(((SOUND IDEAS

Volume 1, Issue 3 *By the Year 2000, all children with hearing loss should be identified before 12 months of age* *July 1, 1997*

(((SOUND IDEAS is a quarterly publication of the National Center for Hearing Assessment and Management (NCHAM).

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Data Management for Universal Newborn Hearing Screening Programs

In theory, detection of potential hearing loss in newborns is a simple process. Every baby is tested once, or if necessary, twice by OAE or ABR prior to discharge from the newborn nursery. Those who do not pass the initial screening receive a diagnostic ABR and, if hearing loss is diagnosed, intervention services prior to age 6 months. Since babies are a captive population, accomplishing the screening prior to discharge from the newborn nursery is a reasonable expectation. The justification for universal newborn hearing screening rests solidly on a growing base of evidence that undetected and untreated hearing loss can produce significant communication and educational deficits.

While hospital based screening is a good first step, data management and coordination beyond the newborn nursery is crucial to follow-up efforts. In many cases, the birthing hospital is able to offer diagnostic audiology services and may actually follow babies after discharge. While a full range of such services is desirable, many small and medium size hospitals are able to provide only initial screening services and must depend on outside agencies or clinics to rescreen and diagnose hearing impaired babies.

Efficient management requires simple and seamless data flow among all the professionals and agencies involved with children. Fortunately, the use of computers and specially designed software allows programs to coordinate all the necessary players without un-

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Guam takes action following NGA meeting

The honorable Mrs. Geri Guiterrez, wife of Guam's Governor Guiterrez, attended this year's (National Governor's Association) meeting where Dr. Karl White spoke about newborn hearing screening. As the westernmost possession of the United States since 1898, the island of Guam is the largest island in Micronesia, approximately 30 miles in length , with a variable width ranging from 12 miles to 4 miles at its narrowest point, and having a total land mass of approximately 212 square miles. The Chamorros (native population) are a mixture of various ethnic and cultural groups originating from Asia, Europe, and the Americas. The birth rate on Guam is approximately 2700 babies per year at Guam Memorial Hospital (2400) and the Naval Hospital of Guam (300) serving U.S. Navy personnel and their

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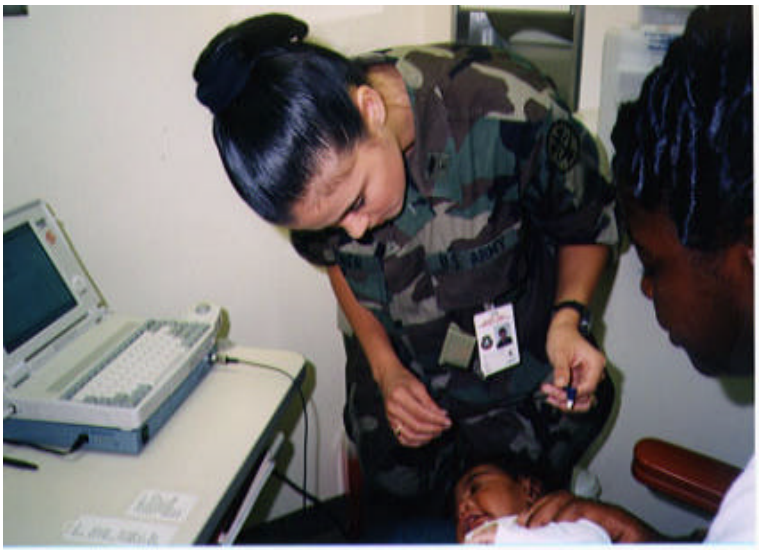
In this issue.....

(((Program Spotlight: Darnall Army Community Hospital Ft. Hood, Texas. Children's National Medical Center - Washington D.C.

Can an **outpatient-based** newborn hearing screening program successfully provide **universal** screening? Audiologists at Darnall Army Community Hospital at Ft. Hood, Texas believe the answer is "yes." Presently the US Army has nine successful universal newborn hearing screening programs (universal refers to those screening more than 90% of newborns) and twelve programs screening all high-risk newborns (and non-high risk on a voluntary basis). Eight of the nine universal programs are inpatient based, screening infants prior to discharge.



