains a database of both infants at high-risk and those who receive UNHS.

CALIFORNIA

To support its mission to "serve the people of California by reducing the emotional and financial burden of disability and death caused by genetic and congenital disorders" the Genetic Disease Branch of the California Department of Health administers screening programs for genetic and congenital disorders to newborns and pregnant women, which includes testing, follow-up and early diagnosis of phenylketonuria, galactosemia, primary congenital hypothyroidism, sickle cell disease and other hemoglobin disorders. The GDB also:

* develops standards and quality assurance procedures for analytical test results and programs, and monitors compliance with these standards;
* provides a combination of patient, professional and public education and accurate information and counseling to encourage participation in its programs;
* provides ongoing critical review, testing, and evaluation of existing programs to ensure that program objectives and goals are being met;
* develops programs to adopt new methods and implement new services that further enhance the effectiveness and efficiency of current and future prevention programs; and
* promotes use of high-quality consumer education materials on genetic disorders, screening for birth defects and genetic services.

HAWAII

The Genetics Program consists of several programs under the supervision of the Children with Special Health Needs Branch. The Genetics Coordinator administers grants, coordinates educational activities, develops legislation, and provides coordination and oversight for genetics activities. The Newborn Metabolic Screening Program administers the state newborn metabolic screening activities, which includes screening of all newborns for congenital hypothyroidism, phenylketonuria (PKU), hemoglobinopathies (including sickle cell disease), biotinidase deficiency, galactosemia, maple syrup urine disease (MSUD), and congenital adrenal hyperplasia (CAH). The Birth Defects Program collects and analyzes data related to birth defects in infants up to one year of age.

The Genetics Program also administers the following grant activities:

* Pacific Southwest Regional Genetics Network Grant
* Dialogue on Genetics for Asian American and Pacific Islanders
* State Genetics Planning Grants

IOWA

The Genetics and Birth Defects Institute, part of the Division of Family and Community Health, administers five programs: the Regional Genetic Consultation Service, the Iowa Neonatal Metabolic Screening Program, the Expanded Maternal Serum Alphafetoprotein Screening Program, the Iowa Birth Defects Registry, and the Neuromuscular and Related Genetic Diseases Program.

* The Regional Genetic Consultation Service (RGSC) provides genetic consultation and counseling services. A second function of the RGSC is educational outreach for health care providers and the community.
* The Iowa Neonatal Metabolic Screening Program screens for six disorders: phenylketonuria, congenital hypothyroidism, galactosemia, congenital adrenal hyperplasia, the hemoglobinopathies, and medium chain acyl-CoA dehydrogenase deficiency (MCAD).
* The Expanded Maternal Serum Alpha-fetoprotein Screening Program (MSAFP) performs prenatal screening and follow-up services to identify those pregnancies in which the fetus may be at risk for having a neural tube defect such as spina bifida or a chromosome abnormality such as Down syndrome.
* The Iowa Birth Defects Registry collects information on birth defect incidence in Iowa, monitors annual trends in birth defect occurrence and mortality, and conducts research studies to identify genetic and environmental risk factors for birth defects. The program also promotes educational activities regarding the prevention of birth defects.
* The Neuromuscular and Related Genetic Disease Program (NMP) provides healthcare services and education to individuals with neuromuscular diseases and their families at locations around the state.

MAINE

The Genetics and Newborn Screening Program of the Maine Bureau of Health provides comprehensive genetic services (risk assessment, diagnosis, counseling, and education) to Maine families who have or who are at increased risk of having genetic conditions/birth defects, by coordinating services and referrals to genetic agencies. The Program performs newborn screening tests, as required by law, for nine conditions, such as PKU and Congenital Hypothyroidism and conducts birth defects surveillance and provides referrals for services.

MARYLAND

The Office for Genetics and Children with Special Health Care Needs (OGCSHCN) services include specialty services and care coordination for children with complex medical conditions. The OGCSHCN is comprised of three divisions: Newborn Screening and Follow-up, including the Universal Infant Hearing Screening Program; Clinical Genetic Services (this division includes the Metabolic Disease Program, The Hemoglobin Disorders Program and the Birth Defects Reporting and Information System); and Specialty Care and Regional Resource Development.

