



Newborn Screening 9th Edition

		Region	Number of Screens	Initial Screening Age (in Hours)	Second Screening Age	RUSP Core Conditions		Adding Screens					Funding					Advisory Committee					Dried Bloodspot Retention (for informational purposes only)										Statute	Regulation	Website
						Number of Core Conditions/ Total Number	Screening for RUSP Core Conditions Grade	RUSP Auto-Inclusion/Add Conditions	National Recommendations Followed (Consider Condition Once on RUSP)	Pilot Studies Required	Time Frame of Implementation for RUSP Addition	Lab Test Implementation Period/Lab Test Addition Requirements	Adding Screens Grade	Fee 1/2 (USD)	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Advisory Committee	AC Meeting Frequency	AC Voluntary	AC Membership	AC Grade	Final Grade	DBS Retention Time	Data Retention Policy Exists?	Data Retention Time Normal/ Abnormal (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	Specimen Sharing Policies	Residual DBS Uses			
Alabama	AL	Southeast Regional Genetics Network (SERN)	2 (not mandated)	48	2-6 weeks	33/59	C	Department can add other heritable disorders	Yes	Yes	As recommended and approved by administration and advisory council	Between 6 months and 1 year	C	\$150/\$0	The newborn screening fee shall be set by the State Committee of Public Health based on the schedule of laboratory fees established by the Centers for Medicare and Medicaid Services (CMS) for use by Medicare and Medicaid	General funds	General funds	A	Yes	Semi-annually (Spring and Fall)	Yes	Consultants, physicians, parents, lab and followup staff, MOD, Sickle Cell Foundation	A	B	3 months	Yes	20+ /20+	N/A	N/A	Religious waiver	None	QA/QC purposes, Repeat purposes	§ 22-20-3	420-10-1	http://www.alabamapublichealth.gov/newbornscreening/
Alaska	AK	Western States Regional Genetics Network (WSRGN)	1	24-48	N/A	32/54	C	The department shall administer and provide services for testing for other heritable diseases that lead to intellectual disabilities, developmental disabilities, or both, and physical disabilities as screening programs accepted by current medical practice and as developed	No	No	None	N/A	C	\$190.50 and \$100 for non-requested repeats	7 ACC 80.030 & Sec.44.29.022: The Commissioner may establish fee through regulation (cannot be higher than the cost of administering the service, which the Commissioner can define)	Department of Health and Social Services	N/A	B	Yes	Semi-annually	Yes	Specialists, pediatricians, family practice, OB/GYN, direct entry midwives, families, hospital lab staff, hospital L&D/MBU staff, state NBS staff, regional lab staff, couriers	A	B	3 years	Yes	16-20/20+	N/A	N/A	Personal or Religious waiver	None	For reference purposes and to match babies/ ensure all were screened	Sec. 18.15.200	7 ACC 27.510	http://dhss.alaska.gov/dph/wcft/Pages/bloodspot/default.aspx
Arizona	AZ	Mountain States Regional Genetics Network (MSRGN)	2	24-36	5-10 days	35	B	The newborn screening program shall include all congenital disorders that are included on the RUSP adopted by the Secretary of the United States Department of Health and Human Services for both core and secondary conditions	Yes	No	2 years	Between 6 months and 1 year, Approval by Advisory Committee, New legislative action or change in state rules, Approval by Commissioner of Health	A	\$171	Director can establish fee by rule	NBS fund	N/A	B	Yes	Annually	Yes	7 physicians, including endocrinology, pediatrics, neonatology, family practice, otology, and obstetrics; neonatal nurse practitioner; audiologist; parent of child with disorder; representative from insurance; director of Medicaid program; representative from hospital	B	B	3 months (specimens of interest or positivity may be kept indefinitely)	Yes	20+ /20+	N/A	N/A	Submitter must supply education to family; if after education is provided, the family refuses screen, a waiver must be signed and kept by the hospital and the lab	None	QA/QC purposes, If there is enough, specimens will be used for re-validating	Sec. 14. Section 36-694, Arizona Revised Statutes	R9-13-201 through R9-13-208	https://azdhs.gov/preparedness/state-laboratory/newborn-screening/index.php
Arkansas	AR	Heartland Regional Genetics Network (Heartland)	1	24-72	N/A	35	B	(i) All newborn infants shall be tested for core medical conditions as listed in the Recommended Uniform Screening Panel recommended by the United States Secretary of Health and Human Services, in order to provide appropriate newborn screening guidelines to protect the health and welfare of newborns; (ii) For each core medical condition added to the list in the recommended uniform screening panel by the United States Secretary of Health and Human Services, the Department of Health or its designee, in accordance with § 20-15-304, shall begin testing for the newly added core medical conditions upon approval of the appropriation of funding by the General Assembly or funding under § 20-15-304, if required, or within thirty-six (36) months upon introduction to the recommended uniform screening panel recommended by the United States Secretary of Health and Human Services.	Yes	No	Testing is to begin 36 months after added to the RUSP	More than one year but less than two years	A	\$131 for initial and repeat	Board of Health may determine the amount based on the Department's cost to process the specimens	NBS fund	Medicaid	A	Yes	Quarterly	Yes	It is voluntary and serves as an advisory body to the health dept; the advisory committee in Arkansas is called the Arkansas Genetic Health Committee	A	A	1 year	Yes	20+ /20+	N/A	Yes	Parents can opt out for religious, medical, or philosophical reasons	Have an MOA with the state Center for Birth Defects Research group to release residual DBS with parental consent	Research purposes, QA/QC purposes	20-15-301	R 007.16.07-001	https://www.healthy.arkansas.gov/programs-services/topics/faqs-for-parents
California	CA	Western States Regional Genetics Network (WSRGN)	1	12-48	N/A	35/64	B	The department shall expand statewide screening of newborns to include screening for adrenoleukodystrophy (ALD) and any other disease that is detectable in blood samples as soon as practicable, but no later than two years after the disease is adopted by the federal Recommended Uniform Screening Panel (RUSP), or enrollment of the act amending this subdivision, whichever is later	Yes	No	2 years	More than 1 year but less than 2 years	A	\$210	The amount of the fee shall be established and periodically adjusted by the director in order to meet the costs of this section	NBS fund	N/A	A	No	N/A	N/A	California Newborn Screening Program; California Biobank Program Community Values Panel (CBCVP) has similar functions as other ad coms	B	A	Indefinitely	Yes	20+ /20+	Yes	Yes	Religious waiver	Policy for quality assurance with private entities to develop tests, Policy for research with appropriate approval, policy for quality assurance with other NBS program, Identified specimens must be consented for research, aggregate and de-identified data may be shared without consent	Research purposes, QA/QC purposes	HSC.Division 106. Part 5. Ch 1, Article 2.	17.1.4.9.3	https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/nbs/default.aspx



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Colorado	CO	Mountain States Regional Genetics Network (MSRGN)	2	by 48	8-14 days	34/45	B	(3) The state board shall promulgate rules concerning the requirements of the newborn screening program for genetic and metabolic disorders, including: (a) In addition to those conditions listed in subsection (1)(b) of this section, any other conditions for which testing must occur	No	No	None	More than 1 year but less than 2 years	C	\$111/\$0	The Executive Director of the Department of Public Health and Environment shall assess a fee that is sufficient to cover the direct and indirect costs	NBS fund	N/A	A	Yes	Quarterly	Yes	Must consist of at least nine members; the executive director of the department shall appoint members to the advisory committee	A	B	6 months	Yes	16-20/16-20	Parents may request DBS be released to them by submitting a letter	N/A	Personal objection	None	No	25.4.1001-06	5 CCR 1005-4	https://www.colorado.gov/pacific/cdphe/newbornscreening
