

13. Hemoglobinopathies

13.0 Introduction

Screening for hemoglobinopathies, particularly those involving sickle hemoglobin, have been included in U.S. screening programs since the 1970's, but the majority of screening programs added this testing in the late 1980's. Initially the screening technique included hemoglobin electrophoresis in basic and alkaline medium to identify potentially affected newborns. Confirmation testing was recommended at 2 - 3 months when fetal hemoglobin concentrations decreased to a point where it no longer interfered with the diagnostic tests. As isoelectric focusing techniques improved, this technique became popular because of its relatively low cost and relative ease of interpretation. Some programs have also included high performance liquid chromatography (HPLC) as either a primary or ancillary screening technique, and some have included DNA as a confirmatory procedure. All data reported here were collected from questionnaires submitted to programs as noted in Chapter 3. Only programs with hemoglobinopathy screening included in their testing scheme are listed in the Tables.

13.1 Laboratory Procedures

In order to identify laboratory procedures in use, programs were asked to report their laboratory protocols for both the primary method and any ancillary testing. These data are reported in Table 13.01.

13.2 Initial Screening Results

In order to ascertain the effectiveness of screening for hemoglobinopathies, programs were asked to report their findings on initial screening for a selected group of hemoglobinopathy findings. Initial screening was defined as the first reportable test, and programs were asked not to include duplicate screenings. By reviewing the number of newborns screened

and confirmed, and the number lost to follow-up, the efficiency of the testing protocol may be evaluated. Programs were also asked to report the number of positive patients 'lost to follow-up' as a means of evaluating the follow-up procedures. These data are reported divided by Race in Table 13.02. Programs wishing to explain some of their responses included information as footnotes to the table. Care should be taken in interpreting these data, since not all programs are designed to confirm and follow all reported results. For example, most programs do not confirm results considered normal such as Hb F,A.

Information was also requested on second testing and repeat testing as with other disorders, but the responses were limited to a handful of programs and it was apparent that the reported data were questionable. For this reason, no data were tabulated on second testing and repeat testing. Comments from readers on the usefulness of this type of information would be helpful for future Newborn Screening Data Reports.

13.3 Time Until Diagnosis for FS Cases (Sickle Cell Anemia)

In order to look at overall program efficiency with respect to speed of diagnosis, programs were asked to report the number of days from birth until diagnosis. For purposes of this Report, diagnosis was defined as, "confirmation of the screening results (usually outside of the original screening environment - e.g. confirmation of sickle cell anemia by repeat electrophoretic techniques at 2-3 months; DNA testing at 1 week; etc.)." Programs using a different definition were asked to give the definition and it is included as a footnote to the Table. These data are reported in Table 13.03.

13.4 Time Until Treatment for FS Cases (Sickle Cell Anemia)

So that programs may know the policies and actions of other programs with respect to treatment for sickle cell anemia, data were gathered relative to time until treatment. Treatment was defined as, "initiation of ... drug regimen." These data are reported in Table 13.04. Similar data were not requested for other sickle cell diseases since this disease was considered sufficiently representative of program actions.

13.5 Time to Diagnosis for FSA Cases (S-~~S~~⁺-thalassemia)

Programs were asked to report the time to diagnosis for FSA cases since these cases may face a health threat and laboratory results may sometimes be confused with FS and FAS at the time of initial screening. These data are reported in Table 13.05.

13.6 Time to Diagnosis for FSC Cases (SC-Disease)

Programs were asked to report the time to diagnosis for FSC cases and these data are reported in Table 13.06.

13.7 Time to Diagnosis for FSE Cases (SE-Disease)

Programs were asked to report the time to diagnosis for FSE cases and these data are reported in Table 13.07.

13.8 Time to Diagnosis for FSD Cases (SD-Disease)

Programs were asked to report the time to diagnosis for FSD cases and these data are reported in Table 13.08.

13.9 Time to Diagnosis for FAS Cases (Sickle Cell Trait)

Programs were asked to report the time to diagnosis for FAS cases and these data are reported in Table 13.09.

13.10 Program Follow-up

In order to look at the activities of programs related to follow-up of sickle trait, programs were asked to report related information. Specifically, programs were asked to indicate whether or not they maintained an aggressive follow-up program for sickle trait, whether there was extra staff available for this follow-up, and any other comments appropriate to follow-up of sickle trait. These responses are tabulated in Table 13.10.

13.11 Historic Data

In order to document the value of screening for hemoglobinopathies, or more specifically for sickle hemoglobinopathies, programs were asked to supply whatever historic data they could on their screening program. In particular, they were asked to give the date the program began and the number of cases detected for each different type of case over the years. These data are given in Table 13.11.

Table 13.01: Hemoglobinopathy Testing Methodology

State/Territory	Primary Laboratory Method	Secondary Laboratory Method
1 Alabama	Electrophoresis	HPLC
2 Arizona	IEF	
3 Arkansas	IEF	Citrate agar electrophoresis
4 California	HPLC	
5 Colorado	IEF	IEF & Citrate Agar
6 Connecticut	IEF	Citrate Agar
7 Delaware	IEF	DA
8 District of Columbia d	Electrophoresis	Citrate Agar Electrophoresis
9 Florida	IEF	HPLC
10 Georgia	IEF	HPLC, Citrate Agar
11 Hawaii a	IEF	
12 Illinois	HPLC	
13 Indiana	IEF	Citrate Agar, Beckman/Paragon, DNA
14 Iowa	IEF	Extended Gradient HPLC
15 Kansas	IEF	
16 Kentucky NR		
17 Louisiana	IEF	HPLC
18 Maine	IEF	Citrate Agar
19 Maryland	IEF	HPLC
20 Massachusetts	IEF	Citrate Agar Electrophoresis
21 Michigan	HPLC	IEF
22 Minnesota	IEF	
23 Mississippi	IEF	IEF
24 Missouri	IEF	IEF
25 Nebraska	HPLC	
26 Nevada NR		
27 New Hampshire NR		
28 New Jersey	IEF	HPLC
29 New Mexico b	HPLC column chromatography	IEF
30 New York	Cellulose Acetate Electrophoresis	Citrate Agar Electrophoresis, IEF
31 North Carolina	IEF	Citrate Agar electrophoresis
32 Ohio	IEF	
33 Oklahoma	IEF	Solubility test & Citrate Agar
34 Oregon	IEF	HPLC
35 Pennsylvania	IEF	Cellulose Acetate/Citrate Agar
35 Rhode Island	IEF	Citrate Agar Electrophoresis
36 South Carolina	IEF	HPLC
37 Tennessee c	IEF	
38 Texas	IEF	Citrate Agar Electrophoresis, DNA
39 Vermont	IEF	Citrate Agar Electrophoresis
40 Virginia	IEF	HPLC for confirmation
41 Washington	IEF	HPLC & PCR/DNA analysis
42 West Virginia	IEF	Monoclonial Antibody (Hemocard)
43 Wisconsin	IEF	HPLC
44 Wyoming	IEF	IEF & Citrate Agar
45 Puerto Rico NR		
46 Virgin Islands NR		

a = Testing done only at one facility: Tripler Army Medical Center, Hemoglobinopathy screening at Tripler not done under state regulations; **b** = initial specimens method HPLC and abnormal specimens method IEF; **c** = no confirmatory testing by state lab - done by Meharry comprehensive sickle cell center. **d** = 8/2/96 isoelectric focusing is primary method.

