



# IDAHO SOUND BEGINNINGS



## Change for the Better . . . . .

Before we talk about changes, you need to be aware that even though your efforts found 48 babies with hearing loss in calendar year 2001, *there were nearly 900 babies who did not pass their first hospital screen, who never returned for the second screen.* They are lost to the process of audiologic evaluation. At this point, the families may be unaware of the need for follow-up; the primary care physician or nurse practitioner has no clue; the audiologist cannot locate them; and this office cannot follow up. And yet these babies who did not pass that first screening are at a higher level of risk for hearing loss. *Studies show that 3 out of every 100 babies (3%) who do not pass the first screen will have some level of hearing loss.*

**Babies who do not complete the two-stage screening process are at higher risk for hearing loss! They must be re-screened in the first few weeks of life!**

This means that we can assume there were at least 27 babies born in 2001 who have hearing loss that was undetected during those first few weeks of life.

**CHANGE #1: PARENT'S SIGNATURE SHOULD BE OBTAINED AS SOON AS THE INFANT DOES NOT PASS THE FIRST SCREEN. IF THE CHILD DOES NOT RETURN FOR RESCREEN WITHIN ONE MONTH, THE HOSPITAL IS THEN ABLE TO DISTRIBUTE THE FORM. IDAHO SOUND BEGINNINGS CAN THEN COORDINATE TRACKING AND FOLLOW-UP.**

The second area of concern is the need for referral and follow-up of all babies who have been identified with any (even one!) of the High Risk Indicators -- even when the infant passes the hospital hearing screen. There is a high prevalence of delayed onset hearing loss or deafness in high-risk infants. The Joint Commission for Infant Hearing recommends that these infants be monitored for hearing by a Pediatric Audiologist every six months until age three. Idaho Sound Beginnings will begin a registry of high-risk infants, and with the help of physicians, audiologists and Child Find Coordinators in District Health Departments, seek to ensure that those children receive timely audiological evaluation.

After seeing these data Idaho's Perinatal Nurse Managers and coordinators generally affirmed these changes in procedure that will make it possible to follow up and track these infants in a timely and appropriate way.

**CHANGE #2: THE "REFERRAL FOR DIAGNOSTIC AUDIOLOGIC EVALUATION" FORM IS CURRENTLY BEING REVISED SO THAT THE LISTING OF RISK INDICATORS WILL APPEAR ON THE FRONT OF THE FORM. UNTIL THESE REVISED FORMS ARE AVAILABLE, NURSE/SCREENERS ARE ASKED TO WRITE IN ANY "RISK INDICATORS" ON THE FRONT OF THE FORM. MOTHERS WILL THEN BE INFORMED OF THE NEED TO RECHECK BABY'S HEARING EVERY SIX MONTHS UNTIL THE AGE OF 3.**

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These two changes will make a big difference for babies who need help with their hearing. Birth hospitals are to be applauded for undertaking these simple steps.  
*Bee Biggs-Jarrell, Project Coordinator*

# Hospital Profile:

Dr. Kathleen Wachtler, Au.D., CCC-A

## St. Luke's Regional Medical Center Boise & Meridian


### A Model UNHS Program

St. Luke's Regional Medical Center in Boise was one of the first hospitals in Idaho to implement a Universal Newborn Hearing Screening Program (1997). Although they had previously been operating a successful hearing screening program for infants at High Risk, as research began to emerge that 50% of infants with hearing loss were born without any risk factors and that there were significant benefits to Early Identification and Intervention, the hospital quickly upgraded to universal screening. When St. Luke's Wood River and Meridian hospitals opened in subsequent years, universal newborn screening was implemented in those nurseries, as well.

Fortunately for Idaho Sound Beginnings, the state's largest birthing hospital has been above average in data management, tracking and follow-up. In over 4 years the program has identified 37 infants with permanent childhood hearing loss (PCHL). This data reveals that approximately 2 of every 1000 babies tracked through the screening and diagnostic process at St. Luke's were identified with PCHL. This is consistent with nationwide data showing a prevalence rate for PCHL of 1-3 per 1000.

