2. Newborn Screening Overview

2.0 Introduction

It is extremely difficult to compare data from various screening programs without the use of standard definitions. As screening has progressed, so has our understanding of the disorders involved. In most instances, screening has led to the discovery of a multitude of manifestations of what previously were considered to be simple disorders. Correspondingly, the definitions of degrees of severity of a disorder, and their relationship to laboratory screening results, determine the actions of both laboratory and follow-up personnel. Consensus definitions have not yet been reached among the various screening programs. In order to try to arrive at such definitions, programs were once again asked to share their definitions of various disorders.

2.1 Disorders Included in Newborn Screening Programs - 1999

Table 2.01 lists each newborn screening program and the disorders included for testing in 1999. Most programs were guided by statutes or rules requiring that certain screening tests be performed. When testing was required, the letter "R" is used in the table. In non-required (or voluntary) screening situations, the letter "V" is used.

2.2 Laboratories Providing Newborn Screening Tests

Table 2.02 provides a summation of the type of laboratory service(s) available. Programs were asked to respond with information denoting the type of laboratory service(s) available. While most programs used a single laboratory, others permitted testing at one or more laboratories within their state or territory. Some programs contract for service from a laboratory outside of their geographic boundaries.

2.3 Components Included in Newborn Screening Follow-Up

Follow-up is a complex issue and is usually approached on several levels (e.g., telephone contact, certified mail, personal visits, etc.) depending on the size of the program, its resources and the anticipated outcome to the patient based on the screening laboratory's results. In order to provide a comparison of follow-up systems, programs were asked to indicate the type(s) of follow-up utilized for pursuing abnormal screening results. This information is displayed in Table 2.03. While all programs reported notifying submitters of abnormal laboratory test results, several did not indicate a formal program of confirmation and treatment, particularly in states with multiple or regional laboratories. Long term follow-up of diagnosed cases was less uniform and some programs indicated a lack of significant follow-up beyond the initial diagnostic and treatment phase.

2.4 Age at Time of Newborn Screening

The use of biochemical markers for detecting genetic and metabolic disorders is dependent on their quantitative levels at the time of screening.

Some disorders are more difficult to detect using samples collected close to the time of birth. Since collection of the initial screening sample is recommended before hospital discharge, it is important to monitor trends in specimen collection, given the national trend towards early hospital discharge for maternity patients.

Table 2.04 lists information from each program relative to the newborn's age at time of sample collection. Not all programs obtain specific time of sample collection and thus estimates were reported in some instances. *These data refer only to initial samples and do not contain information relative to requested or required follow-up after initial testing.*

2.5 Summation of Fees Charged for Newborn Screening

Over the years it has become necessary for programs to consider the initiation of fees as a means of recovering expenses. In some cases these fees cover only the laboratory testing expenses, while in other cases, there are significant other expenses included in the fee calculations. There are also significant differences between programs as to how the fee is charged and how the monies are made available within the program. Table 2.05 lists the answers to the basic questions of the amount and coverage of the fee. If this information is considered useful and other information should be requested for tabulation, please make this suggestion to the editors.

2.6 Criteria for Secondary Screening Tests

Most U.S. newborn screening programs include certain components of follow-up that result in a second filter paper specimen being tested. Additionally, some programs require second testing on all newborns at some period after the baby is discharged from the hospital. Some programs also require an automatic second screen if the first is taken at a time defined as 'too early' by the program. In order to better define the circumstances that result in submission of a second screening sample, programs were asked to submit the information tabulated in Table 2.06.

2.7 Laboratory Specimen Information

Programs were asked to submit certain summary information about their screening programs, sample quality, educational programs, and sample storage policies. These data were accumulated for comparison of program efforts at improving sample quality and to ascertain policy developments relative to sample storage and use. Additionally, information about evaluation of sample quality, computer approaches to quality improvement, and educational emphasis were requested. These data are summarized in Table 2.07.

2.8 Comments

In many cases, definitions of a disorder were essentially the same throughout all programs. In others this was not the case. It is a national goal to arrive at standardized definitions, action levels, and actions for the various screening disorders. More specific definitions are necessary in order to make the data submitted more meaningful. Only programs screening for the disorder listed are included in the tables that follow.

Table 2.01: Disorders for Which Newborns Were Screened in the U.S. (1999)