While many of the U.S. Army's voluntary programs offer outpatient OAE screening for well babies in the Audiology clinic at the parent's or physician's request, the program at Darnall Army Community Hospital at Ft. Hood, TX is unique in that it is the Army's only *universal* screening program using the *outpatient* model. This is an impressive undertaking, since over 3,000 infants per year are born at Darnall Army Community Hospital—the largest birth rate of any U.S. military hospital. Since its inception in mid-April of this year, the program has screened the hearing of approximately 100 % of the hospital's high-risk infants, and is also capturing close to 100% of the well babies. The program at Darnall was developed by audiologists MAJ Lorraine Babeu and 1LT Rhonda Fleener. High-risk infants are identified by the medical

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Infant Hearing Screening - A Parent's story

When they took my baby away to test his hearing in the hospital just hours after he was born, I was not very happy. I had no idea what kind of test it was, whether it would hurt or disturb the baby. I try to protect my children from unnecessary medical intervention. And I have to say I was not thrilled when Jody Brekke called me at home a few days later to tell me that he had failed that test and should be tested again. The second test confirmed his hearing impairment. In those early days while we were trying to understand Ellis's hearing impairment and what is would mean to him and to our family, we kept trying to prove that the tests were wrong (.See? He heard that! Did you see him jump when you dropped your keys?.). While we might have felt a little happier at the time, the ramifications for Ellis, had we been able to ignore his hearing impairment, would have been nearly tragic.

A year later I can say without reservation that we are incredibly lucky that Ellis was born at Covenant where the hearing of all newborns is routinely tested. Finding out about Ellis' hearing impairment early has meant the difference between a bright, well-adjusted, happy, social, communicative boy who tests above average on almost all of the evaluations he has been given and a boy who would now be experiencing severe delays in language acquisition and we wouldn't yet understand why.

Early detection has meant that Ellis was fitted at 3 1/2 months before he had the manual dexterity to pull them out .... so he has grown up thinking they are part of his clothing, if not his very self. I believe that since he had them for so long, he will also have an easier time socially later on when he realizes that most kids don't wear hearing aids.

Early detection has meant that we have had time to adjust to Ellis' hearing loss; to discover what it means, to understand his needs for amplification, to Learn about different communication systems, different choices in education. Emotionally it has meant that we never experienced the grief at .losing. the .normal. child that we thought we had.

We have been better able to allow him to be who he is ..... a wonderful child with a hearing

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Data Management .....

(Continued from page 1)

due hardship. Several data management systems have been designed specifically for newborn hearing screening programs, while other hospitals have adapted existing software to meet their needs. While it is not the purpose of this brief article to describe any of the systems in great detail, there are several factors that should be considered when evaluating any data management system:

* The system should provide a common entry point for each baby, preferably at the time of initial screening. Provisions for adding babies later must also be included.
* Test results should be solidly linked to demographic data for both scoring and archiving purposes.
* Reports should be readily available and meaningful for those tracking the data
* Letters to parents and professionals must be easily generated.
* A "tickler system" to ensure timely follow-up on groups of babies must be an integral part of the software.
* Data must be secure and easily backed-up on a regular basis.
* Coordination among multiple users of the software should allow everyone access to current data regarding the status of each baby.
* Strong technical support and regular updates of the software to ensure currency of procedures and capabilities

Between the newborn nursery and school entry (the next time babies are part of a semicaptive population), there are many points at which infants with suspected hearing loss could fall through the cracks. Communication between the hospital, parents, outside agencies, private clinics and physicians is critical to ensure that no child arrives at kindergarten round-up with an undiagnosed congenital hearing loss. Without an efficient system of data coordination and management, newborn hearing screening and follow-up programs will become a paperwork nightmare!

Data management and coordination procedures must be clearly outlined during initial planning stages of universal newborn hearing screening programs. Software and hardware selection should be made with these procedures in mind.

Guam .....

(Continued from page 1)

dependants.

After attending Dr. White's presentation, Mrs. Guiterrez discussed with him the feasibility of initiating newborn hearing screening on Guam. With the assurance that NCHAM would assist her in her efforts, Mrs. Guiterrez subsequently made contact with Guam Memorial Hospital administrators and arranged for a 4-day training session to be held guided by NCHAM's staff. Head nurses, audiologists, and other nursing staff from Guam Memorial, Naval Hospital, Palau Island and Saipan Island participated in the hands-on training and Guam has been able to implement universal newborn hearing screening as of May 15, 1997.

