

APPENDIX: NEWBORN SCREENING

STATE	Region	Number of Screens	Second Screening Age	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	Adding Screens Grade	Fee First Screening/ Second Screening (USD)	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age (In Hours)
AL	Southeast Regional Genetics Network (SERN)	2 (not mandated)	2-6 weeks	32/47	B	<u>Department can add other heritable disorders.</u>	Yes	Yes	As recommended and approved by administration and advisory council.	Between six months and one year.	B	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	48
AK	Western States Regional Genetics Network (WSRGN)	1	N/A	32/54	B	<u>The department shall administer and provide services for testing for other heritable diseases as screening programs accepted by current medical practice and as developed.</u>	No	No	None	N/A	B	159.50 and 100 for non-requested repeats .	<u>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).</u>	Department of Health and Social Services	N/A	B	24-48
AZ	Mountain States Regional Genetics Network (MSRGN)	2	5-10 days	33	B	<u>Director can add based on recommendations from the Advisory Committee that must include a cost-benefit analysis.</u>	No	No	None	Between six months and one year, Approval by Advisory Committee, New legislative action or change in state rules, Approval by Commissioner of Health.	B	36 for initial screen fee and 65 for second screen fee.	<u>Director can establish fee by rule, but the fee for the first screen cannot exceed 36.</u>	NBS fund	<u>General funds (appropriations) and Title V (Possible confirmation of Title V funds request attn.pg. 24 of the linked doc under q.9)</u>	B	24-36
AR	Heartland Regional Genetics Network (Heartland)	1	N/A	32	B	<u>If reliable and efficient testing techniques are available, all newborn infants shall be tested for other genetic disorders by employing procedures approved by the State Board of Health.</u>	Yes	No	None	N/A	B	131 for initial and repeat	<u>Board of Health may determine the amount based on the Department's cost to process the specimens</u>	NBS fund	Medicaid	A	24-72
CA	Western States Regional Genetics Network (WSRGN)	1	N/A	35/64	A	<u>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.</u>	Yes	Yes	2 years	More than one year but less than two years.	A	210	<u>The amount of the fee shall be established and periodically adjusted by the director in order to meet the costs of this section.</u>	NBS fund	N/A	A	12 to 48 hours

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AL	3 months	Yes	20+	N/A	N/A	Religious waiver	QA/QC purposes	B	Yes	Twice a year (spring and fall)	Yes	Consultants, physicians, parents, lab and followup staff, MOD, Sickle Cell Foundation	A	B	§ 22-20-3	420-10-1	http://www.alabamapublichealth.gov/newbornscreening/
AK	3 years	Yes	16-20 for normal, 20+ for abnormal	N/A	N/A	Personal or Religious waiver	No	C	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	Sec. 18.15.200	7 ACC 27.510	http://dhss.alaska.gov/dph/wcfh/Pages/bloodspot/default.aspx
AZ	3 months (specimens of interest or positiv screens may be kept indefinitely)	Yes	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.	QA/QC purposes	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	Sec 36-694	R9-13-201 through R9-13-208	https://azdhs.gov/preparedness/state-laboratory/newborn-screening/index.php
AR	2 years	Yes	20+	N/A	Yes	Parents can opt out for religious, medical, or philosophical reasons.	Research purposes, QA/QC purposes	A	Yes	Every quarter	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	20-15-301	R 007.16.07-001	https://www.health.arkansas.gov/programs-services/topics/faqs-for-parents
CA	Indefinitely	Yes	20+	Yes	Identified specimens must be consented for research; aggregate and de-identified data may be shared without consent	Religious waiver	Research purposes, QA/QC purposes	A	No	N/A	N/A	California Newborn Screening Program (Propose changing to: There is a yearly NBS Stakeholders Forum, but this is not a decision making body.) California Biobank Program Community Values Panel (CBCVP) has similar functions as other ad coms.	B	A	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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CO	Mountain States Regional Genetics Network (MSRGN)	2	8-14 days	34/45	B	<u>If the Department deems that a new condition should be added, it must report to the General Assembly.</u>	No	No	None	More than 1 year but less than 2 years	D	111/0	<u>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.</u>	NBS fund	N/A	A	by 48 hours
CT	New England Regional Genetics Network (NERGN)	1	N/A	35/66	A	<u>Must be added legislatively.</u>	Yes	Yes	None	N/A	D	110	<u>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.</u>	General funds	N/A	A	24-48
DE	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	35/55	A	<u>The Director of the Division of Public Health or designee shall determine the disorders subject to screening tests.</u>	Yes	No	None	N/A	B	135	<u>The fee is determined annually in July based on the cost of the program.</u>	NBS fund	N/A	A	24-48
DC	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	34/62	B	<u>(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.</u>	Yes	N/A	<u>Advisory letter of recommendations for addition and a legislative process.</u>	N/A	C	0	N/A	N/A	Title V funds, appropriations	B	24-48

