



NEWBORN HEARING SCREENING NATION'S PROGRESS PLATEAUS SHORT OF GOAL

BY KARL R. WHITE, PH.D.

In March 1993, the National Institutes of Health recommended that all newborns be screened for hearing loss prior to being discharged from the hospital. More than a decade later, our nation is still struggling to achieve the goal of universal screening. The current annual screening rate is nearly 90 percent of all newborns and while this is certainly an improvement from the 25 percent reported in 1999 and 69 percent as recently as 2002, it represents only a 3 percent increase from a year ago, marking a significant slowdown.

In addition, an analysis of an annual state-by-state survey of Early Hearing Detection and Intervention (EHDI) programs revealed that most states continue to be primarily dependent on short-term federal grant

monies to operate. Considering that the Bush administration has proposed eliminating all funding for EHDI grants from the 2005 budget, programs relying on federal funds are extremely vulnerable.

Release of the 2004 national screening rate, state figures and a discussion of this good news/bad news scenario took place at a May 5th press conference on Capitol Hill as part of the annual Hearing Healthy Kids Day. The press conference also marked the official launch of the World Council on Hearing Health (WCHH), a global initiative of the Deafness Research Foundation (DRF), one of the sponsors of the Hearing Healthy Kids project. Others include the American Academy of Pediatrics (AAP) and the National Center for Hearing Assessment and Management (NCHAM).

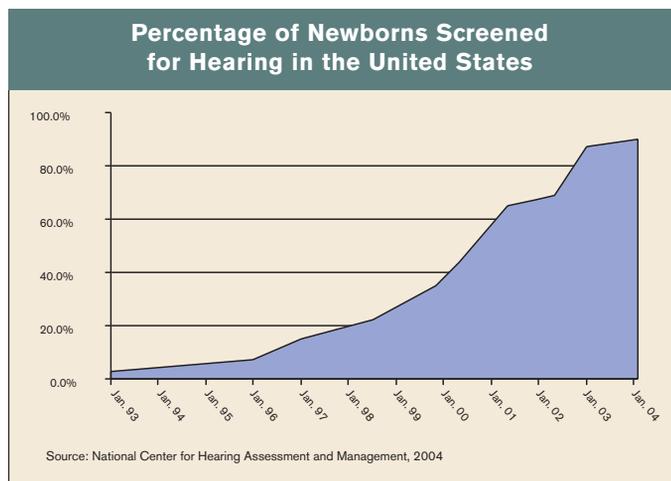
Speaking at the event, U.S. Rep. James Walsh cautioned that although progress toward truly universal newborn hearing screening is good, we still have a great deal of work to do to ensure that all babies with hearing loss are identified during the first few months of life and pro-

vided with the services they need. Walsh has championed early screening for nearly 15 years and was the primary sponsor of legislation effective since 2000 that provides states with financial assistance to build EHDI programs. This relatively modest federal appropriation has had far reaching impact – *all* of the nation's states have begun program development.

Following Walsh at the podium, Reps. Jim Ryun and Carolyn McCarthy, fellow members of the Congressional Hearing Health Caucus, chimed in with their support of ongoing federal funding to assist in the expansion and improvement of the statewide programs. Both of them noted the benefits for children and their families when permanent hearing loss is identified early and they are provided with appropriate services.

Their points were poignantly reinforced with remarks by Jackie Busa, mother of Colton, 4, and Olivia, 6, both with congenital hearing loss. Colton's was detected at birth by a universal newborn hearing screening program newly in place in northern Virginia where the Busas reside. Olivia was less fortunate in that her loss was not identified until she was 2 years old. Colton uses a cochlear implant and Olivia wears hearing aids.

