State Newborn Screening Request Information

Alabama

- Contact: Cindy Ashley, Newborn Screening Director, 334-206-2971
- http://www.adph.org/newbornscreening/Default.asp?id=2226
- With the new NCAA policies, the Alabama Department of Public Health released a statement that it is unable to publicly release information regarding newborn screening for sickle cell trait
- Information can be obtained by contacting an individual's pediatrician at birth or having the student's treating physician access the <u>Voice Response System</u>

Alaska

- Contact: Rebekah Morisse, Newborn Metabolic Screening Program, 917-269-4762
- http://dhss.alaska.gov/dph/wcfh/Pages/metabolic/default.aspx
- Parents are only notified of newborn's test results if there is a problem. Your doctor or clinic will be informed when the tests are complete.

Arizona

- Contact: Office of Newborn Screening, 602-364-1409
- http://www.azdhs.gov/lab/aznewborn/testing/abnormal-results.htm#Q03
- Letters are sent to provider of record and the parents to notify of probable hemoglobin carrier status, but there is no further follow up
- Parents can contact their children's pediatricians at the time of birth for test results

Arkansas

- Contact: Newborn Screening, 866-769-9043
- http://www.healthy.arkansas.gov/programsServices/familyHealth/ChildAndAdolescentHealth/newBornScreening/Parents/Pages/default.aspx
- Parents can obtain their children's test results from their baby's doctor

California

- Contact: Genetic Disease Screening Program, 510-412-1502
- http://www.babysfirsttest.org/newborn-screening/states/california#second-section
- Though highly recommended, newborn testing is not required and may be opted out of
- Positive test results are immediately followed up by telephone to set-up a meeting with a coordinator at the Newborn Screening Area Service Center located throughout the state
- A baby's doctor will be given the recommendations on diagnosis, treatment, and assistance with referrals to specialists

Colorado

- Contact: Newborn Screening Follow-up Program, 303-692-2370
- http://www.colorado.gov/cs/Satellite/CDPHE-PSD/CBON/1251630007210
- State public health labs will give the results of a baby's test to the hospital, baby's doctor, or baby's midwife
- Any of these healthcare personnel will be immediately notified if any test results are "not normal"

Connecticut

- Contact: State of Connecticut, Department of Public Health, 860-509-8081
- http://www.ct.gov/dph/cwp/view.asp?a=3122&q=387740
- All results are sent to the hospital where the baby was born
- A doctor will call the family if the test are not "normal"
- This does not mean the baby has a disease, but additional testing is warranted

Delaware

- Contact: Newborn Screening Program, 302-744-4544
- http://dhss.delaware.gov/dph/chca/dphnsp1.html
- Newborn Screening Program shall maintain and treat as confidential all newborn screening communications with institutions, families, and health care providers
- Information may be disclosed in summary forms but not identify individuals
- Individuals or institutions requesting summary data must submit a proposal to the Newborn Screening Program and to the Institutional Review Board of the Division of Public Health

Florida

- Contact: The Newborn Screening Program, 850-245-4201
- http://www.cms-kids.com/home/faqs/newborn_screening.html
- A baby's doctor is informed of the results, but parents are directly notified of the test results if there is a problem

Georgia

- Contact: Newborn Screening for Metabolic and Sickle Cell Disorders Program, 404-657-4143
- http://health.state.ga.us/programs/nsmscd/faq.asp
- A written report of newborn screening results is mailed to the hospital of birth and the clinician listed on the screening card
- Authorized providers can access newborn screening results online through <u>State Electronic</u> Surveillance System (SendSS)
- Results are also available through the Voice Response System

Hawaii

- Contact: Hawaii Genetics Program, 808-733-9055
- http://health.hawaii.gov/genetics/files/2013/04/scdprotocol.pdf
- Baby's doctor will give you the test results

