

## PKU/Guthrie Cards as Direct References for Missing Persons

### Terms used in this document:

CODIS:	Combined DNA Index System
Direct Reference Sample:	Any item that might contain blood, saliva, or other biological material that could be used to obtain a DNA profile for a missing person, as opposed to profiles from relatives of missing persons.
Phenylketonuria (PKU):	An inherited metabolic disorder caused by an enzyme deficiency, usually causing severe mental retardation and seizures unless phenylalanine is restricted from the diet from infancy.
PKU Card:	Also known as a Guthrie Card. A PKU -- or Guthrie -- card holds samples of blood that are collected from infants at birth to test for genetic disorders. The blood samples are dried onto PKU cards.

### Overview of Direct DNA Reference Samples:

DNA specimens for a missing person case fall into two categories: 1) family reference samples and 2) direct reference samples. Family reference samples are collected from the mother, father, and/or other close biological relative of a missing person. Direct reference samples consist of biological material from the missing person (e.g., baby tooth or biopsy tissue), or an item of evidence that the missing person has come into contact with and may yield cells that contain his or her DNA (e.g., toothbrush).

Unlike profiles developed from family reference samples, which can only be searched against the Unidentified (Human) Remains Index of CODIS, profiles developed from direct reference samples can be searched against all indexes of CODIS. Obtaining and searching direct missing person profiles across all indexes of CODIS can produce leads that will not be obtained with family reference samples alone.

When collecting and submitting direct reference samples for missing persons, at least two family reference samples should also be submitted. These family samples will allow the laboratory to confirm that the profile from the direct reference is indeed from the missing person and has not been contaminated.

PKU/Guthrie cards are collected on all infants born in U.S. hospitals, and are an excellent direct reference sample, especially for missing children who were adopted and no biological parents are known or available for collection. The "PKU/Guthrie Card Contact Information" listed on the following pages will provide investigators with information on the retention policy for PKU/Guthrie cards in each state, along with the points of contact and requirements for release in each state.

**ACKNOWLEDGEMENT:** The PKU/Guthrie card information on the following pages was compiled through a research project conducted by the National Center for Missing & Exploited Children (NCMEC), under the direction of Cold Case Manager Pamela Reed.

## PKU Card Contact Information

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
AL	DEPT OF PUBLIC HEALTH	Bob Hinds, Director Newborn Screening Division (334) 206-5556 Bob.Hinds@adph.state.al.us Dr. Sharon Massingale (preferred) Public Health Director Bureau of Clinical Laboratories (334) 260-3400 sharon.massingale@adph.state.al.us	1964	3 months	AL state lab	No current policy
AK	DEPT OF HEALTH AND SOCIAL SERVICES, DIVISION OF PUBLIC HEALTH	Thalia Wood, Manager Children's Health Unit & Newborn Metabolic Screening (907) 269-3499 Thalia.Wood@alaska.gov	1967	3	2 yr in OR state lab, 1yr in AK public health lab in Anchorage	Only released with request from the parents and health care provider only under certain conditions (i.e. no paternity testing and no repeating of screening tests already performed)
AZ	DEPT OF HEALTH SERVICES	Ward Jacox, Chief Office of Newborn Screening (602) 364-1410 jacoxw@azdhs.gov	1994	3 months	AZ state lab	No past experience, request submitted to Dept of Health or state lab
AR	DEPT OF HEALTH	Leslie Himstedt (preferred) Laboratory Supervisor Dept. of Health, Public Health Lab (501) 661-2445 leslie.himstedt@arkansas.gov JoAnn Bolick Newborn Screening Program (501) 280-4753 JoAnn.Bolick@arkansas.gov	1967	3-6 months	AR state lab	Court order, lawful subpoena or parental consent
CA	DEPT OF HEALTH SERVICES	Fred Lorey Newborn Screening Program (510) 412-1490 fred.lorey@cdph.ca.gov	1980	Indefinitely	CA state lab	Subpoena, request made to Admin Office
CO	DEPT OF PUBLIC HEALTH AND ENVIRONMENT	David Butcher, Director Newborn Screening Program (303) 692-3069 david.butcher@state.co.us	1982	6 months	CO state lab	Only released to parents or by court order
CT	DEPT OF PUBLIC HEALTH	Vine Samuels Newborn Screening Program (860) 509-8081 fax:(860) 509-8650 vine.samuels@ct.gov	1964	6 months	CT state lab	Only from the person who provides the child's health care, e.g.. Social worker, health care provider

