Research Uses that have been Allowed by DSHS

Requestor	Title of Study	Purpose of Study	Number of Blood Spots or Description of Data Released for Study	Date of Use / Release
Michigan Newborn Screening Laboratory	Michigan Newborn Screening Laboratory's evaluation of MS/MS testing cutoffs.	To evaluate Michigan Newborn Screening laboratory MS/MS cutoffs based on specimens from diagnosed cases in Texas.	9 de-identified specimens	February 2013
DSHS and University of Massachusetts	A pilot study for newborn screening of Severe Combined Immunodeficiency (SCID)	To evaluate, validate and implement pilot SCID newborn screening tests and algorithms for identification of infants with SCID.	5525 de-identified blood spots (as of 4/10/2012)	September 2010 through March 2012 (ongoing)
DSHS and ARUP Laboratories	Evaluation and Implementation of Second-Tier Testing for Disorders Identified by MS/MS in Newborn Blood Spots in the Mountain States Region	To evaluate 1) the efficacy of performing second tier newborn screening tests for congenital adrenal hyperplasia and select metabolic disorders detected by tandem mass spectrometry and 2) the efficacy of establishing a regional laboratory to perform these second-tier tests.	342 de-identified blood spots	September 2010 through June 2011
University of Minnesota	Feasibility of Retrospectively Obtaining Guthrie Spots (FROGS) Study	Assess the feasibility of obtaining newborn screening blood spots from childhood cancer cases on a nationwide basis.	2 identified blood spots (advance parental consent obtained)	February 2010
PerkinElmer Life and Analytical Sciences	Development of a biotinidase screening assay	Left untreated, biotinidase deficiency can result in seizures, hearing loss, and death in severe cases. The aim of this study was to develop a semi-quantitative assay to measure biotinidase levels.	20 de-identified blood spots	December 2008
Department of State Health Services	Assessing the role of prenatal lead exposure on infant blood lead levels	Lead is toxic to many organs and tissues in the human body and is particularly toxic to children, causing potentially permanent learning and behavior disorders and in severe cases may cause seizures, coma, and death. The study aimed to determine whether high blood lead levels in infants are associated with prenatal lead exposure from the mother.	251 identified blood spots (used for internal DSHS research)	December 2008

Research Uses that have been Allowed by DSHS

Requestor	Title of Study	Purpose of Study	Number of Blood Spots or Description of Data Released for Study	Date of Use / Release
University of Texas Health Science Center at Houston	Candidate gene testing in nonsyndromic cleft lip and palate	Cleft lip and palate are birth defects that affect the upper lip and the roof of the mouth. They can cause failure to gain weight, feeding problems, poor growth, ear infections, and speech problems. The research sought to identify the specific genes causing nonsyndromic cleft lip and palate.	1376 de-identified blood spots	May 2008, October 2008, November 2008
Centers for Disease Control and Prevention	Development of a method to determine concentrations of polyfluoroalkyl compounds (PFC) in dried blood spots	PFCs have demonstrated developmental, reproductive, genotoxic, and carcinogenic effects in laboratory animal studies. In an effort to determine effects of PFCs on newborns, the study aimed to develop and validate a method for measuring PFC in blood spots as a method for determining perinatal exposure.	200 de-identified blood spots	September 2007
Texas A&M University	Feasibility of using stored Texas newborn screening dried blood spots (DBS) for childhood cancer epidemiological research	To assess the feasibility of using newborn screening blood spots for childhood cancer epidemiology studies and to determine the distribution of polymorphisms of the PON1 gene (a gene involved in the metabolism of organophosphate pesticides) in a sample of childhood cancer cases and non-cancer controls.	100 de-identified blood spots	July 2007
Baylor College of Medicine	Precursor study to identify genetic markers for selected cardiovascular birth defects	To determine the feasibility of using blood spots for genome wide association studies.	10 de-identified blood spots	May 2007

