

**Survey of Nationwide  
Public Health Genetics Activities**

**Coalition of State Genetics Coordinators**

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## Glossary

<b>Active Birth Defects Surveillance</b>	A birth defects program that actively abstracts birth defects information from the baby's and/or mother's medical records.
<b>American Board of Genetic Counselors (ABGC)</b>	Professional Board of Genetic Counseling that certifies genetic counselors.
<b>American Board of Medical Genetics (ABMG)</b>	Professional Board of Medical Genetics that certifies M.D. and Ph.D. geneticists (also certified genetic counselors until 1990 when ABGC was formed).
<b>Clinical Geneticist</b>	A medical doctor who specializes in genetics.
<b>Federal funds</b>	Funds from the federal government sources including: Medicaid, Title V Maternal and Child Health Block grant, and other grants.
<b>Genetic Counselor</b>	A healthcare professional who provides information and support to individuals and families who have a genetic disorder, might be at risk for developing an inherited condition, or are concerned that they may have a child with an inherited disease.
<b>Genetic evaluation</b>	A clinical evaluation done by a clinical geneticist.
<b>Genetics Needs Assessment</b>	A needs assessment of genetic activities in the public and/or private sector.
<b>Medical foods</b>	Formula or food required for the management of individuals who have metabolic disorders.
<b>N/A</b>	Not applicable.
<b>N/R</b>	Not reported.
<b>Newborn Hearing Screening Program</b>	State program that screens for hearing loss in newborns.
<b>Newborn Metabolic Screening Program</b>	State program that use newborn blood samples collected by heelstick to screen for metabolic and other genetic disorders.
<b>Passive Birth Defects Surveillance</b>	A birth defects program that relies on birth defects sent to them from various sources (e.g. birthing facilities).
<b>State</b>	In this report, refers to state, territory or the District of Columbia

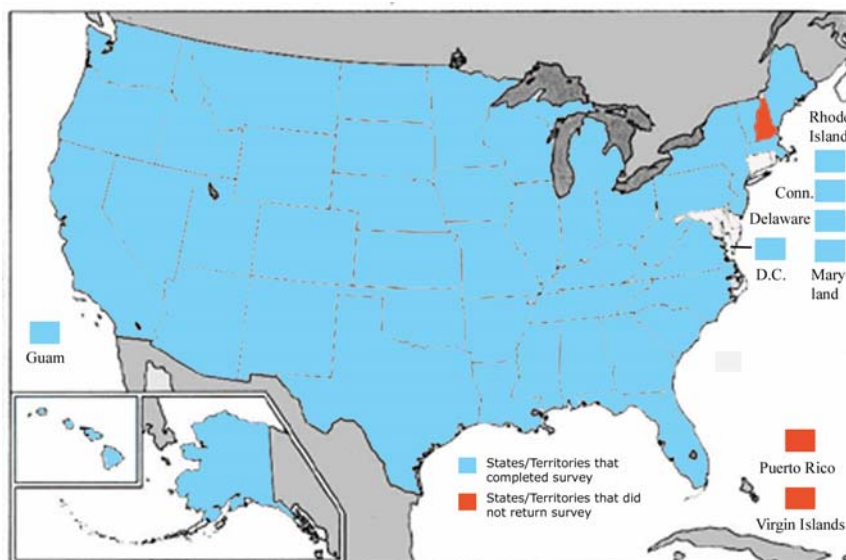
<b>State general funds</b>	Funds from the general fund of the state.
<b>State Genetics Advisory Committee</b>	A formalized committee that advises the state on genetics activities.
<b>State Genetics Coordinators</b>	The person who is designated by the head of each state's health department as the state genetics coordinator.
<b>State Genetics Plan</b>	A formalized plan for public health genetics activities.
<b>Tandem Mass Spectrometry (MS/MS)</b>	MS/MS technology expands the newborn metabolic disorder screening panel (i.e., the number of disorders that can be detected) by allowing the detection of several amino acid, fatty acid oxidation, and organic acid disorders. MS/MS can reliably analyze approximately 20 metabolites in one short-duration run (i.e., ~2 minutes) and provide a comprehensive assessment from a single newborn blood-spot specimen.
<b>Targeted screening</b>	Screening for a limited set of the population.
<b>Universal screening</b>	Statewide screening of all eligible population.
<b>User fee</b>	Funds from users of the program or service.

## Introduction

The Coalition of State Genetics Coordinators (CSGC) strives to collect and disseminate information to promote research, education, and policy development in the area of public health genetics. Towards this goal in December 1999, the CSGC initiated a survey of state level public health genetics activities. This report details the findings from the survey and provides the reader with a nationwide snapshot and state-by-state profile of public health genetics activities. It is hoped that this data and the sharing of information will be used to strengthen or augment state public health genetics programs.

The surveys were sent to the state genetics coordinator (SGC) as designated by the head of each state's health department. The list of contacts used by the CSGC is in Appendix A. By September 30, 2001, forty-nine states, one territory (Guam), and the District of Columbia had responded to the preliminary survey. The information from the initial surveys was compiled and sent back to each state for verification of the data. Due to the lengthy process of collecting and verifying information, this report contains information which reflects the status of the various states as of May 31, 2001. New Hampshire, Puerto Rico, and the Virgin Islands did not respond to the multiple requests for information (Figure 1). Please note that when "state" is used in this report, it means state, territory and/or the District of Columbia.

**Figure 1: States that submitted surveys**



The preliminary survey (Appendix B) assessed the information about each state's genetics coordinator, state genetics plan, genetics needs assessment, newborn metabolic and hearing screening programs, birth defects program, clinical genetics program(s), and genetics legislation. A more detailed survey will be developed after analysis of the preliminary survey results to obtain an in-depth description of the public health genetics programs in each state.