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CO	6 months	Yes	3 to 5	N/A	N/A	Personal objection	No	D	Yes	Quarterly	Yes	<u>Must consist of at least nine members. The executive director of the department shall appoint members to the advisory committee.</u>	A	B	25.4.1001-06	5 CCR 1005-4	https://www.colorado.gov/pacific/cdphe/newborn-screening
CT	3 years	Yes	3 to 5	N/A	N/A	Religious waiver	QA/QC purposes	B	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	B	19a.368a.Sec 19a-55.	CAC §19a-55	https://portal.ct.gov/DPH/Laboratory/Newborn-Screening/Newborn-Screening-Program
DE	3 years	No	20+	No	Yes	Parental choice	<u>Will only be used for activities to improve the screening program and/or develop new screening tests.</u>	B	Yes	Every quarter	Yes	The Advisory Committee is appointed by the Governor. The 13 members consist of three individuals or parents of individuals affected by disorders identified by the screening panel; an ethicist; an attorney not employed by the state of Delaware; three 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	A	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/naidhcsupport/newborn-screening.html
DC	1 year	N/A	N/A	No	N/A	Must be educated about importance of newborn screening prior to opting out.	N/A	D	Yes	Every quarter	Yes	<u>Four consumer members; five nonconsumers (four of which must be licensed physicians in the space- one of which being a geneticist of endocrinologist); Director of the Department of Human Services or his or her designate shall be an ex officio or nonvoting member.</u>	A	B	Ch. 8B § 7-858.02	22.22-B21	https://dhealth.dc.gov/service/newborn-screening

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FL	Southeast Regional Genetics Network (SERN)	1	N/A	34/57	B	<u>Newborns are tested for any condition included on the RUSP that the Council advises the Department should be included.</u>	Yes	No	<u>After the Council makes its recommendation, the state has 18 months to implement if there is already a test in existence.</u>	The Genetics and Newborn Screening Advisory Council recommends the addition of a disorder to the Florida Department of Health.	B	15	<u>Department of Health has the authority to charge and collect fees (not to exceed \$15 for each live birth). 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.</u>	NBS fund	<u>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.</u>	D	24-48
GA	Southeast Regional Genetics Network (SERN)	1	N/A	35	A	<u>Commissioner of Public Health can change the panel listed in regulation. In doing so, the Commissioner may seek the guidance of the Advisory Committee.</u>	Yes	No	None	N/A	B	80.4	<u>Department regulation</u>	General funds	N/A	A	24-48
HI	Western States Regional Genetics Network (WSRGN)	1	N/A	31	B	<u>Any other disease that may be specified by the Department.</u>	Yes	Yes	None	N/A	B	99	The Department of Health	NBS fund	N/A	A	24-48
ID	Western States Regional Genetics Network (WSRGN)	2	7-14 days	35/52	A	<u>[Dir. of Health] To prescribe what tests shall be made for preventable diseases in addition to the test for phenylketonuria.</u>	No	No	None	N/A	B	120.7	<u>Department of Health and Welfare regulates fees, equal to the cost of the test kit, analytical, and diagnostic services provided by the laboratory.</u>	NBS fund	Title V funds	A	24-48

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FL	6 months	Yes	6-10	No	No	Parents can object for any reason. There must be a written record.	QA/QC purposes, use specimens for internal purposes (i.e. repeats)	B	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 four years.	A	B	383.14	64C-7.001 through 64C7.012	https://floridanewbornscreening.com/toolkit/newborn-screening-toolkit/
GA	2 months to 2 years	Yes	2 years or less	Yes (may do so after 12 weeks, in writing)	Yes	Religious beliefs	Research purposes, QA/QC purposes	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	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&lookingfor=511-5-5	https://dph.georgia.gov/NBS
HI	1 year	Yes	6-10	No	N/A	Religious beliefs	QA/QC purposes	B	Yes	Semi-annually	No	Medical staff, state staff, parents, community agencies.	A	B	HRS 6-321-291	HAR 11-143	http://health.hawaii.gov/genetics/programs/nbshome/
ID	18 months	No	16-20	No	Written consent	Religious beliefs	QA/QC, Research purposes w/ consent	A	Yes	Quarterly	Yes	Informal Stakeholders Committee. Currently committee of stakeholders includes: Idaho NBS Program Team; Dr. Perry Brown - CF Specialist; Dr. Leah Fleming - Metabolic Specialist; Dr. Ingrid Lundgren - Immune Deficiency Specialist.	A	A	ID Stat. 39-909 through 910	IDAPA 16.02.12	https://healthandwelfare.idaho.gov/Children/NewbornScreening/tabid/870/Default.aspx

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IL	Midwest Genetics Network (MGN)	1	N/A	36/57	A	<u>The 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.</u>	Yes	Yes	No formal time frame	More than one year but less than two years, Approval by Commissioner of Health, Approval by Advisory Committee, Approval by Board of Health, Administrative Rule Change.	B	128	<u>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.</u>	NBS fund	N/A	A	24-48
IN	Midwest Genetics Network (MGN)	1	N/A	35/58	A	<u>Disorders detected by tandem mass spectrometry or other technologies with the same or greater detection capabilities as tandem mass spectrometry, if the state department determines that the technology is available for use by a designated laboratory under section seven of this chapter" or "Inborn errors of metabolism that result in an intellectual disability and that are designated by the state department" or by legislation.</u>	Yes	No	None	More than three years	B	120	<u>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.</u>	NBS fund	N/A	C	24-48
IA	Heartland Regional Genetics Network (Heartland)	1	N/A	32/53	B	<u>All newborns and infants born in the state of Iowa shall be screened for all congenital and inherited disorders specified by the center and approved by the state board of health.</u>	No	Yes	No formal time frame	More than two years but less than three years- Approval by Advisory Committee, Approval by Commissioner of Health, Approval by Board of Health, New legislative action or change in state rules.	B	122	<u>The department shall annually review and determine the fee to be charged for all activities associated with the INSP. The review and fee determination shall be completed at least one month prior to the beginning of the fiscal year.</u>	NBS fund	N/A	A	24

