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Hearing Loss

March of Dimes Resource Center

Hearing loss is one of the most common birth defects, affecting about 3 in 1,000 babies. Hearing loss that is present at birth is called congenital hearing loss. Hearing loss also can develop later in childhood or during adulthood.

Hearing loss can have a major impact on the life of a child and his family. Because language and communication develop so rapidly during the first 3 years of life, an undetected hearing loss is likely to interfere with a child's speech, language and communication with others. Hearing loss also can result in learning problems that affect a child's performance at school. The goal of early screening, diagnosis and treatment is to help children with hearing loss to develop language and academic skills equal to their hearing peers.

Because hearing loss in infancy is hard to recognize, most hospitals screen all newborns before they are discharged. Most states have an Early Hearing Detection and Intervention program to help ensure that infants who don't pass the screening receive follow-up care. The March of Dimes, the American Academy of Pediatrics, the Maternal and Child Health Bureau, the Centers for Disease Control and Prevention (CDC) and others strongly support these programs.

What causes hearing loss in babies and children?

Hearing loss can be inherited (genetic) or can be caused by illness or injury. In some cases, the cause of hearing loss is not known. About 90 percent of babies with congenital hearing loss are born to hearing parents.

Genetic factors are believed to cause about 50 percent of cases of congenital hearing loss. About 25 genes that play a role in hearing loss have been identified.

About 30 percent of children with hearing loss also have other birth defects. In such cases, hearing loss is part of a syndrome (group of birth defects that occur together).

Illnesses that can cause congenital hearing loss include infections during pregnancy, such as rubella (German measles), cytomegalovirus, toxoplasmosis, herpes or syphilis. Babies born preterm also are at increased risk.

After birth, head injuries or childhood infections, such as meningitis, measles or chickenpox, can cause permanent hearing loss. Certain medications, such as the antibiotic streptomycin and related drugs, also can cause hearing loss. Ear infections (otitis media) may cause temporary hearing loss.

Are there different types of hearing loss?

Hearing loss is the decreased ability to hear sounds. When sound enters the outer ear (auricle or pinna), it moves through the ear canal to the eardrum (tympanic membrane). Incoming sound causes the eardrum to vibrate which moves three small bones (ossicles) in the middle ear. In this way, the ear canal, the eardrum and the middle ear transmit sound from the outside world to the inner ear (cochlea). Within the inner ear, thousands of tiny hair cells detect the incoming vibrations and convert them into signals that are relayed to the auditory nerves, which send neural impulses to the hearing center in the brain.

Hearing loss is often discussed in terms of where the loss occurs in the hearing pathway.

- Conductive hearing loss occurs when something interferes with sound passing through the outer or middle ear. A blockage in the ear canal, damage to the eardrum, or fluid or an infection in the middle ear (called otitis media) are examples of conditions that can cause a conductive hearing loss. This type of hearing loss is usually temporary and can often be corrected with medication or surgery.
- Sensorineural hearing loss usually occurs when the hair cells in the inner ear cannot detect all incoming vibrations or when neural impulses are not transmitted to the brain. Prenatal infections, lack of oxygen at birth, or genetic factors can cause this type of hearing loss, which is generally permanent. However, many children can be aided with devices that amplify sound. Sensorineural hearing loss also can result from damage to the brain's auditory center.
- Mixed hearing loss occurs when a child who has a sensorineural hearing loss also has a conductive loss (such as fluid in the middle ear). It is very important that children with permanent hearing loss be monitored and treated for middle ear problems so hearing is not further reduced.

How are newborns screened for hearing loss?

Newborns are screened with one of two tests, both of which measure how a baby responds to sound. Both tests take 5 to 10 minutes, are painless, and can be done when the baby is resting.

In the otoacoustic emissions (OAE) test, a small microphone is placed in the baby's ear. The microphone, connected to a computer, sends soft clicking sounds into the ear and records the inner ear's response to sound.

In the automated auditory brainstem response (AABR) test, soft clicking sounds are presented to the ear through small earphones. Sensors placed on the head and connected to a computer measure brain wave activity in response to sound.

What happens if a baby doesn't pass the hearing screening?

If a baby does not pass the OAE or the AABR, the test should be repeated or the baby should be referred to a hearing specialist (audiologist) or an ear, nose and throat specialist (ENT or otolaryngologist)for more extensive tests to determine if the baby has a hearing loss. It is important for babies to be assessed by specialists who have experience testing very young children. Diagnostic testing should be completed by 3 months of age.

Parents must keep in mind that the screening tests cannot diagnose hearing loss. Up to 5 percent of babies will have abnormal results on their hearing screening test. However, additional tests show that only about 1 in 10 of these babies actually have hearing loss.

How are babies and children tested for hearing loss?

The most common hearing test for infants under 6 months of age is the diagnostic auditory brainstem response test. It is similar to the automated screening test, but it provides more information and must be administered by a specialist.

Children between 6 months and 2 years of age often are tested with visual reinforcement audiometry (VRA).

During VRA testing, a series of sounds is presented to the child through earphones or speakers. The child is trained to turn toward any sound, and is then rewarded with an entertaining visual image for responding.

Children between 2 and 4 years of age are tested with conditioned play audiometry (CPA). They are asked to perform a simple play activity (like placing a ring on a peg) when they hear a sound. This is similar to the test for older children and adults, who are asked to press a button or raise their hand when they hear a sound.

These tests also may be recommended if a child was not screened as a newborn; if he has had persistent ear infections, meningitis or other illness that can cause hearing loss; has been diagnosed with a syndrome that can include hearing loss; or if a parent suspects the child is not responding normally to sounds.

What are some signs of hearing loss in infants and young children?

Parents should be alert to any signs of hearing loss and discuss them with their child's pediatrician. Some signs include: failure to startle at loud sounds; not turning toward the sound of a voice or imitating sounds after about 6 months of age; lack of babbling at 9 months; not using single words by 18 months; or using gestures instead of words to express needs. Parents should be concerned about hearing loss in older children if they develop vocabulary more slowly than their peers; have speech that is difficult to understand or that is too loud or too soft; often ask you to repeat what was said; turn the TV too loud. At school age, children with hearing loss often appear inattentive and have difficulties learning to read or perform simple mathematics, and fall behind at school.

How is hearing loss treated?

A child with a congenital hearing loss should begin receiving treatment before 6 months of age. Studies suggest that children treated this early are usually able to develop communication skills (using spoken or sign language) that are as good as those of hearing peers. Because of a federal law (the Individuals with Disabilities Education Act), children with a hearing loss between birth and 3 years of age have the right to receive interdisciplinary assessment and early intervention services at little or no cost. After age 3, early intervention and special education programs are provided through the public school system.

There are a number of treatment options available, and parents will need to decide which are most appropriate for their child. They will need to consider the child's age, developmental level and personality, the severity of the hearing loss, as well as their own preferences. Ideally a team of experts including the child's primary care provider, an otolaryngologist, a speech-language pathologist, audiologist and an educator will work closely with the parents to create an Individualized Family Service Plan. Treatment plans can be changed as the child gets older.

Children as young as 4 weeks of age can benefit from a hearing aid. These devices amplify sound, making it possible for many children to hear spoken words and develop language. However, some children with hearing loss are helped more than others by hearing aids. Some children with severe to profound hearing loss may not be able to hear enough sound, even with a hearing aid, to make speech audible. A behind-the-ear hearing aid is often recommended for young children because it is safer and more easily fitted and adjusted as the child grows as compared to one that fits within the ear.

Parents also will need to decide how their family and child are going to communicate. If the child is going to communicate orally (speech), he may need assistance learning listening skills and lip reading skills to help him understand what others are saying. Many children with hearing loss also need speech or language therapy.

A child also can learn to communicate using a form of sign language. The type preferred by most deaf adults is American Sign Language (ASL), which has rules and grammar that is distinct from English. There are also several variations of sign language that can be used along with spoken English.

Surgery may be recommended if a child has a permanent conductive hearing loss caused by malformations of the outer or middle ear, or by repeated ear infections. Although fluid in the middle ear usually results in only temporary hearing loss, chronic infection can cause a child to fall behind in language skills. In some cases, a doctor may suggest inserting a tube through the eardrum to allow the middle ear to drain. This procedure generally does not require an overnight hospital stay.

Surgery also may be an option for some children with severe to profound sensorineural hearing loss. A device called a cochlear implant can be surgically inserted in the inner ear of children as young as 12 months of age to stimulate hearing. The surgery requires a hospital stay of one to several days. With additional language and speech therapy, children with cochlear implants may learn to understand speech and speak reasonably well, but the amount of improvement is variable.

Does the March of Dimes support research on hearing loss?

Several March of Dimes grantees are exploring the role that specific genes play in causing hearing loss, with the goal of developing treatments for hereditary hearing loss. Others are seeking to prevent hearing loss by preventing infections that can cause it and to improve treatment of individuals with hearing loss. One is developing improved hearing aids that amplify speech more clearly.

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Newborn Screening Tests

March of Dimes Resource Center

Every state and U.S. territory now screens newborns for certain disorders of body chemistry. These birth defects have no immediate visible effects on a baby but, unless detected and treated early, can cause physical problems, mental retardation and, in some cases, death. A number of states are also screening babies for hearing loss.

Fortunately, most babies are given a clean bill of health when tested. But when test results are abnormal, early diagnosis and proper treatment can make the difference between lifelong impairment and healthy development.

Here are the answers to some common questions parents ask about newborn screening tests.

Which newborn screening tests are most likely to be given to my baby?

All states and U.S. territories screen newborns for phenylketonuria (PKU). This was the nation's first newborn screening test. Developed with the help of the March of Dimes, it has been routinely administered since the 1960s. PKU affects about 1 baby in 12,000. Babies with the disorder cannot process a part of protein called phenylalanine, which is found in nearly all foods. Without treatment, phenylalanine builds up in the bloodstream and causes brain damage and mental retardation.

When PKU is detected early, mental retardation can be prevented by feeding the baby a special formula that is low in phenylalanine. This low-phenylalanine diet will need to be followed throughout adolescence and, generally, for life.

Women of childbearing age with PKU need to remain on this special diet prior to and during pregnancy. This will prevent mental retardation in their children by avoiding fetal exposure to high maternal phenylalanine levels.

Along with PKU testing, all states and U.S. territories test newborns for hypothyroidism, and most test for galactosemia. Congenital hypothyroidism is the most common disorder identified by routine screening. It affects about 1 baby in 4,000. Congenital hypothyroidism is a thyroid hormone deficiency that retards growth and brain development. If it is detected in time, a baby can be treated with oral doses of thyroid hormone to permit normal development.

Galactosemia, which affects about 1 baby in 50,000, can cause death in infancy, or blindness and mental retardation. A baby with galactosemia is unable to convert galactose, a sugar present in milk, into glucose, a sugar the body uses as an energy source. The treatment for galactosemia is to eliminate milk and all other dairy products from the baby's diet; this dietary restriction is lifelong.

You can find out which tests are routinely done in your state by asking your health care provider or state health department. You can also visit the website of the National Newborn Screening and Genetics Resource Center at http://genes-r-us.uthscsa.edu/resources/newborn/state.htm.

What other disorders can newborn screening tests detect?

Currently, tests are available for over 30 inborn errors of body chemistry. Babies are not tested for all of these disorders for a number of reasons, including the fact that not all of these disorders are treatable. The March of Dimes would like to see all babies, in all states, screened for at least nine specific inborn errors of body chemistry including: PKU, congenital hypothyroidism, congenital adrenal hyperplasia (CAH), biotinidase deficiency, maple syrup urine disease, galactosemia, homocystinuria, sickle cell anemia, medium chain acyl-CoA dehydrogenase deficiency (MCAD), as well as hearing screening.

All of these disorders can be accurately diagnosed in newborns, and treatment is likely to improve the health of these children.

More than 40 states screen newborns for sickle cell anemia, an inherited blood disease that can cause bouts of pain, damage to vital organs such as the lungs and kidneys and, sometimes, death in childhood. Sickle cell anemia affects about 1 in 400 African-American babies and also occurs at a lower frequency among people of Hispanic, Mediterranean, Middle Eastern and South Asian descent.

Early treatment can prevent some of the complications of sickle cell anemia. Young children with the disease are especially prone to certain dangerous bacterial infections, such as pneumonia and meningitis. Studies in recent years have shown that treatment with penicillin, beginning by 2 months of age and continuing to about 5 years, dramatically reduces the risk of these infections and the deaths that result from them. Newborn screening alerts the physician to begin antibiotic treatment before infections begin.

More than 25 states test for CAH. This group of disorders, in which there is a deficiency of certain hormones, affects genital development and, in severe cases, can disturb kidney function and cause death. Lifelong treatment with the missing hormones suppresses this disease, which occurs in about 1 in 5,000 babies.

One newborn screening test, developed by a March of Dimes grantee, detects biotinidase deficiency. About 20 states screen for this disorder. Biotinidase is an enzyme that recycles biotin, one of the B vitamins, in the body. A deficiency of this enzyme, which occurs in about 1 in 70,000 babies, may cause frequent infections, hearing loss, mental retardation and even death. If the deficiency is detected in time, problems can be prevented by giving the baby extra biotin.

Maple syrup urine disease and homocystinuria are rare life-threatening disorders that affect fewer than 1 baby in 250,000. About 20 states screen for maple syrup urine disease, and 15 for homocystinuria.

At least eight states are now testing for MCAD, a disorder that can cause sudden death in infancy and serious disabilities in survivors, such as mental retardation. MCAD affects about 1 baby in 15,000. Normally the body burns fat for energy when it runs out of stored sugar (glucose). Babies with MCAD cannot make this switch, so they may suddenly develop seizures, respiratory failure, cardiac arrest or go into a coma or get infections or other illnesses if they do not eat regularly. When diagnosed early, the disorder can be successfully treated with a steady food intake and avoidance of fasting.

About half of all states now screen newborns for hearing loss. Approximately 1 to 3 in 1,000 babies in well-baby nurseries and 2 to 4 in 100 in intensive care nurseries have significant hearing loss. Without testing, most babies with hearing loss are not

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diagnosed until 2 to 3 years of age. By this time, they often have delayed speech and language development. Detection of hearing loss in the neonatal period allows the baby to be fitted with hearing aids before 6 months of age. Recent studies show that this early intervention helps prevent serious speech and language problems.

How are the tests for inborn errors of body chemistry and hearing loss done?

Inborn errors of body chemistry are detected by a blood test. The baby's heel is pricked to obtain a few drops of blood for laboratory analysis. The same blood sample can be used to screen for a number of disorders. Usually, the baby's blood specimen is sent to a state public health laboratory for testing, and findings are sent to the health care professional responsible for the infant's care.

Babies are tested for hearing loss with one of two tests that measure how the baby responds to sounds. The tests use either a tiny soft earphone or microphone that is placed in the baby's ear. If either of these tests shows abnormal results, the baby may need more extensive hearing testing to see if he or she does have hearing loss.

How soon after birth should screening tests be done?

A blood specimen should be taken from every newborn prior to hospital release. Some of the tests (such as the one for PKU) may not give accurate results, however, if they are done too soon after birth. Because of early hospital discharge, some babies are tested within the first 24 hours of life. Because some cases of PKU can be missed when the test is performed this early, the American Academy of Pediatrics recommends that a repeat specimen be taken 1 to 2 weeks later from infants whose initial test was taken within the first 24 hours of life. Hearing tests are also usually performed before the baby is discharged from the hospital. Babies born outside the hospital should have newborn screening tests done before the 7th day of life.

What does an abnormal test result mean?

Parents should not be overly alarmed by abnormal test results, as the initial screening tests give only preliminary information that must be followed up by more precise testing. Most babies with abnormal thyroid screening test results, for example, prove normal in further testing, as do many with abnormal hearing test results.

What should I do if my child is diagnosed with one of the conditions for which he was tested?

Your child may need follow-up treatment at a pediatric center that specializes in children with inborn errors of body chemistry. It is essential for your child's healthy development that you follow the recommendations of his or her doctor. As your child grows, he or she will need careful, continued evaluations and monitoring.

If one of my children has a disorder, will my other children also have it?

When one child in a family has PKU, galactosemia, biotinidase deficiency, sickle cell anemia, CAH or MCAD, the chance of the same birth defect occurring in a sibling is 1 in 4. The chances remain the same with each pregnancy. Parents who have a baby with one of these disorders can discuss their risk of having another affected child with their health care provider or a genetic counselor.

These disorders are inherited when both parents have the same abnormal gene and pass it on to their baby. A parent who has the abnormal gene, but not the disease, is called a carrier. The health of a carrier is rarely affected.

Congenital hypothyroidism usually is not passed on through parents' genes. The siblings of those who have this disorder are seldom affected.

Hearing loss can be passed on through parents' genes. However, other causes of hearing loss, such as infections that are passed on to the baby during pregnancy or birth, are unlikely to recur in another pregnancy.

You also may wish to read these other March of Dimes Fact Sheets:

Hearing Loss
PKU
Sickle Cell Disease

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Saving babies, together

Birth Defects

March of Dimes Resource Center

About 150,000 babies are born each year with birth defects. The parents of one out of every 28 babies receive the frightening news that their baby has a birth defect.

A birth defect is an abnormality of structure, function or metabolism (body chemistry) present at birth that results in physical or mental disability, or is fatal. Several thousand different birth defects have been identified. Birth defects are the leading cause of death in the first year of life.

What causes birth defects?

Both genetic and environmental factors can cause birth defects. However, the causes of about 60 to 70 percent of birth defects currently are unknown.

A single abnormal gene can cause birth defects. Every human being has at least 30,000 to 35,000 genes that determine traits like eye and hair color, as well as direct the growth and development of every part of our physical and biochemical systems. Genes are packaged into each of the 46 chromosomes inside our cells.

Each child gets half its genes from each parent. A person can inherit a genetic disease when one parent (who may or may not have the disease) passes along a single faulty gene. This is called dominant inheritance. Examples include achondroplasia (a form of dwarfism) and Marfan syndrome (a connective tissue disease). Many other genetic diseases are inherited only when both parents (who do not have those diseases) happen to carry the same abnormal gene and pass it on to a child. This is called recessive inheritance. Examples include Tay-Sachs disease (a fatal disorder seen mainly in people of European Jewish heritage) and cystic fibrosis (a fatal disorder of lungs and other organs, affecting mainly Caucasians). There also is a form of inheritance (X-linked) where sons can inherit a genetic disease from a mother who carries the gene (usually with no effect on her own health). Examples include hemophilia (a blood-clotting disorder) and Duchenne muscular dystrophy (progressive muscle weakness).