Connecticut	CT	New England Regional Genetics Network (NERGN)	1	24-48	N/A	35/66	B	The Commissioner of Public Health shall publish a list of all the abnormal conditions for which the department screens newborns under the newborn screening program, which shall include, but need not be limited to ... and any other disorder included on the recommended uniform screening panel pursuant to 42 USC 300b-10, as amended from time to time, and as prescribed by the Commissioner of Public Health	Yes	Yes	None	N/A	B	\$110	The Commissioner of Public Health sets the fees to be charged to cover all expenses of the program (including testing, tracking, and treatment); there is a floor of \$98	General funds	N/A	A	Yes	Semi-annually	Yes	The Genetics Advisory Committee (GAC) is composed of geneticists, endocrinologists, hematologists, and immunologists from Yale, CCMC, and UCONN Health Center as well as representatives from CT birth hospitals, NICUs, patient advocacy groups and the CT NBS Program	A	A	3 years	Yes	3-5/3-5	N/A	N/A	Religious waiver	None	QA/QC purposes	19a.368a.Sec 19a-55.	https://eregulations.ct.gov/eRegsPortal/Browse/RCSA/Title_19aSubtitle_19a-55_HTML/	https://portal.ct.gov/DPH/Laboratory/Newborn-Screening/Newborn-Screening-Program
Delaware	DE	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24-48	N/A	35/55	B	Director of the Division of Public Health or designee shall determine the disorders subject to screening tests	Yes	No	None	N/A	C	\$135	The fee is determined annually in July based on the cost of the program	NBS fund	N/A	A	Yes	Quarterly	Yes	The Advisory Committee is appointed by the Governor, the 13 members consist of 3 individuals or parents of individuals affected by disorders identified by the screening panel; an ethicist; an attorney not employed by the state of Delaware; 3 pediatric physicians; the Medical Director of the Division of Public Health; the Laboratory Director for the Division of Public Health; a representative from the Department of services for Children, Youth and their Families; the Chair of the Midwifery Council and a member of the general public	A	B	90 days	No	20+/20+	No	Yes	Parental choice	None	Will only be used for activities to improve the screening program and/or develop new screening tests	16 Dec.C. §122.1 & 122.3, 29 Del.C. §7904	Title 16, 4107, sections 1.0-11.0	https://www.nemours.org/services/support/naidcsupport/newborn-screening.html
District of Columbia	DC	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24-48	N/A	35/62	B	The Mayor shall establish specific procedures for each screening through rulemaking and may revise the type of newborn screening that hospitals, birthing facilities, and nurse-midwives are required to conduct	Yes	N/A	Advisory letter of recommendations for addition and a legislative process	N/A	C	\$0	N/A	N/A	Title V funds	B	Yes	Quarterly	Yes	1) The Director of the Department of Health, or designee, who shall also serve as chairperson of the committee; 2) The Director of the Department of Health Care Finance, or designee; 3) The State Superintendent of Education, or designee; 4) Two consumer members with children under the age of 5 years; 5) A doctor practicing as a pediatric primary care provider; 6) A doctor practicing as a neonatologist; 7) A doctor practicing as an obstetrician-gynecologist in an ambulatory setting; 8) A doctor specialized in and practicing maternal-fetal medicine; 9) A health care professional specialized in and practicing genetics and newborn screening; and 10) A certified lactation counselor	A	B	1 year	N/A	N/A	N/A	N/A	Must be educated about importance of newborn screening prior to opting out	None	N/A	\$7-858	22-22-B21	https://dhealth.dc.gov/service/newborn-screening



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Florida	FL	Southeast Regional Genetics Network (SERN)	1	24-48	N/A	35/57	B	Newborns are tested for any condition included on the RUSP that the Council advises the Department should be included	Yes	No	After the Council makes its recommendation, the state has 18 months to implement if there is already a test in existence	More than one year but less than two years	A	\$15	Department of Health has the authority to charge and collect fees (not to exceed \$15 for each live birth) and must also submit a certification of the annual cost in the budget request, by July 1; the addition of a new condition must come with a legislative budget request for appropriations.	NBS fund	Newborn Screening services in Florida are jointly funded through a \$15.00 fee paid by birthing facilities for each live birth and the billing of the newborn screening tests performed by the Florida Newborn Screening Laboratory; Medicaid and private insurance companies are billed for the newborn screening tests; the Florida Newborn Screening Program does not bill families without insurance coverage	D	Yes	At least semi-annually or upon call of the chairperson	No	15 members appointed by the State Surgeon General; the council shall be composed of two consumer members, three practicing pediatricians, at least one of whom must be a pediatric hematologist, one representative from each of the four medical schools in the state, the State Surgeon General or his or her designee, one representative from the Department of Health representing Children's Medical Services, one representative from the Florida Hospital Association, one individual with experience in newborn screening programs, one individual representing audiologists, and one representative from the Agency for Persons with Disabilities; all appointments shall be for a term of 4 years	A	B	6 months	Yes	20+/20+	No	No	Parents can object for any reason. There must be a written record.	None	QA/QC purposes, use specimens for internal purposes (i.e. repeats)	383.14	64C-7.001 through 64C7.012	https://floridanewbornscreening.com/toolkit/newborn-screening-toolkit/
Georgia	GA	Southeast Regional Genetics Network (SERN)	1	24-48	N/A	35	B	The department shall be authorized to consider recommendations from the Newborn Screening and Genetics Advisory Committee established pursuant to subsection (i) of this Code section, to include disorders which are added to the federal Recommended Uniform Screening Panel and may be identified in the future to result in serious illness, severe physical or developmental disability, and death if undiagnosed and untreated	Yes	No	None	More than 2 years but less than 3 years	B	\$80.40	Department regulation	General funds	N/A	A	Yes	Semi-annually	Yes	"Newborn Screening and Genetics Advisory Committee (NBSAC)" is a multi-disciplinary group of professional and consumer representatives with knowledge and expertise in newborn screening programs appointed by the Commissioner of Public Health	A	A	4 months for normal specimens and 1 year for abnormal specimens	Yes	2 years or less	Yes (may do so after 12 weeks, in writing)	Yes	Religious beliefs	Policy for research with appropriate approval, policy for quality assurance with other NBS program	Research purposes, QA/QC purposes	O.C.G.A. 31-12-2, 31-1-3.2	http://rules.sos.state.ga.us/gac/511-5-5?urlRedirected=yes&data=admin&lookinfor=511-5-5	https://dph.georgia.gov/NBS
Hawaii	HI	Western States Regional Genetics Network (WSRGN)	1	24-48	N/A	33	C	Any other disease that may be specified by the Department	Yes	Yes	None	N/A	C	\$99	The Department of Health	NBS fund	N/A	A	Yes	Semi-annually	No	Medical staff, state staff, parents, community agencies	A	B	1 year	Yes	6-10	N/A	N/A	Religious beliefs	Policy for quality assurance with other NBS program	QA/QC purposes	HRS 6-321-291	HAR 11-143	http://health.hawaii.gov/genetics/programs/nbshome/
Idaho	ID	Western States Regional Genetics Network (WSRGN)	2	24-48	10-15 days	35/52	B	[Dir. of Health] To prescribe what tests shall be made for preventable diseases in addition to the test for phenylketonuria	No	No	None	New legislative action or change in state rules	C	\$121	Department of Health and Welfare regulates fees, equal to the cost of the test kit, analytical, and diagnostic services provided by the laboratory	NBS fund	Title V funds	A	Yes	Quarterly	Yes	Data not provided	A	B	18 months	No	16-20/16-20	No	Written consent	Religious beliefs	None	QA/QC	ID Stat. 39-909 through 910	https://adminrules.idaho.gov/rules/current/16/160212.pdf	https://healthandwelfare.idaho.gov/Children/NewbornScreening/tabid/870/Default.aspx