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
DE	DEPT OF HEALTH AND SOCIAL SERVICES	Betsy Voss Newborn Screening Program (302) 744-4544      betsy.voss@state.de.us Pat Scott, Manager (preferred) Newborn Screening Program (302) 223-1493	1972	4 months	DE state lab	Request has to be reviewed by IRB (Internal Review Board?) (provided by Pat Scott)
DC	DEPT OF HEALTH	Yvockeea Monteiro Newborn Screening Program (202) 535-1915      yvockeea.monteiro@dc.gov	1980	1	Perkin Elmer Genetics, Inc.	
FL	DEPT OF HEALTH	Lois Taylor Newborn Screening Program (850) 245-5670 lois_taylor@doh.state.fl.us	1965	Indefinitely	FL state lab	By law enforcement, or medical examiners
GA	DEPT OF HUMAN RESOURCES, DIVISION OF PUBLIC HEALTH	Ginger Stevens Newborn Screening Laboratory (404) 327-7951 gestevens@dhr.state.ga.us				
HI	DEPT OF HEALTH	Christine Matsumoto Newborn Metabolic Screening Program (808) 733-9069 christine_matsumoto@doh.hawaii.gov	email replied	1	OR Public Health Lab, Hillsboro, OR (NOT in HI)	Court order or subpoena, no current policy
ID	DEPT OF HEALTH AND WELFARE	Mitch Scoggins, Manager Children's Special Health Program (208) 334-5963 ScogginM@dhw.idaho.gov Carol Christiansen Newborn Screening Program / Children's Special Health Program (208) 334- 4935 christc3@dhw.idaho.gov	mid-1960s	1	Regional lab (Portland, OR)	Anyone can request, but requires custodial parents' consent. Otherwise court order needed.
IL	DEPT OF PUBLIC HEALTH	Claudia Nash Newborn Screening Program (217) 785-8101 claudia.nash@illinois.gov Mike Petros Lab Director in Chicago (312) 793-4751      mike.petros@illinois.gov	1965	2 months	IL state lab (Chicago)	No past experience, contact Legal Services (217) 782-4977

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
IN	DEPT OF HEALTH	Coutney Eddy, Genomics Program Director Genomics and Newborn Screening HIPAA Program Privacy Coordinator (preferred) 317.233.9260 CEddy@isdh.IN.gov Bob Bowman, Director Genomics and Newborn Screening Program (317) 233-1231 BobBowman@isdh.IN.gov	1965	23	IN state contract lab	Parent or legal guardian consent
IA	DEPT OF PUBLIC HEALTH	Kimberley Piper Newborn Screening Program (515) 281-6466 kpiiper@idph.state.ia.us Marcia Valbracht (preferred) University Hygienic Laboratory (515) 725-1600	1983 official, private started before that	5	IA Public Health Lab, Univ. Hygienic Lab, Ankeny, IO	Court order, subpoena, or parental request.
KS	DEPT OF HEALTH AND ENVIRONMENT	Colleen Peterson, Lab Manager Newborn Screening Program Neonatal Chem (785) 296-1650 ckpeters@kdheks.gov	1967	30 days	KS state lab	No past experience, need to talk to lawyers
KY	CABINET FOR HEALTH AND FAMILY SERVICES	Stephanie Mayfield (preferred) Stephanie Mayfield (preferred) stephaniek.mayfield@ky.gov Lea Mott, Supervisor Newborn Screening Program (502) 564-4446 x4456 lea.mott@ky.gov	1966	45 days, abnormal indefinitely	KY state lab	Would require court order to release
LA	DEPT OF HEALTH AND HOSPITALS	Arthur Hagar, Assistant Dir. Public Health Laboratory (504) 219-4667 ahagar@dhh.la.gov	1963 or 1964	30 days; abnormals indefinitely	LA state lab	No past experience, can make request to Arthur Hagar or Dr. Martin (lab director). Will forward to Legal Dept for review and official response)
ME	DEPT OF HEALTH AND HUMAN SERVICES	Ellie Mulcahy Newborn Bloodspot Screening Program (207) 287-4623 eleanor.a.mulcahy@maine.gov	1999	Indefinitely	Contract lab in MA	Parental request is enough
MD	DEPT OF HEALTH AND MENTAL HYGIENE	Fizza Gulamali-Majid, Division Chief Newborn and Childhood Screening (410) 767-3487 MajidF@dhmh.state.md.us	1965	24 (since 2004)	Newborn and Childhood Screening Lab	Follows state and federal laws
MA	DEPT OF PUBLIC HEALTH	Roger Eaton, Lab Director Newborn and Childhood Screening (617) 983-6317 roger.eaton@umassmed.edu	1990	"At least 10 years" and up to 18 yrs at present	UMASS Medical School	Court Order (subpoena is not sufficient): if no Court Order, then MADPH legal consult

