General requirements for release of newborn blood spot (NBS) are: Child's name, Child's DOB, Hospital of birth, Mother's name, reason for request, location to release specimen to, test to be run, and purpose of retesting the specimen (if applicable). Request must be submitted on official letterhead.

<u>Alabama</u>

Length of Storage: 3 months

Contacts: Rachel Montgomery, Newborn Screening Coordinator, (334) 206-5955 Denita Rollin, State NBS Laboratory Manager, Bureau of Clinical Laboratories, (334) 260-3475 Cindy Ashley, Newborn Screening Director, (334) 206-2971 Sharon Massingale, Laboratory Director, Bureau of Clinical Laboratories, (334) 260-3400 Amy Strickland, Newborn Hearing Screening Coordinator, Department of Public Health, (334) 206-2944 **Requirements to obtain NBS:** Results can be obtained using the Alabama Voice Response System, which must be registered for

<u>Alaska</u>

Length of Storage: 3 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contact: Rebekah Morrisse, Co-manager Newborn Screening Program (907) 269-4762 Cheryl Hermerath Oregon State Public Health Lab (503) 693- 4172 Notes: 1st year of storage is at Oregon State Public Health, next 2 years are at Alaska Public Health Lab

<u>Arizona</u>

Length of Storage: 90 days, if results are abnormal NBS may be kept longer in refrigerator Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contact: William Slanta (602) 542-6128 Ward Jacox, Office of Newborn Screening (602) 364-1409 Notes: Request must be made on official letterhead.

<u>Arkansas</u>

Length of Storage: 1 year Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contact: Leslie Himstedt (501) 661-2445 UAMS Metabolic Genetics and Newborn Screening (501) 686-7000

<u>California</u>

Length of Storage: Indefinitely Requirements to obtain NBS: Submission of request in writing. Parental consent in writing. Information about the consent form and procedure can be found at http://www.cdph.ca.gov/programs/nbs/Pages/NBSConsents.aspx Contact: Robyn Cooley (510) 412-1500 Newborn Screening Program Fax (510) 412 1559 Genetic Disease Screening Program (510)412-1502 Genetic Disease Laboratory (510) 231- 1793

<u>Colorado</u>

Length of Storage: 6 months Requirements to obtain NBS: Signed consent form from parents. Send form to fax (303) 691-4008. Contact: Dan Right (303) 692-3673

Newborn Screening Unit (303) 692-3670 **Notes:** Colorado also processes samples from Wyoming.

Connecticut

Length of Storage: 5 years Requirements to obtain NBS: Parents must sign release form Contact: Joseph Ubaike, Connecticut State Laboratory (860) 509-8565 Newborn Screening Lab (860) 920-6708 Connecticut Department of Public Health (860)509-8081 Notes: fax (860) 509-7720

Delaware

Length of Storage: 3 years Requirements to obtain NBS: Parental consent. Specimen is released to parents only. Contact: Pat Scott (302) 223-1494 Christina Pleasanton, NBS lab (302) 223-1520 Newborn Screening Program (302) 744-4544 Fax (302) 661-7227

District of Columbia

Length of Storage: 1 year Contacts: Yvockeea Monteiro, NBS Program (202) 442-9158 Yvette Clinton- Reid, Medical Consultant, Perinatal and Infant Health Bureau (202) 675-8080 Joseph Quashnock, Laboratory Director at Perkins Elmer (412) 220-2300 Karen Watts, Bureau Chief, Perinatal and Infant Health (202) 442-9405 Notes: No returned phone calls from attempts to contact officials in the District of Columbia. All information obtained from websites.