Illinois	IL	Midwest Genetics Network (MGN)	1	24-48	N/A	36/57	B	Illinois Department of Public Health shall promulgate and enforce rules and regulations requiring that every newborn be subjected to tests for genetic, metabolic, and congenital anomalies as the Department may deem necessary	Yes	Yes	No formal time frame	More than 1 year but less than 2 years, Approval by Commissioner of Health, Approval by Advisory Committee, Approval by Board of Health, Administrative Rule Change	C	\$128	The Department may levy additional fees according to such structure to cover the cost of providing this testing service and for the follow-up of infants with an abnormal screening test; however, additional fees may be levied no sooner than 6 months prior to the beginning of testing for a new genetic, metabolic, or congenital disorder	NBS fund	N/A	A	Yes	Semi-annually	No	Specialists for all disorders; parents; other organizational liaisons; pediatricians; local health department nurses; and state newborn screening laboratory and follow-up staff	A	B	2-6 months	Yes	2 or less/6-10	No	N/A	Religious beliefs	None	QA/QC purposes	410 ILCS 240	ILAC 77-1:i:661	http://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening
Indiana	IN	Midwest Genetics Network (MGN)	1	24-48	N/A	35/58	B	Beginning July 1, 2022, a perinatal genetics and genomics advisory committee with expertise in newborn screening, and through protocols established by the state department, may recommend the addition of a disorder to, or deletion of a disorder from, the required examination under this subsection. The state department shall adopt rules under IC 4-22-2 to add disorders to, or delete disorders from, the required examination under this subsection. The state department shall include any disorder added to or deleted from the required examination on a list on the state department's Internet web site. The perinatal genetics and genomics advisory committee shall affirm the addition of, or deletion of, any disorder to the examination requirement on an annual basis.	Yes	No	None	More than 3 years	C	\$120	The state department shall set the fee and procedures for disbursement under rules adopted under IC 4-22-2; the fee must be based upon the projected cost of the program; the proposed fee must be approved by the budget agency before the rule is adopted.	NBS fund	N/A	C	Yes	Quarterly	Yes	Indiana Perinatal Quality Improvement Collaborative, Perinatal Genetics and Genomics Advisory Board	A	B	6 months or 3 years	Yes	20+/20+	Yes	Yes	Religious waiver	Policy for research with appropriate approval	Research purposes	IC 16-41-17	3-3-1 through 3-3-14	https://www.in.gov/isdh/27437.htm



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Iowa	IA	Heartland Regional Genetics Network (Heartland)	1	24	N/A	34/53	B	All newborns and infants born in the state of Iowa shall be screened for all congenital and inherited disorders on the Iowa newborn screening panel as specified by the center; as new disorders are recognized and new technologies and tests become available, the center shall follow protocols developed by the department in regard to the addition of disorders to or deletion of disorders from the screening panel	Yes	No	Advisory committee must review new RUSP conditions within 12 months of addition to RUSP, and if recommending addition of the condition to Iowa's panel, the newborn screening program has 18 months to implement universal screening	More than 2 years but less than 3 years; Approval by Advisory Committee, Approval by Commissioner of Health, Approval by Board of Health, New legislative action or change in state rules	A	\$162	In consultation with the department, the SHL shall establish the newborn screening fee schedule in a manner sufficient to support the newborn screening system of care including, but not limited to, laboratory screening costs, short-term and long-term follow-up program costs, the newborn screening developmental fund, and the cost of the department's newborn screening data system	NBS fund	N/A	A	Yes	Quarterly	Yes	Membership is nominated from list of specific agencies and organizations; members appointed by director of Iowa HHS	A	A	5 years	Yes	20+ /20+	No	Yes	Waiver provided for any reason	Policy for quality assurance with other NBS program, policy for research with appropriate approval	QA/QC purposes, Research upon parent consent only; prohibited uses include commercial purposes, law enforcement or for forensic databases	None	IAC 641.4	https://dph.iowa.gov/newborn-screening
Kansas	KS	Heartland Regional Genetics Network (Heartland)	1	24-48	N/A	34	B	Secretary of Health and Environment shall adopt rules and regulations as needed to require, to the extent of available funding, newborn screening tests to screen for treatable disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American College of Medical Genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System"	Yes	Yes	No formal time frame	Between 6 months and 1 year/ Approval by Commissioner of Health, Approval by Advisory Committee, Approval by Board of Health	C	\$0	No fee collected	No fee collected	NBS Fund, funded through the medical assistance fee fund	B	Yes	Quarterly	No	The membership of the KACNS shall not be less than 15 nor more than 25 voting members appointed by the secretary of KDHE. Members shall be representative of stakeholders with interest in and concern for screening of newborns for congenital and inherited diseases/disorders and conditions and inborn errors of metabolism. Members shall be appointed for three year terms and may be reappointed for additional term(s). Ideal membership may consist of representation from the following categories: pediatric specialist relevant to each disorder screened; pediatric endocrinologist; pediatrician practicing in a Kansas community; family physician practicing in a Kansas community; neonatologist; pathologist; laboratory Ph.D. level or above chemist; hospital representative; registered/licensed dietitian practicing at a Kansas metabolic clinic; geneticist; genetic counselor; nurse practitioner practicing at a Kansas metabolic clinic; parent or consumer representative for each disorder, or class of disorders screened; medical ethicist; and such others as the Council determines necessary. Members may fulfill representation of more than one role.	A	B	30 days (confirmed cases are de-identified and stored indefinitely)	Yes	20+ /20+	No	N/A	Religious beliefs	Policy for quality assurance with other NBS program	QA/QC purposes	Kansas Stat. 65.180	KAR 28:4:501 through 521	http://www.kdheks.gov/newborn_screening/index.html
Kentucky	KY	Midwest Genetics Network (MGN)	1	24-48	N/A	35/59	B	Tests for inborn errors of metabolism or other inherited or congenital disorders and conditions for newborn infants as part of newborn screening shall be consistent with the U.S. Department of Health and Human Services' Recommended Uniform Screening Panel	Yes	Yes	No formal time frame	Between 6 months and 1 year; New legislative action or change in state rules, funding dependent	B	\$150	The Secretary of the Cabinet of Health	NBS fund	The secretary for health and family services or his or her designee shall apply for any federal funds or grants available through the Public Health Service Act and may solicit and accept private funds to expand, improve, or evaluate programs to provide screening, counseling, testing, or specialty services for newborns or children at risk for heritable disorders	A	Yes	Quarterly	Yes	Lab and follow-up; university specialists and dietitian; university lab personnel; genetic counselors	A	A	2 months	Yes	20+ /20+	No	Yes	Religious beliefs	Policy for quality assurance with other NBS program	QA/QC purposes	214.155	902 KAR 4:030	https://chfs.ky.gov/agencies/dph/dmch/cfhib/Pages/newbornscreening.aspx



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Louisiana	LA	Southeast Regional Genetics Network (SERN)	1	Greater than 24 hours	N/A	34	B	At least annually, the list shall be reviewed by the state health officer, in consultation with departmental genetic disease advisory subject matter experts, to determine whether additional conditions, including conditions added to the United States Department of Health and Human Services' Recommended Uniform Screening Panel (RUSP), should be recommended to the secretary of the department for inclusion therein; the department shall provide an annual report to the legislature, beginning March 1, 2024, of any condition added to the RUSP and the department's review and determination on the condition	Yes	No	No formal time frame	N/A	B	\$30	Fee in regulation	NBS fund	General funds, Medicaid reimbursement	B	Yes	Quarterly	No	There shall be representation from all medical schools within the state; the disciplines of genetics, pediatrics, obstetrics, and hematology shall be represented; representation from OPPHS shall include but not be limited to nutrition, laboratory, social work, handicapped children's services, maternal and child health and the physicians connected with these programs; there shall be two consumer representatives	B	B	1 month	Yes	20+	No	Yes	Any reason	Share specimens with CDC for QA/QC	Research purposes, QA/QC purposes	LA Rev Stat 40:1081.2	LAC 48 Part V Book 2 of 2 CH 63	https://ldh.la.gov/index.cfm/page/3859
