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 provided 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 frustration of being discharged from the hospital without a hearing screening. They have championed for a universal newborn hearing screening program and have worked tirelessly to ensure that all babies are screened for hearing loss.

Their story is a testament to the importance of early detection and intervention. By the time Olivia was identified, it was too late for her to receive the appropriate treatment to help her develop language and communication skills. The Busas’ experience highlights the importance of universal newborn hearing screening and the need for ongoing federal funding to support these programs.

The Busas’ story is one of hope and resilience, and it is an inspiration to all families who have children with hearing loss. They remind us of the importance of early detection and intervention, and the vital role that policymakers play in ensuring that all babies have access to these crucial services.
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.
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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