<u>Florida</u>

Length of Storage: 6 months. Lab retains records of screening results for 6 years Requirements to obtain NBS: Parental consent. Specimen sent to lab or medical examiner only. Contact: Newborn Screening Program (850) 245-4201 Lois Taylor, NBS Follow-up (850)245-4670 Bonafacio Dy, Acting Newborn Screening Director, Florida State Laboratory (904) 791- 1648

<u>Georgia</u>

Length of Storage: 12 weeks. Any tests confirmed or presumptive positive are kept for 2 years
Requirements to obtain NBS: Written request form approved by Georgia Department of Community Health. Parental consent in writing.
Contact: Pam Clark (404) 657-2862
Arthur Hagar, NBS lab (404) 327-6800
Newborn Metabolic Screening and Sickle Cell Disorders Program (404) 657-4143
Johanna Pringle, NBS Follow-up program (404) 463- 3987

<u>Guam</u>

-NBS testing in Guam is dependent on the birth facility. **National contact:** Margarita Gay, Administrator, Bureau of Family Health and Nursing Services (671) 735-7116

Notes: All information obtained from websites. *Guam Memorial Hospital*Length of Storage: 6 months
Notes: 90% of births in Guam take place at Guam Memorial Hospital, however only those with health insurance receive screening. *Sagua Managu*Length of Storage: 1 year
Notes: Specimens tested and stored at Oregon Public Health Laboratory *Naval Hospital*Length of Storage: unknown
Notes: Specimens tested at Pediatrix, a commercial testing facility

<u>Hawaii</u>

Length of Storage: 1 year Requirements to obtain NBS: Call to request release form. Contacts: Gwen Palmer, Program Coordinator, Hawaii Department of Health (808) 733-9069 Hawaii Genetics Program (808) 733-9055 Cheryl Hermerath, Northwest Regional NBS lab (503) 693-4172

<u>Idaho</u>

Length of Storage: up to 18 months Requirements to obtain NBS: Signed release form from parent(s) Web Access to test results, application can be found at http://healthandwelfare.idaho.gov/Portals/0/Health/WebRadApplication.pdf Contacts: Carol Christiansen (208) 334-4935 Idaho Newborn Screening (208)334-5962 Notes: More information can be found at http://nbs.dhw.idaho.gov Specimens sent to Oregon Lab. Signed release form is sent directly to the Idaho state. Alternatively, the MD can call the Oregon lab to get BS released to hospital. Oregon Lab contact is Cheryl Hermerath, (503) 693-4712 or (503) 693-4174

<u>Illinois</u>

Length of Storage: Normal results: minimum of 2-4 months. Abnormal results: 5 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Genetic and Newborn Screening (217)782-4977 Claudia Nash, Follow-up (217) 524- 4900 George Dizikes, Lab (312) 793-4745 Notes: Specimens are stored at room temperature. All requests for NBS are sent through legal department to get okay first.

<u>Indiana</u>

Length of Storage: normally 6 months, up to 3 years
Requirements to obtain NBS: Parental consent in writing.
Contacts: Holly Heindselman, Director, Genomics and Newborn Screening (317) 233- 1231
Genomics and Newborn Screening Program (888) 815-0006
Barb Lesko, Manager, Newborn Screening Lab (317) 491-6682
Notes: As of 11/29/2011, Indiana does not release NBS to other facilities. However, this policy may change in the future.

<u>lowa</u>

Length of Storage: 5 years
Requirements to obtain NBS: Request for release signed by the requesting MD and child's parents on official letterhead.
Contacts: Kim Piper, State Genetics Coordinator (515) 281- 6466
Stan Berberich, Iowa Neonatal Metabolic Screening Lab (319) 335- 4500
Michael Ramirez, IMNS Lab (515) 725-1630
Notes: The first year the NBS is stored at subzero temperatures, then after that at room temperature.