Maine	ME	New England Regional Genetics Collaborative (NEGC)	1	24-48	N/A	35/56	B	The Department will consider changes in conditions to be screened as requested by the Joint Advisory Committee, the medical community or the public; the Department reviews the recommendations from the Advisory Committee on Heritable Disorders in Newborns and Children and the Recommended Uniform Screening Panel (RUSP), and data from medical experts and other newborn screening programs, when considering a new condition; rulemaking to add conditions will be conducted in accordance with 5 MRS §§ 8001-11008	Yes	No	No formal time frame	N/A	C	\$220	Commissioner	NBS fund	N/A	A	Yes	Semi-annually	Yes	Parents, representatives from hospitals, genetic counselors, specialists, nurses, state staff, NICU representatives, family advocate, and specialty clinic coordinator	A	B	Indefinitely	Yes	20+/20+	Yes	N/A	Religious beliefs	None	QA/QC purposes (released only with parental consent)	MRS 22:2:3:261	Rule 10 144c283	https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/bloodspot-screening/index.html
Maryland	MD	New York-Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	2	Collected at the hospital after the baby has been eating for at least 24 hours	7 days	34/61	B	In consultation with the State Advisory Council on Hereditary and Congenital Disorders, the Department shall determine the screening tests that the Department's public health laboratory is required to perform; the Secretary and the Advisory Council shall determine whether to approve the inclusion of a condition in the system for newborn screening within one year after the addition of the condition to the Recommended Uniform Screening Panel	Yes	No	If the Secretary and the Advisory Council approve the inclusion of a condition in the system for the newborn screening under subsection (e) of this section, the Department shall implement testing for the condition within 1 year after the date of the approval	N/A	A	\$106	The Secretary	NBS fund	N/A	A	Yes	Quarterly	Yes	The Advisory Council consists of 11 members appointed by the Secretary: 1 physician with expertise in childhood hearing status that affects speech- language skills, 3 from the field of education, 1 from the Department of Health, 1 mental health professional with expertise in the area of deafness, 2 parents, 1 from the MD Association of the Deaf, 1 audiologist with expertise in childhood hearing, 1 from the Alexander Graham Bell Association of MD	A	A	25 years	Yes	20+/20+	No	Yes	Religious beliefs	Policy for research with appropriate approval	Research purposes	https://phpa.health.maryland.gov/genetics/Pages/NBS-Legislation.aspx	CoMar 10-52-12	https://health.maryland.gov/laboratories/Pages/Newborn-Screening.aspx
Massachusetts	MA	New England Regional Genetics Network (NERGN)	1	24-48	N/A	35/66	B	The physician attending a newborn child shall cause said child to be subjected to tests for phenylketonuria, cretinism and such other specifically treatable genetic or biochemical disorders or treatable infectious diseases which may be determined by testing as specified by the commissioner; the commissioner may convene an advisory committee on newborn screening to assist him in determining which tests are necessary	No	Yes	No formal time frame	N/A	C	\$171	Newborn Screening Program	NBS fund	N/A	A	Yes	Annually	No	Membership of the committee shall include, but not be limited to, parents and other consumers, practicing pediatricians, public health officials, neonatologists, obstetricians, clinicians and researchers specializing in newborn diseases and disorders, clinical geneticists, birth hospital representatives, Newborn Blood Screening Program professionals, medical ethicists, and other experts as needed to represent a variety of related fields such as emerging technologies and health insurance.	B	B	15 years	Yes	11-15/20+	No	Yes	Religious beliefs	Policy for quality assurance with other NBS program, policy for research with appropriate approval	Research purposes, QA/QC purposes	General Laws 1, XVI, 111, 110A	105 CMR 270	https://nensp.umassmed.edu/
Michigan	MI	Midwest Genetics Network (MGN)	1	24-30	N/A	36/58	B	Treatable but otherwise disabling conditions as designated by the department	Yes	No	No formal time frame	N/A	C	135.29/ 122.6	Health department	NBS fund	N/A	A	Yes	Annually	No	10 member Quality Assurance Advisory Committee represents specified stakeholders	B	B	Up to 100 years	N/A	N/A	Yes	Yes	None	Policy for research with appropriate approval	Research purposes, QA/QC purposes	MI Public Health Code 333.5431	None	https://www.michigan.gov/mdhhs/adult-child-serv/childrenfamilies/hereditary



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				Number of Core Conditions/ Total Number	Screening for RUSP Core Conditions Grade	RUSP Auto-Inclusion/Add Conditions	National Recommendations Followed (Consider Condition Once on RUSP)	Pilot Studies Required	Time Frame of Implementation for RUSP Addition	Lab Test Implementation Period/Lab Test Addition Requirements	Adding Screens Grade	Fee 1/2 (USD)	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Advisory Committee	AC Meeting Frequency	AC Voluntary	AC Membership	AC Grade	Final Grade	DBS Retention Time	Data Retention Policy Exists?	Data Retention Time Normal/ Abnormal (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	Specimen Sharing Policies	Residual DBS Uses					
Minnesota	MN	Midwest Genetics Network (MGN)	1	24-48	N/A	35/61	B	The commissioner shall periodically revise the list of tests to be administered for determining the presence of a heritable or congenital disorder; revisions to the list shall reflect advances in medical science, new and improved testing methods, or other factors that will improve the public health. In determining whether a test must be administered, the commissioner shall take into consideration the adequacy of analytical methods to detect the heritable or congenital disorder, the ability to treat or prevent medical conditions caused by the heritable or congenital disorder, and the severity of the medical conditions caused by the heritable or congenital disorder; the list of tests to be performed may be revised if the changes are recommended by the advisory committee established under section 144.1255, approved by the commissioner, and published in the State Register	Yes	No	No formal time frame	More than 1 year but less than 2 years; Approval by Advisory Committee, Approval by Commissioner of Health	C	\$235	Defined in legislation- Commissioner can set fees	NBS fund	N/A	B	Yes	Semi-annually	Yes	The commissioner of health shall appoint an advisory committee to provide advice and recommendations to the commissioner concerning tests and treatments for heritable and congenital disorders found in newborn children. Membership of the committee shall include, but not be limited to, at least one member from each of the following representative groups: (1) parents and other consumers; (2) primary care providers; (3) clinicians and researchers specializing in newborn diseases and disorders; (4) genetic counselors; (5) birth hospital representatives; (6) newborn screening laboratory professionals; (7) nutritionists; and (8) other experts as needed representing related fields such as emerging technologies and health insurance; (b) The terms and removal of members are governed by section 15.059. Members shall not receive per diems but shall be compensated for expenses.	A	B	Indefinitely for specimens collected after August 1, 2014	Yes	20+/20+	Yes	Yes	Any reason	None	Research purposes, QA/QC purposes, see Subd. 5 for permissible uses without consent	MN Statutes 144.125	MAR 4615.0300 through 0760	http://www.health.state.mn.us/newbornscreening/