Idaho

- Contact: Idaho Newborn Screening, 208-334-5962
- http://www.healthandwelfare.idaho.gov/Portals/0/Health/NBS.pdf
- The lab returns test results to the birthing facility and the physician listed on the screening care within 10 to 14 days
- Parents must ask physicians for their baby's results

Illinois

- Contact: Illinois Genetic and Newborn Screening, 217-782-4977
- http://www.idph.state.il.us/HealthWellness/genetics.htm
- Disclosure information not specified

Indiana

- Contact: Lisa Mani, Sickle Cell Program Director, 317-233-1357
- http://www.in.gov/isdh/20356.htm
- Online access to newborn screening results for primary care providers is available through Indiana Newborn Screening Tracking & Education Program (INSTEP)
- Other healthcare professionals seeking newborn screening results can contact the IU Newborn Screening Laboratories
- Fax on your office letterhead with patient name, DOB, patient's mother's name, and birthing facility to 317-491-6679

Iowa

- Contact: Center for Congenital and Inherited Disorders, 1-800-383-3826
- http://www.idph.state.ia.us/genetics/neonatal_parent_page.asp
- Though highly recommended, newborn testing is not required and may be opted out of
- Positive test results are immediately followed up by telephone to set-up a meeting with a coordinator at the Newborn Screening Area Service Center located throughout the state
- A baby's doctor will be given the recommendations on diagnosis, treatment, and assistance with referrals to specialists

Kansas

- Contact: KDHE General Information, 785-296-1500
- http://www.kdheks.gov/newborn_screening/download/parent_info/Hb_Parent_Handout.pdf
- No information on disclosure

Kentucky

- Contact: Kentucky Newborn Screening Program, 502-564-3756
- http://chfs.ky.gov/dph/mch/ecd/newbornscreening.htm#results
- Baby's doctor receives a screening report and notifies parents of the results
- Parents have right to ask the doctor or nurse to explain the screening process and provide results

Louisiana

- Contact: Terry Crockett, 504-219-4696
- http://wwwprd.doa.louisiana.gov/laservices/publicpages/ServiceDetail.cfm?service_id=3326
- Test results are given to a family by a baby's doctor within two weeks of birth

Maine

- Contact: Maine Newborn Bloodspot Screening Program, 207-287-5357
- http://www.maine.gov/dhhs/mecdc/population-health/cshn/documents/pdf/mnbs-brochure.pdf
- Baby's doctor will contact a family if the results suggest the baby may have one of the conditions tested for
- Ask about the test results upon first visit to physician

Maryland

- Contact: Newborn Screening General Requests/Questions, 410-767-6099
- http://dhmh.maryland.gov/laboratories/SitePages/parents.aspx
- Test results are not sent directly to parents, but the baby's doctor can provide a family with the results of the test

Massachusetts

- Contact: Roger Eaton, New England Newborn Screening Program, 617-983-6300
- http://www.umassmed.edu/uploadedFiles/English.pdf
- Results reported to hospital where baby is born and to pediatrician listed on baby's sample

Michigan

- Contact: William Young, 517-335-9205
- http://www.michigan.gov/mdch/0,1607,7-132-2942-233588--,00.html
- Follows up with medical providers for all positive tests

Minnesota

- Contact: Newborn Screening Program, Metro: 651-201-5466, Greater MN: 1-800-664-7772
- http://www.health.state.mn.us/newbornscreening/optout.html
- Minnesota Department of Health mails paper copies of the newborn screening results back to the individual or organization who submitted the request for screening

<u>Mississippi</u>

- Contact: Newborn Screening, 601-576-7619
- http://msdh.ms.gov/msdhsite/_static/41,0,101.html#Contact
- Results are mailed to the hospital of birth
- Doctor of record notified if any abnormalities are present
- Baby's doctor can request screening results from the hospital or the Mississippi State Department of Health's Genetic Services Program

Missouri

- Contact: State Public Health Laboratory, 573-751-3334
- http://health.mo.gov/lab/hemoglobinopathies.php
- Approved healthcare professionals will have access to their patients' Newborn Screening laboratory reports