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
MI	DEPT OF COMMUNITY HEALTH	Harry Hawkins Newborn and Childhood Screening (517) 335-8095 hawkinsh@michigan.gov	1984	Indefinitely	MI state lab, duplicate samples in Techtown, Detroit, MI	Parental consent
MN	DEPT OF HEALTH	Mark McCann, Director Newborn and Childhood Screening (651) 201-5450 Mark.McCann@state.mn.us	1965	Indefinitely at present, but may be subject to change in future	MN state lab (in Dept of Health)	Written consent signed by parents
MS	DEPT OF HEALTH	Beryl Polk, Director Newborn and Childhood Screening (601) 576-7619 beryl.polk@msdh.state.ms.us	1998	3 to 4	Private contract lab	No past experience
MO	DEPT OF HEALTH AND SENIOR SERVICES	Patrick Hopkins, Lab Director Newborn and Childhood Screening (573) 751-2662 patrick.hopkins@dhss.mo.gov	1964 or 1965	30 days	MO state lab	email sent to Patrick Hopkins
MT	DEPT OF PUBLIC HEALTH AND HUMAN SERVICES	Linda Beischel, Coordinator Newborn Screening Program (406) 444-0984 lbeischel@mt.gov	1973	before 2008: few months; since 2008: indefinitely (may discard aft 2 yrs if run out of space)	MT state lab	Parental consent
NE	DEPT OF HEALTH AND HUMAN SERVICES	Julie Miller, Program Manager Newborn Screening & Genetics Program (402) 471-6733 Julie.Miller@nebraska.gov	1962 in some hospitals, 1967 statewide	90 days (required to destroy within 30 days afterwards)	PerkinElmer Genetics, Inc. (from 2003)	Court order, subpoena, or parental request. A law enforcement request needs authorization from the parents
NV	DEPT OF HEALTH AND HUMAN SERVICES, HEALTH DIVISION	Jackson Zenteno (775) 684-3478 jzenteno@health.nv.gov	1978	2-Jan	Lab in OR	Parental consent is sufficient
NH	DEPT OF HEALTH AND HUMAN SERVICES	Marcia Lavochkin, Program Coordinator Newborn Screening Program (603) 271-4225 MLavochkin@dhhs.state.nh.us	1965	6 months	Contract lab	LE request
NJ	DEPT OF HEALTH AND SENIOR SERVICES	Scott Shone Newborn Screening Laboratory (609) 341-5455 Scott.Shone@doh.state.nj.us	PKU-late 70s, others 1991	23	NJ state lab	Court order
NM	DEPT OF HEALTH	Brenda Romero, State Genetics Coordinator Newborn Screening Program (505) 476-8857 brenda.romero@doh.state.nm.us	1978	1	OR Public Health Lab	Subpoena
NY	DEPT OF HEALTH	Mary Graziano, Manager Newborn Screening Genetics Services (518) 486-2911 mgg01@health.state.ny.us	1965, storage since 1997	Indefinitely	Wadsworth Center	Subpoena, court order, ME, physician or parent request