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IL	2-6 months	Yes	2 years or less for normal/6-10 for abnormal	No	N/A	Religious beliefs	QA/QC purposes	B	Yes	Semi-annually	No	<u>Specialists for all disorders; parents; other organizational liaisons; pediatricians; local health department nurses; and state newborn screening laboratory and follow-up staff.</u>	A	A	410 ILCS 240	ILAC 77:1:i:661	http://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening
IN	6 months or 3 years	Yes	20+	Yes	Yes	Religious waiver	Research purposes	A	Yes	Every quarter	Yes	<u>Indiana Perinatal Genetics and Genomics Advisory Committee: the first task force meeting took place in December 2018 with participants from many groups, including geneticists, OB/GYNs, neonatologists, pediatricians, genetic counselors, disease specialists, laboratory specialists, Family and Social Services Administration, advocacy representatives, as well as local representatives from American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American College of Medical Genetics and Genomics, and others.</u>	A	B	IC 16-41-17	3-3-1 through 3-3-14	https://www.in.gov/isdh/27437.htm
IA	5 years	Yes	20+	No	Yes	Waiver provided for any reason	Research purposes, QA/ QC purposes, Forensics uses by court order.	A	Yes	Quarterly	Yes	<u>Membership is nominated from list of specific agencies and organizations. Members appointed by director of IDPH.</u>	A	A	https://www.legis.iowa.gov/docs/ico/code/136A.pdf	IAC 641.4	https://idph.iowa.gov/newborn-screening

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KS	Heartland Regional Genetics Network (Heartland)	1	N/A	34	B	<u>The 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."</u>	Yes	Yes	No formal time frame	Between six months and one 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	24-48
KY	Midwest Genetics Network (MGN)	1	N/A	35/59	A	<u>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.</u>	Yes	Yes	No formal time frame	Between six months and one year, New legislative action or change in state rules, Funding dependent.	A	150	<u>The Secretary of the Cabinet of Health</u>	NBS fund	<u>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.</u>	A	24-48
LA	Southeast Regional Genetics Network (SERN)	1	N/A	34/35	B	<u>The Louisiana Department of Health shall, after consultation with medical geneticists from each of the state's medical schools and by rule adopted in accordance with the Administrative Procedure Act, add to the genetic conditions tested for in Subsection A of this Section; however, no approved test for any genetic condition added shall be given to any child whose parents object thereto.</u>	Yes	No	No formal time frame	N/A	C	30	<u>Fee in regulation</u>	NBS fund	General funds, Medicaid reimbursement	B	Greater than 24 hours

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KS	30 days (confirmed cases are de-identified and stored indefinitely)	Yes	20+	No	N/A	Religious beliefs	QA/QC purposes	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	Kansas Stat. 65.180	KAR 28:4:501 through 521	https://www.kdhe.ks.gov/768/Newborn-Screening-Program
KY	2 months	Yes	20 or more	No	Yes	Religious beliefs	QA/QC purposes	B	Yes	Every quarter	Yes	Lab and follow-up; university specialists and dietician; university lab personnel; genetic counselors.	A	A	214.155	902 KAR 4:030	https://chfs.ky.gov/agencies/dph/dmch/cfhib/Pages/newbornscreening.aspx
LA	1 month	Yes	20+	No	Yes	Any reason	Research purposes, QA/QC purposes	A	Yes	Annually	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	LA Rev Stat 40:1081	LAC 48 Part V Book 2 of 2 CH 63	https://ldh.la.gov/index.cfm/page/3859

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ME	New England Genetics Collaborative (NEGC)	1	N/A	35/56	A	<u>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.</u>	Yes	No	No formal time frame	N/A	C	220	<u>Commissioner</u>	NBS fund	N/A	A	24-48
MD	New York-Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	2	7 days	34/61	B	<u>The Department, with the advice of the Council, shall select the disorders for which screening is required by the Newborn Screening Program.</u>	Yes	No	N/A	N/A	B	106	<u>The Secretary</u>	NBS fund	N/A	A	Collected at the hospital after the baby has been eating for at least 24 hours (or the latest possible time before the baby is discharged).
MA	New England Regional Genetics Network (NERGN)	1	N/A	32/66	B	<u>The commissioner may convene an advisory committee on newborn screening to assist him in determining which tests are necessary.</u>	No	Yes	No formal time frame	N/A	B	165.26	<u>Newborn Screening Program</u>	NBS fund	N/A	A	24-48
MI	Midwest Genetics Network (MGN)	1	N/A	35/58	A	<u>(i) Other treatable but otherwise disabling conditions as designated by the department.</u>	Yes	No	No formal time frame	N/A	B	135.29/ 122.6	<u>Health department</u>	NBS fund	N/A	A	24-30