Abnormalities in the number or structure of chromosomes can cause numerous birth defects. Due to an error that occurred when an egg or sperm cell was developing, a baby can be born with too many or too few chromosomes, or with one or more chromosomes that are broken or rearranged. Down syndrome, in which a baby is born with an extra chromosome 21, is one of the most common chromosomal abnormalities. Affected children have varying degrees of mental retardation, characteristic facial features and, often, heart defects and other problems. Babies born with extra copies of chromosome 18 or 13 have multiple birth defects and usually die in the first months of life.

Missing or extra sex chromosomes (X and Y) affect sexual development and may cause infertility, growth abnormalities, and behavioral and learning problems. However, most affected individuals have essentially normal lives.

Birth defects also may result from environmental factors such as drug or alcohol abuse, infections, or exposure to certain medications (such as the acne drug Accutane) or other chemicals. Many birth defects appear to be caused by a combination of one or more genes and environmental factors (called multifactorial inheritance). Some examples include cleft lip/palate, clubfoot and some heart defects

What are some common types of birth defects?

Birth defects generally are grouped into three major categories: structural/metabolic, congenital infections, and other conditions.

- *Structural/metabolic abnormalities*

When a baby has a structural birth defect, some part of the body (internal or external) is missing or malformed. Heart defects are the most common type of structural birth defect, affecting one baby in 125. While advances in surgery have dramatically improved the outlook for affected babies, these remain the leading cause of birth defect-related infant deaths. Doctors usually do not know what causes a baby's heart to form abnormally, although genetic and environmental factors are believed to play a role.

Spina bifida (open spine, in which the backbone never completely closes and the spinal cord is usually malformed) affects one in 2,000 babies. Affected babies suffer varying degrees of paralysis, and bladder and bowel problems. Both genetic and nutritional factors appear to play a role.

About one baby in 135 has a structural defect involving the genitals or urinary tract. These vary greatly in severity, ranging from abnormal placement of the urinary opening in males (hypospadias) to absence of both kidneys. The cause of hypospadias, which is surgically correctable, is unknown. Babies who lack both kidneys die in the first hours or days of life. This tragic defect is sometimes inherited.

Metabolic disorders affect one in 3,500 babies. These disorders are not visible, but can be harmful or even fatal. Most are recessive genetic diseases. These diseases result from the inability of cells to produce an enzyme (protein) needed to change certain chemicals into others, or to carry substances from one place to another. An example is Tay-Sachs disease. Affected babies lack an enzyme needed to break down certain fatty substances in brain cells. These substances build up and destroy brain cells, resulting in blindness, paralysis and death by age five. Phenylketonuria (PKU) is another metabolic disorder, in which affected babies cannot process a part of protein, which builds up in blood and causes brain damage. PKU is routinely detected with newborn screening tests, so affected babies can be placed on a special diet that prevents mental retardation.

- *Congenital infections*

Rubella (German measles) probably is the best known congenital infection that can cause birth defects. If a pregnant woman is infected in the first trimester, her baby has a one-in-four chance of being born with one or more features of congenital rubella syndrome (deafness, mental retardation, heart defects, blindness). Fortunately, with widespread vaccination, this syndrome is now rare in this country.

The most common congenital viral infection is cytomegalovirus (CMV). About 1 percent (40,000 babies a year) of all newborns in this country are infected, although only about 10 percent of them (3,000-4,000) have serious consequences, including mental retardation, and loss of vision and hearing. Pregnant women often acquire CMV from young children, who usually have few or no symptoms

Sexually transmitted infections in the mother also can endanger the fetus and newborn. For example, untreated syphilis can result in stillbirth, newborn death, or bone defects. About one baby in 2,000 is affected.

• *Other causes*

Other causes of birth defects include fetal alcohol syndrome, which affects one baby in 1,000. This pattern of mental and physical birth defects is common in babies of mothers who drink heavily during pregnancy. Even moderate or light drinking during pregnancy can pose a risk to the baby.

Rh disease of the newborn, which is caused by an incompatibility between the blood of a mother and her fetus, affects about 4,000 infants a year. It can result in jaundice (yellowing of the skin), anemia, brain damage and death. Rh disease usually can be prevented by giving an Rh-negative woman an injection of a blood product called immunoglobulin at 28 weeks of pregnancy and after the delivery of an Rh-positive baby.

Babies of mothers who use cocaine early in pregnancy may be at increased risk of birth defects. A large study has suggested that these babies are five times more likely to be born with urinary tract defects than babies of women who don't use cocaine.

Can birth defects be prevented?

While the causes of most birth defects are not known, there are a number of steps a woman can take to reduce her risk of having a baby with a birth defect. One important step is a pre-pregnancy visit with her health care provider. During this visit, the provider can obtain valuable information about a woman or couple's family history, which may help identify risk factors for birth defects or inherited genetic conditions. This information allows for appropriate testing and screening to be offered prior to or during pregnancy. During a pre-pregnancy visit, providers also can take a good look at a woman's health and lifestyle, and guide her in any changes that could improve her chances of having a healthy baby.

A pre-pregnancy visit is especially crucial for women with medical problems like diabetes, high blood pressure, and epilepsy, which can affect pregnancy. For example, women with poorly controlled diabetes are several times more likely than women without diabetes to have a baby with a serious birth defect. However, if their blood sugar levels are well controlled starting before pregnancy, they are almost as likely to have a healthy baby as women without diabetes.

If a woman has never had chickenpox (and has not been vaccinated), a pre-pregnancy visit is a good time to check whether she should be vaccinated prior to pregnancy. Like rubella, chickenpox can cause birth defects when contracted by the pregnant woman, although the risk is low. If she has not been vaccinated against rubella since childhood, she should ask her doctor about the rubella vaccine or a combination vaccine such as measles-mumps-rubella (MMR). She should avoid pregnancy for one month after chickenpox, rubella or MMR vaccination.

All women who could become pregnant should take a daily multivitamin containing 400 micrograms of the B-vitamin folic acid. Studies show that taking this vitamin prior to and in the early weeks of pregnancy reduces the risk of having a baby with certain birth defects of the brain and spine, including spina bifida. If a woman already has had a baby with one of these birth defects, she should consult her doctor prior to pregnancy about how much folic acid to take. Generally, a higher dose, 4 milligrams, is recommended.

A woman who is pregnant or planning pregnancy should avoid alcohol, smoking, and street drugs — these can cause birth defects and other pregnancy complications. She should not take any medication — prescription, over-the-counter, or herbal — without first checking with her health care provider.

Can some birth defects be diagnosed before birth?

Some birth defects can be diagnosed before birth, using one or more prenatal tests including ultrasound, amniocentesis and chorionic villus sampling (CVS). Ultrasound can help diagnose structural birth defects, such as spina bifida, heart and urinary tract defects. Amniocentesis and CVS are used to diagnose chromosomal abnormalities, such as Down syndrome. They also can detect, or rule out, numerous genetic birth defects that may be suspected because of family history or ethnic background.

Can birth defects be treated before birth?

A small percentage of couples will learn through prenatal diagnosis that their baby has a birth defect. While this news can be devastating, prenatal diagnosis sometimes can improve the outlook for the baby. Advances in prenatal therapy now make it possible to treat some birth defects before birth. For example, biotin dependence and methylmalonic acidemia — two life-threatening inherited disorders of body chemistry — have been diagnosed by amniocentesis and treated in the womb, resulting in the births of healthy babies.

Prenatal surgery has saved babies with urinary-tract blockages, rare tumors of the lung, and congenital diaphragmatic hernia (a hole in the muscle that separates the chest from the abdomen). More than 100 babies have undergone experimental prenatal surgery to repair spina bifida before birth. Preliminary results appear promising: fewer babies who have had surgery for spina bifida require shunts to drain fluid from their brain. However, it is too soon to know how well most of these babies will walk, and the procedure leads to preterm birth. Prenatal blood transfusions have saved numerous babies with severe Rh disease, and heart medications given to the pregnant woman have saved babies with serious heart rhythm disturbances. However, even when a fetus has a condition for which prenatal treatment is not yet possible, prenatal diagnosis permits parents to prepare themselves emotionally, and to plan with their provider the safest timing, location and method of delivery.

Couples who have had a baby with a birth defect, or who have a family history of birth defects, should consider consulting a genetic counselor. These health professionals help families understand what is known about the causes of a birth defect, and the chances of the birth defect recurring in another pregnancy. Genetic counselors also can provide referrals to medical experts as well as to appropriate support groups.

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Locations of Newborn Hearing Screening Hospitals

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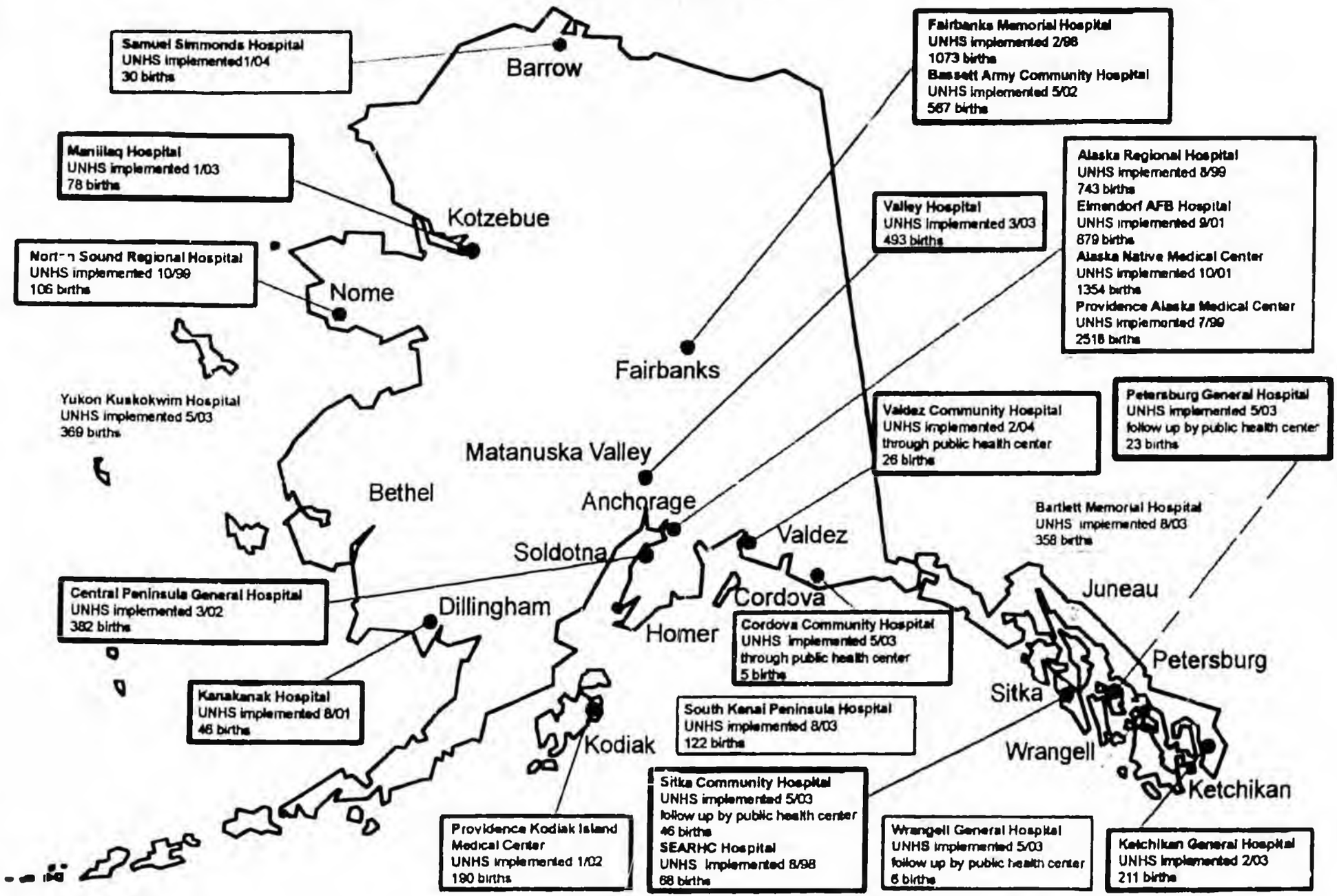

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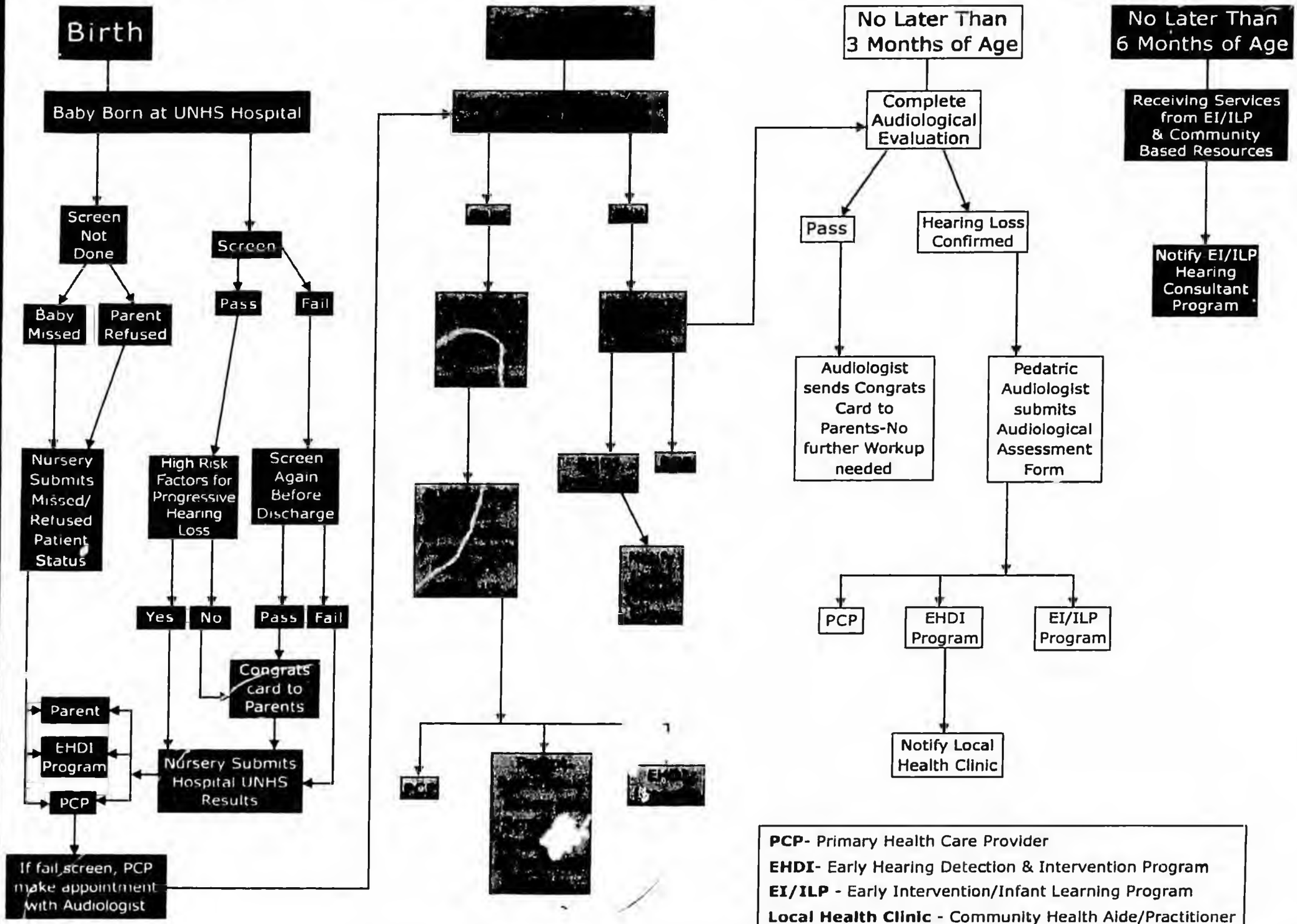

PCP- Primary Health Care Provider

EHDI- Early Hearing Detection & Intervention Program

EI/ILP - Early Intervention/Infant Learning Program

Local Health Clinic - Community Health Aide/Practitioner and/or Public Health Nurse

Alaska Early Hearing Detection & Intervention
Program Overview

January 2005

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss.

Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome and severe mental retardation.

Early Identification is important because:

- The most important period of speech and language development is from birth to age three.
- Delay in diagnosis can impair a child's language, speech, psycho-social and cognitive development.
- The average age of identification of a hearing impairment in the absence of newborn hearing screening is 2-3 years of age.
- Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

Alaska EHDI Program

The Alaska Early Hearing Detection & Intervention (EHDI) Program began in April 2000. the EHDI Program is funded by two federal grants from: the Health Resources & Services Administration (HRSA) and Centers for Disease Control & Prevention (CDC).

Key program include the following:

- Ensure th s born in Alaska have newborn hearing screening prior to hospital discharge
- Ensure th newborns who fail hearing screening receive an audiological evaluation by three month of age.
- Ensure that infants diagnosed with hearing loss are referred to and enrolled in appropriate early intervention and other needed services by six months of age.

Screening

To date, 23 of 23 communities within Alaska have implemented universal newborn hearing screening programs. The majority of screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screen during home visits after hospital discharge.

Legislation

Nationwide, 38 states have enacted legislation requiring hospitals to implement newborn hearing screening programs. In Alaska, newborn hearing screening was introduced and worked on during the 2001, 2002, 2003, and 2004 legislative sessions.

Data & Evaluation
A primary role of the Alaska EHDI Program is to support hospitals, audiologists and other health care providers, and assist early intervention programs (Infant Learning Program) in their tracking and follow-up efforts. The EHDI Program received a grant from the Centers for Disease Control & Prevention (CDC) to develop an electronic data tracking and surveillance system to facilitate the follow-up process and ensure smooth transition occurs through services. The EHDI Program is purchasing the web-based database, Oz, and will begin implementing in communities in 2005.