Mississippi	MS	Southeast Regional Genetics Network (SERN)	1	24-48	N/A	33/63	C	The State Department of Health shall establish, maintain and carry out a comprehensive newborn screening program designed to detect hypothyroidism, phenylketonuria (PKU), hemoglobinopathy, congenital adrenal hyperplasia (CAH), galactosemia, any other conditions listed on the Recommended Uniform Screening Panel (RUSP), and such other conditions as specified by the State Board of Health. The State Board of Health shall ensure that each condition listed on the RUSP is included in the comprehensive newborn screening program within three (3) years after being added to the RUSP and shall adopt any rules and regulations necessary to accomplish the program. If the department does not include a RUSP-listed condition in the comprehensive newborn screening program within three (3) years, the department shall provide a report on the status and reasons for the delay to the House and Senate Public Health Committees once a year after the three-year period.	Yes	No	3 years	N/A	A	\$110	State health officer	General funds	N/A	B	Yes	Semi-annually	Yes	The advisory committee shall be appointed by the Executive Director of the State Department of Health, and shall include at least two (2) pediatricians and one (1) consumer representative from a family that has experience with a newborn infant with an abnormal screening test. The State Department of Health shall maintain a list of each of the conditions included in the comprehensive newborn screening program, which shall be made available to physicians and other health-care providers who are required to provide for newborn screening testing under Section 41-21-201.	A	B	1 year	No	N/A	No	N/A	Religious beliefs	None	No	Miss. Code Ann. § 41-21-201	MSDH Rules 15:4:1:1	http://www.msdh.state.ms.us/msdhsite/_static/41_0_101.html



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Missouri	MO	Heartland Regional Genetics Network (Heartland)	1	24-48	All ill and premature infants require a second screen between 7 and 14 days of age	36/77	B	The Department of Health and Senior Services shall, subject to appropriations, expand the newborn screening requirements in section 191.331 to include potentially treatable or manageable disorders	Yes	Yes	No formal time frame	More than 3 years; Approval by Advisory Committee, new legislative action or change in state rules	C	\$102	Health department, subject to appropriation	MO Public Health Services Fund	Federal funds	D	Yes	Semi-annually	No	The membership of this committee shall consist of members as designated by statute throughout the state, to include health service providers and consumers. The committee shall be composed of persons who reside in the state of Missouri, and a majority shall be licensed physicians. Statutory requirements are that at least: One member shall be a specialist in genetics; One member shall be a licensed obstetrician/gynecologist; One member shall be a licensed pediatrician in private practice; One member shall be a consumer, family member of a consumer or representative of a consumer group; One member shall be a licensed physician experienced in the study and treatment of hemophilia; One member shall be a specialist in sickle cell anemia; and One member shall be a specialist in cystic fibrosis. The remaining members will be appointed based on their interest, experience, and knowledge such as an ethicist, an endocrinologist, an ear, nose and throat (ENT), and an audiologist. The Governor determines the length of the initial appointment and thereafter if reappointed the appointments are for three year intervals. Other members include a representative from the Department of Elementary and Secondary Education designated by the Commissioner of Education and a representative from the Department of Mental Health designated by the Director of the Department of Mental Health. Other non voting members shall include the representatives from each contracted genetic tertiary center. Members of the committee shall not receive any compensation for their services. The members of the committee will appoint a chairperson to serve for a two-year period. The Chairperson shall be appointed from among those members who have served on the committee for at least one year and selected by the group.	A	B	5 years	Yes	20+/20+	Yes	N/A	Religious beliefs	Policy for quality assurance with other NBS program, Policy for quality assurance with private entities to develop tests, Policy for research with appropriate approval	QA/QC purposes, Disorder Pilots and Implementations	191.332	19 CSR 25-36.010	https://health.mo.gov/living/families/genetics/newbornscreening/
Montana	MT	Mountain States Regional Genetics Network (MSRGN)	1	24-48	N/A	32/33	C	Department can add via rulemaking	Yes	No	No formal time frame	More than 3 years; New legislative action or change in state rules	C	\$134	Public Health and Human Services	State laboratory funds	N/A	A	Yes	Semi-annually	N/A	Montana's Newborn Screening Program	A	B	1 year	No	3-5/3-5	Yes	N/A	Any reason	Share specimens with medical consultants if needed	QA/QC purposes	MCA 50.19.2	MT Rule 37.57.3	https://dphhs.mt.gov/ecfsd/cshs/NewbornScreeningPrograms/index
Nebraska	NE	Heartland Regional Genetics Network (Heartland)	1	24-48	N/A	35	B	Other inherited or congenital infant or childhood-onset diseases as the Department of Health and Human Services may from time to time specify	No	No	No formal time frame	Between 6 months and 1 year; Approval by Commissioner of Health, Approval by Advisory Committee, Approval by Board of Health, New legislative action or change in state rules	C	\$86	Department	\$20 of the 86/ infant screened fee is placed in general Cash fund, primarily used for aid for metabolic foods/ formula	Title V Block grant supports admin	A	Yes	Quarterly	Yes	Members appointed by Chief Medical Officer of Dept. of Health and Human Services. Includes 4-5 consumers or parents of patients affected by screened conditions, laboratory representatives of pathology and chemistry, Pediatric, Neonatology and Family Practitioners, Pediatric subspecialist MD's to represent all types of conditions screened (e.g. Endocrine, Hematology, Metabolic etc.), metabolic nutritionists and APRN, Medicaid, Hospital Association and March of Dimes, and a Medical Ethicist. Non-voting participants include the program (management, follow-up and lab) representatives	A	B	3 months	Yes	20+/20+	No	Yes, May only be shared for research with consent, IRB approval and Chief Medical Officer approval	May only be shared for research with consent, IRB approval, and Chief Medical Officer approval	Research purposes, QA/QC purposes	NRS 71-519	NAC Title 181-2-001 through 010	http://dhhs.ne.gov/Pages/Newborn-134dhhs.ne.gov/Pages/Newborn-Screening.aspx	
Nevada	NV	Mountain States Regional Genetics Network (MSRGN)	2	24-48	10-14 days	31/57	D	The State Board of Health shall adopt regulations governing examinations and tests required for the discovery in infants of preventable or inheritable disorders, including tests for the presence of sickle cell disease and its variants and sickle cell trait; except as otherwise provided in this subsection, the examinations and tests required pursuant to subsection 1 must include tests and examinations for each disorder recommended to be screened by the Health Resources and Services Administration of the United States Department of Health and Human Services by not later than 4 years after the recommendation is published	Yes	No	Not later than 4 years after HRSA adds condition, contingency on funding	More than 3 years; Approval by Advisory Committee, Board of Regents and Advisory Committee required	A	\$81/\$0	If the State Public Health Laboratory increases the amount charged for performing such an examination or test pursuant to NRS 439.240, the Division shall hold a public hearing during which the State Public Health Laboratory shall provide to the Division a written and verbal fiscal analysis of the reasons for the increased charges	NBS fund	N/A	B	Yes	Quarterly	Yes	Hemoglobin is mandated but the rest is voluntary but all is combined. Committee members include specialty physicians in metabolic, hemoglobinopathies, cystic fibrosis, endocrine, immune disorders; metabolic dietician; neonatologist; birth hospital newborn screening coordinator, newborn screening program staff, march of dimes coordinator; hearing coordinator, cchd coordinator, and other guest representatives from state public health and hospital associations	A	B	6 months - 1 year	Yes	20+/20+	No	No	Sign test refusal form	None	QA/QC purposes	NRS 442.008	NAC 442.020	https://med.unr.edu/public-health-lab/newborn-screening#:~:text=The%20Nevada%20Newborn%20Screening%20Program,mental%20retardation%20and%20even%20death.



