

Management of CH; the importance of three year follow-up

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Newborn screening for congenital hypothyroidism (CH) was adopted several decades ago and is nearly universal in the United States¹. In order to prevent permanent cognitive and physical delays, infants must be quickly and properly identified and treated. In addition, follow-up of these children for the first three years of life is essential to ensure they receive appropriate treatment and management. The American Academy of Pediatrics (AAP) guidelines² recommend follow-up of CH cases until at least age three, however there is concern by many endocrinologists that many children are not receiving this crucial three year follow-up.

In 2009, Michigan's Newborn Screening Program, in cooperation with the Michigan Pediatric Endocrine Advisory Council (PEAC) and Region 4, collected data on 45 children three years after diagnosis. Many of the children were receiving active treatment by the endocrinologist or pediatrician of record. For cases considered lost to follow-up, alternative sources for case finding were used. The Michigan Care Improvement Registry (MCIR), which includes information about providers of childhood immunizations and was readily accessible, was selected as a source for information. Contact was made with providers identified through MCIR to determine whether testing and/or treatment for CH was continuing. In a few cases where current care providers could not be identified, the program made direct contact with the parents to obtain the information.

Based on Michigan's data, a surprising number of children diagnosed with CH during the newborn period are no longer being treated for CH at three years of age. While a re-evaluation by TSH challenge is recommended practice, only two of the 13 children no longer being treated had been re-evaluated using the challenge. At least eight families stopped treatment on their own accord.

Region 4 recently established a CH Workgroup, chaired by Kupper Wintergerst, MD from the University of Louisville. Endocrinologists and state follow-up representatives from each Region 4 state will build on previous activities by expanding data collection to the other six Region 4 states. The study will increase the understanding of when and why treatment is discontinued for children diagnosed with CH. The CH Workgroup will use the data to develop guidelines for state follow-up systems to support the standard of care recommended by AAP. It is anticipated that these efforts will result in a decrease in the number of children diagnosed with CH whose treatment is discontinued without re-evaluation by TSH challenge.

¹ National Newborn Screening and Genetics Resource Center. All states screen for CH. <http://genes-r-us.uthscsa.edu/nbdisorders.doc> (Last retrieved from on 07/08/2009).

² http://www.guideline.gov/summary/summary.aspx?doc_id=9383&nbr=005029&string=congenital+AND+hypothyroidism (last retrieved 6/18/2009).