Loaner Program
The EHDI Loaner Program provides assistive hearing devices (i.e. hearing aids) for children (0-3 years) whose families cannot otherwise afford them. For example, these families are not eligible for Denali Kid Care and/or do not have private insurance that covers hearing aids and/or cannot afford to purchase hearing aids themselves. The Loaner Program allows these families to "borrow" money to purchase hearing aids for 6-12 months. The Loaner Program is made possible through a grant from the Mental Health Trust Authority.

Education & Outreach
The EHDI Program travels to communities introducing the Alaska EHDI Program. Presentations target primary health care providers in those communities (i.e. pediatricians, public health nurses, community health aide/practitioners) regarding newborn hearing screening and early hearing detection and intervention.

To assist with this effort, educational materials were developed by EHDI Program with assistance by many dedicated providers and parents. The following materials are available from the EHDI Program: 1) general brochure regarding: universal newborn hearing screening for parents and prospective parents, 2) brochure outlining the protocol for parents to follow if their newborn does not pass the newborn hearing screening, 3) basic hearing loss information for parents and the general public, 4) parent resource manual for families of children diagnosed with hearing loss, 5) provider guide for health care providers, 6) hospital orientation manual regarding implementation of universal newborn hearing screening, and 7) video/DVD for community health aide/practitioners (CHA/Ps) in rural Alaskan communities.

For copies of the materials and/or information regarding the EHDI Program, contact:

Margaret Lanier Kossler
4501 Business Park Blvd. Suite 24
Anchorage, AK 99503-7167
Margaret_lanier@health.state.ak.us e-mail

(907) 269-3466 – telephone
(907) 269-3465 – fax

http://hss.state.ak.us/dhcs/newborn

Why Is Mandatory Newborn Hearing Screening and Reporting So Important?

1. Every day, 33 babies (or 12,000 each year) are born in the United States with permanent hearing loss, or 3 in every 1,000 births (1). In Alaska, approximately 10,000 babies are born each year and according to statistics 30-40 will likely have some type of congenital hearing loss.

2. The evidence for the benefits, practicability, and cost-efficiency of universal newborn hearing screening is so compelling that 38 other states have passed legislative mandates requiring that newborns be screened for hearing loss (2).

3. Hearing impairment is the most common disability in newborns, with a higher incidence than cerebral palsy, Down Syndrome, and severe mental retardation (3).

4. Hearing impairment is approximately 30 times more prevalent than PKU and hypothyroidism, screened through the metabolic disorder screening programs, and mandated by law in all 50 states. (4).

5. The cost of identifying a newborn with hearing loss is less than $1/10^{th}$ the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state (5). For most birthing hospitals, the cost for newborn hearing screening per child is between $20 - $60 and continues to decrease (6). Many birthing facilities in Alaska, implementing newborn hearing screening voluntarily, include the cost in the total labor and delivery package cost.

6. Children not detected at birth or soon after, will not be detected, on average, until 2-3 years of age, and the most critical period for speech and language development is from birth to three years of age (7).

7. When children are not identified and served early, special education for a child with hearing loss may cost an additional $420,000, and deafness has an estimated lifetime cost of approximately $ 1 million per individual (8). These savings in special education costs will pay for universal newborn hearing screening many times over.

8. If left undetected, hearing loss can impair a child's language, speech, psycho-social and cognitive development. Recent research has compared children with hearing loss who receive early intervention and amplification (i.e. hearing aids) before 6 months of age versus after 6 months of age. By the time they enter first grade, children identified earlier (prior to 6 months of age) are 1-2 years ahead of their later-identified peers in language, cognitive, and social skills (9, 10, 11).

9. If it remains undetected, even mild hearing loss or hearing loss in only one ear has substantial detrimental consequences. For example, research shows that children

with hearing loss in one ear are ten times as likely to be held back at least one grade compared to a matched group of children with normal hearing (12).

10. The American Academy of Pediatrics, the National Institutes of Health, the American Academy of Audiology, the Joint Committee on Infant Hearing, and the National Association of the Deaf have recommended that all babies be screened for hearing loss before they leave the hospital (13).

11. To date, 23 of 23 communities in Alaska with birthing hospitals have voluntarily implemented universal newborn hearing screening programs. The majority of the screenings are performed in hospitals by nurses prior to discharge. However, in some smaller communities, public health nurses perform the screenings during home visits after hospital discharge. As of December 2003, the total number of newborns in Alaska that received hearing screening was approximately 80% (14).

12. Even though 80% sounds like a large number of Alaska's newborns, because newborn hearing screening is not mandated and the screening, reporting and follow-up is not institutionalized in facilities across the state, Alaska remains in the "unsatisfactory" category when rated nationally.

13. Due to Alaska's large geographic size, high staff turnover occurs as well as difficulty recruiting and keeping healthcare providers in many of it's more rural communities. And because the screening and reporting is not mandated, it is often times not a priority at birthing facilities and among providers. As a result, it is increasingly difficult to keep nurses and other providers with the knowledge necessary to maintain a newborn hearing screening program. Gaps in screening occur in hospitals, thus babies miss their screening and are not followed for high risk factors.

EHDI FACT SHEET REFERENCES

1. National Center on Hearing Assessment and Management. http://www.infanthearing.org/presentations/cdc/prevalence.html.

2. National Center on Hearing Assessment and Management. http://www.infanthearing.org/resources/fact.pdf.

3. National Center on Hearing Assessment and Management. http://www.infanthearing.org/presentations/cdc/prevalence.html

4. National Center on Hearing Assessment and Management. http://www.infanthearing.org

5. Wellness Web. http://www.wellweb.com/INDEX/OSICKLE.HTM#Head7

6. Grosse S. "Cost comparison of screening newborns for hearing impairment and biochemical disorders." Center for Disease Control and Prevention. Paper presented at the Newborn Screening and Genetics Conference, May 2001.

7. Harrison M., Rousn J. "Age of suspicion, identification and intervention for infants and young children with hearing loss: a national study." *Ear and Hearing*. 1996; 17: 55-62.

8. Johnson JL, Mauk GW, Takekawa KM, Simon PR, Sia CCJ, Blackwell PM. "Implementing a statewide system of services for infants and toddlers with hearing disabilities." *Seminars in Hearing*. 1993; 14: 105-119.

9. Yoshinaga-Itano C., Apuzzo ML. "Identification of hearing loss after 18 months of age is not early enough." *Am Ann Deaf*. 1998; 143 (5): 380-387.

10. Yoshinaga-Itano C., Sedey AL, Coulter BA, Mehl AL. "Language of early and later-identified children with hearing loss." *Pediatrics*. 1998; 102: 116801171.

11. Centers for Disease Control and Prevention. National Center for Birth Defects and Developmental Disabilities, Early Hearing Detection & Intervention Program. What is EHDI? http://www.cdc.gov/ncbddd/ehdi.htm

12. National Center on Hearing Assessment and Management. http://www.infanthearing.org

13. National Center on Hearing Assessment and Management. http://www.infanthearing.org

14. Alaska Early Hearing Detection & Intervention Program Data.

FRANK H. MURKOWSKI, GOVERNOR
State of Alaska

GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

P.O. Box 240249 • Anchorage, Alaska 99524-0249 • Phone: 907-269-8990 • Fax: 907-269-8995 • Toll Free 888-269-8990

FY06 Legislative Priorities

Fiscal Plan

Home and community-based services funded by Medicaid and state grants enable Alaskans with severe disabilities to live independently and become productive, gainful members of their communities. In an economy where the source of revenues is unpredictable, Alaskans with severe disabilities, whose independence and productivity is linked to government supports, are at risk for negative, unpredictable life changes.

Recommendation: The Council urges the Legislature to meet the needs of Alaskans with disabilities by developing a consistent revenue stream for supports and services as a part of a long range fiscal plan.

Dental Services

Governor Murkowski will introduce legislation to expand Medicaid coverage for adult recipients that will include preventive and restorative dental services. Proposed coverage will be capped at $1,150 annually. The Alaska Mental Health Trust Authority has agreed to contribute $5.4 million over five years toward the costs of dental services for Trust beneficiaries. In FY03, costs of emergency dental care totaled $2.2 million. Over time, the State's investment, coupled with the Trust funded donated dental and dental training programs, will significantly reduce the cost for emergency dental services.

Recommendation: The Council urges adoption of the Governor's legislation to include adult preventive dental coverage under Medicaid.

Bring the Kids Home

At any given time approximately 400 children are served in costly out-of-state placements. Governor Murkowski's initiative will develop a support system within the state to allow Alaskan children to receive services near their homes and families. State expenditures will decrease as children are moved home and supported in their communities. The Council recommends that all cost savings realized in this initiative be reinvested in Keeping Kids Home.

Recommendation: The Council urges the legislature to supp .he Governor's Bring the Kids Home Initiative.

WORLD COUNCIL
ON HEARING HEALTH
DEAFNESS RESEARCH FOUNDATION

NEWBORN HEARING SCREENING STATE REPORT CARD

Is your state making the grade on infant hearing screenings?

The Deafness Research Foundation (DRF) and World Council on Hearing Health (WCHH), formerly known as the National Campaign for Hearing Health, are proud to bring you the latest data on infant hearing screening across the United States. The WCHH is the public education and advocacy arm of DRF, and works on the platforms of detection, prevention, intervention, and research to make a lifetime of healthy hearing possible to all people.

Each year, more than 12,000 infants in the United States – one in 300 – are born with a hearing impairment. Of these, 4,000 are profoundly deaf. In fact, hearing loss is the number one birth defect in the United States. Despite this, only 89.8 percent of babies are currently screened for hearing loss at birth.

Early detection is vital to diagnosis and intervention. Does your state make the grade?

State	Grade	Babies Screened May 2003	Babies Screened May 2004	Total # of Annual Births
Alabama	*Excellent*	90.0%	95.0%	58,967
Alaska	*Unsatisfactory*	71.0%	70.0%	9,938
Arizona	*Excellent*	95.0%	95.0%	87,837
Arkansas	*Good*	91.0%	91.3%	37,437
California	*Unsatisfactory*	57.7%	66.0%	529,357
Colorado	*Exemplary*	96.0%	97.0%	68,418
Connecticut	*Excellent*	97.0%	99.8%	42,001
Delaware	*Excellent*	95.0%	98.0%	11,090
District of Columbia	*Excellent*	99.5%	98.0%	7,498
Florida	*Excellent*	96.0%	98.0%	205,579
Georgia	*Exemplary*	98.8%	98.0%	133,300
Hawaii	*Exemplary*	98.3%	98.0%	17,477
Idaho	*Excellent*	97.6%	97.0%	20,970
Illinois	*Excellent*	97.0%	98.0%	180,622
Indiana	*Excellent*	97.1%	99.9%	85,081
Iowa	*Good*	84.0%	80.0%	37,559
Kansas	*Excellent*	95.0%	95.0%	39,412
Kentucky	*Exemplary*	99.0%	99.5%	54,233
Louisiana	*Good*	89.6%	93.2%	64,872
Maine	*Excellent*	90.0%	98.0%	13,559
Maryland	*Good*	87.0%	85.2%	73,323
Massachusetts	*Excellent*	99.0%	99.7%	80,645
Michigan	*Excellent*	93.0%	95.0%	129,967
Minnesota	*Good*	90.3%	92.0%	68,025

State	Grade	Babies Screened May 2003	Babies Screened May 2004	Total # of Annual Births
Mississippi	*Excellent*	95.0%	98.0%	41,518
Missouri	*Excellent*	96.9%	97.7%	75,251
Montana	*Excellent*	94.0%	95.0%	11,049
Nebraska	*Excellent*	92.0%	97.0%	25,383
Nevada	*Excellent*	94.0%	97.0%	32,571
New Hampshire	*Good*	79.0%	90.0%	14,442
New Jersey	*Excellent*	96.7%	98.3%	114,751
New Mexico	*Excellent*	94.0%	94.0%	27,753
New York	*Excellent*	95.0%	96.7%	251,415
North Carolina	*Exemplary*	99.1%	98.0%	117,335
North Dakota	*Good*	70.0%	92.0%	7,757
Ohio	*Unsatisfactory*	22.0%	33.0%	148,720
Oklahoma	*Excellent*	94.0%	94.0%	50,387
Oregon	*Excellent*	97.0%	94.0%	45,192
Pennsylvania	*Excellent*	86.0%	95.7%	142,850
Rhode Island	*Excellent*	99.3%	99.6%	12,894
South Carolina	*Exemplary*	98.4%	98.1%	54,570
South Dakota	*Good*	88.0%	85.6%	10,698
Tennessee	*Good*	93.1%	90.0%	77,482
Texas	*Exemplary*	97.0%	99.0%	372,450
Utah	*Excellent*	97.5%	98.2%	49,182
Vermont	*Excellent*	94.7%	95.0%	6,387
Virginia	*Exemplary*	95.2%	99.7%	99,672
Washington	*Good*	62.2%	85.0%	79,028
West Virginia	*Excellent*	96.0%	95.0%	20,712
Wisconsin	*Excellent*	93.0%	95.0%	68,560
Wyoming	*Exemplary*	98.0%	98.0%	6,550
TOTAL			89.8%	

Grading Scale*

Exemplary**: 95% - 100% of babies being screened, of which less than 50% of the funding for the program comes from temporary federal grants.

Excellent: 94 % - 100% of babies being screened, of which most of the funding for the program comes from temporary federal grants.

Good: 80% - 94% of babies being screened.

Unsatisfactory: 80% or less of babies being screened.

*Based on May 2004 data from the National Center for Hearing Assessment and Management at Utah State University, grading scale based on evaluation by the World Council on Hearing Health.

**Exemplary Early Hearing Detection and Intervention (EHDI) programs require more than hospital-based newborn hearing screening. To be exemplary requires that the screening program be connected to pediatric audiology services, appropriate early intervention programs, family support (including appropriate educational materials), and tracking and data management activities to make sure all babies and families receive the services they need. Although

RE: HB 109 Screening for Newborn Hearing

May 8, 2006

Dear Senate Finance Committee, Committee Members, and all Members of the Alaska State Senate,

HB 109 Screening for Newborn Hearing is necessary legislation. Please support it and vote to pass it today. What basis do I have for my conviction and request?

Twenty-four years ago, I was not screened for hearing loss as an infant: my moderate then eventually severe hearing loss was not detected until I was in school. Although I'm one of the lucky ones who struggled and overcame this disadvantage and am now a college graduate and professional, I firmly believe that the relatively small group of babies in Alaska who are not currently being screened are facing an avoidable disadvantage.

As a result of the late detection of loss, I was treated differently as a child; family and others thought I was "slow" and lowered their expectations for me. To this day, my parents are terribly saddened at their incorrect assumption and pained to think of the resulting struggles I faced that could have been avoided if intervention would have occurred earlier. I struggled with speech development and the stigma of being put in the special education program in grade school in the Mat-Su. I struggled with first discovering I had hearing loss at an age when it was difficult to accept my challenge, at an age when peers tended to be insensitive and cruel and make fun of my disability. Had my loss been detected as an infant and intervention occurred then, my speech development and interactions would have been more normal, my acceptance of my disability would have been natural, and I very likely would not have needed any special education services.

Extra and unnecessary laws are not good. This law, however, is a necessary one. The most caring and competent parents have no way to determine a hearing screening is needed for an infant. My parents would have gladly requested and paid for the simple and inexpensive screening had they known to ask; they are both college-educated—one is even in the medical field—but because no outward sign provided a warning signal, they did not request one.

Please, pass HB 109 today and help Alaskan babies and children who have hearing loss avoid unnecessary extra challenges.

Sincerely,

Clara J. Hughes

SENATE COMMITTEE REPORT

DATE: 4/22/05

FURTHER: (Finance)

DATE TURNED IN TO OFFICE: 3.6.06

Health, Education and Social Services Committee considered CS FOR HOUSE BILL NO. 109(FIN)

HB 109 SCREENING NEWBORNS FOR HEARING ABILITY

"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date."

and recommends:

[ ] be **replaced** with _____ **CS** _____ (_____)

[ ] adopt **previous** _____ **CS** _____ (_____)

[ ] attached amendment(s)

[ ] adopt Letter of Intent by _____ Committee

[ ] further referral to _____ Committee

CS Senate Bill:
[ ] Same Title
[ ] New Title

SCS House Bill:
[ ] Same Title
[ ] Technical Title Change
[ ] New Title w/ SCR #____

NEW FISCAL NOTE(S):

Department	Date	Fiscal	Indet.	Zero	FN#
HSS	3/3	x			5

PREVIOUS FISCAL NOTE(S):

Department	Date	Fiscal	Indet.	Zero	FN#

[ ] **APPROPRIATION - no fiscal note**

SIGNATURES AND RECOMMENDATIONS:	DO PASS	DO NOT PASS	NO REC	AMEND
Elton				
Wilken			✓	
Green			✓	
Olson			✓	
Dyson CHAIR:	✓			

HB 109

Public Testimony

Testimony for Senate Finance Committee Hearing
May 8th, 2006

I'm Debbie Golden, Director of Program Services for the Alaska Chapter of March of Dimes. March of Dimes supports HB 109. Thank you to all of you who've helped it get to this point.

I don't intend to repeat my previous testimony. I just want to say that Alaska has a wonderful newborn metabolic screening program to screen for, track, and assist with intervention for conditions like PKU and congenital hypothyroidism. **It makes sense that we should do as well with newborn hearing screening, tracking, intervention since newborn hearing loss occurs 3-4 times more often than the metabolic disorders.** Alaska's babies and families deserve no less.

A lot of people and organizations want HB 109 to become law. On behalf of March of Dimes, the Early H uring Detection and Intervention advocacy group, the 268 individuals who've signed pos .rds for March of Dimes supporting the bill, and the many other organizations and individuals in support, **I ask you to please pass HB 109 out of the Senate Finance Committee.**

Thank you.

RE: HB 109 Screening for Newborn Hearing

May 8, 2006

Dear Senate Finance Committee, Committee Members, and all Members of the Alaska State Senate,

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Twenty-four years ago, I was not screened for hearing loss as an infant; my moderate then eventually severe hearing loss was not detected until I was in school. Although I'm one of the lucky ones who struggled and overcame this disadvantage and am now a college graduate and professional, I firmly believe that the relatively small group of babies in Alaska who are not currently being screened are facing an avoidable disadvantage.