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	FS												FSC																										
		Asian or						Total Reported		Hispanic	Lost to Follow-up	Asian or						Total Reported		Hispanic	Lost to Follow-up																			
		White		Black		P. Islander		Native Am.				Other		Unknown		White		Black				P. Islander		Native Am.		Other		Unknown												
S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C							
25 Nebraska	d	23,455																																						
26 Nevada	NR																																							
27 New Hampshire	NR																																							
28 New Jersey		111,074	4	4	38	36	1	1					3	3	3	3	50	48	1	1		2	4	4	22	22	1	1					1	1	2	2	30	30	1	1
29 New Mexico		27,358															0	0																		0	0			
30 New York		265,167	3	2	147	142	1	1					17	16			168	161	15	14			1	1	76	73					8	8			85	82	7	7	3	
31 North Carolina		103,489			62	58							2	2			64	60								24	22									24	22			2
32 Ohio		151,801													31	28	31	28																18	18	18	18			
33 Oklahoma		49,766			5	2										5	2									3	3									3	3			
34 Oregon		46,387			2	2										2	2									1	1									1	1			
35 Pennsylvania																																								
36 Rhode Island		13,718													1		1																			0	0			
37 South Carolina		49,254			46	45										46	45									23	23									23	23			
38 Tennessee		81,451			28	26										28	26									18										18	0			
39 Texas		321,332			90	88							1	1			94 ¹	92 ¹	3	3						39	39								40 ¹	40 ¹	1	1		
40 Vermont		5,694														0																				0	0			
41 Virginia		94,835			30	0									2		32	0								25	0									25	0			
42 Washington		71,842			2	2	e						1	1			3	3								5	5									5	5			
43 West Virginia		9,109														0										1	1									1	1			
44 Wisconsin		65,874			18	16										18	16									11	11									11	11			1
45 Wyoming		6,114																																						
46 Puerto Rico	NR																																							
47 Virgin Islands	NR																																							
Total	3,484,753	12	8	862	659	4	2	0	0	0	32	29	134	93	1,163¹	897¹	26	25	30	7	7	431	334	1	1	0	0	13	13	67	54	580¹	459¹	12	11	25				

¹Ethnicity counted as a Race and is included in total.

a = one confirmed Hb-S-B-thalassemia was suspected "FSA" on initial screen, one confirmed FS was suspected "F other" on initial screen; b = one confirmed case was suspected "FC other" on initial screen; c = includes one child with FS plus an unknown variant; d = hemoglobin screening not mandated until November therefore data requested not collected by program; e = two babies with initial results FS became FSA on a repeat; f = one referred to Virginia.

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	FSA														FC																							
		Asian or P. Islander										Total Reported				Hispanic		Asian or P. Islander										Total Reported				Hispanic		Lost to Follow-up					
		White		Black		P. Islander		Native Am.		Other		Unknown		S	C	S	C	S	C	Follow-up	White		Black		P. Islander		Native Am.		Other		Unknown		S	C	S	C	Follow-up		
1 Alabama	60,870												6	6																				4	4				
2 Arizona	76,060										4		4	0															1		1								
3 Arkansas	34,201							N/C	N/C				0	0				DA		3	0			N/C	N/C						3	0					3		
4 California	534,275			7	9								7	9						10	10											10	10						
5 Colorado	83,494																																						
6 Connecticut	45,628			3	1								3	a	1				0	0	7	5	0	0	0	0	0	0	0	0	0	0	0	7	b	5	1	0	1
7 Delaware	10,793												0	0						2	2										2	2							
8 District of Columbia	13,761												0	0						1	1										1	1							
9 Florida	189,338												10	6				1													19	15							
10 Georgia	77,904												0	N/A	0				7							1				8									
11 Hawaii	2,937												0	0																	0	0							
12 Illinois	192,283	1		13	0						3		17	0						6								1		7	0								
13 Indiana	83,088			1									2	¹	0	1			2	1									2	1						1			
14 Iowa	37,105			1	1								1	1																0	0								
15 Kansas	35,761										0	5	0	5														0	2	0	2								
16 Kentucky	NR																																						
17 Louisiana	65,186												0	0						6	6									6	6								
18 Maine	975																																						
19 Maryland	71,426			9									9	c		2				4										4									
20 Massachusetts	82,018										1	1	1	1													3	2	3	2									
21 Michigan	131,088												0	0														19	19	0									
22 Minnesota	64,004	1	0	11	0								12							2	2								2	2	1								
23 Mississippi	40,937			5	2								5	2						6	5								6	5									
24 Missouri	77,356			5									5							2									2										

Continued

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	FSA													FC																									
		Asian or P. Islander											Total Reported		Hispanic		Lost to Follow-up	Asian or P. Islander											Total Reported		Hispanic		Lost to Follow-up							
		White		Black		P. Islander		Native Am.		Other		Unknown		S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C			
25 Nebraska	d	23,455																																						
26 Nevada	NR																																							
27 New Hampshire	NR																																							
28 New Jersey		111,074		7	5						1	1	8	6						2	2					7	7	2	2											
29 New Mexico		27,358																																						
30 New York		265,167	1	8	11					1	1	1	9	14			1				4	4			24	22	3	3												
31 North Carolina		103,489																							10	7									3					
32 Ohio		151,801									1	1	1								8	7			8	7									1					
33 Oklahoma		49,766			1	g							0	1											3	3														
34 Oregon		46,387												0																										
35 Pennsylvania																																								
36 Rhode Island		13,718																																						
37 South Carolina		49,254		11	8								11	8											4	4														
38 Tennessee		81,451		11	5								11	5											3	3														
39 Texas		321,332		3	2								3	2											14	12														
40 Vermont		5,694											0	0																										
41 Virginia		94,835	1	8	0						1		10	0							1				4	0														
42 Washington		71,842		3	3					1	1		4	4											1	1														
43 West Virginia		9,109											0	0																										
44 Wisconsin		65,874		1	3								1	3																							1			
45 Wyoming		6,114																																						
45 Puerto Rico	NR																																							
47 Virgin Islands	NR																																							
Total		3,484,753	3	1	107	51	0	0	0	0	1	2	12	9	140 ¹	75	3	1	6					11	3	110	81	1	1	0	0	7	6	33	11	186	121	7	5	10

¹ Ethnicity counted as a Race and is included in total.