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ME	Indefinitely	Yes	20+	Yes	N/A	Religious beliefs	QA/ QC purposes (released only with parental consent)	B	Yes	Semi-annually	Yes	Parents, representatives from hospitals, genetic counselors, specialists, nurses, state staff, NICU representatives, family advocate, and specialty clinic coordinator.	A	B	MRS 22:2:3:261	Rule 10 144c283	https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/bloodspot-screening/index.html
MD	25 years	Yes	20+	No	Yes	Religious beliefs	Research purposes	A	Yes	Quarterly	Yes	The Advisory Council consists of 11 members appointed by the Secretary: one physician with expertise in childhood hearing status that affects speech- language skills, three from the field of education, one from the Department of Health, one mental health professional with expertise in the area of deafness, two parents, one from the MD Association of the Deaf, one audiologist with expertise in childhood hearing, one from the Alexander Graham Bell Association of MD.	A	A	https://phpa.health.maryland.gov/genetics/Pages/NBS-Legislation.aspx	CoMar 10-52-12	https://health.maryland.gov/laboratories/Pages/Newborn-Screening.aspx
MA	15 years	Yes	20+	No	Yes	Religious beliefs	Research purposes, QA/ QC purposes	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	General Laws I, XVI, 111, 110A	105 CMR 270	https://nensp.umassmed.edu/
MI	Up to 100 years	N/A	N/A	Yes	Yes	None	Research purposes, QA/ QC purposes	A	Yes	Annually	No	10 member Quality Assurance Advisory Committee represents specified stakeholders.	B	A	MI Public Health Code 333.5431	None	https://www.health.state.mn.us/newbornscreening/

APPENDIX: NEWBORN SCREENING

STATE	Region	Number of Screens	Second Screening Age	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	Adding Screens Grade	Fee First Screening/ Second Screening (USD)	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age (In Hours)
MN	Midwest Genetics Network (MGN)	1	N/A	35/61	A	<u>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.</u>	Yes	No	No formal time frame	More than one year but less than two years, Approval by Advisory Committee, Approval by Commissioner of Health.	B	235	<u>Defined in legislation- Commissioner can set fees</u>	NBS fund	N/A	B	24-48
MS	Southeast Regional Genetics Network (SERN)	1	N/A	33/63	B	<u>Specified by the State Board of Health and as recommended by the American Academy of Pediatrics.</u>	Yes	No	No formal time frame	N/A	B	110/110	<u>State health officer</u>	General funds	N/A	B	24-48

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
MN	Indefinitely for specimens collected after August 1, 2014	Yes	20+	Yes	Yes	Any reason	Research purposes, QA/QC purposes	A	Yes	Semi-annually and EHD Advisory Committee meets 4x per year	Yes	<u>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.</u>	A	A	<u>MN Statutes 144.125</u>	<u>MAR 4615.0300 through 0760</u>	<u>https://www.revisor.mn.gov/statutes/cite/144.966</u>
MS	1 year	No	N/A	No	N/A	Religious beliefs	No	D	Yes	Semi-annually	Yes	<u>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.</u>	A	B	<u>MS Law Sec 201</u>	<u>MSDH Rules 15:4:1:1</u>	<u>http://www.msds.state.ms.us/msdhsite/static/41,0,101.html</u>

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MO	Heartland Regional Genetics Network (Heartland)	1	N/A	36/77	A	<u>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.</u>	Yes	Yes	No formal time frame	More than three years, Approval by Advisory Committee, New legislative action or change in state rules.	B	95/95	<u>Health department, subject to appropriation</u>	MO Public Health Services Fund	<u>Federal Funds</u>	D	24-48
MT	Mountain States Regional Genetics Network (MSRGN)	1	N/A	33/36	B	<u>Department can add via rulemaking.</u>	Yes	No	No formal time frame	More than three years, New legislative action or change in state rules.	C	134/134	<u>Public Health and Human Services</u>	NBS Fee; State Laboratory Funds	N/A	A	24-48

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
MO	5 years	Yes	20+	Yes	N/A	Religious beliefs	QA/QC purposes, Disorder Pilots and Implementations	A	Yes	Semi-annually	No	(191.305) The "Missouri Genetic Advisory Committee", consisting of fifteen members, is hereby created to advise the department in all genetic programs including metabolic disease screening programs, hemophilia, sickle cell anemia, and cystic fibrosis programs. Members of the committee shall be appointed by the governor, by and with the advice and consent of the senate. The first appointments to the committee shall consist of five members to serve three-year terms, five members to serve two-year terms, and five members to serve one-year terms as designated by the governor. Each member of the committee shall serve for a term of three years thereafter. 2. The committee shall be composed of persons who reside in the state of Missouri, and a majority shall be licensed physicians. At least one member shall be a specialist in genetics; at least one member shall be a licensed obstetrician/gynecologist; at least one member shall be a licensed pediatrician in private practice; at least one member shall be a consumer, family member of a consumer or representative of a consumer group; at least one member shall be a licensed physician experienced in the study and treatment of hemophilia; at least one member shall be a specialist in sickle cell anemia; and at least one member shall be a specialist in cystic fibrosis. 3. Members of the committee shall not receive any compensation for their services, but they shall, subject to appropriations, be reimbursed for actual and necessary expenses incurred in the performance of their duties from funds appropriated for that purpose.	A	B	http://revisor.mo.gov/main/OneChapter.AN28191	19 CSR 25-36.010	https://health.mo.gov/living/families/genetics/newbornscreening/
MT	1 year	No	3-5	No	N/A	Any reason	QA/QC purposes	B	Yes	Semi-annually	N/A	Montana's Newborn Screening Program	A	B	MCA 50.19.2	MT Rule 37.57.3	https://dphhs.mt.gov/ecfsd/cshs/newbornscreeningprograms/