<u>Kansas</u>

Length of Storage: normal results are kept 1 month in freezer, abnormal results kept indefinitely Requirements to obtain NBS: Fax the request with the child's information on official letterhead. Contacts: Colleen Peterson (785) 296-1650 NBS Lab (785) 296- 1652 Newborn Screening (785) 291-3363 Notes: Fax (785) 286-0978

<u>Kentucky</u>

Length of Storage: Normal: 6 months. Abnormal: Indefinitely. Requirements to obtain NBS: Currently there is not formal procedure for release. Contacts: Dr. Mayfield Gibson (502) 564-4446 ext. 4400 Newborn Screening (502) 564-3756 ext 4367 Lea Mott, Newborn screening Lab (502) 564-4446 ext. 4456

<u>Louisiana</u>

Length of Storage: 1 month Requirements to obtain NBS: Legal release signed by parents to send specimen to facility of choice. Contacts: Terry Crockett, Manager, Biochemistry (504) 219-4696 Cheryl Harris, Program Administrator (504) 568-8254

Maine

Length of Storage: Indefinitely Contacts: Ellie Mulcahy, Director, (207) 287-4623 Shirley Helms, Coordinator (207) 287-5351 Newborn Bloodspot Screening Program (207) 287-5357 Notes: Specimens stored at -20.

Maryland

Length of Storage: 25 years

Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. **Contacts:** Fizza Gulamali-Majid, Newborn Screening Lab, General requests (410) 767-6099 **Notes:** Samples are stored for 6 months in freezer and there after at room temperature

Massachusetts

Length of Storage: 22 years

Requirements to obtain NBS: Massachusetts has different forms depending on the test to be done. Please call to request the correct form. Parental consent in writing is required.

Contacts: Dr. Roger Eaton, Newborn Screening Program Lab (617) 983-6300

<u>Michigan</u>

Length of Storage: Indefinitely

Requirements to obtain NBS: Michigan has specific protocol and release request forms. Please call to get forms.

Contacts: Harry Hawkins, Newborn Screening Lab (517) 335-8095 Bill Young, Follow-up program (517) 335- 9205

Notes: NBS from July 1984 to 2009 have been stored in an uncontrolled warehouse. All NBS collected after 2009 are frozen.

<u>Minnesota</u>

Length of Storage: Blood Spots with negative test results are retained for 71 days, with positive test results for 24 months, all tests are destroyed 24 months after being reported
Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing.
Contacts: Amy (651) 201-5451
Newborn Screening (651) 201-5466
Notes: Requests can be faxed to (651) 201-5471.

<u>Mississippi</u>

Length of Storage: Specimen cards stored for 1 year, records are stored for 2 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Can request form from State Department of Health, Genetic Services. Contacts: Philis Hoggatt, Follow-up Program (601) 576-7619 Joseph Quashnock, Newborn Screening Lab (412) 220-2300 ext. 133 Notes: Fax requests to (601) 576-7498

<u>Missouri</u>

Length of Storage: 5 years Requirements to obtain NBS: Parents must submit request in writing with patient's info. Contacts: Jami Kiesling, RN, BSN, Blood Spot Followup Contact (573) 751-6266 Patrick Hopkins, Newborn Screening Lab (573) 751-2662 State Public Health Lab (573) 751-3334 Notes: Requests can be faxed to (573) 522-8155. NBS will be sent to parent's home.

<u>Montana</u>

Length of Storage: Normal: 1 year. Abnormal: Indefinitely. Screening results kept for 2 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Linda Beischel, Newborn Screening Coordinator (406) 444-0984 Vicky Tibieri, NBS Lab Supervisor (406) 444-4030 Notes: Fax requests to (406) 444-1802

<u>Nebraska</u>

Length of Storage: 90 days Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Julie Luedtke, Newborn Screening and Genetics Program Manager (402) 471-6733 Newborn Screening (402) 471-0374

<u>Nevada</u>

Length of Storage: 1 year Contacts: Dawn Lopresti (775) 684- 5889 Mary Pennington, Health Program Manager, Newborn Screening Program (775) 684-3478 Cheryl Hermerath, NBS Laboratory (Oregon State Lab) (503) 693-4174 Requirements to obtain NBS: contact lab directly at (503) 693-4174 *As of July 1st 2014 contact lab at U Nevada (775) 688- 1335 Notes: NBS are tested and stored at Oregon State Public Health Laboratory, as of July 1st, 2014 will transfer to the lab at University of Nevada, Reno (775) 688- 1335

New Hampshire

Length of Storage: 6 months Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Linda Kincaid, Newborn Screening Program (603) 271-4225 Dr. Roger Eaton, NBS lab, roger.eaton@umassmed.edu Notes: NBS stored at -20.