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New Hampshire	NH	New England Regional Genetics Network (NERGN)	1	24-48	N/A	35/42	B	Additional disorders shall be added to the newborn screening panel based upon, but not limited to, the following considerations: (a) The disorder is well-defined with a known incidence; (b) The disorder is associated with significant morbidity and/or mortality; (c) The disorder can be detected with a screening test that is ethical, safe, accurate, and cost-effective; (d) Effective treatment exists for the disorder, and that early treatment, meaning before the onset of symptoms, is more effective in improving health outcomes than later treatment	Yes	Yes	No formal time frame	N/A	C	\$146	The department shall establish and impose fees upon hospitals for the newborn screening tests performed	NBS fund	N/A	A	Yes	Semi-annually	No	(b) The NSAC shall be comprised of at least one individual from each of the following: (1) Health care sub-specialists with expertise relative to newborn screening, including, but not limited to, such specialties as: (2) A member of the health and human services oversight committee, as established by RSA 126-A:13, appointed by the chair of that committee; (3) A genetic counselor; (4) A parent of a child affected by a disorder for which there is a nationally recommended newborn screening test; (5) A midwife practicing outside the hospital setting; (6) A representative from the New Hampshire Pediatric Society; (7) A nurse with child health experience; (8) A representative from the New Hampshire Chapter of the March of Dimes; (9) A representative from the New Hampshire Hospital Association; (10) A representative from the department's public health laboratory; (11) The department's medical director or designee; (12) A representative from the department's maternal and child health program; (13) A representative from the department's children with special health care needs program; (14) A representative from the department's medicaid program; (15) A representative from a health insurance provider; and (16) A representative from the New Hampshire Academy of Family Practitioners; (c) Additional staff from the department may participate in the NSAC, but shall not be voting members.	A	A	6 months	Yes	2 years or less	No	Yes	Parents can refuse for any reason	Policy for research with appropriate approval	Research purposes	NH RSA Title X 132:10-a	NH Rules He-P 3008	https://www.dhhs.nh.gov/programs-services/population-health/maternal-child-health/newborn-screening-program
New Jersey	NJ	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24	N/A	35/62	B	The Newborn Screening Program in the Department of Health shall screen all infants born in this State based on the list of disorders that is recommended by the Newborn Screening Advisory Review Committee and approved by the Commissioner of Health, with consideration of the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services; the Commissioner of Health may issue regulations to assure that newborns are screened in a manner approved by the commissioner	Yes	Yes	No formal time frame	N/A	B	\$150	The Department of Health shall charge a reasonable fee for the screening, follow-up, treatment, and education performed pursuant to this act; the amount of the fee shall be adjusted by the commissioner as necessary to support the screening, follow-up, and treatment of newborn infants, and the education of physicians, hospital staffs, nurses, and the public as required by this act; the procedures for collecting the fee shall be determined by the commissioner	Laboratory revolving fund	NBS Fee, General Funds	A	Yes	Semi-annually	Yes	The Newborn Screening Advisory Review Committee (NSARC) shall include, but need not be limited to, medical, hospital, and public health professionals, scientific experts, and consumer representatives and advocates	A	A	23 years	Yes	20+/20+	No	Yes	Any reason	Policy for quality assurance with other NBS program, Policy for research with appropriate approval	Research purposes, QA/QC purposes	NJ Stats 26:2-11	https://www.nj.gov/health/fhs/nbs/documents/administrative_code_nbs.pdf	https://www.nj.gov/health/fhs/nbs/index.shtml
New Mexico	NM	Mountain States Regional Genetics Network (MSRGN)	2	24-48	10-14 days	35/49	B	In determining which other congenital diseases to screen for, the secretary shall consider the recommendations of the New Mexico pediatric society of the American Academy of Pediatrics	Yes	Yes	No formal time frame	N/A	C	\$240	The department of health's newborn screening program shall set the rate for newborn screening kits; the fees collected from purchase of the kits shall be utilized by the program for testing, quality assurance, and follow up of newborn screening conditions	General Funds	N/A	B	Yes	Annually	Yes	Specialists, genetic counselors, nutritionists, parent advocate and staff from the Department of Health	B	B	1 year	No	N/A	Yes (parents can request the card during the retention period)	N/A	Any reason	None	QA/QC purposes	24-1-6	7.30.6.11	https://nmhealth.org/about/phd/fhb/cms/nbgs/



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New York	NY	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24-36	N/A	36/60	B	It shall be the duty of the administrative officer or other person in charge of each institution caring for infants twenty-eight days or less of age and the person required in pursuance of the provisions of section forty-one hundred thirty of this chapter to register the birth of a child, to cause to have administered to every such infant or child in its or his care a test for diseases and conditions designated by the commissioner under regulations of the commissioner	No	No	No formal time frame	New legislative action or change in state rules, Approval by Commissioner of Health	C	\$0	N/A- Paid with special funds from the New York State and Federal governments	Special Revenue Account	Private/public partners	B	No	N/A	N/A	N/A	F	B	Up to 27 years	No	20+/20+	Yes	Yes	Religious beliefs	No information	Research purposes, QA/QC purposes, Specimens that are de-identified do not need written consent, but have to go through IRB; specimens that are identified must have written consent	PBH 2500-A	NYCRR Title 10 Ch II Subch. H Subpart 69.1-69.9	https://www.wadsworth.org/programs/newborn/screening
North Carolina	NC	Southeast Regional Genetics Network (SERN)	1	24-48	N/A	35/41	B	Commission shall amend the rules as necessary to ensure that each condition listed on the Recommended Uniform Screening Panel developed by the Secretary of the United States Department of Health and Human Services and the Advisory Committee on Heritable Disorders of Newborns and Children (the RUSP) is included in the Newborn Screening Program	No	Yes	3 years	N/A	A	\$128	The Commission, in consultation with the Secretary, Thirty-one dollars (\$31.00) of each fee collected pursuant to subsection (c) of this section shall be credited to this Fund and applied to the Newborn Screening Program to be used as directed in this subsection	NBS fund	N/A	A	Yes	Semi-Annually	Yes	Data not provided	B	B	5 years	Yes	3-5/3-5	No	N/A	Allowed based on religious beliefs	Policy for research with appropriate approval	QA/QC purposes	NC Statutes 130A-125	10A NCAC 43H.0314	https://slph.dph.ncdhhs.gov/newborn/
North Dakota	ND	Heartland Regional Genetics Network (Heartland)	1	24 hours	N/A	32	C	Designated by rule of the state health council	Yes	No	No formal time frame	N/A	C	\$109	Fee is administered and collected by the laboratory	Not touched by ND program	General Funds, Staff time is funded through the Title V Maternal and Child Health Block Grant	B	Yes	Quarterly	Yes	Variety of stakeholders throughout North Dakota, partners from Iowa Laboratory and Short-term Follow-up, Genetic counselors, Physicians, Nurses, Lab Techs, Medicaid representative, North Dakota Hospital Association, EHDI Program, family advocates, Family Voices, and state employees	A	B	18 years	Yes	20+/20+	Yes (parents can request the card)	Yes	May refuse for any reason	Shared with regional lab for QA	QA/QC purposes	ND Century Code 25-17	NDAC 33-06-16	https://nbs.health.nd.gov/