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	FE												F Only																				
		White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported		Hispanic	Lost to Follow-up	White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported		Hispanic	Lost to Follow-up	
		S	C	S	C	S	C	S	C	S	C	S	C	S	C			S	C	S	C	S	C	S	C	S	C	S	C	S	C			
1 Alabama	60,870														1																	642		
2 Arizona	76,060																												77	1	77	1		
3 Arkansas	34,201												0	0																0	0			
4 California	534,275	1	1	0		75	75	0		7	7	5	5	89 ¹	89 ¹	1	1	1	1							1	1			3	3			
5 Colorado	83,494																																	
6 Connecticut	45,628		1							1	2			1	3 a			1							1	1			3	b	0			
7 Delaware	10,793																		3	3										3	3			
8 District of Columbia	13,761												0	0					9											9	0			
9 Florida	189,338																																	
10 Georgia	77,904					2							2					1		1											2			
11 Hawaii	2,937												0	0																0	0			
12 Illinois	192,283					1							2	1		1																		
13 Indiana	83,088																																	
14 Iowa	37,105					4	4						4	4																0	0			
15 Kansas	35,761					2						1	1	3	1			1												1	0		2	
16 Kentucky <small>NR</small>																																		
17 Louisiana	65,186					2	2	0					2	2																	0	0		
18 Maine	975																																	
19 Maryland	71,426																			5						1				6	c		2	
20 Massachusetts	82,018											25	25	25	25													3	3	3	3			
21 Michigan	131,088												0																	0				
22 Minnesota	64,004	1				10				1			12				1							1						2				
23 Mississippi	40,937												0	0																0	0			
24 Missouri	77,356					2							2							1										1				

Continued

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	AF													FA																					
		White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported	Hispanic	Lost to Follow-up	White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported	Hispanic	Lost to Follow-up					
		S	C	S	C	S	C	S	C	S	C	S	C				S	C	S	C	S	C	S	C	S	C	S	C								
25 Nebraska	a	23,455																																		
26 Nevada	NR																																			
27 New Hampshire	NR																																			
28 New Jersey		111,074											1,502															106,658								
29 New Mexico		27,358											N/C																							
30 New York		265,167	319		299		32		1		251		N/A		902		203									140,688	41,641	11,706	232	55,506	4,125	253,898	45,523	N/C		
31 North Carolina		103,489	219		199		18		11		15		1		463				68,760	25,018	3,601	1,227	4,500		466		103,572									
32 Ohio		151,801										366			366										155,523		155,523									
33 Oklahoma		49,766	49		10		6		0		5				70																N/C					
34 Oregon		46,387	15		2		8		1		1		19		46		7		34,789	1,309	1,794	753	711		6,452		45,808		6,417							
35 Pennsylvania																																				
36 Rhode Island		13,718																																		
37 South Carolina		49,254													0												46,959				b					
38 Tennessee		81,451												N/D		N/D		55,037	13,548	469	51	1,652				70,757										
39 Texas		321,332	58		23		7		2		3		56		256 ¹		107		132,533	32,151	5,416	413	5,374		11,383		319,929 ¹		132,659							
40 Vermont		5,694		22													22										5,648									
41 Virginia		94,835	249		153		15		2		77				496	0	33														DA					
42 Washington		71,842	88	88	8	8	5	5	1	1	7	7	23	23	132	132	13															N/A				
43 West Virginia		9,109													0										8,963		8,963									
44 Wisconsin		65,874	97		15		4		5				16		137				54,071	5,200	1,579		1,557		1,280		63,687									
45 Wyoming		6,114																							2	2	2	2								
46 Puerto Rico	NR																																			
47 Virgin Islands	NR																																			
Total		3,484,753	1,628	115	950	9	171	7	27	1	418	9	665	23	5,816 ¹	165 ¹	725	1	79	965,925	28,977	258,563	19,873	71,013	156	5,780	12	92,484	734	391,200	84,465	2,328,733 ¹	134,700	461,894	483	0

¹ Ethnicity counted as a Race and is included in total.

a = hemoglobin screening not mandated until November therefore data requested not collected by program; b = confirmation not required.

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected C = Confirmed

State/Territory	Number of Newborns Screened	FAS												FAC																																			
		White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported	Hispanic		Lost to Follow-up	White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported	Hispanic		Lost to Follow-up																
		S	C	S	C	S	C	S	C	S	C	S	C		S	C		S	C	S	C	S	C	S	C	S	C	S	C		S	C		S	C	S	C	S	C										
25 Nebraska	d 23,455																																																
26 Nevada	NR																																																
27 New Hampshire	NR																																																
28 New Jersey	111,074													2,014																								588											
29 New Mexico	27,358	6		14						1			14	65¹		30																						23¹	6		2								
30 New York	265,167	338		4,008		29		0		1,509		N/A	5,884		1,327										N/C	106		1,274		9		0		309		N/A	1,698		268		N/C								
31 North Carolina	103,489	129		1,990		57		29		56		12	2,273													40		582		11		17		4		5		659											
32 Ohio	151,801											1,907	1,907	685																					558	152	558		152										
33 Oklahoma	49,766	48	19	284	124	11	7			11	6	23	377	166												208	11	8	97	41	1	1		3	3	4	2	116	55				61						
34 Oregon	46,387	36		75		3		5		5		21	145		31											2		27		5				1		7		42											
35 Pennsylvania	46,387																																																
36 Rhode Island	13,718																																																
37 South Carolina	49,254											1,552	1,552		a																				389		389		d										
38 Tennessee	81,451	105		1,162		2				28			1,297													130		69		2		1		7				209											
39 Texas	321,332	387		3,114		22		1		76		264	4,817¹		953											105		944		16		1		26		77		1,287¹		118									
40 Vermont	5,694			11	11								11	11															2	2							2		2										
41 Virginia	94,835		148		1,353		10		1		189	0	0	1,701		79										0	27		459		1				40		0	527		10									
42 Washington	71,842	78	78	170	170	2	2	1	1	93	93	15	15	359	b	359	b	43	43							10	10	40	40					20	20	4	4	74	c	74	c	12	12						
43 West Virginia	9,109											74	74	0																					25		25		0										
44 Wisconsin	65,874	91	91	459	459	2	2			14	14	31	31	597		597										20	20	143	143					1	1	8	8	172		172									
45 Wyoming	6,114											6	6	6	6																				2	2	2		2										
46 Puerto Rico	NR																																																
47 Virgin Islands	NR																																																
Total	3,484,753	2,446	509	28,020	5,342	255	51	45	5	2,206	315	7,250	867	46,164¹	S	7,089¹	C	4,083	135	302							840	103	8,198	1,732	79	13	42	0	428	67	2,054	273	13,029¹	S	2,188¹	C	648	25	83				

¹ Ethnicity counted as a Race and is included in total.

a = confirmation not required; b = includes 9 infants (1 white & 1 black) with FAS + Bart's; c = includes 3 black infants with FAC + Bart's; d = hemoglobin screening not mandated until November therefore data requested not collected by program.