## State Genetics Coordinators

State genetics coordinators had varied backgrounds and degrees (Table 1). Eleven (21.6%) of the SGCs were certified by the American Board of Medical Genetics or American Board of Genetic Counseling. Six (11.8%) had a public health nursing or a master's in public health degree as their highest degree earned. Two of the M.D.s also possessed a M.P.H. degree. Forty-eight (94.1%) of the SGCs worked within the state health department (non-laboratory). The New York genetics coordinator worked in a public health laboratory under the health department. North Dakota and West Virginia had the genetics coordinator working in an University setting. South Dakota's designated SGC reported that the funding for the official position was discontinued; therefore, the designation is in title only.

**Table 1: State Genetics Coordinators' Highest Degree Earned**

DEGREES	NUMBER
R.N.	5
B.S./B.A.	3
P.H.N./M.P.H.	6
M.S./M.A.	22
M.S.W./M.Ed	2
Ph.D.	2
M.D.*	7
Other	4

Tables 2 and 3 show the number of hours a week and percentage of time spent on each activity that a SGC performs. Please note that some of the SGCs reported weekly duties that add up to less than one hundred percent of their time spent as the SGC. Twenty-eight (54.9%) of the coordinators report that they work full-time ( $\geq 35$  hours per week) as SGCs. Of the twenty-three part-time coordinators, eighteen report that less than 50% of their time is spent working as the SGC. The duties have been broken down into the following categories: Policy Development, Administration, Grant Activity, Newborn Screening (NBS), Birth Defects Program (BDP), Clinical, Education Activity, and Other. These data indicate that coordinators spend most of their time involved in administration, newborn screening duties, grant activities and education.

**Table 2: Full-Time Genetics Coordinators and Breakdown of Job Duties**

STATE	HRS/WK	%POLICY DEV	%ADMIN	%GRANT ACTIVITY	%NBS	%BDP	%CLINICAL	%ED ACTIVITY	%OTHER
AL	40	5	0	0	80	5	0	10	0
AR	40	10	20	0	50	0	0	10	10
CA	50	25	20	5	15	5	10	5	15
DC	40	20	30	10	30	0	0	10	0
DE	40	0	10	25	30	0	10	10	15
GA	40	5	40	5	40	2	0	8	0
HI	80	10	20	25	5	5	0	30	5
IA	40	15	25	5	30	0	0	5	20
IL	38	15	20	15	40	0	0	10	0

STATE	HRS/WK	%POLICY DEV	%ADMIN	%GRANT	%NBS	%BDP	%CLINICAL	%ED	%OTHER
IN	38	5	10	20	10	10	0	40	5
LA	40	20	23	10	35	2	0	10	0
MD	60	10	30	10	20	10	5	10	5
ME	40	10	25	10	25	30	0	0	0
MI	40	10	20	25	0	20	0	25	0
MN	40	25	0	0	20	0	10	20	25
MS	80	20	10	20	20	10	10	10	0
NC	40	5	83	0	10	2	0	0	0
NE	35	30	20	30	10	0	0	10	0
OH	40	1	5	4	1	2	0	1	0
OK	40	10	5	40	25	0	0	20	0
OR	40	5	5	10	0	0	0	15	65
PA	38	10	35	15	0	35	0	5	0
TN	38	5	10	5	70	0	0	10	0
WA	40	15	25	15	5	10	0	30	0
WI	40	0	20	5	25	50	0	0	0
WV	40	5	0	5	10	5	70	5	0

**Table 3: Part-Time State Genetics Coordinators and Breakdown of Job Duties**

STATE	HRS/WK	%POLICY DEV	%ADMIN	%GRANT	%NBS	%BDP	%CLINICAL	%ED	%OTHER
MA	30	20	5	3	2	0	0	70	0
MO	25	30	40	0	5	0	0	0	25
ID	22	15	0	0	0	0	60	25	0
NJ	21	25	10	55	0	0	0	10	0
RI	16	30	10	10	20	0	0	10	20
CO	12	10	25	25	10	10	0	0	10
AZ	10	5	5	0	90	0	0	0	0
FL	10	30	20	0	0	5	0	30	15
KY	5	10	0	2	72	0	0	2	1
SC	5	60	15	5	0	0	0	20	0
UT	5	5	5	5	70	5	5	5	0
VA	4	15	60	20	1	1	0	2	1
NV	4	10	5	5	30	20	0	0	30
NY	4	5	5	5	80	0	0	5	0
TX	4	5	40	0	20	15	20	0	0
ND	4	5	10	5	0	0	40	30	10
CT	4	5	90	5	0	0	0	0	0
AK	3	3	5	2	20	0	65	5	0
KS	2	2	3	1	44	44	6	0	0
NM	2	10	20	20	20	0	0	10	20
GU	2	10	15	5	5	0	50	5	10

STATE	HRS/WK	%POLICY DEV		%GRANT ACTIVITY		%BDP	%CLINICAL	%ED ACTIVITY	%OTHER
VT	1	0	0	0	0	0	0	0	0
MT	1	0	0	0	0	0	100	0	0
SD	0	0	0	0	0	0	0	0	0