State/Territory	Hyperphenyl-alaninemia	Hypo-thyroidism	Classical Galactosemia	Maple Syrup Urine Disease	Homo-cystinuria	Biotin-idase	Congenital Adrenal Hyperplasia	Cystic Fibrosis	Tyro-sinemia	Toxo-plasmosis	Hemoglo-binopathy	MCAD
1 Alabama	R	R	R				R				R	
2 Alaska	R	R	R	R		R	R				V	
3 Arizona	R	R	R	R	R	R					R	
4 Arkansas	R	R	R								R	
5 California	R	R	R								R	
6 Colorado	R	R	R			R		R			R	
7 Connecticut	R	R	R	R	R	R	R	V **g**			R	
8 Delaware	R	R	R	R **b**		R **b**					R	
9 District of Columbia	R	R	R	R	R						R	
10 Florida	R	R	R				R				R	
11 Georgia	R	R	R	R	R		R		R		R	
12 Hawaii	R	R	R	R		R	R				R	
13 Idaho	R	R	R	R		R						
14 Illinois	R	R	R **a**			R	R				R	
15 Indiana	R	R	R	R	R	V					R	
16 Iowa	R	R	R				R				R	
17 Kansas	R	R	R								R	
18 Kentucky	R	R	R								R	
19 Louisiana	R	R				R					R	
20 Maine	R	R	R	R	R	R **f**					V	R **f**
21 Maryland **d**	V	V	V	V	V	V			V		V	
22 Massachusetts	R	R	R	R	R	R	R	P	P	R	R	R
23 Michigan	R	R	R	R		R	R				R	
24 Minnesota	R	R	R				R				R	
25 Mississippi	R	R	R								R	
26 Missouri	R	R	R								R	
27 Montana	R	R	R					V				
28 Nebraska	R	R	R			R					R	
29 Nevada	R	R	R	R		R					R	
30 New Hampshire	R	R	R	R	R					R	V	
31 New Jersey	R	R	R								R	
32 New Mexico	R	R	R			R	R				R	
33 New York **c**	R	R	R	R	R	R					R	
34 North Carolina	R	R	R	R	R		R		R		R	R
35 North Dakota	R	R	R				R				V	
36 Ohio	R	R	R		R						R	
37 Oklahoma	R	R	R								R	
38 Oregon	R	R	R	R		R					R	
39 Pennsylvania	R	R	V **e**	R	V **e**	V **e**	V **e**	V **e**			R	
40 Rhode Island	R	R	R	R	R	R	R				R	
41 South Carolina	R	R	R				R				R	
42 South Dakota	R	R	R									
43 Tennessee	R	R	R								R	
44 Texas	R	R	R				R				R	
45 Utah	R	R	R									
46 Vermont	R	R	R	R	R	R					R	
47 Virginia	R	R	R	R	R	R					R	
48 Washington	R	R					R				R	
49 West Virginia	R	R	R								V	
50 Wisconsin	R	R	R			R	R	R			R	
51 Wyoming	R	R	R			R		R			R	
52 Puerto Rico	R	R	P								R	
53 Virgin Islands	R	R	R	R	R						R	

R = Required; V = Voluntary; P = Pilot

a = carrier Duarte & Variants also identified; **b** = MSUD and Biotinidase required until 6/30/99, discontinued 7/1/99; **c** = other disorders screened HIV-1 antibodies;

d = Maryland law requires that hospitals or birthing centers must offer testing, which can be refused without reason; therefore, for purposes of this report, Maryland is listed as voluntary;

e = supplemental newborn screening program through Neo Gen Screening, Inc (did not report data); **f** = started screening 9-1-99.