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
NC	DEPT OF HEALTH HUMAN SERVICES	Shu Chaing, Manager (preferred) Newborn Screening/Clinical Chemistry Unit (919) 733-3937 Shu.Chaing@ncmail.net Ann Grush, Supervisor Newborn Screening Program (919) 807-8881 ann.grush@ncmail.net	1965	Indefinitely since 2002 (may change in the future)	Newborn Screening/Clinical Chemistry Unit of NC State Laboratory of Public Health.	Parental consent
ND	DEPT OF HEALTH	Barb Schweitzer, Director Newborn Screening Program (701) 328-4538 bschweit@nd.gov	1960s	Indefinitely (have samples since 2001)	Lab in University of ND	Parental consent, request submitted to HIPA (Health Information Privacy Act)
OH	DEPT OF HEALTH	Sharon Linard, Director Newborn Screening Program (614) 644-4659 sharon.linard@odh.ohio.gov	1960s	2	OH state lab	Parents' signed consent or court order
OK	DEPT OF HEALTH	SharonVaz, Director Newborn Screening Program (405) 271-6617 sharonav@health.ok.gov	1963	30 days, 42 days max.	Public Health lab in Dept of Health	Parents' signed consent, approved by Advisory Committee
OR	PUBLIC HEALTH DIVISION	Cheryl Hermerath Newborn Screening Section (503) 693-4172 cheryl.a.hermerath@state.or.us	1961	1	Public Health lab in Dept of Health	Written request stating the pertinent information to assist in identifying the correct specimen and parental or guardian permission to release the specimen
PA	DEPT OF HEALTH	Melita Jordan, Director Newborn Screening Section (717) 787-7192 mejordan@state.pa.us	1965	8 months	PerkinElmer Genetics, Inc. and University of Massachusetts, Boston, MA (for New England region in PA)	Only parental consent, NOT subpoena
RI	DEPT OF HEALTH	Barbara McNeilly, Director Newborn Screening Program (401) 222-4640 Barbara.McNeilly@Health.ri.gov	1976	23	Contract lab in MA (New England Regional State Lab)	Parental consent or subpoena
SC	DEPT OF HEALTH AND ENVIRONMENTAL CONTROL	John Reddic or Arthur Wozniak Newborn Screening Laboratory (803) 896-9725 reddicje@dhec.sc.gov	1965	2 years in lab, then return to guardian, others 1 additional year	Bureau of Lab, in Dept of Health and Environmental Control	Court order, subpoena or written request of the parent/legal guardian
SD	DEPT OF HEALTH	Lucy Fossen Newborn Screening Program (605) 773-2944 lucy.fossen@state.sd.us	1973	1 month	SD state lab	No information

State	Agency	Program Contacts	1st Yr	Years Kept	Storage Location	Requirements to Release
TN	DEPT OF HEALTH	Jim Gibson, Director Newborn Screening Laboratory (615) 262-6300 jim.gibson@tn.gov	1968	1 year for normal, no def. time for abnormal	TN state lab	Only parental consent
TX	DEPT OF STATE HEALTH SERVICES	Susan Tanksley, Director(preferred) (512) 458-7111 x3106 susan.tanksley@dshs.state.tx.us Sandra Navarro (512) 458-7111 x2377	1960s	25	TX state lab, archived in College Station, TX	Parental consent, other requests forwarded to lawyers
UT	DEPT OF HEALTH	Fay Keune Newborn Screening Program (801) 584-8255 fkeune@utah.gov	1979	before 2006: 90 days, aft 2006: 2 years	State lab, Salt Lake City, UT	Parental consent
VT	DEPT OF HEALTH	Cynthia Ingham Newborn Screening Program Chief (802) 951-5180 cingham@vdh.state.vt.us	1964	Indefinitely (only have samples from 2002 onwards due to flooding)	VT state lab	No requirements
VA	DEPT OF HEALTH	Sharon Williams Genetics Program Manager (804) 864-7712 sharonk.williams@vdh.virginia.gov	1966-67	10 years for abnormal, 6 months for normal	VA state lab	Only parental consent or medical examiner request
WA	DEPT OF HEALTH	Sheila Weiss Newborn Screening Program Cooperator (206) 418-5509 sheila.weiss@doh.wa.gov	1960s, 1976 statewide	21 (10 years in Shoreline, archived 11 years in Olympia, both in WA), destroyed if requested	WA state lab	Parental consent, need release form, unless criminal cases
WV	DEPT OF HEALTH AND HUMAN RESOURCES	Kathy Cummons, Director Office of Maternal, Child and Family Health (304) 558-7171 kathy.g.cummons@wv.gov	1967	3 months	WV state lab	No experience, parental consent is sufficient
WI	DEPT OF HEALTH SERVICES	Gary Hoffman (608) 262-4692 hoffman@mail.slh.wisc.edu	1978	1	Newborn Screening lab at State Lab of Hygiene	"Request for Information" form required, court orders and subpoenas would be exempt, submit request to Wisconsin State Lab of Hygiene Admin Office