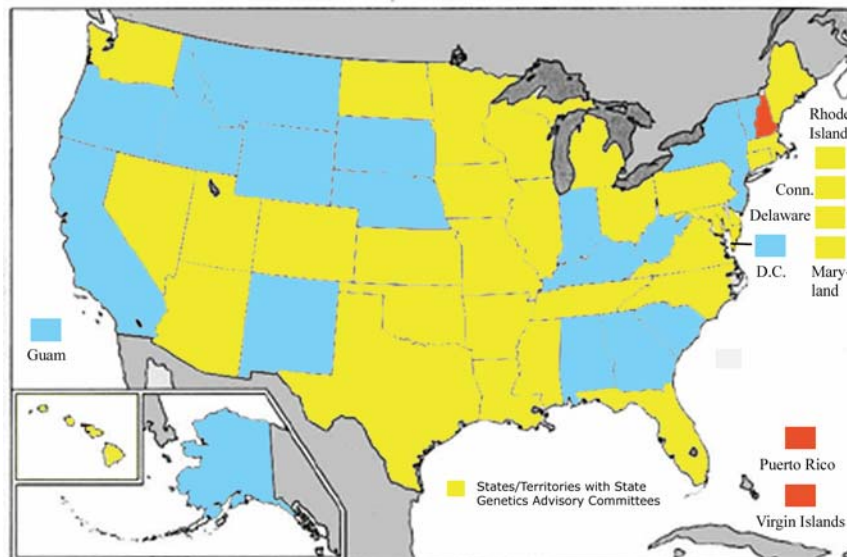
## Organizational Placement of State Genetics Programs

The hierarchical placement of the SGC within a health department is also varied. The data reflects that levels of supervision between the SGC and the State Health Officer ranges from zero to six. Twenty-four (47.1%) of the SGCs reported that they have one or two levels of supervision between the State Health Officer and themselves. Twenty-one (41.8%) of the Coordinators are three or four levels down in their state health organizations. Four (7.8%) of the coordinators did not answer, and the remaining two (3.9%) did not work within the health department.

## State Genetics Advisory Committees

Thirty states (58.8%) reported that they have an existing State Genetics Advisory Committee as shown in Figure 2.

**Figure 2: States with State Genetics Advisory Committees**

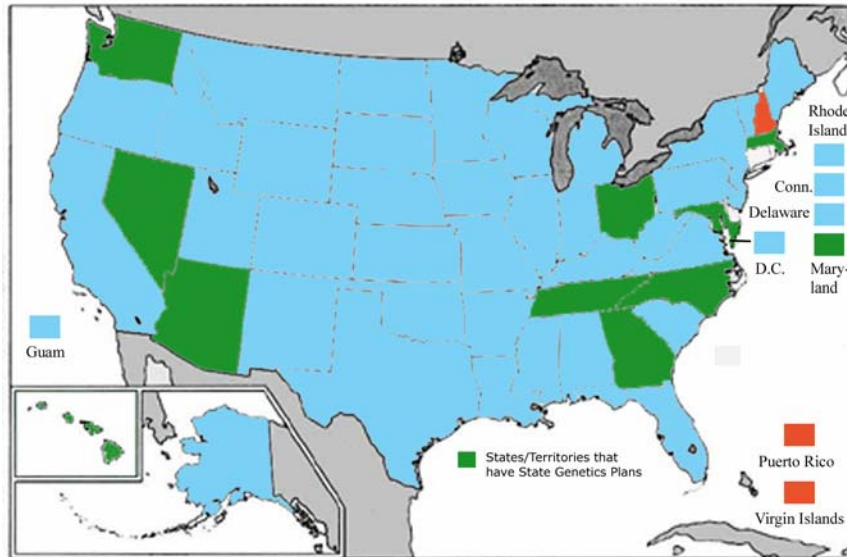


## State Genetics Plans and Genetics Needs Assessments

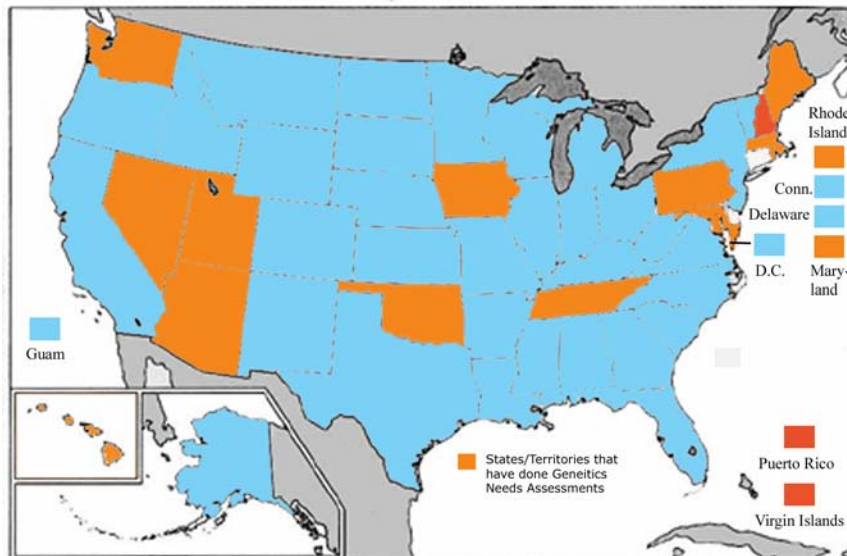
As of May 31, 2001, ten (19.6%) of the states reported that they had state genetics plans (Figure 3) and thirteen (25.5%) of the states had completed state genetics needs assessments (Figure 4). Many states had recently received funding from the Health Resources and Services Administration Genetics Services Branch and were in the process of finishing genetics needs assessments and state genetic plans grants. Thus, it is expected that the number of states with completed genetics needs assessments and state genetics plans will increase in the next few years.



