Appendix B

Survey of State Genetics Coordinators
2001

by the Coalition of State Genetics Coordinators,
Sylvia M. Au, President

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The Coalition of State Genetics Coordinators is seeking input on the types of genetic services in your state. This information will be used to create state profiles of public health genetics activities. Your participation in this survey is very important for justification of future federal funding opportunities. Results of the survey will be distributed to all participants and made available on the website at a later date.

GENERAL INFORMATION

My name is: ____

My degrees/board certifications are (check all which apply):

☐ M.D.	☐ R.N.	☐ ABMG	☐ M.P.H.
☐ Ph. D.	☐ P.H.N.	☐ R.D.	☐ B.A./B.S.
☐ M.S.	☐ ABGC	☐ M.A.	☐ Other

I work in a:
☐ State Department of Health
☐ State Laboratory
☐ University
☐ Clinical Setting
☐ Other

My state/territory is: ______________________________

How many hours per week are dedicated to being the State/Territorial Genetics Coordinator?

________hours per week

What percentage of your time is spent in:

____ Policy development (laws, policy statements)

____ Administration (budgets, personnel)

____ Grant Activity (writing, administering)

____ Newborn Screening activities

____ Birth Defects Monitoring

____ Providing clinical services

____ Educational Activities

____ Other

Has your state/territory conducted a Genetics Needs Assessment? ☐ Yes ☐ No

If yes, in what year was the Needs Assessment done? ________

Does your state/territory have a State Genetics Plan? ☐ Yes ☐ No

If yes, in what year was the State Plan done? ________

Do you have a State/Territorial Genetics Advisory Committee or Subcommittee?
☐ Yes ☐ No

Does your Director of Health know that you are the State/Territorial Genetics Coordinator?
☐ Yes ☐ No ☐ Don't know

How many levels of supervision are there between you and the Director of Health? There are ____ levels.

NEWBORN METABOLIC/HEMOGLOBINOPATHY SCREENING

Is the Newborn Metabolic Screening Program part of your genetics program?
☐ Yes ☐ No

If not, where is it located? ______________________________

Does your state/territory screen newborns for:

PKU and congenital hypothyroidism?	☐ Yes	☐ No	
Maple Syrup Urine Disease?	☐ Yes	☐ No	
Hemoglobinopathies?	☐ Yes	☐ No	☐ only targeted screening
Cystic Fibrosis?	☐ Yes	☐ No	☐ only targeted screening
Congenital Adrenal Hyperplasia?	☐ Yes	☐ No	
Biotinidase Deficiency?	☐ Yes	☐ No	
Galactosemia?	☐ Yes	☐ No	

Other (please specify): ______________________________

Does your state/territory use tandem mass spectrometry as part of your newborn screening program?

☐ Yes, in mandatory program
☐ Yes, in voluntary supplemental program
☐ Yes, in pilot project
☐ No
☐ No, but plan to add some sort of program within 12 months

What is your fee for newborn screening? ______ per newborn
(if no, skip to the funding source question)

Does the fee cover (check all that apply):
☐ Cost of the collection form?
☐ Mailing cost for collection form?
☐ The initial laboratory test?
☐ The second laboratory test (in states that require a second test)?
☐ The confirmatory testing up to diagnosis?
☐ The public health based or contracted follow-up personnel?
☐ Clinical services (e.g. genetic counseling, genetics consult, endocrine consult, hemoglobinopathy consult, etc.)?
☐ Education about newborn screening?
☐ Data collection and analysis?

☐ Other (please specify): ______________________________

List all sources of funding used to run your Newborn Metabolic Screening Program (check all that apply):

☐ State/Territorial general funds
☐ State/Territorial special or dedicated funds
☐ Federal funds
☐ User fees

Other (specify): ______________________________

NEWBORN HEARING SCREENING

Is Newborn Hearing Screening part of your genetics program? ☐ Yes ☐ No

If not, where is it located? ______________________________

In what year did your state/territory mandate Newborn Hearing Screening? ________

Is the Newborn Hearing Screening: ☐ Universal
☐ Targeted
☐ Not applicable

Is referral for genetic services part of your Newborn Hearing Screening follow-up program?
☐ Yes ☐ No ☐ Planning to add

List all sources of funding used to run your Newborn Hearing Screening Program (check all that apply):

☐ State/Territorial general funds
☐ State/Territorial special or dedicated funds
☐ Federal funds
☐ User fees

Other (specify): ____

CLINICAL GENETIC SERVICES

Does your state/territory pay for genetic counseling services by a genetic counselor?
☐ Yes ☐ Yes, under specific criteria ☐ No

Does your state/territory pay for genetic evaluation and consultation by a geneticist?
☐ Yes ☐ Yes, under specific criteria ☐ No

If your state/territory does pay for genetic counseling and/or genetic consults, how is the funding structured?
☐ Contracted service ☐ Fee for service ☐ Other (specify): ________________

Does your state/territory fund regular genetics clinics in your state/territory?
☐ Yes ☐ No

What other clinical genetics services does your state/territory fund? Please specify:

____

Does your state/territory genetics program provide administrative support for clinical genetic services that your state/territory does not fund? ☐ Yes ☐ No

BIRTH DEFECTS MONITORING

Does your state/territory have a Birth Defects Monitoring Program? ☐ Yes ☐ No

If no, skip to the next section, "Genetics legislation"

If yes, is it a mandated program? ☐ Yes ☐ No

Is Birth Defects Monitoring part of your genetics program? ☐ Yes ☐ No

If not, where is it located? ____

What year was your Birth Defects Monitoring Program started? ________

What type of surveillance does your state/territory do?

☐ Active ☐ Passive ☐ Don't know

List all sources of funding used to run your Birth Defects Monitoring Program (check all that apply):

☐ State/Territorial general funds	☐ Federal funds
☐ State/Territorial special or dedicated funds	☐ User fees

Other (specify): ______________________________

GENETICS LEGISLATION

Does your state/territory have legislation and/or regulations specifically related to genetics?
☐ Yes ☐ No

If yes, check the areas that apply:

Clinical genetics service	☐ Have	☐ Proposed
Health insurance	☐ Have	☐ Proposed
Disability insurance	☐ Have	☐ Proposed
Life insurance	☐ Have	☐ Proposed
Prenatal genetics screening	☐ Have	☐ Proposed
Genetics education	☐ Have	☐ Proposed
Long-term care insurance	☐ Have	☐ Proposed
Employment	☐ Have	☐ Proposed
Medical record confidentiality	☐ Have	☐ Proposed
Research	☐ Have	☐ Proposed
Licensure of genetics professionals	☐ Have	☐ Proposed
Newborn metabolic/hemoglobinopathy screening	☐ Have	☐ Proposed

Other (specify): ______________________________

COMMENTS:
Please let us know any other comments or information relating to the topics of this survey:

You may fax the completed survey to Sylvia Au at (808) 733-9068 or mail it back to me at:
Hawaii Dept of Health/CSHNB, 741 Sunset Avenue, Honolulu, HI 96816

For questions regarding this survey, please contact Sylvia Au at sau@hgea.org or (808) 733-9063.