The unique culture of Guam presents different administrative challenges than are faced on the mainland. For example, the number of babies born with the assistance of midwives is higher, and although the official discharge time from hospitals is 24 - 48 hours, quite a few parents sign waivers allowing mothers to go home after 6- 12 hours if they feel healthy. Limited public transportation also makes it very difficult for parents to return to the hospital with their infants for rescreening. Despite these obstacles, Guam Memorial Hospital administration and staff remain committed to the ideal and practice of providing hearing screening to all of Guam's newborns.

(((UPCOMING EVENTS

September 26, 1997 Issues in Reimbursement and Professionalism: From Managed Care to Medicare.
Chateau Sonesta Hotel New Orleans, LA. American Academy of Audiology.
1-800-222-2336 ext 213

September 26, 1997 Educational Audiology : Best Practices in the School Setting.
Chateau Sonesta Hotel New Orleans, LA. American Academy of Audiology.
1-800-222-2336 ext 213

September 26, 1997 TeleSeminar: From Advocacy to Intervention: Steps for Successful Establishment 1:00-3:00 PM (EDT) of Universal Infant hearing Detection Programs
American Speech-Language-Hearing Association

October 1, 1997 TeleSeminar: Issues in Pediatric Amplification, Fitting Strategies and 1:00-3:00 PM (EDT) Considerations for Counseling Multicultural Families
American Speech-Language-Hearing Association

November 8, 1997 Implementing Universal Newborn Hearing Screening.
Wyndham Emerald Plaza. San Diego, CA. American Academy of Audiology.
1-800-222-2336 ext 213

(((A Parent's Story (continued)

(Continued from page 2)

impairment... and accept him and love him and get to know him as he grows, without any sense of disappointment.

Early detection has also meant access to early intervention by professionals who work closely with us to enrich Ellis' language environment, to monitor his hearing aid use, to evaluate his progress and suggest games and activities that further promote his language acquisition

I remain convinced that without early detection, we would just now be beginning to suspect that something was wrong with Ellis. We would be wondering why he was so slow to say his first words. Since he is not totally deaf, and he does respond to some sound even without his hearing aids, I am afraid that we would not suspect a hearing impairment. He would probably be exhibiting classic signs of hearing impairment to a professional. But we are parents, not professsionals.

I shudder to think what his life might be like without early detection and early intervention. Lately his vocabulary is growing daily. He uses a combination of signs and words including bird, dog, cat, cow, moo, thank you, milk, Mama, Papa, more and done...and I begin to lose track of the rest. He loves music and dancing and reading books and enjoys watching me sign nursery rhymes and songs. I shudder to think that all of this richness might yet be a locked door for him. We feel very lucky that Ellis has had this chance to develop to his full potential and hope for the same chance for all children.

Written by Mary Hays (5/97)

More Legislative Mandates for Newborn Hearing Screening

In March 1993, the National Institutes of Health (NIH) recommended that all newborns be screened for hearing loss before being discharged from the hospital. Movement towards screening the hearing of every baby was slow to catch on initially, but has gained acceptance and momentum as evidenced by the number of hospitals which have now begun to implement universal screening programs. Systematic, statewide newborn hearing screening was first instituted in Rhode Island and Hawaii, but many other states are now following their lead: Colorado, Delaware, Iowa, Utah, and Wyoming are currently screening the majority of newborns and are well on the way to universal screening as the standard of care for all babies born in their state. Rapid developments are likewise happening in the area of legislation requiring newborn hearing screening. In 1993, only Hawaii and Rhode Island had legislative mandates (passed in 1990 and 1992, respectively) requiring newborn hearing screening for all infants born in the state. In 1996, bills requiring newborn hearing screening were considered in Minnesota, Pennsylvania, and New York. Although none of them passed, interest was awakened and a solid foundation was established. During the 1997 legislative session, there was legislative activity in the following ten states: Colorado, Connecticut, Massachusetts, Minnesota, Mississippi, New York, Oregon, Pennsylvania, West Virginia, and Utah. This time the outcome has been more successful. Two states (Mississippi and Colorado) have new legislative mandates for newborn hearing screening, there is still a possibility that legislation will pass in two others (Massachusetts and New York), and all of the others received very positive hearings and have generated increased support and expanded public awareness about the feasibility and benefits of newborn hearing screening. It is expected that legislation will be resubmitted in 1998 for all of the states named above who have not yet passed a legal mandate, in addition to a number of other states.

