

## COMMON REASONS TO SEEK GENETIC SERVICES

- ❗ Medical problems of the developing baby detected by prenatal screening or testing.
- ❗ Harmful exposures during pregnancy such as alcohol or prescription or recreational drugs.
- ❗ Birth defects such as heart problems, structural brain abnormalities, and physical differences like cleft lip and palate.
- ❗ Mental retardation or developmental delays - the person does not reach developmental milestones on time or does not function developmentally, intellectually, socially or behaviorally as expected for their age.
- ❗ Changes in body chemistry such as extremely high and low protein, fat or sugar levels in the blood.
- ❗ Sensory impairments like vision or hearing problems.
- ❗ Family history of an inherited disease or cancer.

**State Genetics Coordinator**  
Sylvia Au, MS, CGC  
(808) 733-9063  
sylvia@hawaiigenetics.org

**Genetic Counselors**  
Lianne Hasegawa, MS, CGC  
Genetic Counselor  
(808) 733-9039  
lianne@hawaiigenetics.org

Kirsty McWalter, MS, CGC  
Genetic Counselor  
(808) 733-8387  
kirsty@hawaiigenetics.org

Sarah Scollon, MS, CGC  
Genetic Counselor  
(808) 733-9047  
sarah@hawaiigenetics.org

Arthur Yu, MS, CGC  
Genetic Counselor  
(808) 733-4998  
arthur@hawaiigenetics.org

**Support Staff**  
Pauline Mui  
(808) 733-9072  
pauline@hawaiigenetics.org

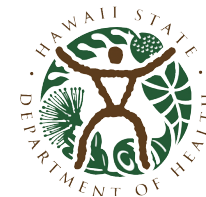
[www.hawaiigenetics.org](http://www.hawaiigenetics.org)



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## Hawai'i Department of Health Genetics Program



741 Sunset Avenue, Honolulu, HI 96816  
Phone: (808) 733-9055 Fax: (808) 733-9068  
[www.hawaiigenetics.org](http://www.hawaiigenetics.org)

## HAWAI'I DEPARTMENT OF HEALTH GENETICS PROGRAM

The **Department of Health Genetics Program** is within the **Children with Special Health Needs Branch**.

The Program aims to:

- 🐛 Assess the needs of the community for genetic services and activities.
- 🐛 Develop and implement activities in the State Genetics Plan.
- 🐛 Develop public policy related to genetics.
- 🐛 Provide information and education about topics in genetics.
- 🐛 Obtain and administer funding related to genetics.
- 🐛 Coordinate and support genetics related programs and activities.
- 🐛 Support clinical genetic services.
- 🐛 Develop and implement research related to public health and clinical genetics.
- 🐛 Provide technical assistance to other programs.



The **Genetics Program** also administers and participates in local, regional, and national projects. Some projects that may be of interest to families and providers are:

### **Western States Genetic Services Collaborative**

This is a HRSA funded multi-state (HI, AK, CA, ID, OR and WA) and territory (Guam) project that seeks to improve access to genetic services and education. One of the project's major activities in Hawai'i is to increase access to clinical genetic services by offering Neighbor Island clinics and telehealth visits. More information can be found at [www.westernstatesgenetics.org](http://www.westernstatesgenetics.org).

### **Newborn Screening Results Project**

This is a HRSA-funded, multi-state (HI, AK, CA, ID, OR and WA) project involving the Genetics Program and state Newborn Screening Programs. The project plans to identify parents' attitudes towards and suggestions for how to best communicate newborn screening results, especially false positive results. This information will be used to develop educational materials for parents.

### **Hawai'i MD STARnet (Muscular Dystrophy Surveillance Tracking and Research Network) Project**

This is a CDC funded multi-state (HI, AZ, GA, IA, CO and NY) project that seeks to identify children with Duchenne and Becker Muscular Dystrophy (DBMD). The Hawai'i Department of Health has partnered with the Hawai'i Muscular Dystrophy Association and its clinics as well as other healthcare organizations and practices in the state.



The Hawai'i MD STARnet project aims to find out information about how often DBMD occurs in Asians and Pacific Islanders, the long term outcomes of individuals with DBMD, methods of care for children and families with DBMD unique to the culture of Hawai'i, and barriers to care for Hawai'i families with DBMD. The findings will help determine the best practices to improve health outcomes.

### **Sickle Cell Disease Project**

This was a HRSA funded project that developed policies and activities to ensure that newborns and families with Sickle Cell Disease or Trait receive comprehensive care and education. Protocol for Sickle Cell Disease and Trait and Alpha Thalassemia were developed and are available on our program website.

### **Tandem Mass Spectrometry Project**

This was a HRSA funded multi-state collaborative project, led by the Hawai'i Department of Health, to obtain research data, identify strategies and develop materials for addressing the financial, ethical, legal and social issues (FELSI) surrounding the use of MS/MS for neonatal metabolic screening of culturally and ethnically diverse populations. One major activity of this project was the development of Parent Fact Sheets (English and Spanish) for each disorder in the expanded NBS panel. More information can be found at [www.newbornscreening.info](http://www.newbornscreening.info).