Figure 2.01: Disorders Screened in 1999

All states screen for Hyperphenylalaninemia and Hypothyroidism

Totals for other disorders may be inaccurate due to some states not reporting

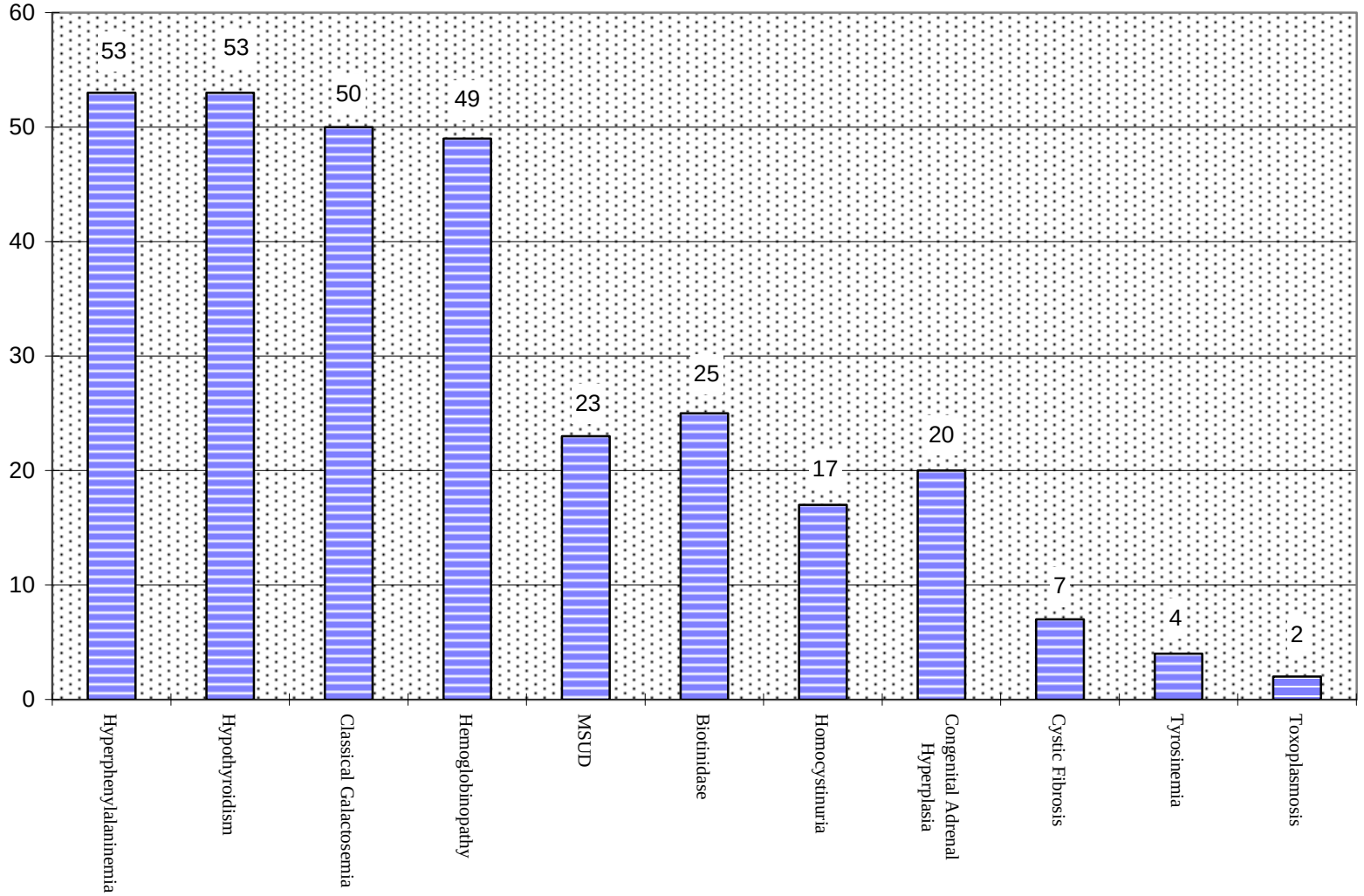

Table 2.02: Summation of Laboratories Providing Newborns Screening Services in the U.S.

State/Territory	Laboratories Operated by State	Using Regional Lab	Private Labs Under State Regulations	Private Labs Without State Regulation	Total Number of Labs Testing
1 Alabama	1				1
2 Alaska		Contracts w/Oregon			1
3 Arizona	1				1
4 Arkansas	1				1
5 California	1		8		9
6 Colorado	1				1
7 Connecticut	1				1
8 Delaware	1	Contracts w/Oregon **a**			1
9 District of Columbia			1		1
10 Florida	1				1
11 Georgia	1				1
12 Hawaii		Contracts w/Oregon			1
13 Idaho		Contracts w/Oregon			1
14 Illinois	1				1
15 Indiana			1		1
16 Iowa	1				1
17 Kansas	1				1
18 Kentucky	1				1
19 Louisiana	1		2		3
20 Maine		1			1
21 Maryland	1				1
22 Massachusetts	1				1
23 Michigan	1				1
24 Minnesota	1				1
25 Mississippi		1			1
26 Missouri	1				1
27 Montana	1				1
28 Nebraska			3 **c**		3
29 Nevada		Contracts w/Oregon			1
30 New Hampshire		Contracts w/Mass.			1
31 New Jersey	1				1
32 New Mexico	1	No			1
33 New York	1				1
34 North Carolina	1			1 **e**	2
35 North Dakota		Contracts w/Iowa			1
36 Ohio	1				1
37 Oklahoma	1				1
38 Oregon	1				1
39 Pennsylvania			1	1 **b**	2
40 Rhode Island		Contracts w/Mass.			1
41 South Carolina	1				1
42 South Dakota				1	1
43 Tennessee	1				1
44 Texas	1				1
45 Utah	1				1
46 Vermont		Contracts w/Mass.			1
47 Virginia	1				1
48 Washington	1				1
49 West Virginia	1				1
50 Wisconsin	1				1
51 Wyoming		Contracts w/Colorado			1
52 Puerto Rico	1	**d**		1	2
53 Virgin Islands					1

a = Oregon PH Lab received our specimens until 6/30/99, DE State PH Lab began Newborn Screening on 7/1/99; **b** = NeoGen Screening, Inc;
c = 3 NBS labs in NE, Colorado Lab conducts NBS tests for births at Federal Military Hosp., 547 births screened by CO lab;
d = Neonatal screening laboratory, UPR, MSC; **e** = for pilot study only, study ended 4-19-99.

Table 2.03: Components Included in Newborn Screening Follow-up in the U.S.