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected C = Confirmed

State/Territory	Number of Newborns Screened	FAE													FAD or FAG																					
		White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported		Hispanic	Lost to Follow-up	White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported		Hispanic	Lost to Follow-up			
		S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C			
25 Nebraska	a	23,455																																		
26 Nevada	NR																																			
27 New Hampshire	NR																																			
28 New Jersey		111,074													29	N/C													32	DA						
29 New Mexico		27,358	3	3			5	4						9 ¹	8	1	1	1										6 ¹	6 ¹	4	4					
30 New York		265,167	15		16		75		0		50		N/A	156		4			N/C	60		33		17	2	41		153		20		N/C				
31 North Carolina		103,489	4		1		25				29		1	60																						
32 Ohio		151,801										64	23	64	23										66	20	66	20								
33 Oklahoma		49,766	7	4	2				9	5	1		2	1	21	10			10	14	7					4	2		18	9		7				
34 Oregon		46,387	14		1		31		0		1		2	49						1						2		3		3		0				
35 Pennsylvania																																				
36 Rhode Island		13,718																																		
37 South Carolina		49,254										26		26		b										20		20		b						
38 Tennessee		81,451	60		26		27				10			123						98		490		22		15		625								
39 Texas		321,332	36		43		99		1		34		18	266 ¹		35		N/A	57		20		4	0	8	14	153 ¹		50		N/A					
40 Vermont		5,694												0						2	2							2	2							
41 Virginia		94,835		12		5		38				24		0	79		1			40		5		2		9		0	56	0	3					
42 Washington		71,842	13	13			134	134			27	27	4	4	178 ^c	178 ^c	3	3		19	19			1	1		1	1	1	1	22 ^d	22 ^d	2	2		
43 West Virginia		9,109												0														0								
44 Wisconsin		65,874	8	8	1	1	38	38					3	3	50	50				17		5				1	1	23								
45 Wyoming		6,114										1	1	1	1											5	5	5	5				7			
46 Puerto Rico	NR																																			
47 Virgin Islands	NR																																			
Total		3,484,753	298	43	156	8	1433	221	10	5	251	53	486	85	S 2,823	C 416	150	5	21	497	91	639	15	91	4	8	0	109	13	259	74	S 1,884	C 201	265	9	19

¹ Ethnicity counted as a Race and is included in total.

a = hemoglobin screening not mandated until November therefore data requested not collected by program; **b** = confirmation not required; **c** = includes 15 infants (1 white, 1 asian & 2 other) with FAE plus Bart's; **d** = includes 1 white infant with FDA (presumably Hb-D b + thalassemia).

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected

C = Confirmed

State/Territory	Number of Newborns Screened	FA + Other																	
		White		Black		Asian or P. Islander		Native Am.		Other		Unknown		Total Reported		Hispanic		Lost to Follow-up	
		S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C		
1 Alabama	60,870														78				
2 Arizona	76,060										327				327				
3 Arkansas	34,201	42		212		11		N/C		3		11			279		3		DA
4 California	534,275	74		404		41		3		21		24			756¹	N/A	189		N/A
5 Colorado	83,494																		
6 Connecticut	45,628																		
7 Delaware	10,793																		
8 District of Columbia	13,761											44			44	0			
9 Florida	189,338																		
10 Georgia	77,904																		
11 Hawaii	2,937	8		11		4		0		6		0			29^a				N/A
12 Illinois	192,283														0				
13 Indiana	83,088	124		275		17				19					441¹		6		
14 Iowa	37,105											0	0		0	0			N/C
15 Kansas	35,761														0	55			
16 Kentucky	NR																		
17 Louisiana	65,186	13	13	54	54	3	3					3	3		73	73			DA
18 Maine	975																		
19 Maryland	71,426	88		61		28				10		9			196		4		
20 Massachusetts	82,018																		
21 Michigan	131,088														0				
22 Minnesota	64,004	100		138		111		3		27		14			393		3		
23 Mississippi	40,937	36	18	41	28										77	46	0	0	3
24 Missouri	77,356	66		33				1		7		6			113		1		

Continued

Table 13.02: INITIAL HEMOGLOBIN RESULTS (continued)

S = Suspected C = Confirmed

State/Territory	Number of Newborns Screened	FA + Other																			
		White		Black		Asian		Native Am.		Other		Unknown		Total Reported		Hispanic		Lost to Follow-up			
		S	C	S	C	S	C	S	C	S	C	S	C	S	C	S	C				
25 Nebraska	b	23,455																			
26 Nevada	NR																				
27 New Hampshire	NR																				
28 New Jersey		111,074												153		DA					
29 New Mexico		27,358	10		1			2				1				27 ¹		13	1		
30 New York		265,167	310		1,275			220			3		362	N/A		2,170		255	N/C		
31 North Carolina		103,489	151		82			13			4		14		4	268					
32 Ohio		151,801												499	48	499	48				
33 Oklahoma		49,766	34	15	3			7	2				2	2	0	46	19	0	16		
34 Oregon		46,387	89		34			32			5		9		34	203		22			
35 Pennsylvania																					
36 Rhode Island		13,718																			
37 South Carolina	c	49,254												214		214		DA			
38 Tennessee		81,451	28		24								1			53					
39 Texas		321,332	220		110			21			0		8		46	691 ¹		286	N/A		
40 Vermont		5,694	9													9					
41 Virginia		94,835	194		727			49			1		87		0	1,058		22			
42 Washington		71,842	86	63	5	92	8	107	3	3			21	73	4	14	127	352	d	45	22
43 West Virginia		9,109													29		29				
44 Wisconsin		65,874	34		3			2							2		41				
45 Wyoming		6,114													1	1	1	1			5
46 Puerto Rico	NR																				
47 Virgin Islands	NR																				
Total		3,484,753	1,716	109	3,493	174	569	112	23	3	598	75	1,271	66		8,395 ^S	594 ^C	849	22	25	