New Jersey

Length of Storage: 23 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Scott Shone PhD, NBS lab (609) 530-8361 Marilyn Gorney-Daley, Follow-up Program (609) 984-0755 Newborn Screening and Genetic Services (609) 292 - 1582 Notes: NBS will be released only to a medical facility. Samples stored at ambient temperature and humidity.

New Mexico

Length of Storage: 1 year Requirements to obtain NBS: Parents must submit written request to Newborn Genetic Screening. Contacts: Brenda Romero, State Genetic Coordinator (505) 476-8857 Newborn Screening Program (505) 476-8868 Cheryl Hermerath, Northwest Regional NBS lab, (503) 693-4172

New York

Length of Storage: 27 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Michele Caggana, Newborn Screening Lab (518) 473-3854 Beth Vogel, Follow-up Program (518)474-7945 Newborn Screening Program (518) 473- 7552 Notes: Fax (518) 486-2693

North Carolina

Length of Storage: 5 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Shu Huey Chaing, NBS lab (919) 733-3937 Lara Percenti, Follow-up Program (919) 707-5634 State Lab of Public Health (919) 733 -7834 Notes: Fax (919) 715-8610

North Dakota

Length of Storage: Indefinitely Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Katie Bentz (701) 328-4538 Becky Bailey, Newborn Screening Director (701) 328-4526

<u>Ohio</u>

Length of Storage: Minimum 2 years

Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing.
Contacts: Sharon Linard, Ohio Department of Health Laboratory (614) 644-4659
Notes: Fax (614) 644-4648. Request must include patient information, testing to be completed, and amount of blood needed in the punch size. Request must state the Ohio Health Department in not financially responsible for the testing in any way. Request must be on hospital letterhead and include MD's signature. After testing, Ohio would like the results of the test run.

<u>Oklahoma</u>

Length of Storage: 42 days, after which parental consent is required to transfer the residual dried blood spot

Requirements to obtain NBS: Fax signed release form to (405) 271- 4892, parental consent on release form, request must include reason for NBS request from specialist

Contacts: Lisa (405) 271-6617

Tonya McCallister, Newborn Screening Lab (405) 271-5070 ext 57714 Soheila Haddad, Newborn Screening Lab (405) 271-5070 ext 57742

Notes: NBS stored at room temperature

<u>Oregon</u>

Length of Storage: 1 year Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Cheryl Hermerath, NBS lab manager (503) 693-4172 Newborn Screening Lab (503) 693-4100 Sara Deniston, Follow-up Coordinator (503) 693-4173 Notes: fax (503) 693-5601

Pennsylvania

Length of Storage: 8 months Requirements to obtain NBS: Signed HIPAA release form. Parental consent in writing. Contacts: Carolyn Ellison (717) 783-8143 Roxann Arbegast-Boes, Division of Newborn Screening and Genetics (717) 783-8143

Puerto Rico

Length of Storage: 2 years Requirements to obtain NBS: Written request stating the use of the NBS. Contacts: Pedro Juan Santiago Borrero, Director, Center for Inherited Diseases (787) 777-3535 ext. 7014 Notes: After 2 years, a random 10% of the NBS are kept.

<u>Rhode Island</u> Length of Storage: 23 years Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing.