State/Territory	Notification by Lab Report, Letter and Phone Call	Confirmation of Additional Lab Results	Confirmation of Treatment	Annual Follow-up of Diagnosed Cases	Number of Years Followed
1 Alabama	X	X			
2 Alaska	X	X	X		
3 Arizona	X	X	X		AZ follows baby until final dx & treatment, then followed by other programs.
4 Arkansas	X				
5 California	X	X	X		
6 Colorado	X	X	X		
7 Connecticut	X	X	X		Maintain permanent files on all confirmed disease cases.
8 Delaware	X	X	X	some cases-esp. PKU	Years-variable
9 District of Columbia	X	X			Lab notifies submittors, DC MCH follow-up with families/physicians.
10 Florida	X	X	X		
11 Georgia	X	X	X	X	Indefinite; depending on Dx.
12 Hawaii	X	X	X	X	Diagnosed cases followed annually up to 21 yrs. of age, if admitted to Children w/Special Health Needs Branch.
13 Idaho	X	X	X	X	Follow-up is available indefinitely, fee charged on ability to pay.
14 Illinois	X	X	X	X	15 years
15 Indiana	X **c**	X **c**	X **b**		1 year
16 Iowa	X	X	X	X	Lifetime
17 Kansas	X	X	X	X	Birth to death if they are a client of Special Health Services.
18 Kentucky	X	X	X	X	Varies
19 Louisiana	X	X	X	X	PKU patients followed for life, congenital hypothyroidism tracked to verification of trtmt., SC followed for 5 years.
20 Maine	X	X	X		
21 Maryland	X	X	X	X	Hgb - 3 years; Metabolic - indefinite as long as on diet.
22 Massachusetts	X	X	X	X	Varies by disorder.
23 Michigan	X	X	X	X	Number of follow-up years varies by disorder.
24 Minnesota	X	X	X	X	
25 Mississippi	X	X	X	X	21 years
26 Missouri	X				
27 Montana	X	X	X	X	19 years
28 Nebraska	X	X	X	X	Followed at treatment center for Galactosemia, Biotinidase Deficiency and Phenylketonuria (PKU).
29 Nevada	X	X	X	X	21 years
30 New Hampshire	X	X	X	X	Diagnosed cases up to 21 years.
31 New Jersey	X	X	X	X (SCD only)	1, 2, 5, 10, 15 and 20 years.
32 New Mexico	X	X	X		PKU clients not followed, remain in contact as desired through provision of formula to age 18 and lab monitoring of blood levels as desired.
33 New York	X	X			Short-term follow-up for abnormal screening results: phenylalanine, Leucine Methionine, Biotinidase, Glucose-1-Uridyl Transferase, and Thyroxine. Hgb followed until confirmatory specimen received.
34 North Carolina	X	DA	X	X	Annual follow-up for PKU only.
35 North Dakota	X	X	X	X	21 years, Title V providing formula for PKU & MSUD patients.
36 Ohio	X	X	X		
37 Oklahoma	X	X	X	X	< 6 years, sickle cell disease followed until six years of age.
38 Oregon	X	X	X		
39 Pennsylvania	X	X	X		
40 Rhode Island	X	X	X	X	indefinite
41 South Carolina	X	X	X	X	Followed indefinitely for PKU only.
42 South Dakota	X	X	X		
43 Tennessee	X	X	X		
44 Texas	X	X	X	X	17 years, Other follow-up includes outreach prog. & home visits.
45 Utah	X	X	X		
46 Vermont	X	X	X	X	Varies by condition.
47 Virginia	X	X	X	X	Annual follow-up is handled by the metabolic specialist.
48 Washington	X	X	X	X	Varies by disorder. **a**
49 West Virginia	X			X	PKU & GAL according to specialist .
50 Wisconsin	X	X	X		
51 Wyoming	X	X	X	DA	
52 Puerto Rico	X	X	X	X	18 yrs, few cases referred to local specialists.
53 Virgin Islands	X	X			

a = Follow-up of infants not screened and with unsatisfactory specimens; **b** = services provided by state (MCH); **c** = services provided by contract lab.

Table 2.04: Infant's Age at Time of Initial Testing in U.S. Newborn Screening Programs