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NE	Heartland Regional Genetics Network (Heartland)	1	N/A	35/36	A	And such other inherited or congenital infant or childhood-onset diseases as the Department of Health and Human Services may from time to time specify.	Yes	No	No formal time frame	Approval by Board of Health, Approval by Commissioner of Health, New legislative action or change in state rules, Approval by Advisory Committee.	B	86 (66 of fee covers all initial testing and requested repeats, filter paper, shipping, data management and results reporting. 20 of fee is returned to the State Program to subsidize the metabolic foods and formula program and administrative costs.)	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	24-48
NV	Mountain States Regional Genetics Network (MSRGN)	2	10-14 days	31/57	C	The State Board of Health shall adopt regulations governing examinations and tests required for the discovery in infants of preventable or inheritable disorders.	Yes	No	Not later than 4 years after HRSA adds condition, Contingency on funding.	More than three years, Approval by Advisory Committee, Board of Regents and Advisory Committee required.	B	81/0	The Newborn Screening Program is supported entirely with fees generated by birth registrations. Each person who is legally responsible for registering the birth of a child shall submit a fee of \$81 to the Division of Public and Behavioral Health.	NBS fund	The Newborn Screening Program is supported entirely with fees generated by birth registrations. Each person who is legally responsible for registering the birth of a child shall submit a fee of \$81 to the Division of Public and Behavioral Health.	B	24-48

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
NE	3 months	Yes	20+	No	Yes, May only be shared for research with consent, IRB approval and Chief Medical Officer approval.	None	Research purposes, QA/ QC purposes	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	A	NRS 71-519	NAC Title 181-2-001 through 010	http://dhhs.ne.gov/Pages/Newborn-Screening.aspx
NV	6 months - 1 year	Yes	20+	No	Consent is implied	Sign test refusal form	QA/QC purposes	B	Yes	Every 4 months	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 dietitian; 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	NRS 442.008	NAC 442.020	https://med.unr.edu/nsph/newborn-screening

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NH	New England Regional Genetics Network (NERGN)	1	N/A	35/42	A	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	B	146		NBS fund	N/A	A	24-48
NJ	(New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	34/61	B	Conditions determined by Commissioner	Yes	Yes	No formal time frame	N/A	B	150	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.	Laboratory revolving fund	NBS Fee, General Funds	A	24

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
NH	6 months	Yes	Less than 2 years	No	Yes	Parents can refuse for any reason.	Research purposes	A	Yes	Semi-annually	No	<p>(b) The NSAC shall be comprised of at least one individual from each of the following:</p> <p>(1) Health care sub-specialists with expertise relative to newborn screening, including, but not limited to, such specialties as:</p> <p>(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;</p> <p>(3) A genetic counselor;</p> <p>(4) A parent of a child affected by a disorder for which there is a nationally recommended newborn screening test;</p> <p>(5) A midwife practicing outside the hospital setting;</p> <p>(6) A representative from the New Hampshire Pediatric Society;</p> <p>(7) A nurse with child health experience;</p> <p>(8) A representative from the New Hampshire Chapter of the March of Dimes;</p> <p>(9) A representative from the New Hampshire Hospital Association;</p> <p>(10) A representative from the department's public health laboratory;</p> <p>(11) The department's medical director or designee;</p> <p>(12) A representative from the department's maternal and child health program;</p> <p>(13) A representative from the department's children with special health care needs program;</p> <p>(14) A representative from the department's medicaid program;</p> <p>(15) A representative from a health insurance provider; and</p> <p>(16) A representative from the New Hampshire Academy of Family Practitioners.</p> <p>(c) Additional staff from the department may participate in the NSAC, but shall not be voting members.</p>	A	A	NH RSA Title X 132:10-a	NH Rules He-P 3008	https://www.dhhs.nh.gov/dphs/bchs/mch/newborn.htm
NJ	23 years	Yes	20+	No	Yes	Any reason	Research purposes, QA/ QC purposes	A	Yes	Semi-annually	Yes	<p>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.</p>	A	A	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

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NM	Mountain States Regional Genetics Network (MSRGN)	2	10-14 days	34/49	B	<u>Determined by the Secretary, considering the recommendations of the New Mexico Pediatric Society of the American Academy of Pediatrics.</u>	Yes	Yes	No formal time frame	N/A	B	190	<u>The department of health's newborn screening program shall set the rate for newborn screening kits.</u>	NBS fund	N/A	A	24-48
NY	(New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	35/60	A	<u>Such other diseases and conditions as may from time to time be designated by the commissioner in accordance with rules or regulations prescribed by the commissioner.</u>	No	No	No formal time frame	New legislative action or change in state rules, Approval by Commissioner of Health	B	0	<u>N/A- Paid with special funds from the New York State and Federal governments.</u>	Special Revenue Account	<u>Private/public partners</u>	B	24-36
NC	Southeast Regional Genetics Network (SERN)	1	N/A	33/39	B	<u>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.</u>	No	Yes	3 years	N/A	A	128	<u>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.</u>	NBS fund	N/A	A	24-48
ND	Heartland Regional Genetics Network (Heartland)	1	N/A	32/32	B	<u>Conditions determined by State Health Council.</u>	Yes	No	No formal time frame	N/A	B	109	<u>Fee is administered and collected by the laboratory.</u>	Not touched by ND program	General Funds, NBS Fee, Staff time is funded through the Title V Maternal and Child Health Block Grant	B	24 hours
OH	Midwest Genetics Network (MGN)	1	N/A	33/38	B	<u>Conditions listed in rules</u>	Yes	Yes	No formal time frame	More than one year but less than two years, New legislative action or change in state rules, Approval by Commissioner of Health, Approval by Advisory Committee, Approved by the Director of Health.	C	74.61/74.61	<u>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.</u>	NBS fund	N/A	B	24 hours - 5 days