As a result of the late detection of loss, I was treated differently as a child; family and others thought I was "slow" and lowered their expectations for me. To this day, my parents are terribly saddened at their incorrect assumption and pained to think of the resulting struggles I faced that could have been avoided if intervention would have occurred earlier. I struggled with speech development and the stigma of being put in the special education program in grade school in the Mat-Su. I struggled with first discovering I had hearing loss at an age when it was difficult to accept my challenge, at an age when peers tended to be insensitive and cruel and make fun of my disability. Had my loss been detected as an infant and intervention occurred then, my speech development and interactions would have been more normal, my acceptance of my disability would have been natural, and I very likely would not have needed any special education services.

Extra and unnecessary laws are not good. This law, however, is a necessary one. The most caring and competent parents have no way to determine a hearing screening is needed for an infant. My parents would have gladly requested and paid for the simple and inexpensive screening had they known to ask; they are both college-educated—one is even in the medical field—but because no outward sign provided a warning signal, they did not request one.

Please, pass HB 109 today and help Alaskan babies and children who have hearing loss avoid unnecessary extra challenges.

Sincerely,

Clara J. Hughes

Clara J. Hughes
340 W. 32nd Ave. #5
Anchorage, AK 99503
(907) 764-4667

Hello my name is Pam Mueller-Guy. I work for Southeast Alaska Independent Living as the Deaf Services & Interpreter Referral Coordinator. I am representing for SAIL in support for the Newborn Hearing Screening test, House Bill 109 and Senate Bill 68.

I was born as a hearing child. However, I had to have a blood transfusion from a stranger when I was five days old, due to my rare blood type. Due to this blood transfusion, I became deaf, but no one realized it till I was about 2 years old.

Even as a toddler, I could speak a little bit and mimicked by brother while playing with toys. My grandmother finally figured out that I could not hear, realizing I never responded when they called my name. Only when a loud noise occurred, such as a stomp on the floor, did I look their way.

They finally took me to have a hearing test and I was diagnosed with severe profound nerve deafness. They were in shock and wept for me because they didn't know what to do. They asked, "How can she can hear music?" My whole family is musical! They had grief until they realized I could experience music.

I started speech classes at 2 ½ years old then started wearing hearing aids at 3 1/2 years old and started half days till four years old to stay at boarding parents house during the week because deaf school was 25 miles away from my home.

I was held back in school twice due to my hearing disability. One time, just because they wanted to keep all the students who were deaf together in one grade. I had to make friends all over again.

If this bill is passed, it will also allow parents of newborn babies with hearing loss to get information immediately and begin preparing for life with a child who is deaf. It is difficult for organizations like SAIL to identify and assist persons who have hearing loss; a much better way to do this is to catch the baby and family at the beginning of life. I do not want to see people with hearing loss have to go the hard way like me.

I hope for the new generation that they can be diagnosed early and begin to learn early so they may be capable of writing English easy instead of the hard way. I see most deaf and hard of hearing have a hard time in alaska for jobs. Schools also should have programs specifically for children who are deaf so they won't be isolated. I am hopeful children who are deaf will be able to communicate in both the hearing world and the deaf world.

The newborn hearing screen would be best for all needs so the parents of the baby can start early to learn to cope with the child and their lives would be easier! This bill will

save a lot of money for the government, schools, and insurance, including Medicaid, in the long run. Thank you for taking your time to listen to me. Keep passing those bills for better lives in Alaska!

Cheryl L. Scott
5000 Country Club Lane
Anchorage, AK 99516

Representative
State Capitol
120- 4th
Juneau, AK 99801

Dear Representative,

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. My son is one of those babies. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down Syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. Without mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

My son's hearing loss was not diagnosed until he was 10 and 1/2 years old, due to his other complex medical issues. If he had been screened at birth and his hearing loss detected, hearing aids, sign language training and other needed supports could have been provided during his early years. Maybe he wouldn't even be considered mentally retarded if he had been provided the opportunity to learn to communicate and to access a whole world of sound during those vital early years. He will be 19 in two days and we grieve for his lost potential every time he struggles to make himself understood or to fit in with hearing and speaking people that have little patience with his few words and halting signs.

Mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children have what they need to become productive members of our communities. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information. Thanks for your attention to this important matter.

Sincerely,

Cheryl L. Scott, (Justin's mom)

Wood, Thalia

From: Sue Benson [Sue_Benson@matsuk12.us]
Sent: Friday, January 20, 2006 8:08 AM
To: Senator_Lyda_Green@legis.state.ak.us
Cc: Thalia_Wood@health.state.ak.us; Rep_Vic_Kohring@legis.state.ak.us
Subject: HB109

1050 Onyx Circle
Wasilla, AK 99654
January 20, 2006

Senator Lyda Green
State Capitol, Room 51
Juneau, AK 99801-1182
Senator_Lyda_Green@legis.state.ak.us

Dear Representative,

As one of your constituents I am writing to ask you to support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. As a parent of a child with hearing loss I want other children to have earlier diagnostics and intervention than my child had.

My son was diagnosed with a hearing loss in one ear when he was almost two years of age. He had several risk factors for hearing loss at birth, but newborn screening was not done at that time. Without mandatory screening in newborns, the average age of identification of hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delays in diagnosis can impair a child's speech, language, psycho-social and cognitive development. Through early identification, children identified at birth can learn and progress at a rate comparable to those without hearing loss.

As an audiologist I still see children that are not diagnosed with hearing loss until they are three years of age or older. With mandatory screening and reporting by birthing facilities to the State's Early Hearing Detection & Intervention (EHDI) Program, children with possible hearing loss will receive timely diagnostic evaluation, amplification and/or medical intervention and, if necessary, enrolled into early intervention services.

January has been designated as Birth Defects Prevention Month. Please support HB109 requiring universal newborn hearing screening, reporting and follow up, so more children have a better chance in the first few years of development.

Thank you for your attention to this important matter.

Sincerely,

Susanne Benson

Susanne Benson, MS, CCC-A
Educational Audiologist
Mat-Su Borough School District
Wasilla High School, 701 Bogard Rd
Wasilla, AK 99654

907-352-8279

Daniel E. Knudsen
P.O. Box 35426
Juneau, AK 99803

February 24, 2006

Senator Fred Dyson
State Capitol, Room 121
Juneau, AK 99801-1182

Dear Senator:

Birth defects are the leading cause of infant mortality in the United States. I am writing as one of your constituents concerned about the public health importance of the major birth defect, congenital hearing loss.

January has been designated as Birth Defects Prevention Month. In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down Syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. In the absence of mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

In addition, mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children are given what is needed to become productive members of our communities. I know you do also. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information. I can be contacted by email at; nomyaudiogram@yahoo.com, or by telephone at (907) 957-1828.

Thanks for your attention to this important matter.

Sincerely,

Daniel E. Knudsen, M.S., CCC-A
Audiologist

I work as an audiologist at the Alaska Native Medical Center. I have lived in Alaska for a long time. I previously worked in the Anchorage School District as an audiologist and as a teacher of preschool deaf children. I also am the mother of an adult deaf woman.

I am writing in support of HB 109, Newborn Hearing Screening and Reporting for Alaska's Children. The State of Alaska, since 1999, has been building the hospital programs to screen hearing for all newborns and insure timely diagnostic evaluation and early intervention. This work has been done by people who passionately believe in the program and through federal grants. The voluntary compliance has been great. However, soon the grants will expire and we need to have legislation that will ensure the continuation of the program. Currently, 38 states have legislation in place mandating newborn hearing screening.

I have worked with persons with hearing impairment for a long time and have seen the positive changes early diagnosis and intervention makes. Before newborn hearing screening, the average age of diagnosis of hearing loss was 2 to 3 years of age. Even with mild/moderate losses of hearing, but especially with severe to profound hearing losses, the impact on speech and language development was devastating. Hearing impaired children maintained lower language levels than their peers and deaf children often left high school with less than 4th grade reading levels. Good research in the last five years has shown that babies who have newborn hearing screening and receive early diagnosis and intervention develop speech and language that is age appropriate by age 5 to 6 years, no matter the level of their hearing loss. Included in this intervention is the improvement in cochlear implants for young children. If diagnosed with profound hearing loss and receiving a cochlear implant before age 2 years, many children are developing age appropriate speech and language skills and are being included successfully in regular education classes.

Early diagnosis is even more important for children who live in remote villages. These children already have more limited access to early intervention. By receiving early diagnosis and intervention, their access to normal speech and language development will be greatly enhanced. This is so important for these children. Without this access to auditory intervention, rural Alaskan deaf children either are sent to Anchorage to live in group homes in order to attend the State School for the Deaf, stay in their villages with no one to communicate with, or their families move to Anchorage and lose their community support system.

On a personal note, my daughter who is deaf is married to a deaf man. They have three children who are hearing. My daughter has worked hard and completed a college degree. However, the opportunities for employment for her are limited due to her communication abilities. She and several of her friends who went to the Alaska State School for the Deaf and completed college degrees are either unemployed or under-employed (e.g. engineering degree working as a teacher assistant). If she was identified today, I would opt for a cochlear implant for her in a heartbeat because I have seen how much they improve a deaf person's access to auditory communication.

The key to an improved quality of life for children with hearing loss is early identification and intervention. We need to ensure that our hospitals are required to screen hearing of newborns and that diagnosis and intervention occurs in a timely manner. Please pass this bill.

Robin M.Gibson
631 W. Gail Drive
Wasilla, AK 99654
March 4, 2006

Representative
State Capitol
120- 4th
Juneau, AK 99801

Dear Representative,

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. Without mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

My daughter was born with mild hearing loss, though we were lucky enough to be diagnosed early, we have still encountered language and speech development issues. We have as a family, learned some sign language that would allow her more opportunity to communicate. I can't imagine what the consequences might have been like if this had not been detected within the imperative time frame.

Mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation. If necessary, the child can be enrolled into early intervention services at the earliest possible time.

I want to ensure that all children have what they need to become productive members of our communities. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information. I can be contacted at Gibson6@mtaonline.net.

Thanks for your attention to this important matter.

Sincerely,

Robin M. Gibson

AARP Alaska

March 3, 2006

The Honorable Fred Dyson, Chair
Senate Health, Education and Social Services Committee
Alaska State Capitol, Room 121
Juneau, AK 99801-1182

RE: HB 109-- (Ramras)--Support

Dear Chair Dyson:

On behalf of the members of AARP in Alaska, we encourage you and your colleagues on the Senate Health, Education and Social Services Committee to support HB 109, authored by Representative Jay Ramras and co-sponsored by your Committee colleague Kim Elton as well as Senators Ellis, Davis, Guess and Kookesh. Twenty House members signed on as co-sponsors, including twelve Republicans and eight Democrats.

AARP is not only a "senior organization." We are also an organization of grandparents concerned about the quality of health of all Alaskans of all ages.

The goal of HB 109 is to have all children born in Alaska screened for hearing problems soon after birth. If screening is not done early, very often hearing losses or problems will not be detected until a child is two or three years of age. The most important period for speech and language development is from birth to three. Most of our newborns are offered this screening. AARP hopes you will enable us to have 100% of them screened at birth. We are pleased to join the March of Dimes in support of this bill.

AARP members often were not fortunate enough to be born when newborn screening was readily available. Many of our members have hearing losses that have been exacerbated by age but they originated at birth. Any efforts to assure that all Alaskans are screened at birth and treatment made available will enhance their lives as long as they live.

AARP urges an "AYE" vote on HB 109.

3601 C Street, Suite 1420 | Anchorage, AK 99503 | toll-free 866-227-7447 | 907-341-2270 fax | toll-free 877-434-7598 TTY
Marie F. Smith, President | William D. Novelli, Chief Executive Officer | www.aarp.org/ak

Should you have any questions about our position, please feel free to contact me (586-3637) or Patrick Luby, AARP Advocacy Director (907-762-3314).

Thank you for your consideration.

Sincerely,

Marie Darlin

Marie Darlin, Coordinator
AARP Capital City Task Force
415 Willoughby Avenue, Apt. 506
Juneau, AK 99801
586-3637 (voice)
46?-3580 (fax)

CC: Vice-Chair Gary Wilken
Senator Lyda Green
Senator Kim Elton
Senator Donny Olson
Representative Jay Ramras

Wood, Thalia

From: Sherris, Cari
Sent: Wednesday, March 01, 2006 11:51 AM
To: Birch, Stephanie; Wood, Thalia; 'Lisa@aktherapedics.com'
Subject: FW. A plea from a constituent- Letter to Senators

From: *"Stephen Popichak" <spopichak@catg.org>*
To:
<Senator_Lyda_Green@legis.state.ak.us>, <Senator_Fred_Dyson@legis.state.ak.us>, <Senator_Kim_Elton@legis.state.ak.us>, <Senator_Donald_O
CC: *"Christina Keenan" <ckeenan@catg.org>, "Carl Sherris" <csherris@msn.com>, "Craig L. Fleener" <cfleener@catg.org>*
Subject: *A plea from a constituent*
Date: *Wed, 1 Mar 2006 11:11:21 -0900*

Honorable Senators-

I am writing to you to implore you to vote to have mandatory hearing screening on all newborns, which is to be addressed in HB 109 on Monday, March 6. My name is Stephen Popichak and I am hearing impaired. I was born with German Measles in 1965, and my hearing loss is a result of that disease. I was not diagnosed as being hearing impaired until I entered kindergarten. I was not fitted for hearing aides until I was 16 years old.

Why is this important? What did it do to my school life and home life? It is very simple, I struggled in almost every aspect of my life. Learning was a struggle for me, as I was unable to hear instructors and had to ask repeatedly to have things shown to me. I could not hear my friends who were trying to help me. It made learning and living very very difficult. Had I been diagnosed earlier and fitted for hearing aides earlier, I believe that my life, both in school and outside, would have been much easier. The need for early detection of possible hearing loss can greatly help children. If parents and teachers are made aware of problems with a child, they can compensate so that learning is individualized making the child feel included, not special or different, thereby providing them with an environment that will help them more efficiently. Having hearing loss detected at birth would increase the chances that a child can get the help they need so they do not lag in school and life.

I cannot stress how important early detection of hearing loss can be. No; you can't make the hearing come back, but you can get hearing aides and teach children. As a child, I felt so different and so alone because I could not understand what was going on around me. When I did get hearing aides, it was at a point where they did nothing but confuse me because I had been used to hearing one way and suddenly I was overwhelmed by the new sounds. Had I gotten them earlier my perception of sound and hearing would have been something that I could have adjusted to easier and it would have made my chances of learning and understanding that much better. Getting the hearing aide at an early age allows for adjusting to new sounds and being accustomed to them.

I hope that you truly consider making the screening of hearing a mandatory requirement from birth onward. Give the children a fighting chance to do the best that they can in school and in life. Every day, hour, minute that is wasted not screening a child, is pushing that child's learning back farther. I treasure the sounds that I hear...give newborns that opportunity as well.

Thank You--

Stephen Popichak

Early Head Start Family Services Manager

Council of Athabascan Tribal Governments

PO Box 33 . Fort Yukon, AK 99740 907.662.3266 spopichak@catg.org

PO Box 367, Fort Yukon, AK 99740-0367 907.662.6440

Alaska Primary Care Association, Inc.
903 West Northern Lights, Suite 200
Anchorage, Alaska 99503
Phone: (907) 929-2722
Fax: (907) 929-2734

Alaska Primary Care Association
Board of Directors

RESOLUTION 2006-01

Title: Support of House Bill 109 Screening Newborns for Hearing Ability

WHEREAS, hearing impairment has been shown to be the most common disability in newborns, affecting about 3 in every 1,000 babies, and 30 to 40 babies are born a year in Alaska with some type of congenital hearing defect; and

WHEREAS, studies have shown that children with hearing impairment not detected at birth, will not be detected until 2-3 years of age, and that the most critical period for speech and language development is from birth to three years of age; and

WHEREAS, Alaska remains in the "unsatisfactory" category when rated nationally because 20% of newborns are not screened for hearing impairment as of December 2003 and because newborn hearing screening is not mandated and the screening, reporting, and follow-up is not institutional in facilities across the state; and

WHEREAS, Community Health Centers are active providers of health care for newborns in Alaska, promoting quality health care for all Alaskans; and

NOW THEREFORE BE IT RESOLVED, that the Alaska Primary Care Association supports the passage of House Bill 109 which is before the Alaska State Legislature, Second Session, and supports legitimate and appropriate efforts necessary to ensure its passage by its staff and members.

SUBMITTED BY: Shelley Hughes, APCA Policy Analyst DATE: January 11, 2006

DONE AND DATED this 18 day of January, in the year 2006.

SIGNED BY Joan L. Fisher
Joan Fisher, APCA Board President

I work as an audiologist at the Alaska Native Medical Center. I have lived in Alaska for a long time. I previously worked in the Anchorage School District as an audiologist and as a teacher of preschool deaf children. I also am the mother of an adult deaf woman.

I am writing in support of HB 109, Newborn Hearing Screening and Reporting for Alaska's Children. The State of Alaska, since 1999, has been building the hospital programs to screen hearing for all newborns and insure timely diagnostic evaluation and early intervention. This work has been done by people who passionately believe in the program and through federal grants. The voluntary compliance has been great. However, soon the grants will expire and we need to have legislation that will ensure the continuation of the program. Currently, 38 states have legislation in place mandating newborn hearing screening.

I have worked with persons with hearing impairment for a long time and have seen the positive changes early diagnosis and intervention makes. Before newborn hearing screening, the average age of diagnosis of hearing loss was 2 to 3 years of age. Even with mild/moderate losses of hearing, but especially with severe to profound hearing losses, the impact on speech and language development was devastating. Hearing impaired children maintained lower language levels than their peers and deaf children often left high school with less than 4th grade reading levels. Good research in the last five years has shown that babies who have newborn hearing screening and receive early diagnosis and intervention develop speech and language that is age appropriate by age 5 to 6 years, no matter the level of their hearing loss. Included in this intervention is the improvement in cochlear implants for young children. If diagnosed with profound hearing loss and receiving a cochlear implant before age 2 years, many children are developing age appropriate speech and language skills and are being included successfully in regular education classes.

Early diagnosis is even more important for children who live in remote villages. These children already have more limited access to early intervention. By receiving early diagnosis and intervention, their access to normal speech and language development will be greatly enhanced. This is so important for these children. Without this access to auditory intervention, rural Alaskan deaf children either are sent to Anchorage to live in group homes in order to attend the State School for the Deaf, stay in their villages with no one to communicate with, or their families move to Anchorage and lose their community support system.