**Figure 3: State with State Genetics Plans**



**Figure 4: States with Genetics Needs Assessments**

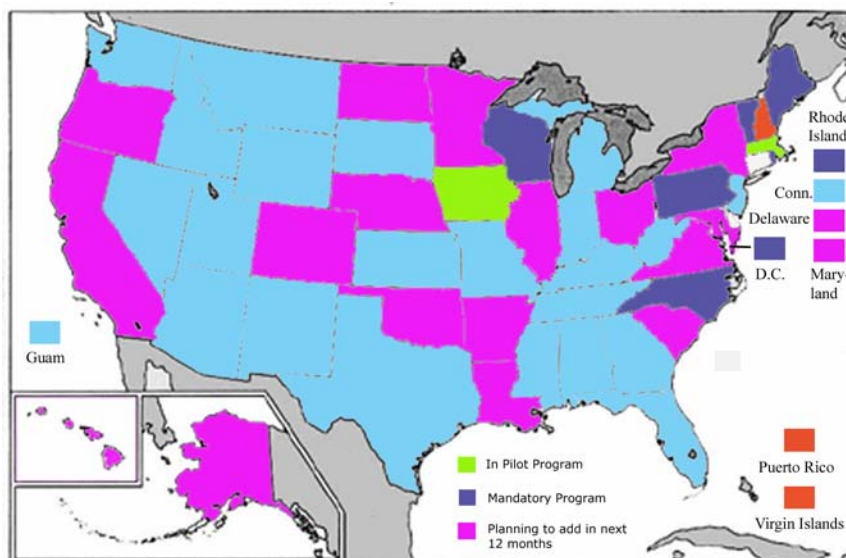


## **Newborn Metabolic Screening**

Twenty-eight (54.9%) of the states reported that the newborn metabolic screening (NBMS) programs are part of the state genetics program. The remaining states reported that their NBMS programs are within their public health laboratories or in other department of health programs (e.g. children with special health needs). See Appendix C for conditions screened for in each state. Also, a listing may be found at the website for the National Newborn Screening and Genetic Resource Center (<http://genes-r-us.uthscsa.edu/resources.htm>).

At the time of the survey, only six (11.8%) states (Maine, North Carolina, Pennsylvania, Rhode Island, Vermont, and Wisconsin) and the District of Columbia reported that they are using tandem mass spectrometry (MS/MS) as part of their mandatory program. Iowa and Massachusetts were using MS/MS in pilot programs. Another 16 (31.4%) states reported that they are planning to add MS/MS to their NBMS program as pilot or state mandated programs within the next 12 months (Figure 5).

**Figure 5: Implementation of Tandem Mass Spectrometry for Newborn Screening**



Newborn metabolic screening fees range from \$0 (funding from state general funds) to \$55.50 and cover a wide range of services. Table 4 shows the funding sources for NBMS programs.

**Table 4: NBMS Fees and Source of Funding**

STATE	FEE	SOURCE OF FUNDING FOR NBMS
AK	\$24.00	User fees, state general funds
AL	\$34.00	User fees, state general funds, grants
AR	\$14.83	User fees, state general funds
AZ	\$20.00	User fees (\$15 for 2 <sup>nd</sup> screening test)
CA	\$42.00	User fees
CO	\$38.85	User fees
CT	\$18.00	User fees, state general funds, federal funds
DC	\$14.52	User fees, state general funds, federal funds
DE	\$40.69	User fees, state general funds
FL	\$20.00	User fees
GA	N/A	State general funds, federal funds
GU	\$35.00	User fees, territorial general funds
HI	\$27.00	User fees, state NBS dedicated fund
IA	\$33.00	User fees

STATE	FEE	SOURCE OF FUNDING FOR NBMS
<b>ID</b>	N/A	State general funds
<b>IL</b>	\$32.00	User fees
<b>IN</b>	\$28.50	State general funds
<b>KS</b>	N/A	State general funds, federal funds
<b>KY</b>	\$14.50	User fees, state general funds
<b>LA</b>	\$18.00	User fees, state dedicated fund, federal funds, Medicaid
<b>MA</b>	\$49.55	User fees, insurance
<b>MD</b>	\$15.75	User fees, state general funds, federal funds
<b>ME</b>	\$26.75	User fees, state dedicated fund,, federal funds
<b>MI</b>	\$39.00	User fees, federal funds
<b>MN</b>	\$21.00	User fees, federal funds
<b>MO</b>	\$13.00	User fees,federal funds
<b>MS</b>	\$25.00	User fees, state general funds, federal funds
<b>MT</b>	N/A	Federal funds
<b>NC</b>	N/A	State general fund
<b>ND</b>	N/A	State dedicated fund, federal funds
<b>NE</b>	\$53.00	User fees, state dedicated fund, federal funds
<b>NJ</b>	\$34.50	User fees, state dedicated fund, sale of IEM kit
<b>NM</b>	\$20.00	User fees (50/50 split), state general funds
<b>NV</b>	\$30.00	User fees
<b>NY</b>	N/A	State general fund, federal funds
<b>OH</b>	\$27.50	User fees
<b>OK</b>	\$10.50	User fees, State general funds, federal funds
<b>OR</b>	\$32.00	User fees
<b>PA</b>	N/A	State general fund, federal funds
<b>RI</b>	\$55.00	User fees, state general funds
<b>SC</b>	\$21.00	User fees, state general funds, federal funds
<b>SD</b>	N/R	No answer
<b>TN</b>	\$17.50	User fees, state general funds, federal funds
<b>TX</b>	\$13.75	User fees, state general funds
<b>UT</b>	\$27.00	User fees
<b>VA</b>	\$16.00	User fees, state general funds, state special fund, federal funds
<b>VT</b>	\$27.00	User fees
<b>WA</b>	\$35.00	User fees, federal funds
<b>WI</b>	\$55.50	User fees
<b>WV</b>	\$14.27	(additional \$6.19 if hemoglobinopathy screening requested. User fees, federal funds
<b>WY</b>	N/A	State general fund, federal funds

The states reported that the newborn screening user fees covered activities such as cost of the collection form, mailing of the form, initial screening, second screening (in some states), confirmatory testing, follow-up personnel, clinical services, education, and data collection. For the states that collect user fees, Table 5 shows the services covered by the newborn screening user fees.

