

One simple test can make a difference for your child.



minnesota newborn screening program

About one in every 300 babies is born with a hearing loss that can be found by newborn screening. Although these babies may startle to sound, they don't have the hearing necessary for development of speech and language.

Finding these babies early and offering education, family support, and intervention before they fall behind in language development can make a big difference.

Newborn hearing screening is now mandatory in Minnesota. Screening must be done at birth and the results reported to the MDH unless the parents decline testing.

Contact the Minnesota Department of Health for more information.

1-800-664-7772

(651) 201-5797 TDD

Email: newbornscreening@health.state.mn.us

www.health.state.mn.us/newbornscreening



Introduction to Mandatory Newborn Hearing Screening Summer 2007



One simple test makes
a difference for Minnesota babies.

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Newborn hearing screening is now mandatory in Minnesota. This spring, legislation passed requiring all hospitals caring for newborns to screen for hearing loss before discharge and to report the results of the screening to the Minnesota Department of Health (MDH). MDH is then required to track all newborns and to provide follow-up to ensure all infants who do not pass the initial screen are retested and that infants with a confirmed hearing loss are connected with appropriate resources.



Switching from voluntary to mandatory screening will require changes on the part of hospitals, health care providers, and MDH. This packet is an introduction to mandatory screening with more detailed information to follow.

The Newborn Hearing Screening Program will be coordinated by the same MDH staff who administers the rest of newborn screening.



From this point forward all calls and correspondence regarding screening infants for hearing loss should be directed to:

Newborn Screening Program

Phone: 1-800-664-7772

Fax: 651-201-5471

Address for UPS and all other deliveries: 601 Robert St N, St Paul, MN 55155

Address for US mail: P.O. Box 64899, St Paul, MN, 55164



The following items are included with this handout:

- Hearing Screening Flyer
Use this to educate staff about newborn hearing screening. Please hang it where it can be seen by all.
- Hearing Screening Parent Fact Sheet
Use this to help parents understand the importance of newborn hearing screening and follow-up.
- Newborn Hearing Screening Provider Fact Sheet
Use this to help professionals understand the importance of follow-up when a baby does not pass hearing screening
- Hearing Screening Technologies Fact Sheet
Use this to further inform staff about equipment issues with newborn hearing screening.
- Parental Screening Option Forms
Use these with parents who ask that MDH destroy screening records or who choose to opt-out of screening
- CPT Code List
Use this as a guide for insurance billing and reimbursement for newborn screening.



minnes^ota newb^orn screening pro^ogram





Why Is Newborn Hearing Screening Done?

In general, newborn screening is done to find conditions that cannot be detected at birth and where babies can benefit from early treatment. Without newborn screening, hearing loss often remains undetected until a child is 2 or 3 years old. Those early years are essential for a child's development of language and family communication. When hearing loss is undetected, language development is delayed and children face frustration in school, as well as life-long economic consequences.

Early identification of hearing loss in the frequencies needed to understand speech allows for early family education and intervention. New developments, including infant education, hearing aids that can be fit for babies, and cochlear implants, offer parents a variety of new ways to help their children learn language.

Identifying newborns with a possible hearing loss before discharge is the first step in finding babies who will benefit from intervention. Like many screening tests, newborn hearing testing has a relatively high false positive rate. Babies with "REFER" results need to be referred for further testing in order to confirm whether there truly is a significant hearing loss. Too many parents fail their appointments for this important evaluation. Parents will often "check" the baby's hearing themselves and when they detect a response to hand-clapping or pot-banging they reassure themselves that the baby can hear. Hearing testing is designed to find hearing loss in the range where speech is heard and it is important to inform parents that babies with this type of hearing loss can still startle to loud noises.

National studies demonstrate that the most important factor in the success of newborn hearing screening is the care and attention to detail paid by the professionals who screen the babies. Nursing staff and others who carefully fit probes, fully document, and thoroughly explain the screening results to parents are the champions in detecting hearing loss and guaranteeing that parents take the next steps to evaluation and intervention with their babies.

Protocols

Your facility needs to have a protocol for screening newborns for hearing loss. With hearing screening changing from a voluntary to a mandatory program, this is a good time to review your screening protocol to see if revisions are needed. The protocol should cover not only the screening procedure and equipment, but how staff will be trained (and re-trained), documentation, result reporting to MDH, contingency planning for equipment failure, communication with parents and other health care providers, and follow-up for infants with abnormal results.

Now that hearing screening is mandatory you will need to ensure that every infant is screened and that the results are documented in the medical chart and reported to MDH. Provisions should also be made to make sure that babies with REFER results have appointments made for additional testing and that their parents understand the importance of following through with the necessary evaluations after hospital discharge.