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
NM	1 year	No	N/A	Yes (parents can request the card during the retention period)	N/A	Any reason	QA/QC purposes	B	Yes	Annually	Yes	Specialists, genetic counselors, nutritionists, parent advocate and staff from the Department of Health.	B	B	NM Stat 24-1-6	https://regulations.justia.com/states/new-mexico/title-7/chapter-30/part-6/	https://nmhealth.org/about/phd/fhb/cms/nbgs/
NY	Up to 27 years	No	N/A	Yes	Yes	Religious beliefs	Research purposes, QA/ QC purposes	A	No	N/A	N/A	N/A	F	B	NY Laws PBH-25-1-2500-a	NYCRR Title 10 Ch II Subch. H Subpart 69.1-69.9	https://www.wadsworth.org/programs/newborn/screening
NC	5 years	Yes	3-5	No	N/A	Allowed based on religious beliefs	QA/QC purposes	B	Yes	Semi-Annually	Yes	North Carolina Newborn Screening Advisory Committee	B	B	NC Statutes 130A-125	10A NCAC 43H.0314	https://publichealth.nc.gov/wch/families/newbornmetabolic.htm
ND	18 years	Yes	20+	Yes (parents can request the card)	Yes	May refuse for any reason	QA/QC purposes	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	ND Century Code 25-17	NDAC 33-06-16	https://nbs.health.nd.gov/
OH	2 years	Yes	20+	No	N/A	Religious beliefs	QA/QC, new test implementation and validation	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	ORC 3701.501	OAC 3701-55	https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Newborn-Screening/welcome-to-newborn-screening

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OK	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	35/58	A	<u>Board of Health</u>	No	No	No formal time frame	More than two years but less than three years, New legislative action or change in state rules, Approval by Commissioner of Health, Approval by Advisory Committee.	B	137.28	<u>Board of Health</u>	NBS fund	N/A	A	24 hours and one minute
OR	Western States Regional Genetics Network (WSRGN)	2	7-15 days	34/42	B	<u>Conditions listed in rules</u>	Yes	Yes	No formal time frame	More than two years but less than three years, New legislative action or change in state rules.	C	80 for 2 specimen kit	<u>Oregon Health Authority</u>	Funds support public health lab as a whole	NBS Fee, General Funds	B	24-48
PA	(New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	35/61	A	<u>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.</u>	Yes	No	Within two years of addition to the RUSP but also added non-RUSP conditions.	N/A	B	39.8	Health Dept	General funds	<u>Title V block grant and State Funds</u>	B	24-48
RI	New England Regional Genetics Network (NERGN)	1	N/A	35/35	A	<u>Conditions listed in rules</u>	Yes	No	Depends on condition being added and infrastructure available.	N/A	C	162.98	<u>Health Department</u>	NBS fund	N/A	A	24-48
SC	Southeast Regional Genetics Network (SERN)	1	N/A	34/55	B	<u>Department with consult from Ad Com</u>	Yes	Yes	No formal time frame	More than three years, New legislative action or change in state rules, Approval by Advisory Committee, Approval by Commissioner of Health.	B	127	<u>Health Department</u>	NBS fund, general funds	<u>MCH Title V Funds</u>	B	24-48

APPENDIX: NEWBORN SCREENING (CONTINUED)

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OK	up to 42 days	Yes	20+	No	Yes	Religious beliefs	QA/QC purposes, at parental request for further testing for research.	A	Yes	Quarterly	Yes	<u>A standing committee of the Oklahoma Genetics Advisory Council (OGAC) shall advise the Department on newborn screening issues.</u>	A	A	<u>OSC 63.1.5.1.533</u>	<u>OAC 310:550-5-2</u>	https://www.ok.gov/health/Family_Health/Screening_&Special_Services/Newborn_Screening_Program/index.html
OR	1 year	Yes	6-10 for normal, 16-20 for abnormal	Yes	Yes	Religious beliefs	<u>Research purposes, QA/QC purposes</u>	A	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	<u>ORS 433.285</u>	<u>OAR 333-024-1070</u>	https://www.oregon.gov/oha/ph/LaboratoryServices/NewbornScreening/Pages/index.aspx
PA	1 year	Yes	20+	No	N/A	Religious beliefs	No	D	Yes	3 times per year	Yes	<u>Newborn Screening and Follow-up Technical Advisory Board: specialists, parents, laboratory representatives, genetic counselors, etc.</u>	A	B	<u>PA Statutes 35.3.621 through 625</u>	<u>PA Code Title 28 § 28</u>	https://www.health.pa.gov/topics/programs/Newborn-Screening/Pages/Newborn%20Screening.aspx
RI	23 years	Yes	20+	No	N/A	Religious beliefs	No	C	Yes	Bi-monthly	Yes	Representatives include staff from birthing hospitals, public health, physicians, specialists, neonatologists.	B	B	<u>RI General Laws 23-13-14</u>	<u>216-RICR-20-05-01</u>	https://health.ri.gov/programs/detail.php?pgm_id=175
SC	1 year, abnormal can be kept for longer	Yes	3-5 for normal, 16-20 for abnormal	No	N/A	Religious beliefs	QA/QC purposes	B	Yes	As needed	No	NBS Advisory Committee: Specialty care providers, primary care providers, program leadership and staff convened as needed by specialty.	C	B	<u>SC Code 44-37-40</u>	<u>SC Code of Regs 61-80 through 61-92</u>	https://scdhc.gov/health-professionals/health-services-facilities/lab-certification-services/newborn-screening

