GENETIC COUNSELING

"It takes as much courage to have tried and failed as it does to have tried and succeeded."

— Anne Morrow Lindbergh

Check List

What indicators are related to hearing loss in newborns?

A baby is "at risk" (has a greater chance) for possible hearing loss if one or more of these signs are present:

- ☐ Family history of childhood hearing loss
- ☐ Infection during pregnancy (rubella, cytomegalovirus/CMV, syphilis, herpes, or toxoplasmosis)
- ☐ Birth defects of the head and neck (for example, deformed outer ear)
- ☐ Low birth weight (under 3.3 pounds)
- ☐ Jaundice or yellowing of the skin at birth (Hyperbilirubinemia)
- ☐ Bacterial meningitis (illness)
- ☐ Medicines for the ear (Ototoxic)
- ☐ Respirator (mechanical ventilation) for more than five days
- ☐ Apgar scores of 0 to 4 at one minute or 0 to 6 at five minutes. (This score is given at the time of birth to figure out the newborn's condition. The score comes from evaluating the newborn's heart rate, respiratory/breathing effort, muscle tone, reflex irritability, and color. A score of 0 –2 is related on each of the five items, the highest possible score being 10.)

Frequently Asked Questions

What is genetic counseling and why should I have it done?
According to the Joint Committee on Infant Hearing, all families who have infants/children with hearing loss that do not have a clear-cut reason for why their child has a hearing loss, should be given the choice of genetic evaluation and counseling by a medical geneticist. Many people think that the main reason for such genetic evaluation (review) and counseling is so the family can know about their chances of having more infants/children with hearing loss. Actually, the genetic evaluation tells much more important information that can have an important impact on how the infant is treated. For example, whether an infant/child's hearing loss will become worse can sometimes be predicted if the specific cause is known. Also, for many infants, deafness is only one of the medical problems the child may have, and genetic testing may tell whether the infant is likely to have other problems with the heart, kidneys, or eyes.

What is the genetics clinic?
As more is learned about how inheritance (family genes) affects health, physicians, health care providers, and patients are looking for information about genetic services. Specifically, people ask for genetic testing for specific disorders and why this is useful.

Sometimes genetic counseling is provided as part of a multidisciplinary (more than one provider) evaluation in a specialty clinic, but usually genetic services are provided through a genetics clinic in a hospital or university setting. The genetic clinic's purpose is to provide an individual or family with one or more of the following:

- Confirm or rule out the diagnosis of a genetic condition
- Find medical management issues and support services
- Figure out and discuss genetic risks/chances
- Provide or arrange for psychosocial support

Diagnostic testing is used to rule out a known or suspected genetic disorder in a symptomatic person. Genetic testing is usually by chromosome analysis (karyotype), DNA test (molecular testing), or biochemical testing. It may give diagnostic information at a lower cost with less risk than other procedures. It may also allow for predictive (foretell) testing, carrier testing or prenatal (before birth) testing in other family members.

Who is involved in the genetic clinic?
The Alaska Genetics Clinics are funded by the State of Alaska, through a contract with Children's Hospital and Medical Center in Seattle. Health care providers travel to different hospitals and public health clinics throughout the state. The staff, or genetics practitioners, consist of:

1. Physicians who are board certified by the American Board of Medical Genetics in clinical genetics
2. Genetic counselors with graduate degrees in human genetics, and are certified by the National Society of Genetic Counselors
3. Public health nurses

In addition to the general genetic appointments, the 2003 Alaska Genetics Clinic schedule will offer clinics with a specific focus. These clinics include adult genetics, pediatric genetics, inherited eye disorders, cancer, hearing loss, and neurogenetics. Two more clinics for the diagnosis and treatment/management of metabolic genetic disorders/conditions include a nutritionist and biochemical geneticist.

Who pays for the genetic clinic appointment?
Usually third party coverage, such as private insurance, Tri-Care, Indian Health Service, Denali Kid Care, Medicaid or Medicare, will cover the cost of the clinic evaluation. The fee is generally between $150-200. Genetic testing is billed separately by the laboratory. If a family has no coverage, a sliding fee scale is offered.

When does the genetic clinic meet?
The Alaska Genetics Clinic meets every other month in Anchorage, and less often in Bethel, Dillingham, Fairbanks, Juneau, Ketchikan, Kodiak, and Sitka. The clinic meets at The Children's Hospital at Providence Alaska Medical Center or