**Table 5: Services Covered by NBMS Fee**

STA	COLLECTION KIT		1 <sup>ST</sup> LAB	2 <sup>ND</sup> LAB	CONFIRM	F/U PERSON	CLINICAL SERVICE	EDUC	DATA COLL.
AK	X	X	X	X	X	X		X	X
AL	X		X	X	X				
AR	X		X	NA		X			
AZ	X	X	X	X	X	X	X	X	X
CA	X	X	X	NA	X	X		X	X
CO	X	X	X	X	X	X	X	X	X
CT	X		X	X					
DC	X	X	X	NA				X	X
DE	X	X	X	X		X	X	X	X
FL	X	X	X	NA		X		X	
GA	NA	NA	NA	NA	NA	NA	NA	NA	NA
GU	X		X	X	X				
HI	X	X	X	NA	X	X	X	X	X
IA	X		X	X		X	X	X	X
ID	NA	NA	NA	NA	NA	NA	NA	NA	NA
IL	X		X	NA		X	X	X	
IN	X	X	X	X	X	X	X	X	X
KS	NA	NA	NA	NA	NA	NA	NA	NA	NA
KY	X	X	X	X					
LA	X		X	NA	X	X	X	X	X
MA	X	X	X	NA				X	X
MD			X	X					
ME	X	X	X	NA		X		X	
MI	X	NA	X	NA	X	X	X	X	X
MN	X	NA	X	X		X			X
MO	X	X	X	NA				X	
MS	X	X	X	NA	X	X	X	X	X
MT	NA	NA	NA	NA	NA	NA	NA	NA	NA
NC	NA	NA	NA	NA	NA	NA	NA	NA	NA
ND	NA	NA	NA	NA	NA	NA	NA	NA	NA
NE	X		X	NA					
NJ	X		X	NA					
NM	X	X	X	X	X	X	X	X	X
NV	X		X	X	X	X		X	X
NY	NA	NA	NA	NA	NA	NA	NA	NA	NA
OH	X	X	X	X			X	X	X
OK	X		X	NA					
OR	X		X	X	X	X		X	X
PA	NA	NA	NA	NA	NA	NA	NA	NA	NA
RI	X	X	X	X		X		X	X
SC	X		X	X	X	X		X	X

STATE	COLLECTION KIT	MAIL	1 <sup>ST</sup> LAB	2 <sup>ND</sup> LAB	CONFIRM	F/U PERSON	CLINICAL SERVICE	EDUC	DATA COLL.
<b>SD</b>	Unknown								
<b>TN</b>	X	X	X	NA					
<b>TX</b>	X		X	NA					
<b>UT</b>	X	X	X	X	X	X	X	X	X
<b>VA</b>	X	X	X			X			
<b>VT</b>	X		X	X		X			
<b>WA</b>	X	X	X	X	X	X	X	X	X
<b>WI</b>	X	X	X	NA	X	X	X	X	
<b>WV</b>	X	X	X		X			X	X
<b>WY</b>	NA	NA	NA	NA	NA	NA	NA	NA	NA

Some states reported additional services that are funded by the NBMS fees. These additional services will be included in a future report.

### Newborn Hearing Screening

Every state, except Montana, reported that they had or were in the process of planning to add a Newborn Hearing Screening (NBHS) program. Delaware, Idaho, and South Dakota had NBHS programs in the private sector. As of May 31, 2001, Alabama, Idaho, and Maine were planning to add Newborn Hearing Screening programs to their health departments. Guam's NBHS program was in its Department of Education. Sixteen (31.4%) of the states had the NBHS program as part of the state genetics program.

Over half of the states (26/47 [55.3%]) with NBHS programs had a state law mandating the program to be established within the health department. Thirty-nine (83.0%) of the states with programs reported universal hearing screening. California, New Jersey, Ohio and Tennessee performed targeted newborn hearing screening. Funding for the NBHS Programs was generally a mix of state/territory general funds and federal funds. Delaware, Oregon, South Carolina, Texas, and Utah also imposed a user fee for the hearing screening services. See Table 6 for program funding.

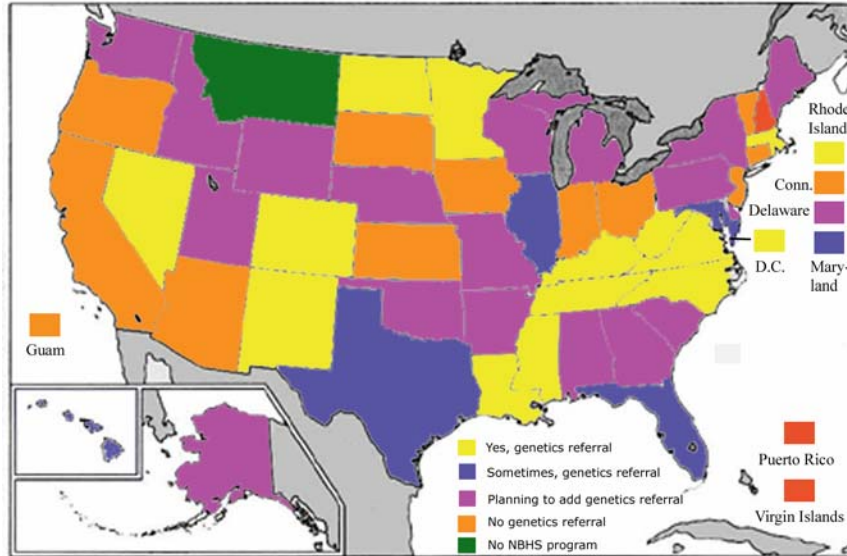
**Table 6: Source of Funding for NBHS Programs**