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SD	Heartland Regional Genetics Network (Heartland)	1	N/A	32/50	B	<u>Determined by state Department of Health</u>	No	No	No formal time frame	N/A	B	75	<u>Dept</u>	No holding, fee goes to contracted lab.	N/A	B	24-48
TN	Southeast Regional Genetics Network (SERN)	1	N/A	35/71	A	<u>Determined by state Department of Health</u>	Yes	Yes	<u>Between 6 months-1 year</u>	Between six months and one year, Approval by Advisory Committee, Approval by Commissioner of Health.	B	165	<u>Commissioner</u>	NBS fund	N/A	A	24-36
TX	Mountain States Regional Genetics Network (MSRGN)	2	7-14 days	33/57	B	<u>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.</u>	Yes	No	As funding allows	More than one year but less than two years, Funding must be approved.	B	63.55	<u>Commissioner</u>	<u>NBS fund, general revenue fund</u>	<u>The department administers the NBS account and may solicit and receive gifts, grants, and donations from any source for the benefit of the account.</u>	A	24-48
UT	Mountain States Regional Genetics Network (MSRGN)	2	14 days	33/53	B	<u>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.</u>	Yes	No	No formal time frame	Approval by Commissioner of Health, Approval by Advisory Committee.	B	125, covers both screens	<u>Legislature</u>	NBS fund	N/A	D	24-48

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
SD	1 month	Yes	Less than 2 years	No	N/A	None	No	F	Yes	Ad hoc meetings through Department of Health	N/A	South Dakota Newborn Screening Program	C	C	SDLRC 34-24-16	ARSD 44:19	https://doh.sd.gov/family/newborn/Screening/AdvisoryCommittee.aspx
TN	1 year, confirmed positive identities indefinitely.	Yes	20+	No	N/A	Religious beliefs	QA/QC purposes	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	A	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
TX	By default, up to 2 years. With parental decision form indicating permission, up to 25 years.	Yes	20+	Yes	Yes	Religious beliefs	Research purposes, QA/ QC purposes	A	Yes	Required 3x 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	Texas Health and Safety Code 2-B-33-A	TAC 25.1.37.D	https://www.dshs.texas.gov/newborn-screening-program
UT	>90 days	Yes	20+	Yes	Yes (need consent for it to be identified)*	Religious beliefs	Research purposes, QA/ QC purposes	A	Yes	Quarterly	No	(1) Newborn Screening Advisory Committee shall be composed of at least 9 members as follows: (a) an individual with an advanced degree (MS/PhD/MD) in genetics or other relevant field, who will serve as Chair; (b) a representative from the Utah Hospital Association; (c) a community pediatrician; (d) the Director of the Division of Disease Control and Prevention; (e) an advocate or a consumer of a newborn screening services; (f) clinical consultants for the Newborn Screening program; (g) a representative from the Utah Public Health Laboratory (h) a representative from the Newborn Screening Follow-up Program; (i) a representative from the research community with knowledge about disorders considered for future addition to the newborn screening panel. (2) The Department Executive Director shall approve committee membership with counsel from the advisory committee. (3) The term of committee members shall be four years; (a) members may serve up to three additional terms as requested; (b) if a vacancy occurs in the committee membership for any reason, a replacement shall be appointed for the unexpired term in the same manner as the original appointment; (c) a majority of the committee constitutes a quorum at any meeting. If a quorum is present, the action of the majority of members shall be the action of the advisory committee. (4) The committee shall: (a) advise the Department on policy issues related to newborn screening services; (b) provide guidance to programs and functions within the Department having to do with newborn screening services and (c) evaluate potential tests that could be added to newborn or population screening and make recommendations to the Department.	A	B	Utah Code 26-10-6	Rule 438-15	https://newbornscreening.health.utah.gov/

APPENDIX: NEWBORN SCREENING

STATE	Region	Number of Screens	Second Screening Age	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	Adding Screens Grade	Fee First Screening/ Second Screening (USD)	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age (In Hours)
VT	New England Regional Genetics Network (NERGN)	1	N/A	35	A	<u>The Commissioner of Health is authorized to... (5) adopt rules for the purpose of screening chronic diseases and developmental disabilities in newborns.</u>	No	No	No formal time frame	N/A	C	203	<u>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.</u>	NBS fund	N/A	A	24-48
VA	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	35	A	<u>Consistent with, but not necessarily identical to the [RUSP].</u>	Yes	No	No formal time frame	More than two years but less than three 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	<u>G. 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.</u>	NBS fund	<u>Title V</u>	A	24
WA	Western States Regional Genetics Network (WSRGN)	2	7-14 days	34/37	B	<u>Determined by State Board of Health</u>	No	Yes	No formal time frame	More than one year but less than two years, Approval by Board of Health, Approval by Advisory Committee, New legislative action or change in state rules	B	119.30	<u>Health Department</u>	NBS fund	N/A	A	18-48
WV	New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC)	1	N/A	32/39	B	<u>Conditions specified by the state Public Health Commissioner.</u>	Yes	No	No formal time frame	N/A	B	125	<u>Reviewed periodically by the Commissioner</u>	NBS fund	<u>Title V funds</u>	A	24 or prior to discharge