On a personal note, my daughter who is deaf is married to a deaf man. They have three children who are hearing. My daughter has worked hard and completed a college degree. However, the opportunities for employment for her are limited due to her communication abilities. She and several of her friends who went to the Alaska State School for the Deaf and completed college degrees are either unemployed or under-employed (e.g. engineering degree working as a teacher assistant). If she was identified today, I would opt for a cochlear implant for her in a heartbeat because I have seen how much they improve a deaf person's access to auditory communication.

The key to an improved quality of life for children with hearing loss is early identification and intervention. We need to ensure that our hospitals are required to screen hearing of newborns and that diagnosis and intervention occurs in a timely manner. Please pass this bill.

Dr. Jessica Voigt, Au.D.
10178 Nantucket Loop
Anchorage Alaska 99517
January 30, 2006

Senator Gary Wilken
State Capitol
120- 4th
Juneau, AK 99801

Dear Senator Wilken,

Birth defects are the leading cause of infant mortality in the United States. I am writing as one of your constituents concerned about the public health importance of the major birth defect, congenital hearing loss.

January has been designated as Birth Defects Prevention Month. In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down Syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. In the absence of mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

In addition, mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children are given what is needed to become productive members of our communities. I know you do also. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information. I can be contacted at 907-561-1326.

Thanks for your attention to this important matter.

Sincerely,

Jessica T. Voigt, Au.D.
Doctor of Audiology

- When children are not identified and served early, special education costs for a child with hearing loss may cost an additional $420,000 and deafness has an estimated lifetime cost of approximately $1 million per individual (6)

The loss of earnings among deaf and hard of hearing adults compared to the average earnings has been calculated in one study as a 28% reduction in lifetime earning potential (7).

- 38 other states have already passed legislation that mandates newborn hearing screening and reporting systems.

References:

1. Harrison, M., Roush J (1996). "Age of suspicion, identification and intervention for infants and young children with hearing loss: a national study". *Ear and Hearing* 17: 55-62.

2. Alaska Early Hearing Detection and Intervention Program Data.

3. National Center on Hearing Assessment and Management. http://www.infanthearing.org.

4. Yoshinaga-Itano, C. Coulter, D., Thomson, V. (2000). The Colorado newborn hearing screening project: effects on speech and language development for children with hearing loss. *Journal of Perinatology*. 20: S132-7.

5. National Center on Hearing Assessment and Management. http://www.infanthearing.org

6. Johnson, J.L, Mauk G.W., Takekawa, K.M., Simon, P.R., Sia C.C. J., Blackwell, P.M. (1993). Implementing a statewide system of services for infants and toddlers with hearing disabilities. *Seminars in Hearing*. 14: 105-119.

7. Honeycutt, A., Grosse, S., Dunlap, L, et al. (2003). The economic cost of mental retardation, cerebral palsy, hearing loss and vision impairment. *Research in Social Science and Disability* (in press).

BACKGROUND INFORMATION
NEWBORN HEARING SCREENING AND REPORTING

- Currently, some level of hearing screening of newborns is taking place in 100% of the 23 communities where births occur. Nurses prior to the newborn's discharge perform the majority of screenings in hospitals. However, in smaller communities such as Cordova, Petersburg, Valdez, and Wrangell hearing screening takes place in the public health centers where screening equipment has been placed. In addition, equipment has been placed in Homer, Kenai and Mat-Su with either a birth center or the public health center where a high number of birthing center and home births occur.

Currently over 80% of newborns are screened. However the reporting of the results, with the follow up and linkage with diagnostic, treatment and early intervention providers is less than satisfactory. By mandating reporting, this gap will be fixed. (2).

- Mandating newborn hearing screening and reporting would assure equal access to detection, diagnostic, treatment and early intervention services for all of Alaska's newborns regardless of their payer source, socioeconomic status or community of residence.

The cost of screening runs between $25-$45 and is included by most hospitals in the costs of maternity care. This cost is usually included in parent's bill as part of the cost of their total delivery care.

- Newborn hearing screening is coordinated with the newborn metabolic screening program mandated by law, which screens newborns for more than 36 metabolic disorders including PKU and hypothyroidism. Hearing loss however is approximately 30 times more prevalent than either of these disorders (3).

If hearing loss is not detected at birth or soon after, it will not be detected, on average until 2-3 years of age resulting in a loss of this period of development (1).

- Children who are screened for hearing loss at birth are more likely to enter early intervention programs by 6 months of age resulting in language development much closer to the norm (4).

If hearing loss remains undetected, even mild hearing loss or hearing loss in one ear has been shown to have detrimental consequences. Research has demonstrated that children with hearing loss in one ear are 10 times more likely to be held back at least one grade compared to a matched group of children with normal hearing (5)

From: Linda Erb

Date: January 27, 2006

To: Senator Fred Dyson, Chair, H&SS Committee
Senator Gary Wilken, Vice-Chair, H&SS Committee
Senator Lyda Green, H&SS Committee
Senator Kim Elton, H&SS Committee
Senator Donny Olson, H&SS Committee

Cc: Senator Con Bunde

I work as an audiologist at the Alaska Native Medical Center. I have lived in Alaska for a long time. I previously worked in the Anchorage School District as an audiologist and as a teacher of preschool deaf children.

I am writing to in support of HB 109, Newborn Hearing Screening and Reporting for Alaska's Children. The State of Alaska, since 1999, has been building the hospital programs to screen hearing for all newborns and insure timely diagnostic evaluation and early intervention. This work has been done by people who passionately believe in the program and through federal grants. The voluntary compliance has been great. However, soon the grants will expire and we need to have legislation that will ensure the continuation of the program. Currently, 38 states have legislation in place mandating newborn hearing screening.

I have worked with persons with hearing impairment for a long time and have seen the positive changes early diagnosis and intervention makes. Before newborn hearing screening, the average age of diagnosis of hearing loss was 2 to 3 years of age. Even with mild/moderate losses of hearing, but especially with severe to profound hearing losses, the impact on speech and language development was devastating. Hearing impaired children maintained lower language levels than their peers and deaf children often left high school with less than 4th grade reading levels. Good research in the last five years has shown that babies who have newborn hearing screening, receive early diagnosis and intervention develop speech and language that is age appropriate by age 5 to 6 years, no matter the level of their hearing loss. Included in this intervention is the improvement in cochlear implants for young children. If diagnosed with profound hearing loss and receiving a cochlear implant before age 2 years, many children care developing age-appropriate speech and language skills and are being included successfully in regular education classes.

Early diagnosis is even more important for children who live in remote villages. These children already have more limited access to early intervention. By receiving early diagnosis and intervention, their access to normal speech and language development will be greatly enhanced. This is so important for these children. Without this access to auditory intervention, rural Alaskan deaf children either are sent to Anchorage to live in group homes in order to attend the State School for the Deaf, stay in their villages with no one to communicate with, or their families move to Anchorage and lose their community support system.

I am also enclosing a fact sheet which you may have received before.

Newborn hearing screening and intervention is so important for our hearing impaired children. Please add your support to this bill.

Sincerely,

Linda Erb

Linda Erb

To Whom It May Concern:

I am writing this letter in support of HB 109 Screening Newborns for Hearing, with particular reference to rural Alaskans. Rural Alaskans are challenged daily in living in communities, many only accessible by small planes.

I have been with Norton Sound Health Corporation (NSHC), an Indian Health Service hospital in Nome, for eight years as an audiologist and the director of audiology for the past two years. The audiology department flies in small aircraft to provide 1 – 3 clinics a year to each of the fifteen villages under NSHC's care that includes Little Diomede, Wales, Shishmaref, Brevig Mission, Teller, White Mountain, Golovin, Elim, Koyuk, Shaktoolik, Unalakleet, Stebbins and St. Michael. In 1999 I organized and initiated the Universal Infant Hearing Screening program at NSHC using the benefit of our close-knit rural community. This was a collaborative effort among nursing staff, medical staff, hospital administration, health aides, clinic travel clerks (CTC's) and the school district. The nursing department at NSHC provides the newborn screening with automated auditory brainstem response (AABR) equipment while Public Health Nurses, both audiologists and school district speech language pathologist have the capacity to follow up with hearing screening using otoacoustic emissions. It is absolutely vital to follow up each child that did not pass the screening and the state EHDI program's organization in tracking this aspect is critical to maintain the integrity of our screening protocol.

Hearing loss is one of the most common birth defects in the United States today and normal hearing is required for proper speech, language and cognitive development. It is well documented that hearing loss without intervention after the first two years of life can significantly impair this development, permanently. Therefore, hearing screening at birth and intervention within 3-6 months is critical. Moreover, the amount of childhood ear infections in rural Alaska is absolutely staggering. It is the number one diagnosis at this hospital for children in this region and even recognized by the school district such that each Nome elementary classroom has a soundfield amplification system to benefit the roughly 30% students that have ear infections at any given time.

I especially want to ensure that all rural Alaskan children are given what is needed to become productive members of our communities. In an already challenging environment you can remove an unnecessary barrier by supporting the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information. I can be contacted by (email or phone number or both).

Sincerely,

Philip J. Hofstetter, MA CCC-A
Director of Audiology
Norton Sound Health Corporation
PO Box 966
Nome, Alaska 99762
907-443-3297
hofstetter@nshcorp.org

Susan Walker
P.O. Box 770658
Eagle River, Alaska
Ph. 907-696-1995 Email:jsjk@mtaonline.net

February 3, 2005

Representative Jay Ramras
State Capitol
Juneau, Alaska 99801-1182

Subject: Letter in Support of House Bill 109
"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants..."

Dear Representative Jay Ramras:

I am writing to thank you for your sponsorship of HB 109. I am a parent of two children with hearing loss. I serve as a parent representative on the State's Early Hearing Detection and Intervention (EHDI) Programs' advisory group and am on the March of Dimes steering committee to introduce newborn and infant screening legislation.

My son Jack has a bilateral profound loss and my daughter Kate has a unilateral mild/moderate loss. Their hearing loss was not identified until six months of age and four years respectively. Identification of my son's loss at 6 months, appropriate intervention from highly skilled professionals, and technology have all been instrumental in providing him access to sound – a critical element in his language, social, and emotional development. Our family goal for Jack was that he will be oral and just prior to his second birthday he received a cochlear implant. His language and speech skills are on par with hearing children his age. Jack is now 5 years old, a phenomenal reader, and mainstreamed in kindergarten at his local elementary school. He receives support services but does not require an interpreter or full-time assistance. The degree of Kate's hearing loss is minor compared with her brother but a unilateral loss can still affect a child's ability to receive clear information. And it is harder to detect because they are obviously hearing.

HB 109 is one of two bills before the Legislature relating to newborn hearing screening. The other is SB 68. HB 109 contains the elements that are needed to successfully implement a screening, tracking, and intervention program for newborns and infants in the State of Alaska. Hearing loss is invisible – it cannot be seen at birth. For many toddlers, the possibility that there may be a problem only begins to emerge when they should be talking but seem to be delayed. By then, it is very hard to make up lost time. Early detection is the first critical step, but the other elements are extremely important and part of the process that will allow newborns and infants with hearing loss to maximize the critical brain development window (0 to 3 years) for language acquisition.

I have testified for previous versions of this bill at an earlier time and stage in my son's speech and language development when we (the family) were still hoping it was all going to work. Now we have no doubts – he is cruising! I make no attempt to quantify or reduce his progress to a dollar value or to predict what he will be when he moves on into the world of work. But I know

Susan Walker
P.O. Box 770658
Eagle River, Alaska
Ph. 907-696-1995 Email:jsjk@mtaonline.net

one thing for certain - he will not be limited by his hearing loss. At 5 years old he can have telephone conversations with family and friends, communicate with them directly when visiting, advocate for himself in the classroom and in the recreational and cultural activities in which he participates.

How often do you think about the importance of good language and writing skills to your success and effectiveness as a legislator? Communication is key to your job. Early detection and intervention works. Early detection and intervention opens doors that have been closed to many: children with hearing loss deserve that key to open up their world to language and sound.

Sincerely,

Susan Walker

Distribution:

Sponsor and Co-Sponsors
Representative Jay Ramras
Representative Les Gara
Representative Jim Elkins
Representative Peggy Wilson
Representative Max Gruenberg
Representative Lesil McGuire

Labor and Commerce Committee
Representative Pete Kott
Representative Gabrielle LeDoux
Representative Bob Lynn
Representative Norman Rokeberg
Representative Harry Crawford
Representative David Guttenberg

House Leaders
Representative Ethan Berkowitz
Representative John Coghill

AARP Alaska

February 3, 2005

The Honorable Tom Anderson, Chair
House Labor and Commerce Committee
Alaska State Capitol, Room 408
Juneau, AK 99801-1182

RE: HB 109 (Ramras)--Support

Dear Chair Anderson:

On behalf of the members of AARP in Alaska, we encourage you and your colleagues on the House Labor and Commerce Committee to support HB 109, authored by Representative Jay Ramras and co-sponsored by Representatives Gara, Elkins, Wilson, Gruenberg and McGuire.

AARP is not only a "senior organization." We are also an organization of grandparents concerned about the quality of health of all Alaskans of all ages.

The goal of HB 109 is to have all children born in Alaska screened for hearing problems soon after birth. If screening is not done early, very often hearing losses or problems will not be detected until a child is two or three years of age. The most important period for speech and language development is from birth to three. Most of our newborns are offered this screening. AARP hopes you will enable us to have 100% of them screened at birth. We are pleased to join the March of Dimes in support of this bill.

We urge an "AYE" vote on HB 109.

Should you have any questions about our position, please feel free to contact me (586-3637) or Patrick Luby, AARP Advocacy Director (907-762-3314).

3601 C Street, Suite 1420 | Anchorage, AK 99503 | toll-free 866-227-7447 | 907-341-2270 fax | toll-free 877-434-7598 TTY
Marie F. Smith, President | William D. Novelli, Chief Executive Officer | www.aarp.org/ak

Thank you for your consideration.

Sincerely,

Marie Darlin

Marie Darlin, Coordinator
AARP Capital City Task Force
415 Willoughby Avenue, Apt. 506
Juneau, AK 99801
586-3637 (voice)
463-3580 (fax)

CC: Vice-Chair Pete Kott
Representative Gabrielle LeDoux
Representative Bob Lynn
Representative Norman Rokeberg
Representative Harry Crawford
Representative David Guttenberg
Representative Jay Ramras

Mary Weymiller
907-479-4395
907-479-7432 fax

Testimony for House Labor & Commerce Committee
February 4, 2005 1:30 p.m.

HB 109 "An act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening test; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date."

Thank you Representative Anderson and committee members for hearing my testimony today.

National Institute for Health

- **Approximately 3 out of every 1,000 children in the United States are born deaf or hard-of-hearing.**
- **Children begin learning speech and language in the first 6 months of life.**
- **Congenital hearing loss should be identified early enough that intervention could start before 6 months of age.**
- **The earlier deafness and hearing loss is diagnosed, the sooner the child can benefit from strategies that will help them learn to communicate.**

Healthy Alaskans for 2010

- **One of the stated goals to improve the hearing health of Alaskans through prevention, early detection, treatment and rehabilitation, is to increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months and are enrolled in appropriate intervention services by 6 months of age.**
- **Executive Summary states four hospitals in Alaska now perform routine hearing screening of newborns. Forty-six percent of the babies born in Alaska in 2000 were screened. With approximately 10,000 births annually, 30 to 40 infants would be expected to have congenital hearing impairments.**

Quota International of Fairbanks

- **Service organization serving the speech and hearing impaired**
- **Each year grants approximately $4,000 for equipment to assist children with speech and hearing problems in the Fairbanks area alone.**
- **Over 600 school age children receiving therapy in the North Star Borough School District.**

Please pass this bill and make a difference for the 30-40 babies born with hearing deficits in Alaska each year.

Mary Weymiller

Quota International of Fairbanks
P.O. Box 74850
Fairbanks, AK. 99707
www.quotafairbanks.org

Resolution in support of establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants

Whereas thirty to forty babies born annually in Alaska are likely to have some type of congenital hearing loss; and

Whereas approximately 50% of newborns with hearing loss are not identified and will not be identified until 18 mos. to 3 years of age; and

Whereas undetected hearing loss can result in lifelong delays in language, cognitive, socio-emotional and academic development; and

Whereas over the educational lifetime of a child, substantial amounts of money would be saved if, as a result of early identification and intervention, the most appropriate educational setting for the child is a regular mainstream classroom instead of a self-contained classroom or a self-contained program; and

Whereas the prevalence of congenital hearing loss at 3 per 1000 births nation wide is substantially higher than the prevalence of phenylketonuria (PKU), hyperthyroidism, or sickle cell anemia, which are required for screening in every state;

Now therefore be it resolved that Quota International of Fairbanks, a service organization focused on the speech and hearing impaired, wholeheartedly supports HB 109 "an act to establish a screening, tracking, and intervention program related to the hearing ability of newborns and infants....."

Resolution #1 Adopted unanimously by the general membership on February 1, 2005, 6 p.m. Regency Hotel, Fairbanks, Alaska.