State/Territory	0-12	13-24	Day 1 (Total of 1st two columns)	Day 2 25-48	Day 3 49-72	Day 4 73-96	Day 5 97-120	Day 6 121-144	Day 7 145-168	Over 7 Days 169-999	Hour Unknown	Calculated TOTAL
1 Alabama											61,038	61,038
2 Alaska	1,363	2,255	3,618	3,191	1,429	521	159	311	122	247	204	9,802
3 Arizona	783	13,164	13,947	41,933	12,561	3,583	1,159	594	21	1,316	2,670	77,876
4 Arkansas	697	1,043	1,740	27,673	3,169	785	522	392	241	841	285	35,506
5 California	18,404	172,351	190,755	239,608	45,921	14,965	8,001	6,131	2,474	4,840	4,036	516,731
6 Colorado	2,620	18,350	20,970	27,663	5,306	1,232	335	181	205	387	3,585	60,092
7 Connecticut											44,391	44,391
8 Delaware **a**	96	876	972	6,489	2,497	519	<---------- 910 ---------->					11,388
9 District of Columbia											14,558	14,558
10 Florida											196,963	196,963
11 Georgia											200,576	200,576
12 Hawaii	48	1,410	1,458	12,769	2,020	527	44	36	20	99	4	16,977
13 Idaho	933	4,531	5,464	7,982	3,068	1,534	417	221	158	788	493	20,125
14 Illinois **f**	235	881	1,116	5,278	949	2,672					1,676	185,266
15 Indiana	2,173	5,674	7,847	23,016	47,750	3,437	1,484	822	577	1,029	43	86,005
16 Iowa	236	637	873	29,604	5,075	768	274	89	30	369	568	37,650
17 Kansas											36,006	36,006
18 Kentucky			1,923	12,963	28,052	2,631	588	189			6,646	52,992
19 Louisiana											67,040	67,040
20 Maine	N/A	N/A	3,028	<---------- 10,130 ---------->			<--- 123 ------>		<--- 52 -------->			13,333
21 Maryland			21,879	37,146	5,174	1,764	744	637	544	2,140		70,028
22 Massachusetts			1,001	12,163	49,265	11,483	2,434	247	78	567 **c**	4,789	82,027
23 Michigan	1,186	28,979	30,165	81,798	6,558	1,316	442	236	161	1,346	9,389	131,411
24 Minnesota	195	2,736	2,931	49,701	10,239	1,374	404	148	82	898	1,299	67,146
25 Mississippi											42,678	42,678
26 Missouri	554	2,701	3,255	20,613	28,260	9,535	5,171	2,277	1,729	5,471	1,300	77,611
27 Montana			988								9,747	10,735
28 Nebraska											24,118	24,118
29 Nevada	2,701	9,252	11,953	10,525	2,432	1,086	142	104	75	767	881	29,299
30 New Hampshire											13,711	13,711
31 New Jersey	688	687	1,375	90,561	16,324	1,133	349	152	98	479	344	110,815
32 New Mexico											26,584	26,584
33 New York	N/A	N/A	1,631	41,012	162,930	32,755	11,364	3,917	1,078	2,511	128	257,326
34 North Carolina	680	14,793	15,473	84,096	10,650	1,652	575	334	234	839	1,345	114,389
35 North Dakota	61	132	193	6,608	1,469	360	119	26	11	24	94	8,904
36 Ohio											151,113	151,113
37 Oklahoma			N/C								52,032	52,032
38 Oregon	2,144	8,789	10,933	22,472	6,473	2,173	278	98	65	823	3,022	46,337
39 Pennsylvania **e**											145,922	145,922
40 Rhode Island			5,633	<---------- 7,304 ---------->			<--- 91 ------>		<--- 209 -------->			13,237
41 South Carolina			1,152	<---------- 51,828 ---------->						786		52,375
42 South Dakota											10,794	10,794
43 Tennesse											77,761	77,761
44 Texas											342,236	342,236
45 Utah											46,982	46,982
46 Vermont	24	84	108	4,850	568	151	206	37	21	54	15	6,010
47 Virginia	3,658	9,881	13,539	67,137	8,374	1,496	765	587	764	3,074	343	96,079
48 Washington	10,426	35,377	45,803	19,586	5,315	1,501	869	186	89	396	1,987	75,732 **b**
49 West Virginia	610	3,245	3,855	10,822	3,493	821	439	281	502	446	591	21,250
50 Wisconsin	411	1,575	1,986	49,147	11,301	1,903	548	561	360	653	333	65,619
51 Wyoming											5,361	5,361
52 Puerto Rico	10	50	60 **d**	55,000	10,083 **d**						900	57,043
53 Virgin Islands			341	1,360								1,701

a = 5-14=834, 14-21=31, 22-30=22, Month 3=1, 3 Months=22; **b** = excludes 3,084, 2,880 military births screened by OR, 136 neonatal deaths, & 68 refusals;

c = includes out of state adoptions; **d** = estimated number; **e** = supplemental newborn screening program did not report data (data by PA lab); **f** = data for abnormal results only.

