Arkansas Department of Health

Newborn Screening Result: Elevated TSH Interpretation Sheet for Parents Infant may have Congenital Hypothyroidism

You have just heard that your infant may have Congenital Hypothyroidism (CH). Please understand that the newborn screening is just that – a screening test. Not all cases that are screened positive will have a diagnosis of CH. Further testing is required to confirm or rule out the diagnosis.

What is congenital hypothyroidism?

Congenital hypothyroidism, also called CH, is a condition that is present at birth. Babies with CH do not make enough thyroid hormone. Thyroid hormone is made by the thyroid gland, which is a butterfly-shaped organ found at the base of the neck. Babies need thyroid hormone for normal physical growth and mental development.

What causes CH?

If the thyroid gland is missing or underdeveloped, there will be inadequate production of thyroid hormone.

Why is newborn screening done for congenital hypothyroidism?

A few babies show symptoms of CH at birth, though most babies do not show effects right away. Babies are protected by their mother's thyroid hormone for the first few weeks of their life. After about 3 or 4 weeks, babies have to produce their own thyroid hormone. If they don't produce enough, symptoms will begin to show. It is likely that the baby has already suffered lasting damage once symptoms show. Newborn screening allows for early diagnosis of babies with CH. If babies are diagnosed early and treatment begins quickly, infants will usually develop normally. In the United States, about 1 in every 3,000 to 4,000 babies born has CH.

Does a positive result of newborn screening mean that a baby has congenital hypothyroidism?

No, not necessarily. This is only a screening test. Your baby will need specific tests to determine if he or she has CH.

What are the signs and symptoms of congenital hypothyroidism?

If CH is not treated, some signs that may occur in early infancy are:

- Jaundice: a yellow color to their skin or the whites of their eyes.
- Feeding problems
- Sleep more than usual
- Low muscle tone (hypotonia)
- Pale, dry, cool skin
- Umbilical hernia
- Swelling of the tongue
- Puffy eyes
- Poor growth
- Constipation

How is congenital hypothyroidism diagnosed?

After receiving a positive newborn screen, the most important thing parents can do is be sure that their baby goes in for a new specimen to be collected and tested as soon as possible.

How is congenital hypothyroidism treated?

Babies will require life-long treatment, and are given daily medication to replace the missing thyroid hormone that the baby needs for growth and development. Babies who start treatment soon after birth usually have normal development and intelligence.

Where can I get additional information? http://www.arkansas.gov/

newborn_screening/index.html