Mississippi and Colorado have new legislative mandates for newborn hearing screening

If your state has not yet considered a legislative mandate, you may want to review the legislation passed or proposed elsewhere for relevant ideas. The complete text

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Using EPSDT to Support Newborn Hearing Screening

Asa part of its Medicaid Program each state is required to have an EPSDT (Early and Periodic Screening, Diagnosis, and Treatment program. By using the EPSDT program in a way that may be of interest to other states, Thomas Mahoney, the Director of Hearing, Speech and Vision Services for the Utah Department of Health, has found that the EPSDT program can substantially assist in the efforts to make newborn hearing screening the standard of care in Utah. Briefly, this is how it works: EPSDT (which is sometimes known by another name in some states) uses Medicaid money to pay for a range of screening, diagnostic, and treatment services (many of which are preventive) for Medicaid eligible children. Each state has a great deal of flexibility in determining what services will be included in EPSDT in their state. By adding a paragraph to the EPSDT regulations, Utah added hearing screening during the first well-baby check (that happens prior to hospital discharge) to the list of services that can be provided by EPSDT. Consequently, as of November 1, 1996, Medicaid pays for newborn hearing screening done with otoacoustic emissions or auditory brainstem response. If the screening is done in a rural hospital, the payment is in addition to the birthing charge. In non-rural hospitals, it is included in the established DRG (Diagnostically Related Group) for the birthing costs. However, the next time the cost for the DRG is negotiated, hearing screening can be added as an additional cost. Because states must match Medicaid expenditures with state money and because it only pays for Medicaid eligible children, EPSDT is not a solution to all your funding concerns, but it can be used to help solve the problems many states are having with finding a way to pay for newborn hearing screening. More information about using EPSDT to support the costs of newborn hearing screening is available from yweir@fs1.ed.usu.edu or 801-797-1121

Legislative Mandates .....

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of the legislation in each of the 12 states who have passed or recently proposed legislation is on the legislative activity page of NCHAM's web site (www.usu.edu/~ncham) or a summary is available by writing NCHAM. If your state is considering legislation, or if you have any updated information about legislative activity in your state contact us at the web site or e-mail yweir@fs1.ed.usu.edu and we will add it to the web site information so that everybody can know what is happening.

The basic contents of the legislation recently passed in Colorado and Mississippi is given below:

Colorado. On May 28, 1997 legislation was signed into law to implement newborn hearing screening for all babies born in Colorado. The legislation required several activities to address the General Assembly's clearly stated intent that at least 85% of all newborns in the state would be screened for hearing loss by July 1, 1997. First, an Advisory Committee was appointed to make a thorough study and recommend an implementation plan to the General Assembly by December 1, 1998. The committee is also to report at that time the number of hospitals who have voluntarily implemented newborn hearing screening programs. Second, beginning July 1, 1997, all hospitals in the state are required to educate parents of all newborns about the importance of screening the hearing of newborn infants and follow-up care. Third, if the number of infants screened does not exceed 85% of all births by July 1, 1999, the Board of Health is directed to promulgate rules requiring screening of newborn infants.

Mississippi. Legislation passed in the 1997 session in Mississippi requires that by July 1, 1997 any newborn child in a hospital is to be tested or evaluated to determine if the child has a hearing impairment. The law also requires that by July 1, 1998, the State Department of Health is to have a registry in place to keep track of all infants who do not pass the newborn screening test. The legislation also gives the Department of Health authority to adopt rules and regulations necessary to implement the program, to establish an advisory committee, and stipulates that the state legislature is to provide fiscal support to the department to assure the best possible development outcomes for infants and toddlers identified through the screening program.

Product Review: Clarity System

SonaMed Corporation
1250 Main Street
Waltham, MA 02154
1-800-Sonamed

The Clarity is a combined DPOAE and ABR screener. It is a portable device that can be used with either a laptop or desktop system. The program is Windows-based and for those comfortable with Windows, it takes approximately one hour to become familiar with the screening program. Individuals who are not familiar with Windows, as well as those unfamiliar with ABR preparation and electrode placement, will need more training time on the equipment.

The Clarity system can function in several modes. It comes loaded with an automated screening mode and different protocols, created through a password-protected option, to run either distortion product emissions or ABR." The following are the system specifications:

ABR Stimuli: Frequency range 500 - 8000 Hz
click, toneburst
Level: 10 - 60 dB nHL

DPOAE: Stimuli: Pure tone pairs 500 - 8000 Hz
Specifiable F1:F2 ratio
Level: 20 - 85 dB SPL

For both tests, the results can be displayed as single series, overlays, and left and right ears. The test time is protocol dependent. If the default screening mode is used test time is approximately 15 minutes per baby, not including preparation time.