Table 2.05: Summation of Fees Charged in 1999 for Newborn Screening

State/Territory	Amount of Fee	Program Components covered by fee
1 Alabama	$24.00	Laboratory
2 Alaska	$24.00	Laboratory, Program Administration/Follow-up
3 Arizona	$20 / $15	Laboratory, Program Administration/Follow-up and Treatment, specialist consultation, nurses.
4 Arkansas	$14.83	Laboratory, Program Administration/Follow-up
5 California	$42.00	Laboratory, Program Administration/Follow-up
6 Colorado	$33.50	Laboratory, Program Administration/Follow-up, Treatment and Genetic Counseling
7 Connecticut **a**	$18.00	Laboratory
8 Delaware	$40.69	Laboratory, Program Administration/Follow-up, Medical Consultant
9 District of Columbia	No charge	
10 Florida **d**	$20.00	Laboratory, Program Administration/Follow-up
11 Georgia	No Charge	
12 Hawaii	$27.00	Laboratory, Program Administration/Follow-up, Treatment, Fed Ex, genetic, education, etc.
13 Idaho	No Charge	
14 Illinois	$32.00	Laboratory, Program Administration/Follow-up, and Treatment
15 Indiana	$22.10	Laboratory, Program Administration/Follow-up and Treatment
16 Iowa	$30	Laboratory, Program Administration/Follow-up
17 Kansas	No Charge	
18 Kentucky	$14.50	Laboratory
19 Louisiana	$18.00	Laboratory, Program Administration/Follow-up and Treatment
20 Maine	$26.75 **g**	Laboratory, Program administration/Follow-up, treatment, surveillance, and education.
21 Maryland	$15.75	Laboratory (reagents only).
22 Massachusetts	$49.55 **f**	Laboratory, Program Administration/Follow-up, in home trait counseling
23 Michigan	$29.38	Laboratory, Program Administration/Follow-up and some treatment
24 Minnesota	$21.00	Laboratory, Program Administration/Follow-up
25 Mississippi	$20.00	Laboratory, Program Administration/Follow-up and Treatment
26 Missouri	$13.00	Laboratory
27 Montana	$35.50	Laboratory (Additional $9.50 if IRT requested)
28 Nebraska	$53.00 - $54.60	Laboratory, Treatment
29 Nevada	$30.00	Laboratory, Program administration/Follow-up
30 New Hampshire	$12.50	Laboratory
31 New Jersey **b**	$27.00/$34.00	Laboratory, Program Administration/Follow-up and Treatment
32 New Mexico	$20.00	Laboratory, Program Administration/Follow-up, Treatment, Education, and Genetic Serv.
33 New York	No Charge	
34 North Carolina	No Charge	
35 North Dakota **c**	$16.00	Laboratory
36 Ohio	$27.00	Laboratory, Program administration/Follow-up, Treatment
37 Oklahoma	$10.50	Laboratory
38 Oregon	$32.00	Laboratory, Program Administration/Follow-up, Treatment
39 Pennsylvania **e**	$18.50	Laboratory, Program administration/Follow-up
40 Rhode Island	$59	Laboratory, Program Administration/Follow-up, specialty formula
41 South Carolina	$21.00	Laboratory and Treatment
42 South Dakota	No Charge	
43 Tennessee	$10.00	Laboratory
44 Texas	$13.75	Laboratory
45 Utah	$27.50	Laboratory, Program Administration/Follow-up
46 Vermont	$27.00	Laboratory, Program Administration/Follow-up
47 Virginia	$16.00	Laboratory, Program Administration/Follow-up and Treatment
48 Washington	$35.75	Laboratory, Program Administration/follow-up, Program evaluation and education.
49 West Virginia	$12.64	Laboratory
50 Wisconsin	$55.50	Laboratory, Program Administration/Follow-up and Treatment.
51 Wyoming	No Charge	
52 Puerto Rico	$18.00	Laboratory, Program administration/Follow-up, confirmatory testing, orientation and initial treatment
53 Virgin Islands		

a = Hosp. billed for each infant tested, hosp. then pass charge to insurance Co. as part of maternity pkg., fee covers testing through State lab; **b** = 1/1/99 to 11/14/99 - $27, 11/15/99 to 12/31/99 - $34; **c** = 1/99 to 6/99 - $15, 7/99 to 12/99 - $16; **d** = Hospitals charged $20 for each live birth up to 3000/year, Birth centers charged $20 for each live birth starting at 61 births; **e** = supplemental newborn screening program through NeoGen Screening did not report data; **f** = Fee $42 - 1/1/99 to 8-31-99, Fee $49.55 - 10/1/99 to 12/31/99; **g** = Fee $21.50 - 1/1/99 to 7/31/99, Fee $26.75 - 8/1/99 to 12/31/99.

Table 2.06: Criteria for Second Screening Tests in U.S. Newborn Screening Programs

State/Territory	Required Second Screening on all	Only If Tested Prior to 24 Hours	Only If Tested Prior to 36 Hours	Only If Tested Prior to 48 Hours	Definitions of Selected Groups Receiving 2nd Screening Tests
1 Alabama					Second test recommended on all newborns at 2-6 weeks of age.
2 Alaska				X	
3 Arizona		X			Recommended for all babies
4 Arkansas NC					
5 California					N/A
6 Colorado	X				
7 Connecticut					Recommended between 7-14 days of age - 2nd PKU routinely done on all 2nd specimens.
8 Delaware	X				
9 District of Columbia		X			
10 Florida				X	All specimens receive all tests whether initial or repeat.
11 Georgia				X	For low birthweight newborns at 1 month of age.
12 Hawaii		X			
13 Idaho				X	
14 Illinois		X			
15 Indiana				X	
16 Iowa		X			
17 Kansas		X			
18 Kentucky				X	
19 Louisiana				X	
20 Maine		X			
21 Maryland	X				Maryland is a voluntary newborn screening program and all testing is recommended.
22 Massachusetts		X			Retest VLBW (<1500g) & NICU infants-retest at 2 wks of age.
23 Michigan					
24 Minnesota		X			
25 Mississippi		X			< 24 hours of age
26 Missouri		X			
27 Montana		X			
28 Nebraska		X			
29 Nevada	X				Second test required routinely within three weeks.
30 New Hampshire		X			Repeat for VLBW (< 1000 gms); NICU babies at 2 weeks of age.
31 New Jersey		X			
32 New Mexico	X				
33 New York		X			3-5 days.
34 North Carolina		X			
35 North Dakota		X			
36 Ohio				X	
37 Oklahoma		X			< 24 hours of age, repeat at 3-5 days of age.
38 Oregon	X				
39 Pennsylvania **a**		X			When the Phe level is between 2 to <5 a repeat is requested.
40 Rhode Island		X			
41 South Carolina		X			Recommended if specimen collected < 24 hours of age.
42 South Dakota		X			If sample taken < 24 hours.
43 Tennessee		X			
44 Texas	X			X	Required for all infants.
45 Utah	X				
46 Vermont		X			
47 Virginia		X			1) antibiotics or transfusion are indicated; 2) interfering substances limit interpretation of results.
48 Washington					Routine second NBS recommended for all infants between 7 & 14 days.
49 West Virginia				X	
50 Wisconsin					Repeat recommended when initial collection is made prior to 24 hours of age.
51 Wyoming					
52 Puerto Rico		X			< 48 hours
53 Virgin Islands		X			