When the program's initial referral rate increased to unacceptable levels, hospital administration responded by researching ways to reduce the rate of false positives (or false refers). Throughout 2002, the program was analyzed and re-structured to ensure screening occurred in the most efficient manner, quietest location, and that the screening skills of staff were improved with multiple "refresher training" sessions. Finally, it was determined that the equipment itself needed to be replaced. Administration and physicians were convinced that upgrading to Automated Auditory Brainstem Response (AABR)\* would lower the false positive rate, reduce parental stress of unnecessary re-screenings, and improve the accuracy of the program. The purchase of the AABR system in September yielded immediate improvements. While the program's initial referral rate had been at or above 10% in recent months, the referral rate dropped to 1% in October using the new AABR system. This reduction in false positive rate means that fewer than 50 babies will require re-screening per year, as compared to 500 to 1000 babies that would have had false positive tests each year using the OAE\*\* equip-

ment. This allows physicians and audiologists to focus follow-up energies on babies who are truly at greater risk for hearing loss, rather than track hundreds of infants with normal hearing.

Four other hospitals in Idaho currently use AABR to screen infants. Screening by OAE's will result in a high false positive rate, which is why 2-stage screening protocols are always recommended. However, due to the increased sensitivity of the AABR, a 2-stage screening protocol is not necessary. The Joint Committee on Infant Hearing (JCIH) 2000 position statement defines a successful initial referral rate as being below 4%. 

\***AABR**: This test is not as susceptible to middle ear obstructions, such as fluid or wax, therefore, sensitivity is near 1%.

\*\***OAE**: The most common test used in nurseries; it is easily affected by middle ear obstructions. There is a higher false positive rate (10%). 2-stage screening protocols are used to reduce this referral rate. (See bottom of page 3 for more information)

## Highlights—Recent Idaho Sound Beginnings Events

### Idaho Sound Beginnings Roundtable –

Sun Valley with Idaho Hospital Assn. October 8: Over 20 representatives from hospitals and some audiologists generated lively discussion on current issues and answers in newborn hearing screening, data reporting, audiological evaluation, and early intervention and follow-up. It was great to hear participants learning from one another! A very needed piece of "policy" emerged from Madison Memorial Hospital that will help ISB formulate a statewide policy for "Border Babies" – infants who are referred for newborn care in another state. Watch for the draft policy on *Tracking Border Babies*.

### Perinatal Nurse Managers Summit -

McCall, October 10. At the invitation of St. Luke's Perinatal Project and the Idaho Chapter of American Academy of Pediatrics, Dr. Kathleen Wachtler, Audiologist, and ISB Coordinator Bee Biggs-Jarrell, R.N. "invaded" the Brundage Ski Resort Lodge. The main topic was the high incidence of late onset hearing loss in infants with risk indicators.

After lively presentations, the Nurse Managers generally agreed with the ISB program's assessment, that we should indicate on the parent-signed ISB Referral form, every risk indicator that is apparent during the neonatal hospital stay. Parents will need to be informed of the importance of audiological evaluation for their baby, every six months until the age of 3. A parent information template was provided to the nurses for potential use at discharge of infants who have even 1 risk factor.

# Newborn Hearing Screening in Idaho – 2001 Outcomes

Dr. Kathleen Wachtler, Au.D., CCC-A

As coordinating Audiologist for Idaho Sound Beginnings's Early Hearing Detection and Intervention (EHDI) project, I am frequently asked if Universal Newborn Hearing Screening (UNHS) is making a difference in Idaho. The answer is definitely **YES!** But, remember the adage, "There's good news, and there's bad news...?"

## ***First the GOOD NEWS...***

By the end of 2001, 27 hospitals had submitted their screening data to Idaho Sound Beginnings. We found that the average coverage rate (i.e. number of babies screened before discharge) was 96%. A successful UNHS program is defined as 95% coverage, so as a State we do well in making sure infants are screened before discharge. The referral rate at the first stage screening was 16%; a little higher than the recommended 10%, but a definite improvement over the year 2000 rate of over 30%!

As one would expect, hospitals do much better at passing babies at the outpatient, second stage re-screening appointments. At that point, only 2% of infants were referred for diagnostic Audiological evaluation, which is less than 1% of total births – a very acceptable number of 130 babies.

**Forty-eight (48) infants were identified with hearing loss in 2001**, which represents 35% of the children who were referred for diagnostic evaluations. Twenty-one (21) of those infants had permanent, sensorineural type hearing loss. Twenty-four (24) had a conductive hearing loss, which is frequently medically treatable.