MASSACHUSETTS

The Massachusetts Genetics Program aims to keep consumers and professionals informed about medical and scientific developments in human genetics, and the associated ethical, legal and social issues.

The Genetics Program is a statewide program designed to:

* Gather up-to-date information on genetic conditions, tests and treatments;

* Present genetics education and training programs to consumers, and to both professional and nonprofessional staff of agencies that serve consumers with genetic conditions or concerns;
* Provide technical assistance to consumers and professionals regarding availability of medical, genetic and support services;
* Provide information and referral about genetic-related conditions and health services; and
* Collect and analyze data related to public health genetics issues and service needs.

The program works with the New England Regional Genetics Group on publication of "The Genetic Resource" newsletter and is presently collaborating with other Department of Public Health programs to design a congenital anomaly surveillance system.

MICHIGAN

The Hereditary Disorders Program coordinates statewide services, including counseling, to Michigan citizens with a genetic diagnosis and provides information about birth defects and inherited diseases. Six regional coordinating centers are funded annually to provide a network of clinics for diagnosis, counseling and medical management. They also provide outreach education to community groups including families, health professionals, and teachers. The Hereditary Disorders Program serves as a central resource which maintains a listing of all genetic service providers, a directory of state genetic support groups, an Internet home page with links to state and national resources (http://www.mdch.state.mi.us/dch/clcf/hdp), a videotape lending library, and informational brochures.

NEW YORK

Babies born in New York State are tested for seven rare and serious disorders through the NYS Newborn Screening Program. The diseases screened for are phenylketonuria, branched-chain ketonuria (maple syrup urine disease), galactosemia, homocystinuria, hypothyroidism, sickle cell disease, and biotinidase deficiency. There are 49 genetics services programs available in New York State, including programs that target specific ethno-cultural groups, Cooley's Anemia Programs, Sickle Cell Services Programs, and cancer genetics counseling services.

Genetic service programs offer patients the opportunity to:
* work with genetic counselors and clinical geneticists in pinpointing the origin of an inherited health problem or disease;
* understand the natural history and most appropriate management of the genetic disease or birth defect;
* attend a support group for a genetic health problem or disease and learn how people in similar situations manage;
* have their newborns tested for rare and serious diseases; and
* benefit from referrals, such as to specialty clinics and counseling

NORTH CAROLINA

The North Carolina Newborn Screening Program screens for phenylketonuria, galactosemia, primary hypothyroidism, congenital adrenal hyperplasia, and sickle cell disease. The program also screens for amino acid disorders, fatty acid disorders, and organic aciduria by tandem mass spectrometry. The Division of Public Health also offers genetic counseling to anyone suspected of having a genetic disorder.

WASHINGTON

The Office of Newborn Screening tests the infants born in Washington State for four disorders: phenylketonuria (PKU), congenital hypothyroidism (CH), congenital adrenal hyperplasia (CAH), and hemoglobinopathies (such as sickle cell disease). The Office of Newborn Screening administers both laboratory and follow-up services. These include monitoring birth records to assess the completeness of screening, laboratory testing, advising health care providers about appropriate diagnostic and treatment follow-up response to test results, evaluating short and long term outcomes and providing communication and education regarding the program.
The Office of Newborn Screening also develops and distributes three educational publications.

WISCONSIN

Wisconsin's Newborn Screening Program tests for biotinidase deficiency, congenital adrenal hyperplasia, congenital hypothyroidism, cystic fibrosis, galactosemia, phenylketonuria, sickle cell disease and other related red blood cell disorders, fatty acid oxidation disorders, and organic acidemias. The Wisconsin Department of Health and Family Services also administers the Birth Defects Prevention and Surveillance Program and the Universal Newborn Hearing Screening Program through its Family Health Program.