STATE	RC FUN G
<b>AK</b>	Federal funds
<b>AL</b>	No state program, currently done using private and federal funds
<b>AR</b>	Federal funds
<b>AZ</b>	State general fund, MCHB federal funds
<b>CA</b>	State general funds, federal funds
<b>CO</b>	State general funds, federal funds
<b>CT</b>	State general funds, federal funds
<b>DC</b>	Federal funds
<b>DE</b>	User fees and hospital donation of time and equipment
<b>FL</b>	State dedicated fund
<b>GA</b>	State general funds, State dedicated fund, federal funds

<b>STATE</b>	<b>SOURCE OF FUNDING</b>
<b>GU</b>	Federal funds
<b>HI</b>	State general funds, federal funds, hospital billing
<b>IA</b>	Federal funds
<b>ID</b>	Private funds, currently done in a private consortium
<b>IL</b>	State general funds, federal funds, interdepartmental mandate
<b>IN</b>	No funding attached currently
<b>KS</b>	State general funds
<b>KY</b>	State general funds, federal funds
<b>LA</b>	State dedicated fund, federal funds
<b>MA</b>	State general funds, federal funds
<b>MD</b>	State general funds, federal funds, hospital billing
<b>ME</b>	New program using federal funds
<b>MI</b>	State dedicated fund, federal funds, hospital billing, private funds
<b>MN</b>	Federal funds, hospitals, hospital billing
<b>MO</b>	State general funds
<b>MS</b>	State general funds, state dedicated fund
<b>MT</b>	Grass roots effort currently, no funding
<b>NC</b>	State general fund
<b>ND</b>	Federal funds
<b>NE</b>	State general funds, federal funds
<b>NJ</b>	Federal funds
<b>NM</b>	State general funds, federal funds
<b>NV</b>	User fees
<b>NY</b>	State general fund, federal funds
<b>OH</b>	Federal funds, user fees
<b>OK</b>	State general fund, federal funds
<b>OR</b>	Federal funds, user fees
<b>PA</b>	Planning to add using state general funds
<b>RI</b>	State general funds, federal funds, user fees
<b>SC</b>	State general funds, federal funds, user fees
<b>SD</b>	No state program. Done voluntarily at hospitals
<b>TN</b>	State general funds, state dedicated fund, federal funds, Medicaid, user fees
<b>TX</b>	State general funds, state dedicated fund, federal funds, user fees
<b>UT</b>	Federal funds, user fees
<b>VA</b>	State general funds, federal funds
<b>VT</b>	User fees, federal funds
<b>WA</b>	Not funded
<b>WI</b>	Federal funds
<b>WV</b>	Federal funds
<b>WY</b>	State general funds, federal funds

Only 20/47 (42.6%) states reported any type of genetics referrals for the infants confirmed to have hearing loss. However, 17/47 (36.2%) were planning to add genetics referral to their programs. See Figure 6.

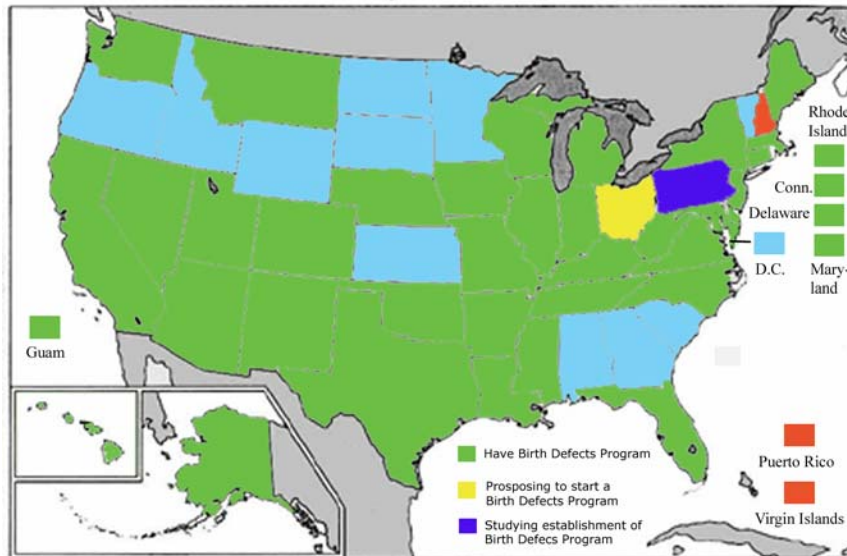
**Figure 6: Genetics Referrals as Part of NBHS Programs**



**Birth Defects Programs**

Thirty-seven (72.5%) of the states participating in the survey had established Birth Defects (BD) programs. Ohio was planning to start a program, and Pennsylvania was doing a study to determine if a statewide program should be established (Figure 7). 9/37 (24.3%) of the established BD programs were not mandated by the state. Ohio’s proposed program was being established under a state mandate. Only Arkansas, Hawaii, and Iowa had the BD programs situated in university settings. The other state programs were located as part of state departments of health (DOH).

**Figure 7: Status of State Birth Defects Programs**



7/38 (18.4%) of the BD programs performed active birth defect surveillance. Twenty-one (55.2%) states did passive birth defect surveillance. Seven (18.4%) states did a combination of active and passive surveillance. Three state genetics coordinators reported that they were unaware of the type of birth defects surveillance performed in their state. See Table 7 for a summary of the BD programs.