Reporting Newborn Hearing Screening Results

Newborn Hearing Screening results should be reported on the newborn screening card. The area in the lower right hand corner of the card is designed to collect this information. If hearing screening is completed before the blood sample is put on the card, then you can send in the hearing result with the blood specimen for testing. For most infants, the newborn screen can be done this way. Since the blood specimen should be collected between 24 and 48 hours of age and the hearing screening can be done any time after 12 hours of age, most hearing results can be recorded on the screening card before the blood is collected and sent to MDH together. This approach to sending the hearing screening results with the specimens may be different than the way slips were submitted by your facility in the past.

Because the blood collection is designed to screen for disorders that can be serious or even fatal if not found as early as possible, submission of the blood specimen should never be delayed in order to wait for the hearing screening result.

If the hearing screening is not complete at the time of blood collection, there is an alternate way to report hearing screening results to MDH using the specimen card. First, complete the demographic information on the specimen card, then remove the second page of the card labeled 'Hearing Screening Copy' in red (This sheet also has a picture of an ear at the top). After separating the sheets, you can submit the blood specimen in a timely fashion and then fill out the hearing copy when hearing screening results are available.

Hearing screening results should be sent to MDH as soon as possible. If you have separated the 'Hearing Screening Copy' from the rest of the screening card, submit it separately to MDH as soon as the hearing screening is complete. Otherwise, the hearing forms should be sent to MDH together with the newborn screening blood specimens. Sending the hearing results and blood specimens by courier or UPS allows the results to be recorded as soon as possible. Although the hearing slips can be mailed to MDH through the postal service, this is the slowest route of delivery.

If no hearing result is submitted from an infant, a staff member from the newborn screening program is likely to contact you to ask why the result was not submitted.

If there is a reason why it was impossible for you to screen the baby, (such as the baby's death) faxing this information to MDH at 651-201-5471 will minimize the number of times we contact you.

Parent Education

Staff need to educate parents about newborn hearing screening and the benefits of checking a baby's hearing before discharge. Information on screening is covered in the brochure "One simple test can make a difference for your child." The brochure is provided free by MDH in both English and Spanish. Fact sheets on hearing screening for parents and professionals are included in this packet and are also available on the MDH website.

For parents whose children do not pass their hearing screen, it is important to help them understand the importance of following through with further testing. While it is tempting to reassure parents that the baby can probably hear fine, it is essential that they understand the importance of more testing to check that their baby can hear well enough to develop language skills.

Parent Options

Minnesota state law allows parents to choose to have their child's hearing screened, but to request that the MDH record of the hearing test be destroyed. If the parent does not want MDH to keep a record of the hearing screening, a form available from the MDH website at <http://www.health.state.mn.us/newbornscreening> needs to be completed.

This request to have the record destroyed can be made at any time by the parents or even by the child during adulthood.

Minnesota state law allows parents to choose not to have their child's hearing screened. Because the decision to opt-out of any part of newborn screening is a serious one, families need to review the benefits of hearing screening with their medical provider. If after learning about the test, the parent wants to refuse, signatures must be obtained on an appropriate form available on the MDH website at <http://www.health.state.mn.us/newbornscreening>

Hospital staff need to follow the instructions on the form and fax it to MDH. The parent's refusal should also be documented in the infant's medical record and shared with the provider responsible for infant follow-up after discharge.

The forms asking that the record of screening be destroyed or that hearing screening not be done at all are the same for hearing screening as for newborn screening done on blood samples. Parents now need to check a box on the form indicating which part of screening they are declining.

When hearing screening was voluntary, many hospitals asked parents to complete release of information forms authorizing the institution to release information to MDH, audiologists, etc. Now that hearing screening is mandatory, it is no longer necessary to obtain signatures on those release forms.

Minnesota Department of Health Newborn Hearing Screening

July 2007

What is newborn hearing screening?

When your baby was just a few days old, simple tests were done to check your baby's hearing.

All babies born in Minnesota have their hearing checked shortly after birth. While asleep, your baby's hearing was checked using special computerized equipment. The screening test is painless and takes only a few minutes.

Why is hearing screening important?

Identifying hearing loss early is important. Speech and language start to develop right after birth, even though babies don't usually talk until about 1 year of age. A child with hearing loss may have difficulty with speech and language.

If a baby has a hearing loss it is usually not noticeable to parents or doctors. Checking to see if the baby responds to loud noises does not find hearing loss. Screening and follow-up testing are the **only** ways to find hearing loss early. Learning that your baby has hearing loss gives you and your baby a better chance to communicate and connect.