Montana

- Contact: Montana Newborn Screening Coordinator, 406-444-0984
- http://www.dphhs.mt.gov/publichealth/newborn/screening.shtml
- Baby's doctor, nurse, midwife will notify a family if there is a problem with tests
- Ask about screening results upon baby's first doctor's visit

Nebraska

- Contact: Newborn Screening, 402-471-0374
- http://dhhs.ne.gov/publichealth/Pages/nsp_parents.aspx
- Ask baby's doctor or healthcare provider for screening results during a baby's 2 week check up

Nevada

- Contact: Mary Pennington, 775-684-3478
- http://www.babysfirsttest.org/newborn-screening/states/nevada#third-section
- Though highly recommended, newborn testing is not required and may be opted out of
- Positive test results are immediately followed up by telephone to set-up a meeting with a coordinator at the Newborn Screening Area Service Center located throughout the state
- A baby's doctor will be given the recommendations on diagnosis, treatment, and assistance with referrals to specialists

New Hampshire

- Contact: New Hampshire Newborn Screening Program, 603-271-4225
- http://www.dhhs.state.nh.us/dphs/bchs/mch/documents/sickle-cell-trait-fs.pdf
- Parents notified of test results if there is a problem
- May also ask health professional for test results

New Jersey

- Contact: Newborn Screening and Genetic Services, 609-292-1582
- http://www.state.nj.us/health/fhs/nbs/hemo.shtml
- Baby's test results are sent to hospital where the sample is taken
- Ask doctor for baby's test results upon first visit to doctor

New Mexico

- Contact: Newborn Screening Genetic nurse consultant, 505-476-8858
- http://nmhealth.org/phd/nbs/documents/New%20Mexico%20Newborn%20Screening%20Program.mht
- Provides follow up of all children diagnosed on newborn screening up to age 21
- No information on disclosure

New York

- Contact: Newborn Screening Program, 518-473-7552
- http://www.wadsworth.org/newborn/newborn_health.html
- Ask baby's doctor at first check up for test results

North Carolina

- Contact: North Carolina State Laboratory of Public Health, 919-733-7834
- http://slph.ncpublichealth.com/newborn/
- No information on disclosure

North Dakota

- Contact: Becky Bailey, Newborn Screening Director, 701-328-4526
- http://www.babysfirsttest.org/newborn-screening/states/north-dakota
- Though highly recommended, newborn testing is not required and may be opted out of
- Positive test results are immediately followed up by telephone to set-up a meeting with a coordinator at the Newborn Screening Area Service Center located throughout the state
- A baby's doctor will be given the recommendations on diagnosis, treatment, and assistance with referrals to specialists

Ohio

- Contact: Public Health Laboratory, 888-634-5227
- http://www.odh.ohio.gov/odhprograms/phl/newbrn/nbfaq1.aspx
- Baby's doctor given test results

Oklahoma

- Contact: 405-271-6617
- http://www.ok.gov/health/Child_and_Family_Health/Screening_and_Special_Services/Newborn_Screening_Program/Disorders_screened/Sickle_Cell_Disease.html
- Baby's doctor given test results
- Can also obtain results from Voice Response System

Oregon

- Contact: Cheryl Hermerath, 503-693-4174
- http://public.health.oregon.gov/LaboratoryServices/NewbornScreening/Documents/sicklecell.pdf
- Ask baby's doctor for test results