**Table 7: Summary of State Birth Defects Programs**

<b>STATE</b>	<b>MANDATED</b>	<b>LOCATED IN</b>	<b>TYPE OF SURVEILLANCE</b>	<b>FUNDING</b>
<b>AK</b>	YES	DOH	PASSIVE	Federal funds
<b>AR</b>	NO	UNIV	ACTIVE	State dedicated fund
<b>AZ</b>	YES	DOH	ACTIVE	State general fund/NBS funds
<b>CA</b>	NO	DOH	ACTIVE	State general fund/Birth certificate fee
<b>CO</b>	NO	DOH	PASSIVE	Federal funds
<b>CT</b>	YES	DOH	PASSIVE	Federal funds
<b>DE</b>	YES	DOH	PASSIVE	State general fund/user fee
<b>FL</b>	YES	DOH	PASSIVE	State dedicated fund/fed funds
<b>GU</b>	NO	DOH	DON'T KNOW	Federal funds
<b>HI</b>	NO	UNIV	ACTIVE	State general fund/fed funds
<b>IA</b>	NO	UNIV	ACTIVE	State dedicated fund/fed funds
<b>IL</b>	YES	DOH	PASSIVE	State general fund
<b>IN</b>	YES	DOH	PASSIVE	State dedicated fund/birth certificate fee (\$2)
<b>KS</b>	NO	DOH	PASSIVE	Federal funding
<b>KY</b>	YES	DOH	PASSIVE	State general fund/fed funds
<b>LA</b>	NO	DOH	PASSIVE	Unknown
<b>MA</b>	YES	DOH	ACTIVE/PASSIVE	State general fund/fed funds
<b>MD</b>	YES	DOH	PASSIVE	State general fund
<b>ME</b>	YES	DOH	ACTIVE/PASSIVE	State dedicated fund/fed funds
<b>MI</b>	YES	DOH	PASSIVE	State general fund/fed funds
<b>MO</b>	NO	DOH	PASSIVE	State general fund
<b>MS</b>	YES	DOH	ACTIVE/PASSIVE	State general fund/fed funds
<b>MT</b>	YES	DOH	PASSIVE	Federal funds
<b>NC</b>	YES	DOH	ACTIVE/PASSIVE	State general fund/fed funds/March of Dimes
<b>NE</b>	YES	DOH	ACTIVE/PASSIVE	Federal funds
<b>NJ</b>	NO	DOH	PASSIVE	Federal funds
<b>NM</b>	YES	DOH	ACTIVE/PASSIVE	State general fund/fed funds
<b>NV</b>	YES	DOH	ACTIVE/PASSIVE	Federal funds
<b>NY</b>	YES	DOH	DON'T KNOW	
<b>OH</b>	PROPOSED			
<b>OK</b>	YES	DOH	ACTIVE	State general fund/fed funds
<b>PA</b>	STUDY			
<b>RI</b>	NO	DOH	PASSIVE	Federal funds



STATE	MANDATED	LOCATED IN	TYPE OF SURVEILLANCE	FUNDING
TN	YES	DOH	DON'T KNOW	State general fund/fed funds
TX	NO	DOH	ACTIVE	State general and dedicated fund/fed funds
UT	YES	DOH	PASSIVE	Federal funds
VA	YES	DOH	PASSIVE	Federal funds
WA	YES	DOH	PASSIVE	State general funds
WV	YES	DOH	PASSIVE	State general fund/fed funds
WI	YES	DOH	PASSIVE	State general funds

## Clinical Genetic Services

Seventeen (33.3%) of the states in the survey, provided funding to pay for consultations and evaluations by a clinical geneticist. Eighteen states (35.3%) paid for genetic counseling services performed by a genetic counselor. Fourteen states did not pay for consultations or evaluations by clinical geneticists and eleven states did not pay for genetic counseling. The remaining states paid for genetic consultation and evaluation and/or genetic counseling under specific conditions such as “within a state contracted service.” Also, thirty-three (64.7%) of the states reported that they regularly fund genetics clinics in their state. Other programs within the state health department (e.g. Early Intervention Services) may provide funding for clinical genetic services. Information about these other publicly funded genetic services will be included in a future report. Table 8 is the summary of clinical genetic services covered by the state genetics programs.

**Table 8: Clinical Genetic Services Paid for by State Genetics Programs**

STATE	EVALUATION	GENET COUNSELING	HOW B	GENETIC CLINICS
AK	Yes, under spec cond	No	Fee for service	Yes
AL	Yes, under spec cond	No	Unknown	No
AR	No	Yes	Fee for service	No
AZ	Yes	Yes, under spec cond	Contracted Service	Yes
CA	Yes, under spec cond	Yes, under spec cond	Fee for service	No
CO	Yes, under spec cond	No	Contracted Service	Yes
CT	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
DC	Yes	Yes	Grants to community	Yes
DE	Yes, under spec cond	Yes, under spec cond	Contracted Service	No
FL	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
GA	No	Yes, under spec cond	Contracted Service	Yes
GU	No	No	N/A	No
HI	Yes, under spec cond	Yes, under spec cond	Fee for service	Yes
IA	Yes, under spec cond	Yes, under spec cond	Contracted Service	No
ID	No	Yes	Done by Staff	Yes
IL	Yes	Yes	Grants to community	Yes