Ethnicity counted as a Race and is included in total.
a = Hb Bart's data; **b** = hemoglobin screening not mandated until November therefore data requested not collected by program; **c** = confirmation not required, we will recommend confirmation of Hgb Barts if it is higher percentage; **d** = bart's hemoglobin includes 10 infants (1 black, 5 asian, 3 other & 1 unknown) with high Bart's indicative of a 3 gene deletion

Table 13.03: Summation of Confirmed FS Cases (Sickle Cell Anemia) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									38
2 Arizona				2				2	4
3 Arkansas	0	4	3	2	1	1	4	6	21
4 California	2	11							N/C
5 Colorado									0
6 Connecticut	2	11							13
7 Delaware									N/C
8 District of Columbia									
9 Florida	1	9	13	8	8	11	42		92
10 Georgia									0
11 Hawaii	0	0	0	0	0	0	0	0	0
12 Illinois								82	82
13 Indiana		1	1	4	2		2	5	15
14 Iowa									0
15 Kansas								5	5
16 Kentucky NR									
17 Louisiana	29	17	6	1	0	2	1	0	56
18 Maine									
19 Maryland			4	4	4	4	7	12	3
20 Massachusetts									
21 Michigan	0	2	8	4	5	8	5	0	32
22 Minnesota						3	3	5	11
23 Mississippi	0	0	0	9	0	0	1	0	10
24 Missouri									
25 Nebraska				1					1
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey	3	14	7	3	5	2	5	0	39
29 New Mexico									0
30 New York	16	75	30	17	5	7	11	0	161
31 North Carolina									N/D
32 Ohio					3	10	5	9	27 N/C
33 Oklahoma	2	0	0	0	0	0	0	0	2
34 Oregon								2	2
35 Pennsylvania									
36 Rhode Island NR									
37 South Carolina	3	19	8	0	0	0	3	12	45
38 Tennessee									
39 Texas									N/A
40 Vermont									0
41 Virginia	0	12	18	0	1	1	0	0	32
42 Washington				1	1			1	3
43 West Virginia									N/D
44 Wisconsin		6	9		1				16
45 Wyoming									0
46 Puerto Rico NR									
47 Virgin Islands NR									

Table 13.04: Summation of Confirmed FS Cases (Sickle Cell Anemia) by Days from Birth Until Treatment Initiated

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									
2 Arizona								4	4
3 Arkansas	4	4	3	1	2	1	4	2	21
4 California	1	6	15	12	7	2	5	9	57
5 Colorado									
6 Connecticut	2	11							13
7 Delaware									0
8 District of Columbia									
9 Florida									
10 Georgia									0
11 Hawaii	0	0	0	0	0	0	0	0	0
12 Illinois	1	63						18	82
13 Indiana								15	15
14 Iowa									0
15 Kansas								5	5
16 Kentucky NR									
17 Louisiana	4	10	16	6	1	1	9	9	56
18 Maine									
19 Maryland		2	13	6	2	3	2	7	35
20 Massachusetts									
21 Michigan									0
22 Minnesota	4	2						5	11
23 Mississippi	0	0	0	9	0	1	0	0	10
24 Missouri									
25 Nebraska				1					1
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey	1	10	6	6	7	2	6	1	39
29 New Mexico									
30 New York	4	8	4	4	0	1	1	0	22 a
31 North Carolina									N/D
32 Ohio						4	14	9	27
33 Oklahoma	0	1	1	0	0	0	0	0	2
34 Oregon								2	2
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	1	8	8	3	5	0	11	9	45
38 Tennessee									
39 Texas									N/A
40 Vermont									0
41 Virginia									N/A
42 Washington			2			1			3
43 West Virginia									N/D
44 Wisconsin			1	6	9				16
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

a = FC (Homozygous Hb-C).

Table 13.05: Summation of Confirmed FSA Cases (S- β -thalassemia) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									6
2 Arizona									0
3 Arkansas	0	0	0	0	0	0	1	0	1
4 California									9
5 Colorado			1						1
6 Connecticut		1							1
7 Delaware									N/C
8 District of Columbia									
9 Florida	0	0	0	3	0	0	3	0	6
10 Georgia									0
11 Hawaii	0	0	0	0	0	0	0	0	0
12 Illinois									0
13 Indiana									
14 Iowa							1		1
15 Kansas								5	5
16 Kentucky NR									
17 Louisiana									0
18 Maine									
19 Maryland					1		2	1	4
20 Massachusetts									
21 Michigan							5		5
22 Minnesota									
23 Mississippi	0	0	1	0	1	0	0	0	2
24 Missouri									
25 Nebraska									
26 Nevada NR									
27 New Hampshire NR									N/C
28 New Jersey	0	1	1	1	1	0	2	0	6
29 New Mexico									
30 New York	0	2	2	2	4	0	4	0	14
31 North Carolina									N/D
32 Ohio									N/C
33 Oklahoma	1 a	0	0	0	0	0	0	0	1
34 Oregon									0
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	0	3	3	0	1	0	1	0	8
38 Tennessee									N/R
39 Texas									N/A
40 Vermont									0
41 Virginia									0
42 Washington		1	1	1		1			4
43 West Virginia									N/D
44 Wisconsin			2					1	3
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

a = initial screen FS.

Table 13.06: Summation of Confirmed FSC Cases (SC-Disease) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									24
2 Arizona						3			3
3 Arkansas	0	1	0	1	0	0	2	2	6
4 California									29
5 Colorado			4						4
6 Connecticut	3	1	1						5
7 Delaware								2	2
8 District of Columbia									
9 Florida	0	4	4	2	8	5	25	0	48
10 Georgia									0
11 Hawaii	0	0	0	0	0	0	0	0	0
12 Illinois									0
13 Indiana			3		1			4	8
14 Iowa							2		2
15 Kansas	0	0	0	0	0	0	0	0	0
16 Kentucky NR									
17 Louisiana	1	16	2	1	1				21
18 Maine									
19 Maryland	1		3	4	4	1	3	6	22
20 Massachusetts									
21 Michigan		2		6	5	2	11		26
22 Minnesota									4
23 Mississippi	0	0	2	5	0	0	0	0	7
24 Missouri									
25 Nebraska									0
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey	1	5	4	4	4	1	12	0	31
29 New Mexico									0
30 New York	9	29	16	8	7	1	12	0	82
31 North Carolina									N/D
32 Ohio									N/C
33 Oklahoma	1	1	1	0	0	0	0	0	3
34 Oregon								1	1
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	2	16	0	0	0	0	1	4	23
38 Tennessee									
39 Texas									N/A
40 Vermont									0
41 Virginia									
42 Washington	1	2	2						5
43 West Virginia									N/D
44 Wisconsin		4	5	1				1	11
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