The system contains a patient management data base that allows the screener to store, review and print all waveforms and patient demographics.

"The product review section of this newsletter is not intended as a product endorsement. For further information, please contact the company directly"

Universal Newborn Hearing Screening Programs in the U.S.A.

State	Name of Hospital (Operational since)
AL	Huntsville Hospital (1995)
AZ	Flagstaff Med. Cen. (1993) Scottsdale Memorial North (1994) Scottsdale Memorial Osborne (1995)
AR	Arkansas Children's (1993) Conway (1995)
CO	Boulder Community Hospital (1992) Colorado Plains Med. Cen. (1993) Colorado Spring Memorial (1995) Heart of the Rockies Med. Cen. (1994) Kit Carson County Hospital (1995) Lincoln Community Hospital (1996) Mercy Med. Cen. (1993) Mt. San Rafael Hospital (1996)
CT	Lawrence & Memorial (1994)
DOD	Brooke Army Med. Cen., Tx (1996) 6th Medical Group-MacDill Air Force Base (1995) Dwight D. Eisenhower Army Med. Cen., Ft. Gordon, GA (1995) Ft Campbell, KY-Blanchfield Army Com. Hospital (1994) Ft. Jackson, Moncrief, SC (1995) Ft. Polk, LA - US Army Community Hospital (1995) Naval Hospital - Camp Pendleton (1994) Tripler Army Med. Cen-Honolulu, HI (1996) William Beaumont Army Med. Cen., El Paso, TX (1995)
FL	Bay Med. Cen. (1986) Winter Park Memorial Infant Hearing Program (1984)
GA	Phoebe-Putney Memorial (1994) Promina Kennestone Hospital (1995) St. Joseph Hospital (1994) University Hospital (1994)
HI	Castle Med. Cen. (1995) Kapiolani Med. Cen. (1994) Kaiser Med. Cen. (1992) Maui Memorial Hospital (1993) Queens Med. Cen. (1993)

State	Name of Hospital (Operational since)
IL	Covenant Hospital (1986) Illinois Masonic Med. Cen. (1996)
IA	Finley Hospital (1996) Jackson County Public Hosp. (1996) Muscatine General Hospital (1996)
KS	Via Khristi Regional MedCen (1995)
KY	Baptist East Hospital (1995) Hardin Memorial (1995) Mary Chiles Hospital (1995) Med. Cen. of Bowling Green (1994) Murray-Calloway (1995) Pikeville United Methodist (1992) University of Louisville (1994) University of Kentucky (1994) Western Baptist Hospital (1994)
LA	**Beauregard Memorial Hosp. (1994)** Bossier Med. Cen. (1994) HCA Highland Hospital (1995) Homer Memorial Hospital (1995) Lake Area Med. Cen. (1993) Leonard J. Chabert Med. Cen. (1993) Riverland Med. Cen. (1994) St. Patrick Hospital University Med. Cen. (1994) West Calcasieu-Cameron (1994)
MA	Harrington Hospital (1996) Mt. Auburn Hospital (1994)
MI	Constance Brown Hrg & Speech Cen Crittendon (1996) Lakeland Reg. Health Sys-Lakeland Hrg & Speech (1995) Memorial Health Care Cen. (1995) William Beaumont Hospital (1994)
NJ	Hackensack Med. Cen. (1994) Overlook Hospital (1994) Pascack Valley Hospital (1996) St. Barnabas Med. Cen. (1992)
NY	St. Charles (1995) Long Island Jewish (1995) "Montifiore" Albert Einstein College of Medicine - Jacobi Medical Center (1995) Stonybrook Hospital (1995) Strong Memorial (1995) St. Joseph Riverside (1994)

If you have additions or corrections to this listing, please contact: Yusnita Weirather. Fax: 801-797-1448
Please use the reply form on page 10.