<b>STATE</b>	<b>GENETIC EVALUATION</b>	<b>COUNSELING</b>	<b>HOW PAID BY STATE</b>	<b>NETIC CLINICS</b>
<b>IN</b>	Yes	No	Contracted Service	Yes
<b>KS</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
<b>KY</b>	Yes	Yes, under spec cond	Contracted Service	No
<b>LA</b>	No	Yes	Contracted Service	Yes
<b>MA</b>	No	Yes, under spec cond	Special Medical Fund	No
<b>MD</b>	Yes	Yes	Contracted Service	Yes
<b>ME</b>	Yes, under spec cond	Yes, under spec cond	Grants to community	Yes
<b>MI</b>	Yes, under spec cond	Yes, under spec cond	Contract/Fee for Serv	Yes
<b>MN</b>	Yes, under spec cond	Yes	Fee for service	No
<b>MO</b>	Yes	Yes	Contracted Service	Yes
<b>MS</b>	Yes	Yes	Contracted Service	Yes
<b>MT</b>	No	No	N/A	No
<b>NC</b>	Yes	Yes	Contracted Service	Yes
<b>ND</b>	No	Yes	Contracted Service	Yes
<b>NE</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
<b>NJ</b>	Yes, under spec cond	No	Grants to community	No
<b>NM</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
<b>NV</b>	Yes	Yes	Contract/Fee for Serv	Yes
<b>NY</b>	Yes, under spec cond	Yes, under spec cond	Grants	Yes
<b>OH</b>	Yes	No	Grants to community	No
<b>OK</b>	No	No	N/A	No
<b>OR</b>	Yes, under spec cond	No	Contracted Service	Yes
<b>PA</b>	Yes	No	Fee for service	No
<b>RI</b>	No	No	N/A	No
<b>SC</b>	Yes	Yes	Contracted Service	Yes
<b>SD</b>	No	No	N/A	No
<b>TN</b>	Yes	Yes	Contracted Service	Yes
<b>TX</b>	Yes, under spec cond	Yes, under spec cond	Fee for service	Yes
<b>UT</b>	Yes	Yes, under spec cond	Contracted Service	Yes
<b>VA</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
<b>VT</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes
<b>WA</b>	Yes	Yes	Contracted Service	Yes
<b>WI</b>	Yes, under spec cond	No	Contracted Service	No
<b>WV</b>	Yes	Yes	Contracted Service	Yes
<b>WY</b>	Yes, under spec cond	Yes, under spec cond	Contracted Service	Yes

Several states reported that they fund other clinical genetics activities beyond those specified in the survey. Some of these activities include sickle cell clinics and outreach, educational activities for health care providers and staff, teratogen information services, and genetic laboratory testing. Table 9 has a summary of the other clinical genetics activities reported by some states.

**Table 9: Other Clinical Genetics Activities Funded by the State Genetics Program**

<b>STATE</b>	<b>OTHER ACTIVITIES FUNDED BY THE STATE</b>
<b>AL</b>	Community Sickle Cell Organizations
<b>CA</b>	Rh testing/Tay Sachs testing/Prenatal testing, genetic hereditary disease program, Cystic fibrosis, hemoglobinopathy, and spina bifida clinics
<b>DC</b>	Education to community clinics and staff
<b>FL</b>	Confirmatory and laboratory testing
<b>HI</b>	Education outreach
<b>IN</b>	Teratogen Information Service/General pediatric & prenatal genetic services/Education
<b>KS</b>	Some funding for multidisciplinary specialty clinics
<b>LA</b>	Sickle cell, Hemophilia, and Metabolic clinics
<b>MD</b>	Case management for NBS, MSAFP and carrier screening
<b>ME</b>	Education
<b>MI</b>	Education outreach/Genetic counseling in specialty clinics
<b>MN</b>	Genetic counseling in CSHN clinics 15 times per year
<b>MO</b>	Teratogen Information Service,/Data Collection
<b>MS</b>	Laboratory work
<b>NC</b>	Contracts with five medical centers in state
<b>ND</b>	Cleft lip/Cleft palate, myelodysplasia, metabolic, and cardiac clinics
<b>NJ</b>	Co-sponsors statewide education conference
<b>NV</b>	Genetic laboratory tests
<b>OR</b>	Some genetic diagnostic tests/interpreters/transportation, hotel, meals for families
<b>RI</b>	Child Development Center/Hemophilia and Sickle Cell clinics
<b>SC</b>	Pediatric genetics visits/Laboratory work
<b>VT</b>	Support for genetic clinic operations
<b>WA</b>	Community education/Continuing education for Regional Genetics Centers/Telephone consults through the Regional Genetics Center

## **Genetics Legislation**

All states reported that they have some type of genetics laws in their state, the majority of which pertain to newborn metabolic screening. Appendix D shows the types of genetics related legislation in each of the states.

## **Conclusion**

The survey revealed that the state genetics coordinators have varied backgrounds and over one-third of the SGCs spend 25% or less of their time working as SGCs. Also, the majority of state genetics coordinators do not have formal training in genetics.

The data shows that newborn metabolic and hearing screening programs are well established in each state. All the states had newborn metabolic screening programs and almost half of the states were either currently using or planning to add tandem mass spectrometry to their NBMS programs. Newborn Hearing Screening programs are almost as established in states as NBMS programs, although the screening done by the NBHS programs is not as universal as

the NBMS programs. And even though at least fifty percent of hearing loss has a genetic cause, only 37/47 states (78.7%) have a genetics referral as part of their state NBHS program.

Other genetics related programs are not as well established. Birth Defects programs are not as prevalent as the newborn screening programs. Only 39/51 (76.5%) of the states reported that they had an established or were planning to establish a BD program.

At least some type of clinical genetic services seems to be provided by most states. Only 5 (9.8%) of the states reported that they do not provide funding for genetic evaluation by a clinical geneticist, genetic counseling by a genetic counselor, or any regular genetics clinics.

The data from this survey will be used by the CSGC to develop a more detailed survey instrument for the future. After the collection, analysis and reporting of the data from the detailed survey, the CSGC will be able to create a comprehensive state genetics profile for each state. It is intended that these profiles will be accessible to all the State Genetics Coordinators as we develop our state genetics plans and implement our public health genetics activities. The data will also be accessible to other individuals who would want to know information regarding state level public health genetics activities.