Table 13.07: Summation of Confirmed FSE Cases (SE-Disease) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									
2 Arizona									0
3 Arkansas									
4 California									1
5 Colorado									
6 Connecticut									0
7 Delaware									N/C
8 District of Columbia									
9 Florida									0
10 Georgia									0
11 Hawaii									0
12 Illinois									
13 Indiana									
14 Iowa									0
15 Kansas									0
16 Kentucky NR									
17 Louisiana									N/D
18 Maine									
19 Maryland									
20 Massachusetts									
21 Michigan									0
22 Minnesota									
23 Mississippi									0
24 Missouri									
25 Nebraska									0
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey									0
29 New Mexico									
30 New York	0	1	0	0	0	0	0	0	1
31 North Carolina									N/D
32 Ohio									N/C
33 Oklahoma									0
34 Oregon									0
35 Pennsylvania									
36 Rhode Island									
37 South Carolina									0
38 Tennessee									NR
39 Texas									N/A
40 Vermont									0
41 Virginia									0
42 Washington									0
43 West Virginia									N/D
44 Wisconsin									0
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

Table 13.08: Summation of Confirmed FSD Cases (SD-Disease) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									
2 Arizona									
3 Arkansas									
4 California									1
5 Colorado									0
6 Connecticut									0
7 Delaware									N/C
8 District of Columbia									
9 Florida									0
10 Georgia									N/D
11 Hawaii									0
12 Illinois									
13 Indiana									
14 Iowa									0
15 Kansas									0
16 Kentucky NR									
17 Louisiana									N/D
18 Maine									
19 Maryland									
20 Massachusetts									
21 Michigan									0
22 Minnesota									
23 Mississippi									0
24 Missouri									
25 Nebraska									0
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey									0
29 New Mexico									
30 New York									N/D
31 North Carolina									N/D
32 Ohio									N/C
33 Oklahoma									0
34 Oregon									0
35 Pennsylvania									
36 Rhode Island									
37 South Carolina									0
38 Tennessee									NR
39 Texas									N/A
40 Vermont									0
41 Virginia									0
42 Washington									0
43 West Virginia									N/D
44 Wisconsin									0
45 Wyoming									0
46 Puerto Rico NR									
47 Virgin Islands NR									

Table 13.09: Summation of Confirmed FAS Cases (Sickle Cell Trait) by Days from Birth Until Diagnosis

State/Territory	0-15	16-30	31-45	46-60	61-75	76-90	> 90	Unknown	Total
1 Alabama									1,314
2 Arizona									
3 Arkansas									
4 California									N/C
5 Colorado								191	191
6 Connecticut									0
7 Delaware									N/C
8 District of Columbia									
9 Florida									N/D
10 Georgia									0
11 Hawaii								48	48
12 Illinois									
13 Indiana									
14 Iowa									0
15 Kansas								3	3
16 Kentucky NR									
17 Louisiana								2215	2,215
18 Maine								21	21
19 Maryland									
20 Massachusetts									
21 Michigan	20,097								20,097
22 Minnesota									
23 Mississippi	0	5	78	518	468				1,069
24 Missouri									
25 Nebraska	5	2	1	1	1	1	5		16
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey									N/C
29 New Mexico	111								111
30 New York									N/C
31 North Carolina									N/D
32 Ohio									N/C
33 Oklahoma									N/C
34 Oregon								145	145
35 Pennsylvania									
36 Rhode Island									
37 South Carolina									DA
38 Tennessee									NR
39 Texas									N/A
40 Vermont	11								11
41 Virginia									0
42 Washington									359
43 West Virginia									N/D
44 Wisconsin	597								597
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

Table 13.10: Program Follow-up

State/Territory	Program have an Aggressive Follow-up Program for Sickie Carriers	Program has Extra Staff Dedicated to Sickie Carrier Follow-up	Sickle Follow-up Performed for Carriers
1 Alabama			
2 Arizona	Yes	Yes	SC disease and carriers referred to AZ Sickie Cell Program for follow-up.
3 Arkansas	Yes	Yes	Parents of carriers offered additional counseling, info via home visit, mail or phone.
4 California	No	Yes	Free counseling and testing offered to all families.
5 Colorado		Yes	In home counseling offered and fee for both trait and diagnosis.
6 Connecticut	No	No	Letter sent to primary care provider & mother. Copy of Trait log sent to the 2 SC centers and they attempt to contact families for counseling.
7 Delaware	No	No	Letters to parent and primary care provider.
8 District of Columbia	Yes	Yes	Letter notification to parent, recommends confirmatory test, counseling of parents.
9 Florida	No	No	Trait letters sent to family to encourage further testing & contact with physician.
10 Georgia	No	No	Parents sent letter for counseling by Georgia Sickie Cell Foundation or health dept.
11 Hawaii	No	No	Letter sent to family whose child is identified as carrier. Repeat test at 6 mo. and carrier status testing of both parents is also recommended. No active follow-up.
12 Illinois	Yes	Yes	Families of infants w/trait status are referred to a pediatric hematologist and / or public health department to provide education to the families.
13 Indiana	No	No	
14 Iowa	No	No	Family screening and genetic counseling services.
15 Kansas	No	No	
16 Kentucky NR			
17 Louisiana	Yes	No	Letters are sent to parent/guardian w/results indicating sickie carrier status.
18 Maine			
19 Maryland	No	No	
20 Massachussetts	Yes	Yes	In home counseling and carrier testing offered.
21 Michigan	Yes	Yes	Letters and telephone calls to schedule counseling sessions.
22 Minnesota			
23 Mississippi	Yes	Yes	Field staff available for counseling carriers (RN's & Genetic Social Workers).
24 Missouri			
25 Nebraska	No	No	Follow-up letters sent to parents.
26 Nevada NR			
27 New Hampshire NR			
28 New Jersey	No	No	Follow-up letters are sent to the M.D. and parent.
29 New Mexico	No	No	Follow-up letters sent to Sickie cell council and parents.
30 New York	No	No	
31 North Carolina	No	No	
32 Ohio			
33 Oklahoma	Yes	No	Carriers are referred to the Ok SC Assoc. for counseling & follow-up testing on AS & AC traits.
34 Oregon	No	No	
35 Pennsylvania			
36 Rhode Island			
37 South Carolina	No	No	Follow-up by the Sickie Cell community based organization.
38 Tennessee	Yes	No	Counseling of families affected.
39 Texas	No	No	Reports are returned to submitter & submitter is responsible for reporting & following carriers.
40 Vermont	No	No	Counseling offered - pediatric hematologist.
41 Virginia	No	No	Parents are sent follow-up letters & toll free number for questions.
42 Washington	No	Yes	A letter & educational materials sent to child's health care prov. when 2 screens are matched. A request for 2nd screen is made to the provider when there is only one screen.
43 West Virginia	No	No	Suggest genetic counseling by provider.
44 Wisconsin	No	No	Family education provided by health educators, pediatric practices, clinics & public health dept. & post natal home visits.
45 Wyoming		Yes	Track disease and confirm.
46 Puerto Rico NR			
46 Virgin Islands NR			