Amy Richards

Amy Richards, President
907-452-1751 wk.
907-456-5982 fax

	A	B	C	D	E	F	G	H	I	J	K
1	Name	Address	Profession	Hm Phone	Wk Phone	Fax	Cell	Spons.	Entry	B-Day	E-Mail
2	Alexander, Gay	1020 Kellum Street Fairbanks, AK 99701	GDM, Inc. Chief Fin. Officer	456-5933	452-7213	452-2268			12/7/1988	24-Jun	galexander@polarnet.com
3	Babers, Terri	P.O. Box 85281 Fairbanks, AK 99708	Alzheimers Resource Agency	474-0727	452-2277			Cora K. Leslie C.	5/3/2003	6-Jun	babers@ptialaska.net
4	Bidwell, Melissa	P.O. Box 71659 Fairbanks, AK 99707	MB Mngt. Services, Inc. MM Realty	488-2118	479-0265 ext.6	479-5223	322-9872	Cindy Shilling	12/7/1989	29-Jul	mbmgt@polarnet.net
5	Borgeson, Diana	P.O. Box 74246 Fairbanks, AK 99707	Regen Mackenzie Financial Consultant	452-6238	451-7767 ext. 2	451-6665		Barbara Hamaesch	4/2/2002	18-Aug	dianaborgeson@worldnet.att.net
6	Burton, Marla	PO Box 83323 Fairbanks, Ak 99708	Program Director- North Star Youth Court	479-5385	457-0752	457-0791	322-7869	Buzzy	11/4/2003	30-Aug	marlaburton@hotmail.com
7	Carnahan, Randi	1115 Vail View Dr Fairbanks, AK 99712	Regency Fairbanks Hotel	455-8638	452-3200 x702	452-6595	590-1166	Melissa Bidwell	12/2/2003	2-Apr	
8	Chapman, Richard	2036 Cem St. Fairbanks, AK 99709	ReTrac	456-7285	N/A				4/2/1984	12-Nov	
9	Chiu, Buzzy	P.O. Box 71045 Fairbanks, AK 99707	Fountainhead Dev.Bridgewater Manager	479-8772	452-6651	452-6126			12/7/1993	12-Mar	buzzchiu@worldnet.att.net
10	Colledge, Tammy	450 S. Santa Claus Ln. North Pole, AK 99705	State Farm Insurance Agent-Owner	488-5017	488-7082	488-7140	460-2915		9/6/1997	13-Mar	tammycolledge@aol.com
11	Coler, Mary	794 Quaser Drive Fairbanks, AK 99712	FBKS Day Care Food-Exec. Dir. Frontier Bus.	457-1562	451-7229	451-7228		Rhonda Curtin	3/3/1988	25-Jun	coler@gci.net
12	Gibbonson, Marguerite	3321 Chelsea Dr. Fairbanks, AK 99709	Machine-Manager/Gibbonson & Assoc.-Owner	457-3969	451-4155	451-6360	322-1445		3/3/1992	16-Jun	MGibbonson@alaska.com
13	Gustafson, Leslie	10293 Old Valdez Trail Salcha, AK 99714	White Spruce Enterprises, Inc.-Owner	488-2073	488-3054	488-2551	388-4511	Bert Rasgh	12/7/1998	25-Dec	wildspruce@mosquitonet.com

	A	B	C	D	E	F	G	H	I	J	K
1	Name	Address	Profession	Hm Phone	Wk Phone	Fax	Cell	Spons.	Entry	B-Day	E-Mail
14	Hall, Barrie	10 Trinidad Dr. Fairbanks, AK 99709	Guess & Reed-Paralegal/BKH Paralegal Services-Owner	457-4257	452-8986	452-7015	347-7217	Wendy Harlan	6/5/2001	13-Dec	hall@guessandreed.com
15	Harlan, Wendy	P.O. Box 70622 Fairbanks, AK 99707	Arctic Office Products-Commercial Designer	457-7442	459-0303	459-0304	590-3612	Charal Vansant	11/19/1976	27-Jun	
16	Heskath, Olga	P.O. Box 10099 Fairbanks, AK 99710	K&K Recycling Inc-Accountant	452-7219	488-1409	488-4053			6/7/1994	4-Nov	
17	Hornbeck, Barbara	P.O. Box 81534 Fairbanks, AK 99708	Hornbeck & Evans PC Tax Accountant	479-8218	452-1700	456-5693		Chris McLear	1/2/2001	14-Jul	
18	Hovda, Ann	1560 Tanaka Dr Fairbanks, AK 99709	Tupperware/Freelance Photography	452-8475				Rita Valentine	10/7/2003	19-Feb	Andromeda@hotmail.com or Ancalis@pobox.com
19	Kelley, Cora	P.O. Box 70923 Fairbanks, AK 99707	State of AK DOT	456-7183	474-2548	474-2570	978-4057	Melissa Driscoll	4/6/1987	14-Aug	cora_kelley@dot.state.ak.us or headhog@gci.net
20	Kingkade, Kaye	P.O. Box 55285 North Pole, AK 99705	Mt. McKinley Bank Manager	488-1610	474-1770	474-1771	322-4170	Amy Richards	5/1/2001	21-Jul	Mkingkade@mtmckinleybank.com
21	Long, Victoria	PO Box 58179 Fairbanks, AK 99711	Gold Coast Mortgage/Long Rentals	488-0399	451-7375	451-7381	322-0968	Rita Valentine	10/7/2003	2-May	mvlong@alaska.net
22	Phipps, Becki	P.O. Box 70143 Fairbanks, AK 99707	World Traveler	451-6825		451-6543	347-3478		2/2/1988	28-Mar	bcpa@gci.net
23	Renfrew, Helen	4477 Pikes Landing Rd. Fairbanks, AK 99709	Princess Riverside Lodge-Sales Manager	907-522-0082	455-5022	455-6085	907-441-5468	Rita Valentine	11/3/1998	30-Jul	hrenfrew@princesslodges.com
24	Richards, Amy	2406 Englewood Ct. Fairbanks, AK 99709	Mt. McKinley Bank VP, Operations	479-7218	452-1751	456-5982	378-1858	Becki Phipps	5/1/2001	2-Jan	amrichards@mtmckinleybank.com

Miller, Cyndia 4430 Dartmouth Dr 99709 AK McKinley Assistant Vice President 452-1751 456-5982 Amy Hayes 9-7-04 12-11-57 Cmiller@MTMcKinleyBank.com 474-3734

	A	B	C	D	E	F	G	H	I	J	K
1	Name	Address	Profession	Hm Phone	Wk Phone	Fax	Cell	Spons.	Entry	B-Day	E-Mail
25	Roderick, Sheri	452 Shannon Dr. Fairbanks, AK 99701	Polar Fuel, Owner	456-6772	451-8255	451-9301	590-3990	Patty W. Marquette	2/4/2003	11-Feb	sheri.polarfuel@gci.net sheriroderick@yyl.net
26	Schok, Elizabeth	1107 Nenana St. Fairbanks, AK 99709	FBKS Montessori School Director	474-4077	451-8185	452-4872	322-8188		5/6/1997	13-Feb	schok@arcsalaska.net
27	Shilling, Cincy	P.O. Box 83744 Fairbanks, AK 99708	Schneider & Shilling CPA-Owner	479-8274	474-1831 ext. 2	474-1632			4/2/1935	10-Sep	cincy@arcsalaska.net
28	Shoemaker, Diana	1840 Chena Ridge Rd. Fairbanks, AK 99709	Fountainhead Dev. Sales Coordinator	457-8340	459-6117	451-8376	378-3827	Melissa Bedd	12/4/2001	3-Jan	dshoe@mosquitonet.com
29	Simon, Lisa	2851 Gold Street North Pole, AK 99705	Owner-Composition	490-5935		490-5935	322-7821	Mari Sulay	12/5/2000	26-Oct	lisasimon@mosquitonet.com
30	Swanson, Syd	2655 Richardson Hwy. North Pole, AK 99705	M. Rentals-Owner	488-4123	488-3407	488-9584	388-3322	Jeri Wigdahl	5/3/1994	23-Jun	fcgsas@arcsalaska.net
31	Thoma, Kris	3171 Penguin Lane Fairbanks, AK 99712	Jack Rindloch: State Farm: Marketing/Public Relations	490-2325	452-7881	456-5069	347-7898	Tammy Collecge	12/4/2001	20-Jan	kris.thoma.s96@statefarm.com
32	Valentine, Rita	2671 Perimeter Dr. North Pole, AK 99705	Avis Rent-A-Car-Manager	488-7138	474-0500	474-2913	322-3820		2/2/1988	25-Jun	rita@mosquitonet.com
33	Weaver, Patty	1704 Carr Ave. Fairbanks, AK 99709	General Manager "Pikes On The River"	479-7289	456-5200	456-5214	378-8065		5/3/1994	5-May	pikesbigsam@gci.net
34	Westervelt, Fred	PO Box 73032 Fairbanks, AK 99707	President/Owner - Diamond Fence Co.	452-2570	456-8067	457-2259	322-3244	Becky Phipps	11/4/2003	29-Sep	diamondfence@ptialaska.net
35	Weymiller, Mary	686 11th Ave. #302 Fairbanks, AK 99701	Retired-Nursing	479-4395		479-7432	322-6111	Nancy Herter	5/6/1997	5-Oct	maryw@gci.net

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

February 4, 2005

Alaska Chapter

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Representatives: Tom Anderson, Chair, House Labor and Commerce
Pete Kott, Vice-Chair
Gabrielle LeDoux
Bob Lynn
Norm Rokeberg
Harry Crawford
David Guttenberg

Dear Representative Anderson and Members of the House L&C Committee:

On behalf of the pediatricians of the Alaska Chapter of the American Academy of Pediatrics I am writing to encourage your support of HB 109: Newborn Hearing Screening, Tracking and Intervention. We recommend that all babies be screened for hearing loss before they leave the hospital.

The cost of identifying a newborn with hearing loss is less than 1/10th the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state. For most birthing hospitals, the cost for newborn hearing screening per child is between $20 and $60 and continues to decrease. The evidence for the benefits, practicability and cost-efficiency of universal newborn hearing screening is so compelling that 37 states have passed legislation requiring that newborns be screened for hearing loss. Most importantly, children not detected at birth or soon after, will on average not be detected until 2-3 years of age. The most critical period for speech and language development is from birth to three years of age.

Thank you for supporting HB 109.

Sincerely,

Thomas J. Porter, MD FAAP
President
American Academy of Pediatrics, Alaska Chapter

Alaska State Legislature

Please enter into the record my testimony to the House HESS Committee
Committee name

Committee on HB 109 dated 17 February 2005
Bill/Subject

I would like to write in support of HB 109. The Grange, the organization I belong to, has supported mandatory infant hearing screening since 1999. I have 2 children of my own and know firsthand how important the first years of life are in language development. Early identification and intervention of hearing loss is so very important. I consulted the National Center for Hearing Assessment and Management website, infanthearing.org, and learned that 2-4 babies per 1000 screened at birth had permanent congenital hearing loss. Alaska's babies deserve early identification and care. Please help Alaska join the 32 other states that have enacted legislation for Newborn Hearing Screening.

Signed: Lori Bilak
Testifier

Northland Pioneer Grange No. 1
Representing (Optional)

PO Box 2304 Palmer
Address

746-4900
Phone number

Rep. Ramras - Thanks for sponsoring HB109! Marie

ALASKA PUBLIC HEALTH ASSOCIATION

Committed To Advancing Alaska's Public Health Since 1978

ALPHA

February 17, 2005
(H) HESS HB 109

IN SUPPORT OF HB 109 "SCREENING NEWBORNS FOR HEARING ABILITY"

Dear members of the (H)HESS Committee:

On behalf of the Alaska Public Health Association, representing two hundred and twenty public health professionals who are deeply committed to developing sound public health policy to improve the health of all Alaskans, we encourage you to vote yes on HB 109 and move it out of Committee today.

Recognizing the importance of universal hearing screening of newborns as a critical public health intervention, the Alaska Public Health Association encourages you to support HB 109. Hearing impairment is the most common disability in newborns, impacting 2-3 children out of every thousand. Identified early, these children will not be left behind during the most critical period for speech and language development: birth to 3 years.

Late identification of infant hearing loss presents a significant public health problem. Without screening, children with hearing loss are usually not identified until two years of age or later, which results in significant delays in speech, language, social, cognitive, and emotional development – and a greater cost for services.

Research has shown that children identified at birth with mild-to-severe hearing loss who receive intervention before they are 6 months of age fall within a normal range of language comprehension and expression as well as social development by the time they are ready to begin school. By contrast, children with hearing loss diagnosed after six months of age experience significant delays in both language and social development. The cost savings of early intervention is significant.

HB 109 offers an important first step in providing newborn hearing loss screening. Yet we urge you to not stop at the hospital or birth center, as what happens after screening is also important. Families need to receive appropriate information and services following newborn hearing screening and to have their children begin receiving intervention services by six months of age. It is also critical the team working with the child measure the impact of early identification of hearing loss on development, tracking gains made and areas to develop. The public health surveillance system must be in place for the Early Hearing Detection Program to be effective.

To quote from Dr. Marion Downs, the world-renowned pioneer in pediatric audiology, "If a child can be identified at birth and receive immediate intervention, we have done our jobs," she said. "On the other hand, if we don't detect the hearing loss until the child reaches [illegible] years of age or later, that child has, in most cases, lost the opportunity to catch up with others his or her own age. *Why, with all the tools we have, would we not speed the time to establish a model for screening and early intervention in our nation's hospitals?*" That is the challenge before us in Alaska.

HB 109 takes an important step in bringing forth universal hearing, building on the success of Alaska's hospitals and birthing centers who are already voluntarily screening, to assure all newborns will be screened. With appropriate screening and follow up services, HB 109 will assure our children who are deaf or hearing impaired receive the early intervention services they need to develop their fullest potential. Thank you.

Marie J. Lavigne, Executive Director Alaska Public Health Association

P.O. Box 91825 Anchorage, AK 99509 907/332-1030 e-mail: publichealth@alaska.net www.alaskapublichealth.org

Josh Applebee

From: Phyllis Kiehl [pkiehl@pol.net]
Sent: Friday, February 04, 2005 8:45 AM
To: Rep. Tom Anderson
Subject: HB 109, Hearing screening

Dear Rep. Anderson,

I am writing to ask you to support and vote for House Bill 109 ("related to screening Newborns for Hearing Ability. I am a pediatrician who has been in private practice in Anchorage for 30 years. The American Academy of Pediatrics supports the development of programs for universal screening of all infants for hearing deficits at or soon after birth. This enables early identification of hearing impaired children in order to be able to intervene to maximize their potential. This program is important because:

1. Hearing loss if one of the most common birth defects. One in 3000 infants are born in Alaska with permanent congenital hearing loss. Without universal newborn hearing programs, the average age of detection of even severe hearing loss is 2-3 years old 2. Hearing loss has a significant negative effect on children. This would seem obvious, but many studies indicate the negative impact of hearing loss on a child's emotional and social development as well as language delays (that do not seem to progress even after diagnosis in some children, when that diagnosis is delayed).
Even mild hearing loss or even when only one side is affected may have long lasting negative effects to the child. It affects interactions in the family, too.
3. Early detection and intervention of hearing deficits significantly helps children. Numerous studies show that when children are diagnosed with hearing loss and appropriate intervention to augment hearing and provide appropriate communication options are started early in life, preferably before 6 months of age, significant and long lasting benefits are achieved by the children in language skills, emotional development, social and familial adjustment.

. Due to new advancements in screening technology ,non-audiologists can administer the screen (and bill appropriately for this service). By asking insurance companies to cover this "standard of care" evaluation, all infants in the state can have this evaluation before they leave the hospital or birthing facility.

Universal hearing screen for all newborns is essential for Alaskan children.
Please support HB 109.

Thank you.
Sincerely,
Phyllis Kiehl, M.D.

--
Phyllis' numbers:
Home: 907/345-3394
Office: 907/562-2120
Beeper: 907/275-2030

AARP Alaska

February 15, 2005

The Honorable Peggy Wilson, Chair
House Health, Education and Social Services Committee
Alaska State Capitol, Room 108
Juneau, AK 99801-1182

RE: HB 109 (Ramras)--Support

Dear Chair Wilson.

On behalf of the members of AARP in Alaska, we encourage you and your colleagues on the House Health, Education and Social Services Committee to support HB 109, authored by Representative Jay Ramras and co-sponsored by Representatives Gara, Elkins, Gruenberg, McGuire, Anderson, LeDoux, Guttenberg, Lynn, Joule and you.

AARP is not only a "senior organization." We are also an organization of grandparents concerned about the quality of health of all Alaskans of all ages.

The goal of HB 109 is to have all children born in Alaska screened for hearing problems soon after birth. If screening is not done early, very often hearing losses or problems will not be detected until a child is two or three years of age. The most important period for speech and language development is from birth to three. Most of our newborns are offered this screening. AARP hopes you will enable us to have 100% of them screened at birth. We are pleased to join the March of Dimes in support of this bill.

We urge an "AYE" vote on HB 109.

Should you have any questions about our position, please feel free to contact me (586-3637) or Patrick Luby, AARP Advocacy Director (907-762-3314).

Thank you for your consideration.

Sincerely,

Marie Darlin

Marie Darlin, Coordinator
AARP Capital City Task Force
415 Willoughby Avenue, Apt. 506
Juneau, AK 99801
586-3637 (voice)
463-3580 (fax)

CC: Vice-Chair Paul Seaton
Representative Vic Kohring
Representative Tom Anderson
Representative Lesil McGuire
Representative Berta Gardner
Representative Sharon Cissna
Representative Jay Ramras

2330 Nichols Street
Anchorage, Alaska 99508-3495
(907) 279-6617

Assets, Inc.

Diana Stroz
Executive Director

FEB 09 2005

FAX COVER SHEET

Page 1 of 2 pages Date 2/9/05

To Legislators Fax Number ( )

Company ____ Telephone ( )

From Josie Paguero Fax number (907) 274-0636

Company Assets, Inc. Telephone (907) 279-6617

Regarding Key Campaign - "Platform"

Comments Wednesday - March 2, 2005

Key Platform 2005

1. Appropriate $6.2 million for wait list reduction
2. Appropriate $351,576 to bring the 72 infants off the iLP wait list
3. Implement reforms to the DSD$ system to assure timely reimbursements to providers so beneficiaries remain healthy and safe.
4. Support HB105 and SB79 to add Adult Dental coverage under Medicaid
5. Support HB109 to provide early hearing screening for newborns

We of course having talking points on all of these, but will deliver them in person to the legislators.

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

February 4, 2005

Alaska Chapter

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Representatives: Tom Anderson, Chair, House Labor and Commerce
Pete Kott, Vice-Chair
Gabrielle LeDoux
Bob Lynn
Norm Rokeberg
Harry Crawford
David Guttenberg

Dear Representative Anderson and Members of the House L&C Committee:

On behalf of the pediatricians of the Alaska Chapter of the American Academy of Pediatrics I am writing to encourage your support of HB 109: Newborn Hearing Screening, Tracking and Intervention. We recommend that all babies be screened for hearing loss before they leave the hospital.

The cost of identifying a newborn with hearing loss is less than 1/10th the cost of identifying newborns with metabolic disorders such as PKU and hypothyroidism, for which screenings are required in every state. For most birthing hospitals, the cost for newborn hearing screening per child is between $20 and $60 and continues to decrease. The evidence for the benefits, practicability and cost-efficiency of universal newborn hearing screening is so compelling that 37 states have passed legislation requiring that newborns be screened for hearing loss. Most importantly, children not detected at birth or soon after, will on average not be detected until 2-3 years of age. The most critical period for speech and language development is from birth to three years of age.