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
VT	1 year unless parent requests otherwise	Yes	20 or more	<u>Yes (may be destroyed earlier than one year at the written request of the infant's parent(s) or legal guardian(s)).</u>	N/A	May opt out for any reason	QA/QC purposes	B	Yes	As needed	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.	A	B	<u>VSA 18.003.115</u>	<u>CVR 13-140-057</u>	https://www.healthvermont.gov/children-youth-families/health-care-children-youth/newborn-screening
VA	Normal 6 months, abnormal 10 years	Yes	20+	No	N/A	Religious beliefs	QA/QC purposes	B	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	<u>VA Code 32.1-65</u>	<u>VAC 12.5.71</u>	http://www.vdh.virginia.gov/newborn-screening/
WA	21 years	Yes	20+	Yes	Yes	Religious beliefs	<u>Research purposes, QA/QC purposes, also forensic studies and additional testing that is not research based.</u>	A	Yes	Ad hoc	Yes	Newborn Screening Panel Advisory Committee	C	B	<u>70.83 RCW</u>	<u>WAC 246-650</u>	https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/NewbornScreening
WV	3 months	No	20+	No	N/A	None	No	F	Yes	Semi-annually	Yes	Lab and Follow-up, pediatric specialists, other members with an interest in Newborn Screening.	B	B	<u>WV Code 16-22-1-5</u>	<u>CR 64-91-1 through 11</u>	http://www.wvdhhr.org/nbms/

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WI	Midwest Genetics Network (MGN)	1	N/A	33/49	B	<u>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.</u>	No	No	N/A	Lab test implementation period six months-one year, Approval by Commissioner of Health, Approval by Advisory Committee.	B	109	<u>Health Department</u>	State Laboratory of Hygiene	N/A	B	24-48
WY	Mountain States Regional Genetics Network (MSRGN)	2	7-14 days	32/52	B	<u>Determined by Advisory Committee</u>	Yes	No	No	Approval by Advisory Committee	B	84	<u>Department of Health determines fees in consultation with the advisory committee.</u>	NBS fund	General funds	A	24-48

Newborn Screening Sources:

- 1) NORD Review of State Statutes and Administrative Code
- 2) NewSTEPS, "NewSTEPS State Profiles" November 2021. <https://www.newsteps.org/data-resources/state-profiles>
- 3) Baby's First Test, "What your state offers" November 2021. <https://www.babysfirsttest.org/>
- 4) Association of Public Health Laboratories, "State Regulatory and Legislative Tracking" November 2021. <https://www.aphl.org/policy/Pages/State-Legislative-Tracking.aspx>
- 5) Health Resources & Services Administration (HRSA), "Newborn Screening Information Center" November 2021. <https://newbornscreening.hrsa.gov/>

APPENDIX: NEWBORN SCREENING (CONTINUED)

STATE	DBS Retention Time	Data Retention	Data Retention Time (Years)	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt-Out Policy for Screening	Research of DBS	DBS Use Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Final Grade	Statute	Regulation	Website
WI	1 year	Yes	20+	No	Yes	Religious purposes, personal convictions	Research purposes, QA/ QC purposes	A	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	WI Statutes, Ch. 253.12	WI Admin. Code DHS 115.01-06	http://www.slh.wisc.edu/clinical/newborn/
WY	6 months	No	3 to 5 years	No	N/A	Can opt out for any reason, but must sign waiver.	No	D	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	https://law.justia.com/codes/wyoming/2021/title-35/chapter-4/article-8/section-35-4-801/	Wyoming Administrative Rules Ref No, 048.0035. 1.09072017	https://health.wyo.gov/publichealth/mch/newbornscreening/

RUBRIC- NEWBORN SCREENING

GRADE	Screening for RUSP Core Conditions	Adding RUSP Conditions	Funding	DBS Use	Advisory Council
A	Screens for all core conditions.	When conditions are added to the RUSP, such conditions are added automatically to the state panel.	NBS program has a distinct stream of revenue and health department can set fee.	Uses for research and for QA/QC.	Has an entity that includes a wide range of non-governmental stakeholders and meets more than once a year.
B	Screens for up to 3 core conditions that it does not screen.	Health department can add conditions on its own.	NBS program has a distinct stream of revenue or health department can set fee.	Uses for QA/QC only.	Has an external entity that meets once a year or more.
C	Screens for 4-5 core conditions that it does not screen.	Health department can add conditions, but conditions must be added by rulemaking.	Revenue comes from general funds and fee changes must be done by rulemaking OR there are supplemented appropriations (e.g., Title V.)	Retains for > 1 year but conducts no further research.	Has an external entity that only meets on an ad hoc basis.
D	Screens for more than 5 core conditions that it does not screen.	Legislature must approve the addition of conditions.	The NBS fee and the resulting revenue are subject to the legislature.	Retains for 6-12 months but conducts no further research.	Has only an intra-governmental entity and no external entity.
F	Screens for more than 10 core conditions that it does not screen.	State does not specify how to add conditions.	No funding in statute or regulation.	Destroys in 6 months or less and conducts no further research.	Does not have any intra-governmental or external advisory body.