Table 13.11: Summation of Years Covered and Number of Cases Detected by Program

State/Territory	FS: [Probable SCD (May be Hb-S-β-Thalassemia), Hb S-β-thalassemia with hereditary persistent fetal hemoglobin]			FSC: (Presumably Sickle-Hemoglobin C Disease)			FSA [Probable Hb-S-β-Thalassemia (Maybe Hb-S with Transfusion)]		
	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases
1 Alabama	1988		NR	1988		NR			
2 Arizona	1994	2	9	1994	2	3	1994	2	4
3 Arkansas	1988	8	125	1988	8	61	1988	8	6
4 California	1990	5	473	1990	5	236	1990	5	52
5 Colorado									
6 Connecticut	1989	7	91	1989	7	39	1989	7	5
7 Delaware									
8 District of Columbia	1996	0	10	1996	0	4	1996	0	0
9 Florida	1988	7	555	1988	7	258	1988	7	35
10 Georgia									
11 Hawaii	May-93	2 1/2	3	May-93	2 1/2	0	May-93	2 1/2	0
12 Illinois	1989	7	973	1989	7	327	1989	7	68
13 Indiana	Jul-85	10 1/2	168	Jul-85	10 1/2	79	Jul-85	10 1/2	N/D
14 Iowa	1987	8	16	1987	8	11	1987	8	3
15 Kansas	1992	4	22	1992	4	11	1993	3	6
16 Kentucky NR	N/A		N/A				1991	4	4
17 Louisiana	N/C		N/C	N/C		N/C	N/C		N/C
18 Maine									
19 Maryland	1983	13	384	1989	7	212	1989	7	31
20 Massachusetts	Mar-90	5 3/4	123	Mar-90	5 3/4	75	Mar-90	5 3/4	6
21 Michigan	1982	14	446	1987	9	270	1987	9	61
22 Minnesota	1988	8	21	1988	8	10	1988	8	3
23 Mississippi	1991	5	165	1991	5	105	1991	5	80
24 Missouri									
25 Nebraska	Nov-96	1/6	1	Nov-96	1/6	0	Nov-96	1/6	1
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey	1990	5	~279	1990	5	~125	1990	5	~25
29 New Mexico	1988	8	0	1988	8	0	1995	1	0
30 New York	1975	21	2,914	1975	21	1,464	1993	3	41
31 North Carolina	1987	9	364 a	1987	9	182 a			
32 Ohio	1994	2	71	1994	2	41	1996	1	1
33 Oklahoma	1991	5	57	1991	5	30	1991	6	57
34 Oregon	1995	1	3	1995	1	1	1995	1	0
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	1996	0	45	1996	0	23	1996	0	8
38 Tennessee	1991	4	139	1991	4	79	1991	4	11
39 Texas	Nov-83	12 3/4	1,174	Nov-83	12 3/4	492	Nov-83	12 3/4	67
40 Vermont	Mar-90	5 1/3	0	Mar-90	5 1/3	1	Mar-90	5 1/3	0
41 Virginia	1989	7	305	1989	7	169	1989	7	52
42 Washington	May-91	4 1/2	22	May-91	4 1/2	9	May-91	4 1/2	12
43 West Virginia				N/D		N/D	N/D		N/D
44 Wisconsin	1989	7	110	1989	7	64	1989	7	13
45 Wyoming									
46 Puerto Rico NR									
47 Virgin Islands NR									

a = Target screening.

Table 13.11: Summation of Years Covered and Number of Cases Detected by Program (continued)

State/Territory	FC: [Probable Homozygous Hb-C (May be Hb-C-β-Thalassemia)]			FE: [Probable Homozygous Hb-E (May be Hb-E-β-Thalassemia)]			F Only: (Possible Homozygous β-thalassemia or Normal Biologic Variation)		
	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases
1 Alabama									
2 Arizona	NR		NR	NR		NR	NR		NR
3 Arkansas	1989	7	14	1988	8	6	N/A		N/A
4 California	1990	5	52 a	1990	5	791 b	1990	5	29
5 Colorado			0			0			
6 Connecticut	1989	6	9	1989	7	17	1989	7	1
7 Delaware									
8 District of Columbia	1996	0	1	1996	0	0	1996	0	c
9 Florida	1988	7	71	N/D		N/D	N/D		N/D
10 Georgia									
11 Hawaii	May-93	2 1/2	0	May-93	2 1/2	1	May-93	2 1/2	0
12 Illinois	1989	7	19	1989	7	N/A			
13 Indiana	Jul-85	10 1/2	25	N/D		1	N/D		N/D
14 Iowa	1987	8	3	1987	8	18	1987	8	1
15 Kansas	1992	4	9	1992	4	3	1992	4	5
16 Kentucky	NR								
17 Louisiana	N/C		N/C	N/C		N/C	N/C		N/C
18 Maine									
19 Maryland	1985	11	61	1985	11	5	1987	9	5
20 Massachusetts	Mar-90	5 3/4	19	Mar-90	5 3/4	159	Mar-90	5 3/4	16
21 Michigan	1987	9	10	1987	9	0	1987	9	0
22 Minnesota									
23 Mississippi	1991	5	43	1991	5	0	1991	4	4
24 Missouri									
25 Nebraska	Nov-96	1/6	0	Nov-96	1/6	0	Nov-96	1/6	0
26 Nevada	NR								
27 New Hampshire	NR								
28 New Jersey	1990	5	~22	1990	5	~29	1990	5	~17
29 New Mexico	1995	1	0	1995	1	1	1995	1	1
30 New York	1975	21	420	1993	3	18	1993	3	3
31 North Carolina	1987	9	59	1987	9	15	1987	9	4
32 Ohio	1996	0	7	1996	0	2	1996	0	3
33 Oklahoma	1991	4	30	1991	5	1	1991	5	203
34 Oregon	1995	1	0	1995	1	2	1995	1	0
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	1996	0	4	1996	0	1	1996	0	2
38 Tennessee	1991	4	12	1991	4	7	1991	4	0
39 Texas	Nov-83	12 3/4	151	Nov-83	12 3/4	124	Nov-83	12 3/4	4
40 Vermont	Mar-89	6 1/2	0	Jul-89	6 1/2	0	Jul-89	6 1/2	0
41 Virginia	1989	7	52	1989	7	14	1989	7	14
42 Washington	May-91	5 1/2	9	May-91	4 1/2	77	1991	4 1/2	2
43 West Virginia	N/D		N/D	N/D		N/D	N/D		N/D
44 Wisconsin	1989	6	6	1989	7	25	1989	7	2
45 Wyoming			0			0			
46 Puerto Rico	NR								
47 Virgin Islands	NR								

a = 4 confirmed as C/β-thalassemia; **b** = includes 29 confirmed as E/β-thalassemia, all confirmed as FE; **c** = no follow-up on these patients.