Thank you for supporting HB 109.

Sincerely,

Thomas J. Porter, MD FAAP
President
American Academy of Pediatrics, Alaska Chapter

Alaska Center for Pediatrics
1200 Airport Heights Drive, Ste 140
Anchorage, AK 99508
Phone: 907.777.1800, Fax: 907.278.2066

Representative Jay Ramras
10th House District

Fax: (907) 465-2070

Re: House Bill 109

February 1, 2005

Dear Representative Ramras:

I am writing in support of House Bill 109 ("related to screening Newborns for Hearing Ability"), which you have agreed to sponsor. I am a pediatrician in private practice in Anchorage with 26 years of experience. I also serve as the Alaska Chapter Champion for the Early Hearing Detection and Intervention Program for the American Academy of Pediatrics. The American Academy of Pediatrics supports the development of programs in each state for universal screening of all infants for hearing deficits at or soon after birth in order to allow for early identification and intervention of hearing impaired children in order to maximize their potential. There are several reasons that this program is important:

1. Hearing loss if one of the most common birth defects. One in 3000 infants are born in Alaska with permanent congenital hearing loss. Without universal newborn hearing programs, the average age of detection of even severe hearing loss is 2-3 years old
2. Hearing loss has a significant negative effect on children. This would seem obvious but many studies indicate the negative impact of hearing loss on a child's emotional and social development as well as language delays that do not seem to progress even after diagnosis, in some children, when that diagnosis is delayed. Even mild and unilateral hearing loss – problems that often defy detection much longer without an objective early hearing screen- may have long lasting negative effects to the child.
3. Early detection and intervention of hearing deficits significantly helps children. Numerous studies show that when children are diagnosed with hearing loss and appropriate intervention to augment hearing and provide appropriate communication options are started early in life, preferably before 6 months of age, significant and long lasting benefits are achieved by the children in language skills, emotional development, social and familial adjustment.

In order to achieve these benefits for children and their families, there are several steps that must occur that are benchmarks for a successful early hearing detection and intervention program and each of these can be greatly aided by HB 109 as written:

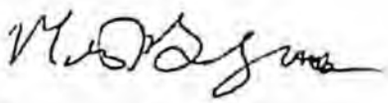
1. Universal hearing screen for all newborns – This first step is already nearly achieved in Alaska. Due to new advancement in screening technology almost all birthing hospitals either are or soon will be screening newborns for hearing loss. By allowing non-audiologists to administer the screen and bill appropriately for this service, and asking insurance companies to cover this "standard of care" evaluation, all infants in the state can have this evaluation before they leave the hospital or birthing facility.
2. When a hearing screen is failed, they are referred for evaluation – This step may have one or two parts. A child who fails the initial screen is referred for re-screen and if still abnormal, diagnostic intervention is performed by 3 month of age. Each institution and/or the infant's medical provider are responsible for this step. The failure to return for re-screening or for diagnostic testing markedly reduces the effectiveness of the entire program. With the tracking provision of your bill,

information will be shared with a state program that can make sure that each infant that needs further intervention have this option provided for them. Without a state mandate, this information will have to be shared voluntarily between institutions, which will allow for some institutions to ignore this critical step. Diagnostic intervention involves testing called auditory brainstem response testing (ABR) which is only done by audiologists trained in this procedure.

3. Once diagnosed, in order to receive maximum benefit, parents should be presented with communication options and intervention should begin before 6 months of age. These options may include hearing aids (which are accepted by infants much better if started in early infancy), and various communication options including sign language and other visual cues. The parents and the infant's medical provider must serve as a medical home and have information to make appropriate referrals for subspecialty evaluation and community based resources in accordance with the Individuals with Disabilities Education Act.

Thank you for sponsoring HB 109 which will assure that our youngest Alaskans have the opportunity to have this most common, but invisible, birth defect diagnosed early with appropriate intervention that will offer long term benefits for their future. If I can be of any assistance, please let me know.

Sincerely,



Martin F. Beals, Jr., M. D., FAAP
Alaska AAP Chapter Champion, EHDI program

Suzanne Rust
7930 Ingram Street
Anchorage, Alaska 99502
907-243-3160

February 1, 2005

Representative Tom Anderson
Special Assistant Health and Human Services
State Capitol
Juneau, Alaska 99801-1182

Dear Representative Anderson:

I want to take this opportunity to tell you about Lauren, my 12-month-old daughter. Besides being a marvelous girl, she happens to be hard of hearing. Providence Hospital's New-Born Screening identified Lauren's condition at birth. Although it took us 13 weeks of hard work to verify that she has a hearing loss, the screening was essential. Since she is hard of hearing, we may not have detected her loss until her language was affected. We would have lost the opportunity for laying a solid foundation of speech and language development.

I am contacting you today because I would like you to support House Bill 109 which requires universal hearing screening for new-born infants and mandatory reporting by birthing facilities of the hearing screening results to the State of Alaska's Early Hearing Detection and Intervention Program. This will ensure that children with possible hearing loss receive a timely diagnostic evaluation and, if necessary, are enrolled in early intervention services at the earliest possible time. The reasons I believe this bill should be whole-heartedly supported are many but I will list a few:

- Hearing impairment is the most common disability in newborns.
- The low cost of screening is minimal when compared to the additional hundreds of thousands of dollars the state may have to spend in special education.
- The most important period of speech and language development is from birth to age three. The average age of identification in the absence of the newborn hearing screening is 2-3 years.
- Children with hearing loss can develop and progress like those without hearing loss if they are identified early.

Because Lauren was identified in the screening process, she has had hearing aids since she was three months old. Her language and speech seem to be on track and, thankfully, she has been able to hear my voice. Please join me in assuring that everyone's child gets the same chance for success Lauren received. Thank you in advance for your support.

Sincerely,

Suzanne Rust

Douglas Owen

From: Lisa Owens [lowens@tetongravity.com]

Sent: Thursday, January 27, 2005 11:23 PM

To: Rep. Jay Ramras

Dear Rep. Ramras,

I want to thank you and give my support for HB 109. As an audiologist and speech pathologist working with children with hearing loss I feel that it is critical that children with hearing loss are found early. Research and personal experience show that children who are identified with a hearing loss early and receive appropriate intervention, do better academically. They are provided more choices in communication options and develop better speech and language skills. Please let me know if there is anything I can do to help support the passage of this bill.

Sincerely,

Lisa Owens, M.A., CCC-SLP/A

Quota International of Fairbanks
P.O. Box 74850
Fairbanks, AK. 99707
www.quotafairbanks.org

Resolution in support of establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants

Whereas thirty to forty babies born annually in Alaska are likely to have some type of congenital hearing loss; and

Whereas approximately 50% of newborns with hearing loss are not identified and will not be identified until 18 mos. to 3 years of age; and

Whereas undetected hearing loss can result in lifelong delays in language, cognitive, socio-emotional and academic development; and

Whereas over the educational lifetime of a child, substantial amounts of money would be saved if, as a result of early identification and intervention, the most appropriate educational setting for the child is a regular mainstream classroom instead of a self-contained classroom or a self-contained program; and

Whereas the prevalence of congenital hearing loss at 3 per 1000 births nation wide is substantially higher than the prevalence of phenylketonuria (PKU), hyperthyroidism, or sickle cell anemia, which are required for screening in every state;

Now therefore be it resolved that Quota International of Fairbanks, a service organization focused on the speech and hearing impaired, wholeheartedly supports HB 109 "an act to establish a screening, tracking, and intervention program related to the hearing ability of newborns and infants....."

Resolution #1 Adopted unanimously by the general membership on February 1, 2005, 6 p.m. Regency Hotel, Fairbanks, Alaska.

Amy Richards

Amy Richards, President
907-452-1751 wk.
907-456-5982 fax

Post-it® Fax Note 7671 | Date 2/2/05 | # of pages ▶ 4
To INT. DELEGATION | From MARY
Co. | Co. FBX LEG
Phone # | Phone #
Fax # | Fax #
FROM MARY WEYMILLER

Representative Jay Ramras
Co-Chair, House Resources
V-Chair, Economic Develop.
Tourism & Trade
House State Affairs
119 N. Cushman St., Suite 207
Fairbanks, Alaska 99701
Phone: (907) 452-1088
Fax: (907) 452-1146

Alaska State Legislature

House of Representatives

While in session
State Capitol, Room 104
Juneau, Alaska 99801-1182
(907) 465-3004
Fax: (907) 465-2070
Toll Free: 877-465-3004

House District 10

February 10, 2006

Senator Fred Dyson
State Capitol, Room 121
Juneau, Alaska 99801-1182

Re: House Bill 109 – Newborn Hearing Screening

Dear Senator Dyson:

This letter is being written in response to your memorandum concerning House Bill 109, *"An Act relating to establishing a screening, tracking, and intervention program related to the hearing ability of newborns and infants; providing an exemption to licensure as an audiologist for certain persons performing hearing screening; relating to insurance coverage for newborn and infant hearing screening; and providing for an effective date."*

The Early Hearing Detection and Intervention program (EHDI) is not a welfare program. The Early Hearing Detection and Intervention Program is designed to include all newborns in Alaska, regardless of their socioeconomic or insurance status. Birthing facilities in Alaska already include the costs of newborn hearing screening in their total labor and delivery package. As far as non-traditional births, Section 4 of this bill requires the state Bureau of Vital Statistics to forward the names and address of Alaskans that choose nontraditional birthing options to the Department of Health and Social Services, so that they may notify the parents of the merits of hearing screening.

The authorship of this bill included several families both Native and non-Native and represents the system of care and tracking that these families expressed would be the most helpful in identifying newborns with hearing loss and assisting their families in linking them with available services they may need. The grant component of this bill's fiscal note only includes dollars for increasing specialized hearing services for children ages 0-3, in the already established early intervention program. At the present time, one full time employee, who now serves all 19 statewide Early Intervention/Infant Learning grantees, and the specialized hearing resources program, is running at capacity. Due to this fact, the effect of this bill on families in the Indian

Health Services system should be minimal, unless their newborn has an unsatisfactory initial hearing screening, then they too would serve to benefit from the program.

With regards to medical protocols, a subcommittee of the EDHI advisory committee comprised of private and Indian Health Services medical specialists, pediatricians, parents, audiologists and speech language therapists developed the medical care protocols in 2002 based on best practices and national standards of care. They continue to meet quarterly to review and update protocols and conduct quality assurance integrity of the medical components of care, to improve the system. The committee of individuals comes together voluntarily three to four times a year, donating a full day out of their schedules to perform this work.

The staff in the EDHI program has been very successful in engaging all 23 communities where births take place in participating in the first step of the program, the screening of newborns prior to their discharge from the hospital. Specifically, in those communities where only a very small number of births occur in the hospital, such as Cordova, Petersburg, Valdez, Wrangell, and Sitka. Hearing screening equipment has been purchased using federal funds and placed in the public health centers where nurses provide free hearing screenings for newborns. In addition, equipment has been placed in a birth center in Kenai, the Homer public health center and in the Mat-Su public health center where a high number of birthing center and home births occur. Hospitals in Anchorage, Fairbanks and Palmer also offer free hearing screening services to families who deliver children outside of hospitals. Additionally, to assure that the direct entry midwives are engaged in the success of developing this comprehensive approach, the president of the direct entry midwife association is an active member of the EHDI advisory committee and has been key in assisting with the program.

Regarding your question about where the insurance companies stand, there was testimony from Jack McGray, Senior Vice President, Premera Blue Cross on this bill in the House HESS Committee (a copy of his testimony is attached). Mr. McGray did offer an amendment to the bill that deleted the exception for fraternal benefit societies, making sure that no sources of payment should be excluded from the requirement. Mr. McGray did say, "we're supporting HB 109 ... we cover this hearing test now ... in a pediatric setting or in a hospital or birthing center ... what our amendment will do is change the bill to reflect the standard practices in the health plan design ... it will only modify the bill so that it will come into sync with standard practices in health plan designs that we have in Alaska, now."

Finally, regarding the question of treatment for newborns and young children diagnosed as deaf or hard of hearing. The approach to treatment and services is very much directed by the parents once they are provided with the information they might need. Most parents chose to seek treatment regimes that will assist their children as hearing or partially hearing. Hearing aides, auditory assistive systems, cochlear implants are just some of the choices that a child can be evaluated for by a medical provider in collaboration with an audiologist. Some parents may choose to raise their child as a member of the deaf community. With either choice a family will need to receive speech and language services to learn a method of communication, be it sign language, SEE sign, finger spelling, lip reading, or a combination of techniques. It should be understood that, most children who are hard of hearing rely on a combination of auditory support such as hearing aides and sign language.

The goal is to support a child's language acquisition, early in life, while the brain is still developing its connections. If left undetected, hearing loss can impair a child's language, speech, psychosocial, and cognitive development. Recent research has compared children with hearing loss that receive early intervention and amplification before six months of age versus after six-months of age. By the time they enter first grade, children identified prior to six-months of age are one to two years ahead of the later identified peers, in language, cognitive and social skills. (Attached is a list of references regarding some of the research done in this area as well as a fact sheet).

In closing, HB 109 provides not only the support of the continuation of the newborn hearing screening of all Alaskan newborns, but also provides support to continue the work of building the system of care through early identification and diagnosis of the most commonly occurring congenital defect. In addition, the bill provides for the capacity to establish and sustain linkages with treatment and early intervention services, ongoing screening for newborns and children at high-risk for late onset hearing loss evaluation of the outcome of care over time. Statistics are being compiled with the initiation of the EHDI program's data system to assist in the evaluation of this comprehensive effort.

Hopefully, this letter addresses your concerns. Should you have any additional questions concerning HB 109, please do not hesitate to contact my office.

Sincerely,

Representative Jay Ramras
District 10 – Fairbanks

JR/jwp
Enclosures as stated

CHAIR WILSON asked how many children a year are born with hearing loss.

DR. BEALS stated that the incidents of hearing loss diagnosable at birth is about 3 in 1,000 live births and there are about 10,000 live births in Alaska per year. He estimated that there are about 30 children a year born [in Alaska] who would be diagnosed using this technology.

3:47:58 PM

JACK MCGRAY, Senior Vice President, Premera Blue Cross, began discussion of Amendment 1 [submitted by Premera Blue Cross, labeled as 2/16/05, 4:07 p.m.] which read [original punctuation provided]:

CSHB 109(L&C) Version "F" page 3, lines 9-24:

Sec. 5. AS 21.42 is amended by adding a new section to read:
Sec.21.42.349. Coverage for newborn and infant hearing screening. (a)If a health care insurer offers, issues for delivery, delivers, or renews in this state a health care insurance plan that covers services provided to women during pregnancy and childbirth and the dependents of a covered individual, including routine newborn care, the health care insurer must comply with the requirements of this subsection.

(1)The health care insurer may not deny coverage for a newborn or infant screening to be performed within 30 days after the child's birth; and

(2)If the initial screening under (1) of this section determines that the child may have a hearing impairment, the plan may not deny coverage for a confirmatory hearing diagnosis evaluation.

(b)The coverage required by this section may be subject to standard policy provisions, such as deductible or copayment provisions.

Rationale: (a): Deletes exception for fraternal benefit societies. Because the intent of the bill is to assure that 100% of newborns are screened, no sources of payment should be excluded from the requirements. (a)(1) through (b): Under current practice, any costs for the initial screening are typically included in the hospital or other facility's charge for newborn care or in the physician or other practitioner's charge for routine follow-up care. Diagnostic tests, including hearing examinations, are covered under existing medical benefits. The amendment changes the bill language to reflect standard practice and health plan design.

MR. MCGRAY said:

> we're supporting HB 109 ... we cover this hearing test now ... in a pediatric setting or in a hospital or birthing center ... what our amendment will do is it will change the bill to reflect the standard practices in the health plan design ... it will only modify the

> bill so it will come into sync with standard practices in health plan designs that we have up in Alaska, now.

CHAIR WILSON inquired as to the specific changes included in Amendment 1.

MR. MCGRAY explained that the amendment is technical and it will allow [Premera Blue Cross] to utilize existing contracts. Without the amendment, he said, administration costs would rise due to the creation of new contracts.

REPRESENTATIVE SEATON inquired as to the HB 109 requirements for testing being covered under existing procedures.

MR. MCGRAY stated that they are covered now under "hearing screening."

CHAIR WILSON inquired as to the purpose of Amendment 1 if there is coverage [for screening] now.

MR. MCGRAY said that this is a technical issue that deals with how the contract is written in relation to how the legislation is written.

3:50:21 PM

REPRESENTATIVE GARDNER clarified that the Alaska State Legislature makes the law and insurance company contracts comply with the law.

MR. MCGRAY stated that one of the goals [of Premera Blue Cross] is to keep administrative costs low; this amendment will not modify the intent of HB 109.

REPRESENTATIVE ANDERSON stated:

> if you look at Version F of the bill ... page 3 ... lines 22 through 24 ... section 5, subsection 6 ... it states, "The coverage required by this section may be subject to standard policy provisions that are applicable to other benefits, such as deductible or co-payment provisions." Your amendment, as proposed ... states ... "the coverage required by this subsection may be subject to standard policy provisions, such as deductible or co-payment provisions." ... you have deleted, "that are applicable to other benefits" and that was bought up in the Labor & Commerce Committee, can you explain ... why that was deleted.

MR. MCGRAY stated that the intent [of Amendment 1]:

> if the language went through as is presently listed in the bill, we'd modify our contracts and have a stand-alone benefit for this, for the hearing screen. Now what we do is we include that in the benefit package that the hospitals and physicians used when they're screening for hearing. So, ... the amendment changes won't reflect anything different than our standard practices ... instead of having a stand-alone benefit

> that states "hearing specific," it's part of the package that's used that the doctors and hospitals use in screening and we pay for it that way.

3:54:13 PM

CHAIR WILSON stated that she needs to be convinced as to why the language, "that are applicable to other benefits" should be deleted from HB 109.

MR. MCGRAY stated that [Premera Blue Cross] consulted with its legal department and concluded that if the language in HB 109 remains as it is now, all contracts in Alaska will require revision. He explained that the submitted amendment does not change [Premera Blue Cross] practices in Alaska or the intent of HB 109.