a = supplemental newborn screening program through NeoGen Screening, Inc, did not report data, (data by PA lab)

Table 2.07: Laboratory Specimen Information

State/Territory	Total Number of Specimens Received	Number of Specimens Unacceptable for Analysis	% of Samples Deemed Unacceptable from Total Tests	Length of Time Blood Specimens Kept	Written policy for storage and Disposal of left-over Specimens (Yes/No)	Type of Computer Evaluation of Submissions	Type of Education Provided to Submitter
1 Alabama	189,332	17,168	9.07%	4 months. 2-10°C	Yes	Neometrics Software	Quality assurance program.
2 Alaska	17,861	289	1.62%	2 years at room temperature	Yes-Lab keeps 1 yr & ships to state.	Weekly, AK matches births	Brochures, video's, presentations, and practitioners manual.
3 Arizona	132,518	1,126	0.85%	3 months at room temp.	Yes	None	NBS professional staff provides in-service training.
4 Arkansas	36,643	188	0.51%	One year at 20°C	Yes	Queries compiled by lab rpting.	Inservice training for local health units and hospital staff.
5 California	516,731	3,589	0.69%	Indefinitely (-20ºC)	Yes		
6 Colorado	148,225	3,767	2.54%	3 months at room temp.	No **c**	None	NBS staff provides in-service training, videos, brochures.
7 Connecticut	88,997 **a**	271	0.30%	6 months	No	No	In-services & site visits at birthing facilities.
8 Delaware	11,079	75	0.68%	4 months @ 28°C	Yes	All data shared by lab & NSP Office.	Written procedures for handling specimens.
9 District of Columbia	14,830	95	0.64%	Indefinitely	Yes	Provided by DC MCH	Educational update on DC NBS program by lab director.
10 Florida	296,911	9,948	3.35%	~ 4 years	No	Profile Report sent to Hospitals	
11 Georgia	200,576	21,734 **b**	11%	6 weeks	No		Seminars conducted by the Program NLTN around the State.
12 Hawaii	16,977	12	0.07%	One year, room temperature	Yes	Screening practice profiles	In-service training provided on specimen collection to submitters as necessary. Written material & video avail. upon request.
13 Idaho	33,847	474	1.40%	One year, room temp.	Yes, OPHL policy NOT written into Idaho rules & reg.	Provided by OPHL.	Practioners manual and parent brochures.
14 Illinois	185,266	775	0.42%	Minimum 3 months Pos. specimens indefinitely	Yes		Brochures, videos, in-services, conferences, practitioners manual, workshops.
15 Indiana	120,383	2,691	2%		No	tracking samples/Qtrly reports	NCCLS video on coll., S&S posters & onsite inservices.
16 Iowa	38,992	1,272	3.26%	4 weeks	Yes		Pamphlet written for parents, video for submitters.
17 Kansas				30 days @ -10 - 20°C	Yes	N/C	Phone consultations, site visits and conf. presentations.
18 Kentucky	52,992	1,636	3.09%	6 mo. hypothyroid refrig.	Yes	Unsat. specimen rpt. generated.	Onsite inservice training, send out film & materials on req.
19 Louisiana	101,457	4,109	4.05%	4°C for 2 weeks @ room temp for 1 mo.	Yes	No	Assist providers in developing NBS protocols and collection of satisfactory specimens.
20 Maine	13,333	79	0.59%	3 years	Yes	Specimen & date of receipt reports	In-service.
21 Maryland	150,343	16,228 **d**	10.79%	3 years	Yes	None	Continuing education, NCCLS video, & other literature.
22 Massachusetts	89,898	656	0.73%	1991 to present	Yes	Internal QC rpt. of specimens.	Inservice consultation of hosp. staff, NCCLS video, website.
23 Michigan	142,165	3,074	2.16%	21.5 yrs	Yes	Quarterly reports.	Inservice training and videos.
24 Minnesota	67,146	1,495	2.23%	3 years	Yes	Internal QC reports.	Posters, web site, patient brochure.
25 Mississippi **NR**							
26 Missouri	99,087	1,624	1.64%	6 mos @ < -30°C	Yes	Neometrics MSDS System	No

continued

Table 2.07: Laboratory Specimen Information (continued)