Contacts: Barb McNeilly, Community Health Nurse (401) 222-4640 Newborn Screening Coordinator (401) 921- 7619 Chrisolee Larose (401) 222-5950 Khristine Campagna (401) 222-5927

South Carolina

Length of Storage: 12 months Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Kathy Tomashitis (803) 898-0619 John Reddic, Newborn Screening Lab (803)896- 9725 Notes: fax (803)898-0337

South Dakota

Length of Storage: 1 month Requirements to obtain NBS: Currently no formal procedure for release. Contacts: Lucy Fossen, SD Newborn Screening Program (605) 773-3737 Stanton Berberich, Iowa State Hygienic Lab (515) 725-1630

<u>Tennessee</u>

Length of Storage: Normal NBS: 12 months. Abnormal: Indefinitely. Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Chris McKeever, NBS lab (615) 262-6352 Newborn Screening Coordination and Follow-up (615) 532- 8462 Notes: Fax (615) 262-6447

<u>Texas</u>

Length of Storage: 2 years, unless parents indicated on a release form saying they would like the specimen to be stored up to 25 years. NBS collected before June 1, 2012 maybe stored for up to 25 years.

Requirements to obtain NBS: Contact Lynette for consent form. If unable to contact, the MD needs to submit the request in writing on letterhead with specific purpose of the release, indication that the person signing has the authority to request the sample and the signature of the mother. **Contacts:** Lynette Borgfeld (512) 776-7111, ext 2471 Laboratory Services Section (512) 776-7318

US Virgin Islands

Length of Storage: 1 year

Contacts: LaVerne Ragster, PhD, University of the Virgin Islands (340) 693-1000 Darlene Carty, US Virgin Islands Department of Health (340) 773-1311 C. Patricia Penn, Assistant Director, MCH and CSHCN Program (340) 776-3580 Mavis Matthew, Director, MCH and CSHCN Program (340) 713-9924 or (340) 713-9925 **Notes:** No returned phone calls from attempts to contact officials in the US Virgin Islands. All information obtained from websites.

<u>Utah</u>

Length of Storage: minimum of 90 days

Requirements to obtain NBS: Utah has specific protocol and release forms. Contact Kimberly Hart to obtain.

Contacts: Kimberly Hart (801) 584-8256, email kimhart@utah.gov Norm Brown, Newborn Screening Lab (801) 965-2556

<u>Vermont</u>

Length of Storage: Indefinitely Requirements to obtain NBS: Email a parental release form. Contacts: Cindy Ingham, Newborn Screening Program (802) 951-5180, Cindy.Ingham@ahs.state.vt.us Newborn Screening Program Fax (802) 951-1218

<u>Virginia</u>

Length of Storage: Normal: 6 months. Abnormal: 10 years. Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Kathleen Moline (804) 864-7712 Thomas Hickey (804) 648-4480, ext. 170 Newborn Screening Fax (804) 864-7807

Washington

Length of Storage: 21 years Requirements to obtain NBS: Consent form signed by both parents. Form available by request Contacts: Santosh Shaunak (206) 418-5410 Catherine Riley (206) 418-5508 Notes: Fax (206) 418-5415

West Virginia

Length of Storage: 3 months Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Newborn Metabolic Screening (301) 558-3530, (800) 642-8522 Kristel Fijolek, NBS Laboratory (304) 558-3530, ext. 2501 Debbie Templin, Follow-up Program (304) 356-4448

<u>Wisconsin</u>

Length of Storage: 1 year Requirements to obtain NBS: Fax request on hospital letterhead, include patient's name, DOB, mother's name at time of birth and hospital/city where born Contacts: Gary Hoffman (608) 262-4692 Newborn Screening Program Coordinator (608) 266-8904 Mei Baker, Newborn Screening Lab (608) 262-6547 Notes: Fax (608) 262-5494

Wyoming

Length of Storage: 6 months Requirements to obtain NBS: Submission of the request in writing. Parental consent in writing. Contacts: Carleigh Soule, Newborn Screening Program (307) 777- 6297 David Butcher, Colorado Dept. of Public Health lab (303) 692-3069 Notes: NBS stored at Colorado state lab. Consent forms need to be fax directly to lab at (303) 344-9989.