What is a REFER Newborn Screen?

A REFER result means that your baby did not pass the hearing screen in one or both ears. Most babies with REFER test results can hear perfectly well. There may have been fluid or debris in the baby's ear that interfered with testing. Babies with a REFER hearing screen result need to see an audiologist. Your doctor, the nurses at the hospital, the local public health department, or other members of your baby's health care team can help you make an appointment with an audiologist

What is an audiologist?

An audiologist is a person who specializes in testing for hearing loss and who has more sensitive equipment to tell if the screening test was wrong or if the baby has a **confirmed** hearing loss

What kind of help is available for a baby with a hearing loss?

If the audiologist confirms that your baby has a hearing loss, there are many professionals who will help you learn more about what kind of hearing loss the baby has and the best ways to help the baby.

Contacting the following people will help you learn how best to help your baby with a confirmed hearing loss.

- **Your baby's doctor:** who can provide regular medical care to your baby as well as referral to medical specialists in areas such as otolaryngology (ear, nose, and throat specialists), genetics, and ophthalmology (vision specialists)
- **Audiologists:** who not only test hearing but can provide treatment for babies such as hearing aids and cochlear implants, if needed
- **Hands and Voices or other groups of parents whose children have hearing loss:** who can share how they helped their own children.
- **Your local school district :** where free early intervention services are available to infants with confirmed hearing loss
- **MDH:** where follow-up services are available to families

What causes hearing loss?

There are many things that cause hearing loss in a baby:

- Hearing loss can be inherited (passed through a family). Hearing loss can be genetic even if there are no other family members who were born deaf or hard of hearing.
- Hearing loss can be caused by certain infections, medications, or problems at birth.
- In some cases, even after testing the cause of the hearing loss may not be known.

Resources

Minnesota Hands & Voices –
<http://www.handsandvoices.org/chapters/Minnesota.htm>
651-265-2435

Minnesota Department of Human Services, Deaf and Hard of Hearing Services – www.dhhsd.org/
651-431-2351

My Baby's Hearing – www.babyhearing.org/
PACER Center – www.pacer.org/ (952) 838-9000 or
800-537-2237



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Newborn Hearing Screening

Why screen for hearing loss:

Early diagnosis of hearing loss gives babies and their parents a chance to communicate with each other. Advances in education and technology provide the opportunity for infants with hearing loss to maximize their linguistic and communicative development. Mandated hearing screening allows for the early detection of babies with hearing loss and the efficient referral to follow-up services.

What causes infant hearing loss?

Each year, about 200 children born in Minnesota are found to have some degree of hearing loss. The etiology of hearing loss is heterogeneous, and may be of genetic, non-genetic, or idiopathic origin.

Genetic forms of deafness may be syndromic or an isolated finding. Most genetic hearing impairment is inherited in an autosomal recessive pattern.

Non-genetic causes of deafness can result from pre- or post-natal infection (i.e. cytomegalovirus and bacterial meningitis), ototoxic medications, and severe hyperbilirubinemia. Other risk factors include low birth weight, asphyxia, or NICU admission.

How hearing screening is done:

There are two types of hearing tests that may be used to screen a baby. Auditory brainstem response (ABR) measures the brain's response to a stimulus through small earphones. Otoacoustic emissions (OAE) measure the response of the outer hair cells within the cochlea by placing a small probe in the baby's ear. Both tests are quick, and usually performed when the baby is in a natural sleep.

Managing infant hearing loss:

Children who have hearing loss are managed by a multidisciplinary team of physicians, otolaryngologists, audiologists, and speech pathologists. Medical interventions can include use of hearing aids, cochlear implants, training in sign language and oral communication, as well as evaluation for associated problems.

What is a REFER result?

A REFER result indicates that an infant did not pass the hearing screen in one or both ears. A REFER newborn screening result does not mean that an infant has hearing loss. Both ABRs and OAEs are affected by many outside factors which can lead to a high false positive rate for hearing screening. Follow-up evaluation by an audiologist is necessary to confirm a diagnosis and determine etiology.

The possibility that a baby might have hearing loss can provoke significant anxiety in parents. Care providers must carefully balance encouraging the parents to seek prompt follow-up testing without unnecessarily alarming them.

PASS results

Since not all forms of prelingual hearing loss are expressed at birth, a child who passes the hearing screen, but who has hearing loss risk factors should continue to be monitored by the provider.

What should I do with a REFER result?

- Review information from the hospital.
- Initiate referral for further evaluation by an audiologist
- Contact the family and encourage prompt follow-up
- If hearing loss is confirmed, refer to early intervention, parent support, and specialty services.

