

Medical Management of Congenital Hypothyroidism: The Importance of 3-Year Follow-up

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 North America, more than 5 million newborns are screened and approximately 1400 infants with CH are detected annually.³ A small number of infants with abnormal screening values will have transient hypothyroidism.⁴ Because the transient nature of the hypothyroidism will not be recognized clinically or through laboratory tests in some infants, initial treatment will be similar to that in any infant with permanent CH. In these cases, it is important to determine at some later time whether the hypothyroidism is permanent and whether the infant in fact requires lifelong treatment.⁵

According to Parks, et.al, “all children diagnosed with hypothyroidism, except those with confirmed thyroid aplasia, should receive a trial off of therapy at 3 years of age to determine if the hypothyroidism is transient.⁶ If no permanent cause of CH was found by scan or there was no TSH increase after the newborn period, then an aggressive follow-up regimen should be implemented some point after the child is 3 years of age.⁷ This includes 1) discontinuing treatment for 30 days and 2) after 30 days without treatment, obtaining a measurement of FT4 and TSH serum values. It is critical that this follow-up laboratory assessment be obtained in a timely manner and there be no loss to follow up.⁸

It appears that many US children with CH may have treatment discontinued inappropriately. This could potentially cause long-term harm for at least some children with permanent CH. Unfortunately, newborn screening program records are inadequate for the surveillance of CH, both to assess prevalence and time trends. Without additional data, we cannot determine the degree to which discontinuation of thyroid hormone treatment may be appropriate. Public health

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).

³ Rose, Susan R. and the American Academy of Pediatrics Section on Endocrinology and Committee on Genetics; Brown, Rosalind S. and the American Thyroid Association Public Health Committee; and Lawson Wilkins Pediatric Endocrine Society. Update of Newborn Screening and Therapy for Congenital Hypothyroidism. *Pediatrics* 2006; 117;2290-2303.

⁴ ibid

⁵ ibid

⁶ Parks, John S.; Lin, Michelle; Grosse, Scott D.; Hinton, Cynthia F.; Drummond-Borg, Margaret; Borgfeld, Lynett; and Sullivan, Kevin M. The Impact of Transient Hypothyroidism on the Increasing Rate of Congenital Hypothyroidism in the United States. *Pediatrics* 2010; 125;S54-S56.

⁷ ibid

⁸ ibid

responsibility requires the collection of long-term follow-up data to address these fundamental questions. Such data need to include findings from laboratory tests of thyroid hormone status and be representative of all children with CH, not just those managed by pediatric endocrinologists.⁹

⁹ Kemper, Alex R., Ouyang, Lijing; Grosse, Scott D. Discontinuation of thyroid hormone treatment among children in the United States with congenital hypothyroidism: findings from health insurance claims data. *BMC Pediatrics* 2010, **10**:9doi:10.1186/1471-2431-10-9