Like thousands of other families across the country, the Busas know firsthand the frus-





At Hearing Healthy Kids Day on Capitol Hill, Colton and Olivia Busa enthusiastically lead the Pledge of Allegiance for (from left) DRF Exec. Dir. Sue Greco, Dr. Karl White, Rep. Jim Ryun, Jackie Busa and Reps. Carolyn McCarthy and Jim Walsh. WCHH's Hearing Healthy Van was on hand to offer free hearing tests throughout the day. PHOTO COURTESY OF DRF

trations and challenges of late identification as in Olivia's case and as her mother so movingly described. Busa spoke too about the immense difference it makes when a child is identified at birth as was Colton. And she shared how valuable it has been for her family to have access to the type of coordinated services states are striving to create with federal funding.

Data collected from state EHDI coordinators in NCHAM's recent survey emphasizes the importance of the integration of newborn screening with other components in order to have an exemplary program. To be fully effective, screening must be connected

to pediatric audiology services, appropriate early intervention programs, family support and tracking and data management activities to make sure all babies and families receive appropriate and necessary services. EHDI programs also need to be coordinated with the child's primary healthcare provider, often referred to as the child's medical home.

Finally, even though temporary financial assistance from the federal government continues to be critical to assist states in developing comprehensive EHDI programs, it is extremely important that states develop alternative sources of ongoing funding.

NCHAM assessed the following variables

in its analysis of each state's EHDI program:

- Percentage of newborns screened for hearing loss prior to 1 month of age
- Portion of funding that comes from sources controlled by the state as opposed to temporary federal grant programs
- Degree of development of a comprehensive program with necessary components to complement newborn screening, which are:

- 1) guidelines and support for pediatric audiological assessments
- 2) coordination and cooperation with the state's early intervention program for infants and toddlers with disabilities
- 3) communication of screening results to the baby's medical home
- 4) provision of appropriate educational materials for parents and physicians concerning newborn hearing screening and services for infants and toddlers identified with hearing loss
- 5) reporting of screening results to the state Department of Health for tracking and follow-up services
- 6) systematic evaluations of the EHDI program for program improvement and quality assurance

Based on the above criteria, DRF/WCHH used the NCHAM data to rate the success of each state in implementing its EHDI program and to develop an annual state report card.

RATING OF EHDI PROGRAM IMPLEMENTATION

EXEMPLARY

- 95 percent or more of newborns screened
- Four or more of six complementary EHDI program components in place
- Less than 50 percent of funding from temporary federal grants

EXCELLENT

- 94 percent or more of newborns screened
- Three or fewer of six com-

plementary EHDI program components in place

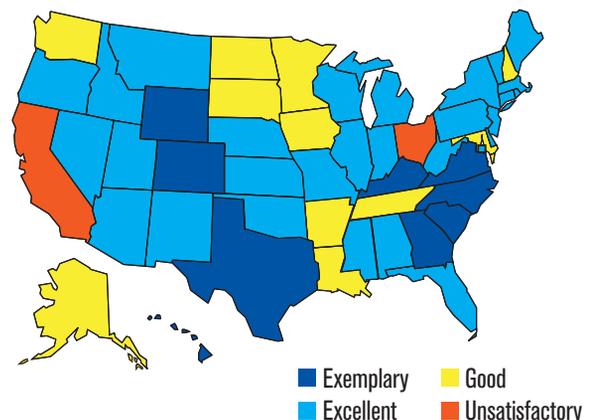
- Or most of the funding for the program comes from temporary federal grants.

GOOD

- 80 to 94 percent of newborns screened.

UNSATISFACTORY

- Fewer than 80 percent of newborns screened



Based on May 2004 data from the National Center for Hearing Assessment and Management. Grading scale based on evaluation by Deafness Research Foundation/World Council on Hearing Health.

As indicated on the report card at right and the color-coded map on p. 20, nine states achieved an exemplary rating, an impressive showing. Two states, California and Ohio, were rated as unsatisfactory. The primary problem in each of these states is that too few babies are being screened prior to hospital discharge. The majority of states received excellent and good ratings but much remains to be done to make sure that babies and families receive the benefits they need and deserve.

Most urgent is the funding issue. In fact, EHDI coordinators from eight states indicated that their program would cease to exist if federal funding were eliminated in 2005. An additional 26 reported that the loss of federal backing would cause major problems in providing services.