State	Name of Hospital (Operational since)
OR	Emanuel (1996)
PA	Nesbitt Hospital (1994)
RI	Fatima Hospital (1994) Kent County Hospital (1994) Landmark Medical Center (1994) Newport Hospital (1994) Pawtucket Memorial Hospital (1994) South County Hospital (1994) Westerly (1994) Women & Infants (1993)
TX	Charlton Methodist (1995) Harris Methodist, Ft. Worth (1992) Hearing and Speech Care Cen. at Univ. Med Cen (1995) Methodist Med.Cen., Dallas (1994) Plaza Medical, Ft. Worth (1995) Presbyterian Hosp., Dallas (1993) Wadley Regional Med. Cen. (1995)
UT	Lakeview (1995) LDS Hospital (1995) Logan Regional Hospital (1993) McKay Dee (1995) Ogden Regional Med. Cen. (1995)
VA	Medical College of Virginia (1994)
DC	Georgetown Univ. Med. Cen. (1994)
WY	Cambell County Memorial (1995) St. John's Hospital (1994) West Park Hospital (1995)

Can Outpatient .....

(Continued from page 2)

staff in the Nursery/NICU, according to guidelines established by the Joint Committee on Infant Hearing , and an audiologist is available for an hour each weekday morning to screen these infants prior to discharge using TEOAE. Parents of well babies receive information on the importance of early screening for hearing loss and are instructed to schedule a hearing screening appointment with the Audiology/ ENT Clinic prior to discharge. Well babies are screened in the Clinic before two months of age by a nursing assistant using TEOAE; the primary care physician then verifies that the screening was done at the two-month well-baby visit. Obviously, this type of program requires a tremendous amount of cooperation from parents and participating physicians alike, but so far seems to be working very well.

Can an outpatient-based newborn hearing screening program successfully provide universal screening?

Gil Herer, Ph.D., audiologist and Chair of the Department of Hearing and Speech at Children's National Medical Center (CNMC) in Washington, D.C. is not so optimistic about the feasibility of outpatient universal newborn screening programs in the civilian sector, however. Dr. Herer initiated a universal outpatient screening program several years ago by contacting all of CNMC's referral sources with information regarding the importance of early identification and intervention and also made OAE screenings available at the CNMC's Children's Hosptal and five satellite outpatient centers. According to Dr. Herer, while some physicians referred some of their newborn patients, particularly those with risk factors, most did not refer any at all. Despite continuing public relations efforts with physcians for a year, the response remained poor. Since that time, Dr. Herer has undertaken universal inpatient screening with a consortum of cooperating hospitals under the umbrella program of CNMC.

One of the hospitals, Holy Cross Hospital in Silver Spring, MD, has over 7,000 births per year. Three full-time technicians do the screenings using TEOAE as the first order method, and screening ABR as needed seven days per week. Although it has been in effect only since February of 1997, the Holy Cross Hopsital program shows every indication of being a very successful large program. The other universal program operating in cooperation with CNMC is Calvert Memorial Hospital in Calvert Co., MD, which began in September 1996 and births 1,000 babies a year.

Dr. Herer currently favors an inpatient screening program in the civilian population due to inconsistent referrals from pediatricians and family practitioners, but stated that perhaps with more aggressive public relations work, an outpatient program may yet be successful. An outpatient screening at the time of the one-month well-baby examinations program may be feasible where a managed-care plan provides direct comprehensive healthcare services including pediatrics and audiological services and where screening is the standard of care in a healthcare delivery system.

Will the outpatient universal newborn hearing screening program at Darnall Army Community Hospital maintain its initial success? Much will depend on the continued cooperation of medical staff and parents. But if the initial enthusiasm for the program is any indication, the outlook is very promising. The medical staff in the primary care centers at Darnall briefed extensively on the benefits of early screening and intervention prior to the start of the program and are very excited about it, while support from the broader medical community is also excellent. The discharge planning staff stresses the importance of keeping hearing screening appointments to parents and, in general, the return rate for followup care and well-baby checks at U.S. Army hospitals tend to be quite high. Follow-up is fostered by the fact that military dependents tend to live in proximity to the birthing hospital, which is ususally on the military post, and that they return to one of the primary care clinics at that hopsital for all follow-up care. In addition, a complete outpatient medical record containing recommendations and test results is maintained for each family member, accompanies him/her to all medical appointments, and is transferred if the service member and family are assigned to a new duty station. This helps to ensure that care is continuous, and that recommendations for follow-up are carried out. Hopefully, a high percentage of healthy newborns at Ft. Hood will continue to be screened on an outpatient basis prior to the two-month well-baby check.

For more information about this outpatient program, please contact:
Lt. Rhonda Fleener
817-288-8490

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