Talking with parents:

- Help parents understand that most babies with REFER newborn screens do not actually have hearing loss
- Learning that a baby has hearing loss early in life can help the parents and baby communicate with each other
- Encourage parents to schedule and keep follow-up appointments with the audiologist
- Know that social, educational, and financial resources may be available to help children with hearing loss.



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Newborn Hearing Screening Technologies

Auditory Brainstem Response (ABR)

When the auditory system is excited by a stimulus, small electrical currents are generated. These electrical responses are measured during an ABR test. ABR responses are measured by placing sensors on the baby's head. Sound is introduced to the baby's ears through small earphones while the child is in a natural sleep. A computer records the baby's brainwave activity and indicates whether the auditory system is appropriately responding to sound.

Advantages

- Requires no interpretation by the screener
- ABR results are less affected by middle ear or external ear debris than OAEs
- Results are immediately available
- Easy to administer by nursery staff
- May detect neural or central auditory pathologies

Disadvantages

- May take longer if baby is in a noisy environment
- ABR is susceptible to electrical interference
- Higher cost per screen than OAE
- Infants with very mild hearing loss may pass an ABR screen

What to do if equipment fails:

- *Have a plan in place for a back-up unit*
- Many hospitals have close facilities that may be able to loan equipment
- Some manufacturers offer loaner equipment. Contact a sales representative about this possibility
- Check with local audiologists or ENT practices to see if they have equipment you could loan

Important Note:

Babies who miss screening due to equipment problems must be brought back for screening when the equipment is repaired. Being prepared for equipment problems will decrease delays.



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Otoacoustic Emissions (OAE)

The cochlea produces sound in response to external stimuli. This internally generated sound is measured during an OAE test. OAEs are measured by placing a small probe in the infant's ear canal and presenting sound through small speakers. There are two types of OAEs commonly used in clinical practice. Transient OAE (TEOAE) emits sound in the speech frequency range. Distortion product OAE (DPOAE) emits sounds in specific frequency ranges.

Advantages

- Results are immediately available
- Easy to administer by nursery staff
- Lower cost per screen than ABR
- Average screening time is less than ABR
- Can give frequency specific information

Disadvantages

- Debris or fluid in the external or middle ear can affect results
- Failure rates are high during first 24 hours after birth
- May take longer if infant is in noisy environment
- Infants with very mild hearing loss or central auditory pathologies may pass an OAE screen

Equipment Manufacturers

Below is a list of ABR and OAE equipment suppliers for your convenience:

- Bio-Logic: 1-800-323-8326
- Madsen: 1-800-362-3736
- Natus: 1-800-255-3901
- Otodynamics: 1-800-659-7776



Instructions for Birth Facilities Regarding Parental Newborn Screening Options

Newborn screening is an important, even life-saving, part of infant health care. Minnesota Statutes §144.125 Subd. 3 and §144.966 Subd. 3 provide several options to Minnesota parents and guardians regarding newborn screening. It also requires birth facilities and other healthcare providers to educate parents about specific benefits and risks associated with choosing the various options.

To offer the best care to the infants born in your facility and to inform parents of their rights under the law, the Minnesota Department of Health Newborn Screening Program recommends taking the following steps:

- _____1. Review the *One Simple Test Can Make a Difference for Your Child* brochure with parents. It is available free from the Newborn Screening Program and can be ordered by calling 651-201-5466 or 800-664-7772.
- _____2. Tell parents that their infant's newborn screening specimen and hearing screening results will be sent to the Minnesota Department of Health and that test results and the blood sample will be retained by the department.
- _____3. Tell parents about the benefits of keeping their infant's newborn screening specimen. See *Benefits of retaining newborn screening specimens* below.
- _____4. Tell parents that they can have their infant's newborn screening specimen and test results destroyed. See *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* form for a list of associated risks.
- _____5. Inform parents that they can decline to have their infant screened. See *Risks of not screening a newborn* below.
- _____6. Tell parents that if they decline to have their infant screened, the choice will be recorded and documented in their infant's medical record and documented with the Minnesota Department of Health. See *Documenting a refusal of newborn screening* below.

Risks of not screening a newborn

Babies can die or become developmentally delayed as a result of not being screened. Children with the diseases screened for or with hearing loss often appear healthy at birth and may not display symptoms for days or weeks. By the time symptoms appear, damage can be irreversible. Therefore, an affected child not screened may not receive treatment needed to prevent developmental delay, illness, or death.