Clearly, an increase in allotments of state monies to EHDI efforts is essential. It is key to program survival should state grants be excluded from the federal budget and to our nation finally attaining the goal of universal newborn hearing screening.

DRF/WCHH, in collaboration with constituents, fellow advocacy groups, professional organizations and legislators, continues to work to restore federal funding for 2005 to the current levels. For more information about the status of EHDI programs in your state, visit www.infanthearing.org. For details about legislative advocacy efforts, go to WCHH's online legislative action center at www.wchh.com. ■

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2004 EHDI National Report Card

STATE	% Screened 2003 / 2004	State EHDI Legislation	State Funds > 49% of Program	Rating
Alabama	90.0% / 95.0%			Excellent
Alaska	71.0% / 81.0%			Good
Arizona	95.0% / 95.0%			Excellent
Arkansas	91.0% / 91.3%	X		Good
California	57.7% / 66.0%	X	X	Unsatisfactory
Colorado	96.0% / 97.0%	X	X	Exemplary
Connecticut	97.0% / 99.8%	X		Excellent
Delaware	98.0% / 98.0%			Excellent
District of Columbia	99.5% / 98.0%	X		Excellent
Florida	96.0% / 98.0%	X		Excellent
Georgia	98.8% / 98.0%	X	X	Exemplary
Hawaii	98.3% / 98.0%	X	X	Exemplary
Idaho	97.6% / 97.0%			Excellent
Illinois	97.0% / 98.0%	X		Excellent
Indiana	97.1% / 99.9%	X		Excellent
Iowa	84.0% / 80.0%			Good
Kansas	95.0% / 95.0%	X		Excellent
Kentucky	99.0% / 99.5%	X	X	Exemplary
Louisiana	89.6% / 93.2%	X	X	Good
Maine	90.0% / 98.0%	X		Excellent
Maryland	87.0% / 85.2%	X		Good
Massachusetts	99.0% / 99.7%	X		Excellent
Michigan	93.0% / 95.0%			Excellent
Minnesota	90.3% / 92.0%			Good
Mississippi	95.0% / 98.0%	X	X	Excellent
Missouri	96.9% / 97.7%	X		Excellent
Montana	94.0% / 95.0%	X		Excellent
Nebraska	92.0% / 97.0%	X	X	Excellent
Nevada	94.0% / 97.0%	X		Excellent
New Hampshire	79.0% / 90.0%	X		Good
New Jersey	96.7% / 98.3%	X		Excellent
New Mexico	94.0% / 94.0%	X		Excellent
New York	95.0% / 95.0%	X		Excellent
North Carolina	99.1% / 98.0%	X	X	Exemplary
North Dakota	70.0% / 92.0%			Good
Ohio	22.0% / 33.0%	X	X	Unsatisfactory
Oklahoma	94.0% / 94.0%	X	X	Excellent
Oregon	97.0% / 94.0%	X		Excellent
Pennsylvania	86.0% / 95.7%	X	X	Excellent
Rhode Island	99.3% / 99.6%	X	X	Excellent
South Carolina	98.4% / 98.1%	X	X	Exemplary
South Dakota	88.0% / 85.6%		X	Good
Tennessee	90.0% / 90.0%			Good
Texas	97.0% / 99.0%	X	X	Exemplary
Utah	97.5% / 98.2%	X		Excellent
Vermont	94.7% / 95.0%			Excellent
Virginia	95.2% / 99.7%	X	X	Exemplary
Washington	62.2% / 85.0%			Good
West Virginia	96.0% / 95.0%	X		Excellent
Wisconsin	93.0% / 95.0%	X		Excellent
Wyoming	98.0% / 98.0%	X	X	Exemplary
TOTAL	85.6% / 89.7%			



Newborn
Hearing
Screen
Program

Hearing Health's presentation of the 2004 EHDI report is made possible by PEDIATRIX, www.pediatrix.com, 800.243.3839 V.