## ***Now the BAD NEWS...***

The risk of hearing loss in a healthy newborn is approximately 3 per 1000. This means that 0.3% of infants missed are at risk for hearing loss. Almost 600 babies were missed in 2001!

The risk of hearing loss increases to 3% if the child does not pass the initial screening. Unfortunately, not all who need to return for re-screening will. In 2001, 891 babies failed to follow-up with re-screen.

**An infant who fails both the inpatient and outpatient screenings, and has been referred for Audiological evaluation is at 30% or greater risk of having hearing loss.** In 2001, 60 infants are unaccounted for. There are a variety of obstacles that face parents; e.g. finances, transportation, schedules, language, and denial. There are also obstacles in the tracking and follow-up of these infants; were referral forms completed, signed and distributed? Was a diagnostic evaluation done, but results not shared with Idaho Sound Beginnings? We may never know where the breakdowns occurred.



Despite our successful identification of 48 infants with hearing loss in 2001 – if we add up all the infants missed (594), those lost before re-screen (891), and lost to follow up after two failed hearing screenings (60), **THERE MAY BE BETWEEN 25 TO 45 BABIES BORN IN 2001 WHO HAVE UNDETECTED HEARING LOSS!**

Idaho's EHDI project has made tremendous improvements in coverage rates and initial pass rates over the last few years. Our goal for the upcoming year is to strengthen the tracking and follow-up components so that fewer infants "fall through the cracks", risking serious negative consequences related to undetected hearing loss in early childhood. *✍*

**ABR:** While the baby is sleeping naturally, small sensors (electrodes) are placed behind each ear and on the baby's head. Sounds are presented to the ears with earphones; the electrodes pick up the response of the hearing nerve and send it to a computer to be analyzed. This test is not as susceptible to middle ear obstructions and, therefore, sensitivity is near 1%.

**OAE:** Otoacoustic Emissions testing assesses the function of the cochlea, specifically the hair cells of the inner ear. It is the most common screening test used in nurseries. OAE's can determine if the nerve cells of the inner ear function normally. The response is easily affected by middle ear obstructions, such as fluid or wax, and there is a higher false positive rate (10%). Two stage screening protocols reduce the referral rate significantly.

# Parent Support Corner



**Idaho Hands and Voices** is designed for parents to have their own forum for emotional and mental support, for help and hope in making the early intervention system work better than ever, and for developing a unified voice for parents on local and statewide issues affecting children who are deaf or hard-of-hearing. **Idaho Hands and Voices** expects to have parent-led support groups in every region of the state during the next few months.

If you have questions, need help, or want to offer assistance please call **Idaho Hands and Voices** at 208-334-0829, **800-433-1323**, or TTY at 800-433-1361.

### **Audiologists, Physicians, and Others:**

Please feel free to share these numbers with any parent whose infant has been diagnosed in the last two years. They will be offered sensitive parent support and be linked with a group near their home. The outcomes of this kind of parent-driven support in other states tell us that it will make a positive difference for Idaho's deaf and hard of hearing infants and their families



**800-433-1323**



Editor: Cynthia Carlin, B.S., Administrative Assistant

## Upcoming Events:

### **December 2: Twin Falls Workshop on Early Hearing Detection, Intervention and Follow-up at Magic Valley Regional Medical Center.**

All newborn hearing screening personnel, audiologists and early intervention specialists in southeastern Idaho are being invited to this one-day seminar, updating knowledge, skills and practices. Six hours of Nursing CEUs are being granted. Faculty include Brindie Henderson, Audiologist in Twin Falls; Dr. Kathleen Wachtler, Pediatric Audiologist, Boise; Ginger Payant, Technical Consultant in Hi-Track data system, from National Center for Hearing Assessment and Management in Logan, Utah; and Bee Biggs-Jarrell, R.N., Coordinator for Idaho Sound Beginnings. **Seating is limited, so if you would like to attend, register today at 208-334-0829**

### **Joyous Holidays & A Happy New Year**

### **January 6, 2003 ISB's 4<sup>th</sup> Year Continuation Grant Application due in Washington, D.C.**

### **February 24-26: National EHDI Meeting, Atlanta, Georgia**

### **March 25: Idaho Sound Beginnings Workshop at Kootenai Medical Center, Coeur d'Alene**

### **Idaho Sound Beginnings**

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