State/Territory	Total Number of Specimens Received	Number of Specimens Unacceptable for Analysis	% of Samples Deemed Unacceptable from Total Tests	Length of Time Blood Specimens Kept	Written policy for storage and Disposal of left-over Specimens (Yes/No)	Type of Computer Evaluation	Type of Education Provided
27 Montana				6-8 weeks refrigerated	No	No computer evaluation.	Practitioner's manual, S&S posters,in-service on request.
28 Nebraska	24,118	25	0.10%	Each lab has own policy	Yes	N/C	N/C
29 Nevada	54,105	858	1.59%	1 year	Yes	Monthly rpts. sent from OR. PHL	PRN/Annually
30 New Hampshire	13,711	119	0.87%	7 yrs @ room temp.	Yes	Customized rpts as needed.	Hosp inservices, telephone followup, printed matter.
31 New Jersey	120,536	274	0.23%	23 years - room temperature	Yes	Submitter compliance.	On-site training, NCCLS video tape, practioners guidance manual.
32 New Mexico	51,004	531	1.04%	3 months @ room temp.	Yes	PH and HCP	Pamphlets, in-service training, verbal education from lab.
33 New York	275,823	4,351	1.58%	6 mos. @ 20°C desiccant	Yes	Annual statistics.	Video, posters, NBS guide, phone consultation, parent brochures.
34 North Carolina	128,477	1,796	1.40%	2 Yrs. room temp.	No	Unsat reports to submitter mthly.	
35 North Dakota	9,334	132	1.41%	10 years	Yes	None	Pamphlet & video tape.
36 Ohio	199,169	7,124	3.58%	specimens retained until all tests are completed	Yes		Inservices offered to all hosp. on collection & follow-up, phone consultations.
37 Oklahoma	52,591	559	1.06%	1 month, 2-8°C w/dessicant	Yes		NBS program rules/regulations mailed to all submitters.
38 Oregon	46,337	33	0.07%	1 year, room temp.	Yes	Screening Practice profiles sent monthly to hosp. admin. & mang.	Screening practice consultations, procedure & policy review provided by Educational coord., and NBS RN's.
39 Pennsylvania	**e**	**e**	**e**	3 months	No		
40 Rhode Island	13,684	120	0.88%	23 years room temperature	No	Data by hospital	
41 South Carolina	53,833	1,185	2.20%	Indefinitely	Yes		Laboratory and follow-up training. On-site updates held at request of submitter.
42 South Dakota	12,680	41	0.32%	2 months @ 2-8°C in sealed bags.	Yes		Onsite visits, written materials, charts, phone consultations.
43 Tennessee	89,924	6,693	7.44%	Nrml 3 mo refrig, Abn indefinitely.	Yes	Quarterly reports.	In-service edu, video & pamphlets to hospitals.
44 Texas	680,247			6 months	Yes		Publication "A Practitioners Guide" by TDH Lab.
45 Utah	93,599	1,317	1.41%	3 months at 4°C.	No	ND	No education provided by lab.
46 Vermont	6,335	108	1.70%	Indefinitely, room temp.	No	Database w/HCP, hosp. lab, & nursery staff, hosp. QC every 6 mo.	Newsletters, in-service presentations for hosp. lab & nursery staffs, PH nurses by program coordinator.
47 Virginia	109,821	561	0.51%	nml = 6 mos; abn = 10 yrs	Yes	Submitter profiles.	Site visits, training seminars, literature prov, video.
48 Washington	144,500	1,013	0.70%	21 years	Yes	Quarterly & annual reports.	tech. asst. by phone, in-service, and training upon request.
49 West Virginia	31,648	2,485	7.85% **f**	3 months, room temp.	No	Monthly reports.	NCCLS video.
50 Wisconsin	69,904	1,173	1.68%	1 year at 4 - 8 °C	No		Newsletter, NCCLS video, website w/links, NBS Manual.
51 Wyoming				3 months, room temp.			
52 Puerto Rico	57,043	575	1.01%	6-12 months	Yes	No	New hosp. initial training of 1-2 hours.
53 Virgin Islands	1,701	17	1.00%	12 months/35-38 F	Yes	With program director (MCH)	Letter, video, demo to nursing, supervisors, & lab staff.

NBS = Newborn Screening, HCP = Health care providers, PH = Public Health

a = includes 1st, 2nd, and 3rd specimens; **b** = includes specimens collected < 48 hours; **c** = but will be included in current revision of SOP's; **d** = includes < 24 hrs. & unacceptable specimens, 6,655 were IMF, 9,573 were unsatisfactory. Unacceptable specimens are tested if results are normal, reported as unsatisfactory specimen or IMF, if results are abnormal reported as abnormal but unsatisfactory or IMF specimen; **e** = Supplemental Newborn Screening program; did not report data (data from PA lab); **f** = program screens all specimens received - only panic values are reported on unacceptable specimens;

Figure 2.02: Specimen Storage Time - 1999