Ohio	OH	Midwest Genetics Network (MGN)	1	24 hours - 5 days	N/A	35/38	B	In the case of a disorder included within the federal Recommended Uniform Screening Panel, the council shall determine not later than six months after the date of the disorder's inclusion on the federal panel whether or not to recommend to the director that each newborn child be screened for the disorder, if the council recommends screening for the disorder, the council shall submit to the director as soon as practicable a recommendation for such screening	Yes	Yes	The director shall specify for screening a disorder recommended as described in division (C) (3)(b) of this section, with such screening to begin not later than one year after the date that the rule specifying the disorder for screening becomes effective	More than 1 year but less than 2 years; Approval by Advisory Committee, Approval by Commissioner of Health, New legislative action or change in state rules, Approved by the Director of Health	A	\$99	The director shall adopt rules in accordance with Chapter 119. of the Revised Code establishing a fee that shall be charged and collected in addition to or in conjunction with any laboratory fee that is charged and collected for performing the screenings required by this section	NBS fund	N/A	B	Yes	3 times per year	Yes	The council consists of fourteen members appointed by the director including individuals and representatives of entities with interest and expertise in newborn screening, including such individuals and entities as health care professionals, hospitals, children's hospitals, regional genetic centers, regional sickle cell centers, regional cystic fibrosis centers, newborn screening coordinators, and members of the public	A	B	2 years	Yes	20+/20+	No	N/A	Religious beliefs	Policy for research with appropriate approval	QA/QC, new test implementation and validation	ORC 3701.501	OAC 3701-55	https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Newborn-Screening/welcome-to-newborn-screening
Oklahoma	OK	Heartland Regional Genetics Network (Heartland)	1	24 hours and one minute	N/A	35/58	B	The State Board of Health shall make such rules and regulations pertaining to such tests as accepted medical practice shall indicate	Yes	No	No formal time frame	More than 2 years but less than 3 years; Approval by Advisory Committee, Approval by Commissioner of Health	C	\$160	The State Board of Health is hereby authorized to set up laboratory facilities and use existing facilities for the performance of examinations and tests for the detection of these diseases and make a reasonable charge therefor	NBS fund	N/A	A	Yes	Quarterly	Yes	This diverse group of 24 members includes clinical genetic and laboratory providers, primary care providers, related specialists, Indian health representatives, clergy, consumers, insurance and community representatives and 21 ex-officio members from Oklahoma State Department of Health (OSDH) programs and the Department of Human Services (DHS)	A	A	up to 42 days	Yes	20+/20+	No	Yes	Religious beliefs	None	QA/QC purposes, If there are requests for specimens to be used for research, there must be parental consent.	OSC 63.1.5.1.533	https://www.oscn.net/applications/oscn/DeliverDocument.asp?CiteID=98096	https://oklahoma.gov/health/services/children-family-health/screening-and-special-services/newborn-screening-program.html



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Oregon	OR	Western States Regional Genetics Network (WSRGN)	2	24-48	7-15 days	35/42	B	Every infant shall be given tests approved by the Oregon Health Authority for the detection of the disease of phenylketonuria and other metabolic diseases	Yes	Yes	No formal time frame	More than 2 years but less than 3 years; New legislative action or change in state rules	C	\$175	Oregon Health Authority	Funds support public health lab as a whole	N/A	B	Yes	Semi-annually	Yes	Medical consultants, parents, March of Dimes, Oregon Center for Children & Youth with Special Health Care Needs, genetic counselors, Oregon Pediatric Society, Maternal Child Health program	A	B	1 year	Yes	6-10/16-20	Yes	Yes	Religious beliefs	Policy for research with appropriate approval, Policy for quality assurance with other NBS program	Research purposes, QA/QC purposes	ORS 433.285	https://www.oregon.gov/oha/PH/LABORATORYSERVICES/NEWBORNSCREENING/Pages/newborn-screening-news.aspx	https://www.oregon.gov/oha/PH/LaboratoryServices/NewbornScreening/Pages/index.aspx
Pennsylvania	PA	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24-48	N/A	36/61	B	The department, with the approval of the Newborn Screening and Follow-up Technical Advisory [Committee] Board, shall establish, by transmitting notice to the Legislative Reference Bureau for periodic publication in the Pennsylvania Bulletin, changes to the lists under subsection (a)(1) and (2) of those diseases for which newborn children shall be screened and laboratory screening results reported. Diseases and conditions mandated for screenings and follow-up services shall, at a minimum, include: (1) diseases listed under section 3(a); (2) diseases added by the board under section 3(d) to the list of diseases under section 3(a); and (3) conditions listed in the Recommended Uniform Screening Panel by the United States Department of Health and Human Services	Yes	No	Within 2 years of addition to the RUSP but also added non-RUSP conditions	N/A	A	\$42	Health Department	General funds, used to pay lab for NBS	Title V block grant and State Funds	B	Yes	3 times per year	Yes	Newborn Screening and Follow-up Technical Advisory Board: specialists, parents, laboratory representatives, genetic counselors, etc.	A	B	1 year	Yes	20+	No	N/A	Religious beliefs	None	No	PA Statutes 35.3.621 through 625	http://www.pacodeandbulletin.gov/	https://www.health.pa.gov/topics/programs/Newborn-Screening/Pages/Newborn%20Screening.aspx
Rhode Island	RI	New England Regional Genetics Network (NERGN)	1	24-48	N/A	35	B	Conditions listed in rules	Yes	No	Depends on condition being added and infrastructure available	N/A	C	\$163	Health Department	NBS fund	N/A	A	Yes	Bi-monthly	Yes	Representatives include staff from birthing hospitals, public health, physicians, specialists, neonatologists	B	B	23 years	Yes	20+	No	N/A	Religious beliefs	N/A	No	RI General Laws 23-13-14	216-RICR-20-05-01	http://health.ri.gov/programs/detail.php?pgm_id=21/index.php
South Carolina	SC	Southeast Regional Genetics Network (SERN)	1	24-48	N/A	34/55	B	Department with consult from Advisory Committee	No	Yes	No formal time frame	More than 3 years; New legislative action or change in state rules, Approval by Advisory Committee, Approval by Commissioner of Health	C	\$127	Health Department	NBS fund, general funds	MCH Title V Funds	B	Yes	As needed	No	NBS Advisory Committee: Specialty care providers, primary care providers, program leadership and staff convened as needed by specialty and required by SC law	C	B	1 year, abnormal can be kept for longer	Yes	3-5 for normal, 16-20 for abnormal	No	N/A	Religious beliefs	None	QA/QC purposes	SC Code 44-37-40	SC Code of Regs 61-80 through 61-92	https://www.scdhec.gov/health-professionals/lab-certification-services/newborn-metabolic-screening
South Dakota	SD	Heartland Regional Genetics Network (Heartland)	1	24-48	N/A	33/50	C	Determined by Department of Health	No	No	No formal time frame	N/A	C	\$75	Nothing about fee in statute or regulation	No holding, fee goes to contracted lab	N/A	F	Yes	Ad hoc meetings through Department of Health	N/A	By Nomination to DOH	C	C	1 month	Yes	Less than 2 years	No	N/A	None	N/A	No	SDLRC 34-24-16	ARSD 44:19	https://doh.sd.gov/topics/maternal-child-health/pregnancy-early-childhood/newborn/newborn-screening/newborn-screening-advisory-committee/



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Tennessee	TN	Southeast Regional Genetics Network (SERN)	1	24-36	N/A	35/71	B	Every newborn infant shall be tested for phenylketonuria, hypothyroidism, galactosemia and other metabolic/genetic defects that would result in intellectual disability or physical dysfunction as determined by the department, through rules and regulations duly promulgated in accordance with the Uniform Administrative Procedures Act	Yes	Yes	Between 6 months and 1 year	Between 6 months and 1 year; Approval by Advisory Committee, Approval by Commissioner of Health	B	\$165	Commissioner	Placed into general funds	N/A	B	Yes	Quarterly	Yes	Genetics Advisory Committee: members include geneticists, hematologists, pulmonologists, immunologists, neonatologists, and a lawyer. The committee is chaired by the Assistant Commissioner of Family Health and Wellness and a Division Director from the Division of Laboratory Services.	A	B	1 year, confirmed positive identities indefinitely	Yes	20+	No	N/A	Religious beliefs	None	QA/QC purposes	https://law.justia.com/codes/tennessee/2021/title-68/chapter-5/part-4/section-68-5-401/	Tennessee Department of Health Rules 1200-15-01	https://www.tn.gov/newbornscreening