CHAIR WILSON offered comments concerning the language used within the submitted amendment:

> at the end of that first paragraph [of Amendment 1] where it says "care insurer must comply with the requirements of this subsection," I would suggest that we change that to say "care insurer shall comply [with the requirements of this subsection]." ... under number 1 ... leave out "The health insurer may not deny" and ... [insert] "Coverage for a newborn or infant screening to be performed within 30 days of the child's birth" ... number 2 ... in the middle line, "the plan may not deny" ... [insert] "the plan shall provide coverage for confirmatory hearing diagnostic evaluation."

MR. MCGRAY said that he has no problem with Representative Wilson's comments and corrections to Amendment 1.

3:57:30 PM

REPRESENTATIVE CISSNA inquired as to the availability of an attorney to assist with the questions brought up by Representative Anderson.

CHAIR WILSON stated that "Bill Drafting" has been contacted and the person who drew up HB 109 will be able to provide guidance.

CHAIR WILSON asked if someone would move the amendment before the committee [in an attempt to make Representative Wilson's aforementioned corrections].

REPRESENTATIVE MCGUIRE stated her concerns about the moving the amendment and questioned phrasing within HB 109.

4:02:34 PM

REPRESENTATIVE SEATON offered Amendment 1 [labeled 2/16/05, 4:07 p.m.] to be brought before the committee.

REPRESENTATIVE ANDERSON objected for the purpose of discussion.

REPRESENTATIVE SEATON offered a Conceptual Amendment to amend

Amendment 1, as follows:

In Subsection (1), remove "the health care insurer may not deny"
Insert "Provide"
In Subsection (2), remove "may not deny"
Insert "shall provide"
In first paragraph, remove "must"
Insert "shall"

4:04:03 PM

CHAIR WILSON stated that hearing no objection, those changes have been made to read, "the health care insurer shall comply with the requirements of this subsection ... they shall provide coverage for a newborn infant and they shall provide coverage for confirmatory hearing diagnostic evaluation."

4:05:17 PM

REPRESENTATIVE SEATON offered Amendment 2, to amend Amendment 1, as follows:

Remove Subsection (b)
Adopt the rest of the Amendment 1.

REPRESENTATIVE MCGUIRE objected for the purpose of discussion.

4:06:35 PM

JEAN MISCHEL, attorney, Legislative Legal and Research Services, Legislative Affairs Agency, stated that there is a structural problem with Amendment 1.

CHAIR WILSON explained the specific changes the House Health, Education and Social Services Standing Committee have made to Amendment 1.

4:08:39 PM

REPRESENTATIVE ANDERSON, for the benefit of Jean Mischel, clarified the changes within HB 109 [and Amendment 1] that the committee had been discussing.

4:10:29 PM

JEAN MISCHEL stated that Amendment 1 could significantly change HB 109. She explained that what the current language change does, in Subsection C, Section 5, of HB 109, is limit it t standard policy provisions that are applicable to other benefits. If the standard policy provision were changed, with respect to infant hearing and screening assessments, other benefits would also have to be changed. She stated that what is being proposed in Amendment 1 is a much broader limitation.

CHAIR WILSON asked Jean Mischel to review Amendment 1 and inform Representative Ramras of the effects of the changes. She stated that the House Health, Education and Social Services Standing Committee will pass HB 109 to the next committee. In the meantime, she said, legal counsel will provide information

concerning language changes.

REPRESENTATIVE SEATON withdrew his aforementioned amendments.

4:13:06 PM

REPRESENTATIVE ANDERSON moved to report CSHB 109(L&C), Version F, with individual recommendations, attached fiscal note and with supplemental legal comments. There being no objection, CSHB 109(L&C) was reported from the House Health, Education and Social Services Standing Committee.

Bill Root: Display Bill Root

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Alaska Center for Pediatrics
1200 Airport Heights Drive, Ste 140
Anchorage, AK 99508
Phone: 907.777.1800, Fax: 907.278.2066

Senator Lyda Green
Senate District G

Fax (907) 465-3305

Re: House Bill 109

April 28, 2005

Dear Senator Green:

I am a pediatrician in Anchorage,) is serving as Chapter Champion for the Early Detection of Hearing Impairment and Intervention (' iDi) Program for the Alaska Chapter of the American Academy of Pediatrics. The principles of the El IDI Program have been endorsed by the American Academy of Pediatrics, the Center for Disease Control, the National Institute of Health and numerous other organizations. The basic goals of the program are (1) Screening of all newborns for hearing impairment by 1 month of age (preferably before hospital discharge), (2) Identification of all children born with hearing impairment (using diagnostic testing by audiologists) by 3 months of age, and (3) Intervention for children diagnosed with hearing loss with appropriate communication options and technologies by 6 months of age. The essential goal of the program is to allow children with hearing impairment to develop language skills equivalent to hearing children. There is plentiful evidence that deaf children who are diagnosed and receive appropriate help early in life can develop language skills along normal lines, even before school entry.

In order to further the development of the EHDI program in Alaska, I am endorsing and asking for your support of House Bill 109, sponsored by Rep. Jay Ramras. This bill seems to contain elements that will help Alaska achieve the goals of this program for Alaska's children

Hearing loss is the most common birth defect. The ability to minimize the negative effects of deafness on children is why the Alaskan March of Dimes is supporting this bill. Before the technology that permits the screening of newborns, pediatricians tried to pick up children with hearing problems as early as we could, but it was often not until 2-3 year of age, and often later with milder hearing impairments. Several Alaskan hospitals have been doing routine newborn hearing screening for over 6 years and incorporated the charges into their routine newborn charges. Due to the efforts of o state EHDI coordinator, working through the division of Maternal/Child Health, and using fede grant money, the equipment that is used to test newborn hearing is now available in all the state's birthing hospitals. Despite this availability, without requiring hospitals to routinely offer this service and report their results, we are sure that many of our state's parents do not receive the opportunity to have this (hopefully) reassuring test of their child's hearing. It is estimated that Alaska is 48 out of 50 states in newborn hearing screening.

I was concerned to hear from Rep. Ramras, that you were hesitant to support this bill. I understand you have some concern about the insurance ramifications. While I certainly can't speak for the insurance company, they have not opposed this bill. As I said, the test has been done in the largest birthing hospitals in Alaska for many years and will continue to be. Nationwide, over 90% of all newborns undergo this screening and in over half of the states all the hospitals are screening 99% of newborns. In other words, this is not a new burden to the insurance industry and I can't imagine that a relatively inexpensive screening test that is almost universally accepted as "standard of care" for all newborns would have almost no impact on any insurance plan. It would only affect plans that already cover maternity benefits.

The economic impact of the program is another issue that I'm sure a legislator must consider. I have nothing to do with the fiscal note and I'm sure if a child's deafness is diagnosed earlier, then

services to that child will be started earlier. I have already stated the positive benefits of this early diagnosis. I believe there are significant cost savings for children who are diagnosed earlier. As an educator, I'm sure you realize that a child who starts school with significant language delays require many more special services than children with normal language skills. Special Education students cost about twice what "normal students" cost the school system. But the cost savings go beyond that. One study indicated that, comparing lifetime costs for deaf children with normal language skills and with delayed language skills, children with delayed language skills will cost $50,000 more in Special Ed services, require 4 times the cost in vocational rehabilitation and have a lost earnings productivity of over $350,000. How much early diagnosis can offset these discrepancies cannot be calculated. But that there are fiscal as well as social, behavioral, educational, and humanistic advantages to this program are undeniable.

Senator Green, I have been a pediatrician for 26 years and this is the first time I have been involved with endorsing a bill and trying to educate legislators about its advantages. As I have said, my task is to support the EHDI program and I have been told that House Bill 109 will be necessary if Alaska is to succeed in effectively offering this program to its citizens. When someone with your legislative stature and experience is concerned about our bill, I want to do all I can to alleviate these concerns. I hope that you will review this letter and other correspondence coming to you and listen to the testimonies when the bill comes before your Health, Education, and Social Services committee. If you are still not convinced of its merits, please allow me to meet with you after the session is over, so we can discuss it further. Practice concerns will not allow me to fly to Juneau this session, but if there are any questions I can answer, please feel free to call me at my work number during the day, or at my home number (907.349.1594) in the evenings.

Thank you for your attention,

Martin F. Beals, Jr., M. D., FAAP
Alaska AAP Chapter Champion, EHDI program

5820 Yukon Road
Anchorage, Alaska 99507

907-345-4422 ph/fax

Anne Ver Hoef, CCC-SLP
Speech-Language Pathologist

Fax

To: Sen. Lyda Green **From:** Anne Ver Hoef, CCC-SLP

Fax: 907-465-3805 Juneau 907 376-3157 Wasilla **Pages:** 1

Phone: **Date:** 3/16/06

Re: HB 109 Newborn Hearing Screening **CC:**

☐ Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

Dear Senator Lyda Green,

I am requesting - and urging - you to please schedule HB109 for a hearing in the Senate Finance Committee. This is important legislation - a critical healthcare issue. Newborn hearing screenings are vital to detect hearing loss in newborns so proper care and treatment ensues - and these children develop functional communication skills and become competent, productive citizens. You do not have to personally support this legislation, but please allow it to be heard and voted upon.

Anne Ver Hoef

To: Senator Lyda Green, Co-Chair Finance Committee
Fax: 907-465-3805
Senator Gary Wilken, Co-Chair Finance Committee
Fax: 907-465-4714
Senator Con Bunde, Vice-Chair Finance Committee
Fax: 907-465-3871
Senator Fred Dyson
Fax: 907-465-4587
Senator Bert Stedman
Fax: 907-465-3873
Senator Lyman Hoffman
Fax: 907-465-4523
Senator Donny Olson
Fax: 907-465-4821

March 13, 2006

From: Linda Erb
Audiologist,
Alaska Native Medical Center
907-729-1422
Fax: 907-729-1474

Re: Enclosed please find testimony I presented to the Senate Health and Social Services Committee regarding HB 109.

I urge you to schedule this bill for a hearing. This bill is very important to ensure that the newborn hearing screening continues so that we can diagnose and begin intervention early for hearing impaired children.

Thank you for your consideration.

I work as an audiologist at the Alaska Native Medical Center. I have lived in Alaska for a long time. I previously worked in the Anchorage School District as an audiologist and as a teacher of preschool deaf children. I also am the mother of an adult deaf woman.

I am writing in support of HB 109, Newborn Hearing Screening and Reporting for Alaska's Children. The State of Alaska, since 1999, has been building the hospital programs to screen hearing for all newborns and insure timely diagnostic evaluation and early intervention. This work has been done by people who passionately believe in the program and through federal grants. The voluntary compliance has been great. However, soon the grants will expire and we need to have legislation that will ensure the continuation of the program. Currently, 38 states have legislation in place mandating newborn hearing screening.

I have worked with persons with hearing impairment for a long time and have seen the positive changes early diagnosis and intervention makes. Before newborn hearing screening, the average age of diagnosis of hearing loss was 2 to 3 years of age. Even with mild/moderate losses of hearing, but especially with severe to profound hearing losses, the impact on speech and language development was devastating. Hearing impaired children maintained lower language levels than their peers and deaf children often left high school with less than 4th grade reading levels. Good research in the last five years has shown that babies who have newborn hearing screening and receive early diagnosis and intervention develop speech and language that is age appropriate by age 5 to 6 years, no matter the level of their hearing loss. Included in this intervention is the improvement in cochlear implants for young children. If diagnosed with profound hearing loss and receiving a cochlear implant before age 2 years, many children are developing age appropriate speech and language skills and are being included successfully in regular education classes.

Early diagnosis is even more important for children who live in remote villages. These children already have more limited access to early intervention. By receiving early diagnosis and intervention, their access to normal speech and language development will be greatly enhanced. This is so important for those children. Without this access to auditory intervention, rural Alaskan deaf children either are sent to Anchorage to live in group homes in order to attend the State School for the Deaf, stay in their villages with no one to communicate with, or their families move to Anchorage and lose their community support system.

On a personal note, my daughter who is deaf is married to a deaf man. They have three children who are hearing. My daughter has worked hard and completed a college degree. However, the opportunities for employment for her are limited due to her communication abilities. She and several of her friends who went to the Alaska State School for the Deaf and completed college degrees are either unemployed or under-employed (e.g. engineering degree working as a teacher assistant). If she was identified today, I would opt for a cochlear implant for her in a heartbeat because I have seen how much they improve a deaf person's access to auditory communication.

The key to an improved quality of life for children with hearing loss is early identification and intervention. We need to ensure that our hospitals are required to screen hearing of newborns and that diagnosis and intervention occurs in a timely manner. Please pass this bill.

DAVID F. GIBSON
631 W. GALE DR.
WASILLA, AK 99654

April 12, 2006

Senator Green
State Capitol
Room 516
Juneau, AK 99801

Dear Senator Green,

Birth defects are the leading cause of infant mortality in the United States. I am concerned about the public health importance of the major birth defect, congenital hearing loss.

In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. In the absence of mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psychosocial, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

In addition, mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children are given what is needed to become productive members of our communities. I know you do also. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information.

Thanks for your attention to this important matter.

Sincerely,

Nana M. Knowles
P.O. Box 879538
Wasilla, Ak 99687
907-357-8262

March 15, 2006

Representative
State Capitol
120- 4th
Juneau, AK 99801

Dear Representative,

Birth defects are the leading cause of infant mortality in the United States. I am writing as one of your constituents concerned about the public health importance of the major birth defect, congenital hearing loss.

January has been designated as Birth Defects Prevention Month. In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down Syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. In the absence of mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

In addition, mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children are given what is needed to become productive members of our communities. I know you do also. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information.

Thanks for your attention to this important matter.

Sincerely,

Nana M. Knowles

March 15, 2006

Raylene Murr
1001 Elsinore #2
Wasilla, AK 99654

Representative
State Capitol
120- 4th
Juneau, AK 99801

Dear Representative,

Birth defects are the leading cause of infant mortality in the United States. I am writing as one of your constituents concerned about the public health importance of the major birth defect, congenital hearing loss.

January has been designated as Birth Defects Prevention Month. In Alaska each year, approximately 10,000 babies are born and according to national statistics, about 30 of them will have some type of congenital hearing loss. Hearing impairment is the most common birth defect, more common than cerebral palsy, Down Syndrome and severe mental retardation.

Mandatory newborn hearing screening of all babies born in the state allows them to be screened for hearing loss. In the absence of mandatory screening in the newborn period, the average age of identification of a hearing impairment is 2-3 years of age. Since the most important period of speech and language development is from birth to age three, delay in diagnosis can impair a child's language, speech, psycho-social, and cognitive development. Through early identification, children identified at birth with a hearing loss can learn and progress at a rate comparable to those with normal hearing.

In addition, mandatory reporting by birthing facilities of hearing screening results to the State of Alaska's, Early Hearing Detection & Intervention (EHDI) Program, will help to ensure that children with possible hearing loss receive timely diagnostic evaluation and, if necessary, are enrolled into early intervention services at the earliest possible time.

I want to ensure that all children are given what is needed to become productive members of our communities. I know you do also. Please support the addition of HB 109 requiring newborn hearing screening, reporting and follow up. Let me know how I can assist you or your staff with additional information.

Thanks for your attention to this important matter.

Sincerely,

Raylene Murr

Melissa Muldoon
PO Box 876505
Wasilla, AK 99687
2150 Broadway Drive
Palmer, AK 99645
907-745-4211

March 15, 2006

Representative
State Capitol
120- 4th
Juneau, AK 99801

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Thanks for your attention to this important matter.

Sincerely, Melissa Muldoon

Support the 3.4 + million increase to reduce the Developmental Disabilities Waitlist! MM

Rebecca Marinelli
851 W. Westpoint
Wasilla AK
March 15, 2006

Representative
State Capitol
120- 4th
Juneau, AK 99801

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Thanks for your attention to this important matter.

Sincerely,
Rebecca Marinelli

Roann Gibson
6131 W. Trail Dr.
Wasilla, AK 99654

March 15, 2006

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State Capitol
120- 4th
Juneau, AK 99801

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Thanks for your attention to this important matter.

Sincerely,

Roann M Gibson

KOBIN M. GIBSON
631 W. GAIL DRIVE
WASILLA, ALASKA
99654

April 12, 2006

Senator Green
State Capitol
Room 516
Juneau, AK 99801

Dear Senator Green,

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Thanks for your attention to this important matter.

Sincerely,

Robin M. Gibson

NORTHERN HEARING SERVICES
4200 LAKE OTIS PKWY, SUITE #302
ANCHORAGE, AK 99508
Fax (907) 561-2865 Anchorage
(907) 561-1326 Anchorage (907) 357-1326 Wasilla (888) 391-1326 toll-free

Fax Cover Sheet

ATTENTION: Senator Lyda Green **DATE:** 5/3/06

Subject: HB 109 **Fax Number:** 907-465-3805

FROM:

___Joyce F. Sexton, M.A., CCC-A
Audiologist & President

___Jessica T. Voigt, Au.D.
Audiologist

___Heidi Brown, M.S., CCC-A
Audiologist

✓ Susan Mermelstein, Au.D.
Audiologist

___Tory Burns, M.A., CFY-A
Audiologist

___Sharon Baker
Accounts Manager

___Jared Miller
Clinical Services Coordinator

___Karen Bowlus
Clinical Coordinator Database Manager

YOU SHOULD RECEIVE 1 PAGE (S), INCLUDING THIS COVER SHEET. IF YOU DO NOT RECEIVE ALL THE PAGES, PLEASE CALL (907) 561-1326

Comments:

Please schedule the HB-109 for a Senate Finance Committee hearing NOW.

Thank you.
S. Mermelstein, Au.D.
Doctor of Audiology

March of Dimes
Saving babies, together

To: Senator Green
From: Debbie Golden
Attn:
Date: 5/2/06
Fax: 907 465 3805
Fax: 907-276-3375
Phone:
Phone: 907-276-2290
Re: HB 109
Pages: 68

☐ Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

Notes

Dear Senator Green,

Many Alaskans want HB109/ newborn hearing screening to become law! Here's an updated fax of signatures in support for your consideration. PLEASE schedule HB 109 for a Senate Finance hearing, Senator Green! THANK you!

Regards, Debbie Golden

Director of Program Services
Alaska Chapter of March of Dimes