Pennsylvania

- Contact: 1-800-986-2229
- http://www.portal.state.pa.us/portal/server.pt/community/infant_newborn's_health/14173/newborn_screening_and_follow_up_homepage/558183
- If an athlete born in Pennsylvania after Sept. 19, 1992, needs the results of his/her Sickle Cell Disease/Trait screen for NCAA Clearance, it is recommended that the individual or the individual's legal guardian contact his/her primary care physician (PCP) or hospital of birth to obtain a **complete** copy of the newborn screening result
- If the individual does not have a PCP, or their PCP and/or hospital of birth does not have a complete newborn screen report, the individual or the individual's legal guardian may complete the Commonwealth of Pennsylvania Department of Health Authorization to Obtain Newborn Screening Results Form and fax the form to the Department of Health's Bureau of Family Health Newborn Screening Section at 717-213-3785
- Upon receipt of a complete form, department staff will confirm the information and honor the request, if the information is available. Incomplete forms will require follow-up with the requestor for additional information. It is the department's policy that screening results will only be released to the student athlete's PCP or legal representative, the student athlete (if 18 years of

- age or older), or the student athlete's parent/legal guardian, if the student in question is under 18 years of age upon receipt and verification of a complete consent for release
- It is the department's position that medical information related to an individual's heritage and/or lineage carries many social, legal and ethical implications. Other persons receiving such information, except the individual or his/her parent/legal guardian, must possess sufficient medical knowledge to interpret and translate screening results to the individual

Rhode Island

- Contact: Newborn Screening Coordinator, 401-921-7619
- http://www.health.ri.gov/newbornscreening/for/parents/
- All Rhode Island babies are enrolled in KIDSNET, an information system that helps families and doctors make sure that children receive complete preventative health care
- KIDSNET will contain newborn blood screening information

South Carolina

- Contact: John Reddic, Newborn Screening Laboratory, 803-896-9752
- http://www.babysfirsttest.org/newborn-screening/states/south-carolina
- Results from children with sickle-cell trait are sent by the laboratory to regional sickle-cell centers for counseling and follow up
- Physicians and hospitals obtain test results

South Dakota

- Contact: Lucy Fossen, South Dakota Newborn Screening Program, 605-773-3737
- http://doh.sd.gov/family/assets/pamphlet.pdf
- Results returned to baby's doctor and hospital
- Parents notified if test results are abnormal

Tennessee

- Contact: Newborn Screening, 615-532-8462
- http://health.state.tn.us/MCH/NBS.shtml
- Newborn Screening Results can be quickly accessed with Voice Response System
- Tennessee Physicians can gain access by filling out the VRS Access Form

Texas

- Contact: Laboratory Services Section, 512-776-7318
- http://www.dshs.state.tx.us/lab/nbsParentRes.shtm
- Get results from baby's doctor

Utah

- Contact: Kim Hart, 801-584-8256
- http://health.utah.gov/newbornscreening/Disorders/HB/SickleTrait_FAS/Athletes_HbFAS_En.pdf
- Ask a baby's medical provider for results

Vermont

- Contact: Vermont Newborn Screening Program, 802-951-5180
- http://healthvermont.gov/family/newbornscreening/parents.aspx#resources
- Parents notified by healthcare provider of their child's results

Virginia

- Contact: Kathleen Moline, 804-864-7712
- http://www.vahealth.org/VNSP/index.htm
- No information on disclosure

Washington, D.C.

- Contact: Perinatal and Infant Health Bureau, 202-442-9158
- http://doh.dc.gov/service/dc-newborn-metabolic-screening-program
- Follow up with parents if abnormal test results

Washington

- Contact: Newborn Screening Program, 206-418-5410
- http://www.doh.wa.gov/Portals/1/Documents/5220/s_trait_pam.pdf
- Baby's doctor will receive results within 5-7 days
- Parents should ask their baby's doctor about results

West Virginia

- Contact: Newborn Screening, 301-558-3530
- http://www.wvdhhr.org/labservices/labs/newborn/index.cfm
- No information on disclosure

Wisconsin

- Contact: Newborn Screening Laboratory, 608-262-4692
- http://www.slh.wisc.edu/newborn/brochures/b2p1.dot
- Doctor will receive test results and parents can find out results at baby's first check up

Wyoming

- Contact: Carleigh Soule, 307-777-6297
- http://www.health.wyo.gov/familyhealth/newborn/index.html
- Parents can obtain test results from their baby's health care provider