Table 13.11: Summation of Years Covered and Number of Cases Detected by Program (continued)

State/Territory	FAS: [Presumably Sickie-Carrier (Trait)]			FAC: [Presumably Hb-C Carrier (Trait)]			FAE: [Presumably Hb-E Carrier (Trait)]		
	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases
1 Alabama				1988	8		N/A		N/A
2 Arizona	1994	2	38	1994	2	5	NR		NR
3 Arkansas	DA			DA					
4 California	N/C		N/C	N/C		N/C	N/C		N/C
5 Colorado									
6 Connecticut	1989	7	3,758 a	1989	7	1,080 a	1989	7	64
7 Delaware									
8 District of Columbia	1996	0	0	1996	0	0	1996	0	0
9 Florida	N/D		N/D	N/D		N/D	N/D		N/D
10 Georgia									
11 Hawaii	May-93	2 1/2	150	May-93	2 1/2	38	May-93	2 1/2	26
12 Illinois	1994	2	13,759	1994	2	4,058	1994	2	273
13 Indiana	Jul-85	10 1/2	6,282	Jul-85	10 1/2	2,047	DA		DA
14 Iowa	1987	8	632	1987	8	178	1987	8	290
15 Kansas	1992	4	404	1992	4	193	1992	4	80
16 Kentucky NR									
17 Louisiana	N/R		N/R	N/R		N/R	N/A		N/A
18 Maine									
19 Maryland									
20 Massachusetts	Mar-90	5 3/4	5,508	Mar-90	5 3/4	1,589	Mar-90	5 3/4	1,495
21 Michigan	1987	9	20,097	1987	9	6,027	1987	9	0
22 Minnesota									
23 Mississippi	1991	5	8,300	1991	5	2,364	1991	5	37
24 Missouri									
25 Nebraska	Nov-96	1/6	16	Nov-96	1/6	3	Nov-96	1/6	1
26 Nevada NR									
27 New Hampshire NR									
28 New Jersey	1990	5	11,972	1990	5	3,308	1992	3	142
29 New Mexico	1995	1	69	1995	1	31	1995	1	11
30 New York	1975	21	114,668	1975	21	33,381	1987	9	1,344
31 North Carolina	1987	9	15,033 b	1987	9	4,740 b	1987	8	226 b
32 Ohio	1996	-1	685	1996	-1	152	1996	-1	23
33 Oklahoma	1991	5	2,399	1991	5	757	1991	5	91
34 Oregon	1995	1		1995	1		1995	1	
35 Pennsylvania									
36 Rhode Island									
37 South Carolina	DA	DA	DA	DA	DA	DA	DA	DA	DA
38 Tennessee	1993	2	3,968	1993	2	1985	1993	2	344
39 Texas	N/A		N/A	N/A		N/A	N/A		N/A
40 Vermont	Mar-90	5 1/3	21	Mar-90	5 1/3	4	Mar-90	4 1/3	5
41 Virginia	1989	7	N/A	1989	7	N/A	1989	7	N/A
42 Washington	May-91	4 1/2	1,538	May-91	4 1/2	488	May-91	5 1/2	1124
43 West Virginia	N/D		N/D	N/D		N/D	N/D		N/D
44 Wisconsin	1989	7	4,927	1989	7	1,502	1989	7	180
45 Wyoming			18			4			5
46 Puerto Rico NR									
47 Virgin Islands NR									

a = traits are not confirmed by program; **b** = Target screening.

Table 13.11: Summation of Years Covered and Number of Cases Detected by Program (continued)

State/Territory	FAD or FAG: [Presumably Hb-D or Hb-G (Trait)]			FA + Other [Presumably Other Carrier (Probably insignificant clinically but not known w/o further study)]		
	Year Started	Total Years	Total Cases	Year Started	Total Years	Total Cases
1 Alabama				1988	8	
2 Arizona	1994	2	5	1994	2	11
3 Arkansas			DA			
4 California	1990	5	1,888	1990	5	637
5 Colorado						
6 Connecticut	N/D		N/D	N/C		N/C
7 Delaware						
8 District of Columbia	1996	0	0	1996	0	0
9 Florida	N/D		N/D	N/D		N/D
10 Georgia						
11 Hawaii	May-93	2 1/2	0	May-93	2 1/2	92
12 Illinois	1994	2	500			
13 Indiana	DA		DA	DA		DA
14 Iowa	1987	8	91	1987	8	560
15 Kansas	1992	4	32	1992	4	238
16 Kentucky NR						
17 Louisiana				N/R		N/R
18 Maine						
19 Maryland						
20 Massachusetts	Mar-90	5 3/4	194			
21 Michigan	1987	9	0	1987	9	0
22 Minnesota						
23 Mississippi	1991	5	235	1991	5	164
24 Missouri						
25 Nebraska	Nov-96	1/6	1	Nov-96	1/6	0
26 Nevada NR						
27 New Hampshire NR						
28 New Jersey	1992	3	132	1990	5	1,277
29 New Mexico	1995	1	8	1991	5	153
30 New York	1987	9	1,284	1987	9	20,649
31 North Carolina						
32 Ohio	1996	0	152	1996	0	48
33 Oklahoma	1991	5	172	1993	3	129
34 Oregon	1995	1		1995	1	
35 Pennsylvania						
36 Rhode Island						
37 South Carolina	DA	DA	DA	DA	DA	DA
38 Tennessee	1993	2	1,584	1993	2	132
39 Texas				N/A		N/A
40 Vermont	Mar-90	6 1/4	2	Mar-90	5 1/4	9
41 Virginia	1989	7	N/A	1989	7	N/A
42 Washington	May-91	4 1/2	149	May-91	4 1/2	2,354 ^a
43 West Virginia	N/D		N/D	N/D		N/D
44 Wisconsin	1993	3	69	1989	7	948
45 Wyoming			5			5
46 Puerto Rico NR						
47 Virgin Islands NR						

^a = 1,728 Hgb Bart's.