Research Uses that have been Allowed by DSHS

Requestor	Title of Study	Purpose of Study	Number of Blood Spots or Description of Data Released for Study	Date of Use / Release
Centers for Disease Control and Prevention	Development of reference ranges for use in screening newborns for X-linked adrenoleukodystrophy	Children with X-linked adrenoleukodystrophy experience learning and behavioral problems by 10 years of age. The disease is degenerative and total disability within several years is not uncommon. The study goal was to determine normal newborn reference ranges for use in a new test to screen newborns for X-linked adrenoleukodystrophy.	300 de-identified blood spots	September 2006
University of Minnesota	Neonatal blood spot bank for childhood cancer studies	To establish a control database for studies of childhood cancer.	100 de-identified blood spots	March 2006
University of Texas Health Science Center at Houston	Pilot study for association study of genetic study markers & Idiopathic Talipes Equinovarus (club foot)	To assess the feasibility of using newborn screening blood spots for Birth Defects research.	84 de-identified blood spots	May 2005
National Institutes of Health; University of California at San Francisco	Investigation of inherited immune disorders	Individuals with a severe immune disorder have frequent infections and subsequently, a reduced lifespan. The inherited disorders of the immune system were studied with the goal of developing a newborn screening test for severe immune disorders.	8 identified blood spots (advance parental consent obtained)	August 2004 through September 2007, as individual parental consent was received
Centers for Disease Control and Prevention	Technical evaluation of cytokine measurements in dried blood spots (2nd follow-up)	Second follow-up study to 'Technical evaluation of cytokine measurements in dried blood spots.' To determine if cytokine measurements in blood spots using refined MSA assays could be reproduced.	120 de-identified blood spots	July 2004
Centers for Disease Control and Prevention	Technical evaluation of cytokine measurements in dried blood spots (follow-up)	Follow-up study to 'Technical evaluation of cytokine measurements in dried blood spots.' To determine if refinements in assay methods improved cytokine measurements in blood spots using MSA assays.	100 de-identified blood spots	October 2003

Research Uses that have been Allowed by DSHS

Requestor	Title of Study	Purpose of Study	Number of Blood Spots or Description of Data Released for Study	Date of Use / Release
Armed Forces Institute of Pathology	Enhancing the size, sampling, and quality of forensic mtDNA databases	To improve data used in forensic analyses.	600 de-identified blood spots	May 2007
Armed Forces Institute of Pathology	Precursor study to 'Enhancing the size, sampling, and quality of forensic mtDNA databases' (immediately following)	To assess genetic variation in mitochondrial DNA as preliminary groundwork for improving data used in forensic analyses.	200 de-identified blood spots	May 2003
PerkinElmer Life and Analytical Sciences	Preliminary development of immunoassay to identify hemoglobin variants	This was an effort to improve efficiencies of newborn screening methodologies. The goal was to assess the feasibility of creating an automated test to detect hemoglobin variants.	36 de-identified blood spots	March 2003
Centers for Disease Control and Prevention	Using newborn dried blood spots to assess the contribution of selected congenital infections (Cytomegalovirus (CMV), Lymphocytic Choriomeningitis Virus (LCMV), and Toxoplasmosis gondii) to the etiology of hydrocephalus	There is strong evidence that congenital infections cause birth defects. Hydrocephalus is a birth defect in which cerebrospinal fluid builds up inside the skull, typically requiring surgical treatment. The goal of this study was to determine the contribution of congenital infection with CMV, LCMV or Toxoplasmosis gondii to the occurence of hydrocephalus.	183 de-identified blood spots	January 2008
University of Texas MD Anderson Cancer Center	Role of genetic polymorphisms of glutathione S-transferases and related genes in the pediatric population	The glutathione S-transferase pi gene (GSTP1) is a gene thought to play a role in susceptibility to cancer and other diseases. The study aimed to establish the frequency of GSTP1 mutations in a normal pediatric population and to determine any correlations of the mutations with specific demographics.	1000 de-identified blood spots	March 2002

Research Uses that have been Allowed by DSHS

Requestor	Title of Study	Purpose of Study	Number of Blood Spots or Description of Data Released for Study	Date of Use / Release
University of California at Los Angeles, Department of Pediatrics	Development of alternative mutation detection technologies for hemoglobinopathies	Hemoglobinopathies are inherited defects of the hemoglobin molecule that cause mild to acute anemia, among other symptoms. Sickle cell anemia is one of the most common and well known hemoglobinopathies. The goal was to develop a simple yet accurate technique using blood spots to detect known mutations causing hemoglobinopathies.	3 de-identified blood spots	February 2002
Baylor College of Medicine	Population incidence of mitochondrial mutations associated with aminoglycoside-induced deafness	Aminoglycosides like streptomycin and gentamycin appear to generate free radicals within the inner ear, with subsequent permanent damage to sensory cells and neurons, resulting in permanent hearing loss. The study aimed to determine the frequency of two mutations that are associated with aminoglycoside-induced damage to the ear.	1173 de-identified blood spots	March 2001 and July