Benefits of retaining newborn screening specimens

Stored newborn screening specimens enable (a) continuous quality improvement of newborn screening; (b) evaluation and comparison of new testing methods; (b) epidemiological research (on anonymous specimens); (c) special health-related studies for specific patients or families; and (d) the identification of missing or deceased

children. Each of these activities benefits either public health or families of those from whom specimens are obtained.

Private testing

Parents may choose to have newborn screening performed by a private testing laboratory instead of by MDH.

The specific diseases screened for by private testing laboratories may vary from those screened for by the Minnesota Department of Health. Minnesota is a national leader in newborn screening and screens for all the diseases recommended for screening by the American College of Medical Genetics.

Private testing must be arranged by the parent or guardian through their doctor and a private testing laboratory.

Birth facility requirement associated with private testing option – If private testing is chosen, the birth facility must provide documentation to the Minnesota Department of Health that the parent or guardian refused to have their child screened by the Minnesota Department of Health.

Documenting a refusal of newborn screening

- ____1. Have the parent read and sign the *Parental Refusal of Newborn Screening* form. Have a witness from the birthing facility sign the form.
- ____2. Insert the original document in the child's medical record.
- ____3. Provide copies to the parent, the child's physician, and the Minnesota Department of Health Newborn Screening Program at the address below.

Documenting a directive to destroy newborn screening specimen and/or test results

- ____1. Have the parent read and sign the *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* form. Have a birthing facility witness or a notary public sign the form (to authenticate parental identity).
- ____2. Insert the original document in the child's medical record.
- ____3. Provide copies to the parent, the child's physician, and the Minnesota Department of Health Newborn Screening Program at the address below.

Parental Refusal of Newborn Screening forms and *Directive to Destroy Newborn Screening Test Results and/or Blood Sample* forms are available at: <http://www.health.state.mn.us/newbornscreening>

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Parental Refusal of Newborn Screening

Name of infant: _____ Birth date: _____

Hospital of birth: _____

By signing below, I acknowledge that:

I have received and read the Minnesota Department of Health (MDH) brochure explaining newborn screening testing for heritable and congenital disorders and have been informed of the risk of not screening a newborn.

I understand that delays in treatment of diseases detectable by newborn screening may result in permanent damage to my child, which may include profound mental retardation, growth failure, hearing loss, and/or death, and that diseases detectable by newborn screening may not cause symptoms for several weeks or months.

I understand that I also have the option of having my child screened and having his or her blood sample and test results destroyed within 24 months of testing.

(Parent or guardian: Check the box or boxes below indicating your directive.)

I do not want _____ to receive blood testing for the diseases
Name of child
screened for by the Minnesota Newborn Screening Program.

I do not want _____ to receive screening for hearing loss.
Name of child

Parent or guardian signature: _____

Parent or guardian printed name: _____

Relationship to child: _____ Date: _____

Street address: _____

City: _____ Zip: _____ Phone: _____

The parent or guardian must present photo identification to a public health or medical professional, who must then sign as a witness. Alternatively, the parent or guardian's signature (i.e., identity) may be authenticated by a notary public.

Witness signature: _____ Witness phone: _____

Witness printed name and position: _____

Send completed form to:

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Protecting, maintaining and improving the health of all Minnesotans

Newborn Screening

Current Procedural Terminology (CPT) Codes

Result category	Test listed in Current Procedural Terminology, Fourth Edition	CPT code	Minnesota Health Care Programs (MHCP) fee schedule as of May 15, 2007
Amino Acidemias (includes PKU)*	Tandem mass spectrometry (MS/MS)	83788	\$25.23
Biotinidase	Biotinidase	82261	\$23.57
Congenital Adrenal Hyperplasia	Hydroxyprogesterone, 17-d	83498	\$37.95
Congenital Hypothyroidism	Thyroid stimulating hormone (TSH)	84443	\$23.47
Cystic Fibrosis	Immunoassay for analyte, qualitative or semiquantitative; multiple step method	83516	\$16.12
Fatty Acid Oxidation*	<i>See note below.</i>		
Galactosemia	Galactose-1-phosphate uridyl transferase; screen	82776	\$11.71
Total Galactose	Galactose	82760	\$15.31
Hemoglobinopathies	Hemoglobin fractionation and quantitation; electrophoresis (e.g., A2, S, C, and /or F)	83020	\$15.74
Organic Acidemias*	<i>See note below.</i>		
Hearing Screening	Evoked otoacoustic emissions; limited	92587	\$39.77 APC/ASC \$52.40
	Auditory evoked potentials; limited	92586	APC/ASC \$72.97

* The *Amino Acidemia*, *Fatty Acid Oxidation*, and *Organic Acidemia* disorders are screened for in one multiplex MS/MS test.

June 13, 2007