Texas	TX	Mountain States Regional Genetics Network (MSRGN)	2	24-48	7-14 days	33/57	C	Newborn screening in Texas includes the disorders found on the national Recommended Uniform Screening Panel for which funds are available and allocated for the screening	Yes	No	As funding allows	More than 1 year but less than 2 years; Funding must be approved	B	\$64	Commissioner	NBS fund, general revenue fund	The department administers the NBS account and may solicit and receive gifts, grants, and donations from any source for the benefit of the account	A	Yes	Required 3 times per year, at least one time in person	No	At least four physicians (at least two specializing in neonatal-perinatal medicine), at least two hospital representatives, at least two persons who have family members affected by a condition that is screened for, at least two healthcare providers involved in the delivery of screening services, follow up, or treatment	A	A	By default, up to 2 years. With parental decision form indicating permission, up to 25 years	Yes	20+	Yes	Yes	Religious beliefs	Policy for quality assurance with other NBS program, Policy for quality assurance with private entities to develop tests, Policy for research with appropriate approval	Research purposes, QA/QC purposes	Texas Health and Safety Code 2-B-33-A	TAC 25.1.37.D	http://www.dshs.state.tx.us/lab/newbornscreening.shtm
Utah	UT	Mountain States Regional Genetics Network (MSRGN)	2	24-48	7-16 days	36/53	B	The Department of Health, after consulting with the Newborn Screening Advisory Committee, will determine the disorders on the Newborn Screening Panel, based on demonstrated effectiveness and available funding	Yes	No	No formal time frame	Approval by Commissioner of Health, Approval by Advisory Committee	C	\$140 covers both screens	Legislature	NBS fund	N/A	D	Yes	Quarterly	No	In rules to have a committee; chair must have MD or PhD in genetic/metabolic or other relevant field; minimum of 7 people; Utah Hospital Association representative; community pediatrician; one family advocate; others as recommended	A	B	Minimum 90 days	Yes	20+	Yes	Yes (need consent for it to be identified)*	Religious beliefs	Policy for research with appropriate approval	Research purposes, QA/QC purposes; parents can request specimens for clinical testing (e.g. CMV)	https://le.utah.gov/xcode/Title26B/Chapter4/26B-4-5319.html	Rule 438-15	https://newbornscreening.health.utah.gov/
Vermont	VT	New England Regional Genetics Network (NERGN)	1	24-48	N/A	35	B	The Commissioner of Health is authorized to . . . adopt rules for the purpose of screening chronic diseases and developmental disabilities in newborns	No	No	No formal time frame	N/A	C	\$203	Health Department; The Department is authorized to accept contributions or gifts which are given to the State for any of the purposes as stated in this section, and the Department is authorized to charge and retain monies to offset the cost of providing newborn screening program services	NBS fund	N/A	A	Yes	As needed, according to current issues	Yes	Includes consumers; public health professionals; primary care; hospital medical, NICU, and laboratory representatives; state hospital association; and consulting specialists in genetics/metabolics; endocrinology; hematology; infectious diseases; cystic fibrosis	C	B	1 year unless parent requests otherwise	Yes	20 or more	Yes (may be destroyed earlier than 1 year at the written request of the infant's parent(s) or legal guardian(s))	N/A	Sign test refusal form for any reason	None	QA/QC purposes	VSA 18.003.115	CVR 13-140-057	https://www.healthvermont.gov/children-youth-families/health-care-children-youth/newborn-screening



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Virginia	VA	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24	N/A	35	B	Consistent with, but not necessarily identical to the [RUSP]	Yes	No	No formal time frame	More than 2 years but less than 3 years; Approval by Commissioner of Health, New legislative action or change in state rules, Approval by Board of Health, Approval by Advisory Committee	B	\$138	The testing laboratory is authorized to set the fee charged to birthing hospitals and physicians for purchase of newborn dried-blood-spot screening specimen collection kits in consultation with the department and in accordance with applicable state statutes and regulations	NBS fund	Title V	A	Yes	Semi-annually	Yes	Membership consists of 20 voting members including representation from major medical centers and higher institutions of learning, parents, American Academy of Pediatrics, Virginia Hospital & Healthcare Association, March of Dimes, etc. and represents multiple professions that contribute to the NBS system including midwives, genetic counselors, geneticists, pediatricians and obstetricians. Workgroups of the Advisory Committee may be formed in between meetings to address certain issues and report back to the larger committee.	A	B	Normal 6 months, abnormal 10 years	Yes	20+	No	N/A	Religious beliefs	Samples are only shared with the parent/legal guardian upon receipt of a notarized written consent form	QA/QC purposes	VA Code 32.1-65	VAC 12.5.71	http://www.vdh.virginia.gov/newborn-screening/
U.S. Virgin Islands	VI					34	*																												
Washington	WA	Western States Regional Genetics Network (WSRGN)	2	18-48	7-14 days	35/37	B	Determined by State Board of Health	No	Yes	No formal time frame	More than 1 year but less than 2 years; Approval by Board of Health, Approval by Advisory Committee, New legislative action or change in state rules	C	\$135	Health Department	NBS fund	N/A	A	Yes	Ad hoc	Yes	The Washington State Board of Health convenes a technical advisory committee (TAC) in order to determine which conditions to include in the newborn screen (NBS) panel	C	B	21 years	Yes	20+	Yes	Yes	Religious beliefs	Policy for quality assurance with other NBS program. Policy for research with appropriate approval	Research purposes, QA/QC purposes, also forensic studies and additional testing that is not research based	70.83 RCW	WAC 246-650	https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/NewbornScreening
West Virginia	WV	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	24 or prior to discharge	N/A	36/39	B	The hospital or birthing center in which an infant is born, the parents or legal guardians, the physician attending a newborn child, or any person attending a newborn child not under the care of a physician shall require and ensure that each such child be tested for phenylketonuria, galactosemia, hypothyroidism, sickle cell anemia and certain other diseases specified by the Bureau for Public Health	Yes	No	No formal time frame	N/A	C	\$186	Reviewed periodically by the Commissioner	NBS fund	Title V funds	A	Yes	Semi-annually	Yes	Lab and Follow-up, pediatric specialists, other members with an interest in Newborn Screening	B	B	3 months	No	20+	No	N/A	None	N/A	No	https://www.wvdhhr.org/nbms/HB2583_enr.pdf	CR 64-91-1 through 11	http://www.wvdhhr.org/nbms/
Wisconsin	WI	Midwest Genetics Network (MGN)	1	24-48	N/A	33/49	C	The department may direct the state laboratory to perform other tests on specimens for research and evaluation purposes related to congenital and metabolic disorders or laboratory procedures	No	No	N/A	Between 6 months and 1 year; Approval by Commissioner of Health, Approval by Advisory Committee	C	\$109	Health Department	State Laboratory of Hygiene	NBS Fee	B	Yes	Semi-annually	Yes	The present Wisconsin advisory process relies on seven subcommittees, with a wide range of expertise. The chairs of these subcommittees serve on an Umbrella Committee, joined by individuals representing various areas of expertise and stakeholders. In addition, there is a newly formed Addition/Deletion Advisory Committee that could meet on an ad hoc basis, unconstrained by the Umbrella Committee's present six-month schedule, to address screening for a new condition. This committee is constituted of individuals whose areas of expertise and experience include medicine and science; statistics and epidemiology; ethical, legal, social and policy analysis; laboratory medicine; and include representation from practicing physicians, the newborn screening program, and individuals with target conditions or their parents.	A	B	1 year	Yes	20+	No	Yes	Religious purposes, personal convictions	None	Research purposes, QA/QC purposes	https://docs.legis.wisconsin.gov/statutes/statutes/253/12	WI Admin. Code DHS 115.01-06	http://www.slh.wisc.edu/clinical/newborn/
Wyoming	WY	Mountain States Regional Genetics Network (MSRGN)	2	24-48	7-14 days	34/52	B	Determined by Advisory Committee	Yes	No	No	Approval by Advisory Committee	C	\$97	Department of Health determines fees in consultation with the advisory committee	NBS fund	General funds	A	Yes	As needed	No	State health officer, president of Wyoming state medical society, member designated by WY state pediatric society, board certified OB/GYN	C	B	6 months	No	3 to 5 years	No	N/A	Can opt out for any reason, but must sign waiver	None	No	35-4-801	Wyoming Administrative Rules Ref No. 048.0035.1.09072017	https://health.wyo.gov/publichealth/mch/newbornscreening/