

## Parent Education and Medical Treatment Survey for Congenital Hypothyroidism Diagnosed by Newborn Screening

### Patient Information:

Child's Birth Date	Child's Name		Parent's Name	
	Last	First	Last	First
DD-Mon-YY	LastName	FirstName	LastName	FirstName

- 1.) Are you a parent or legal guardian of the child listed in the above table [check one]?
  - a.  Yes (if yes, proceed to question 2)
  - b.  No; **If no, please call ###-###-#### to notify Health Department and/or return this survey in the attached self-addressed stamped envelope.**
  
- 2.) What state performed the Newborn Screening for your child?
  - a.  Illinois
  - b.  Indiana
  - c.  Kentucky
  - d.  Michigan
  - e.  Ohio
  - f.  Wisconsin
  
- 3.) Was your child diagnosed with Congenital Hypothyroidism by a Newborn Screen blood test?
  - a.  Yes
  - b.  No (please contact ###-###-#### and/or return this survey in the attached self-addressed stamped envelope)
  
- 4.) What information did you receive about Congenital Hypothyroidism at the time your child was diagnosed? [check all that apply]
  - a.  Face-to-face education was provided by my child's general pediatrician
  - b.  Face-to-face education was provided by my child's thyroid doctor (pediatric endocrinologist)
  - c.  Printed literature was given to me
  - d.  Internet references were given to me to look up on the computer
  - e.  I received information about my child's diagnosis in the mail
  - f.  No education was provided (proceed to #6)
  
- 5.) What informational resource about Congenital Hypothyroidism was or would be the most helpful? [check all that apply]
  - g.  Face-to-face education provided by my child's general pediatrician
  - h.  Face-to-face education provided by my child's thyroid doctor (pediatric endocrinologist)
  - i.  Printed literature given to me
  - j.  Educational CD or DVD given to me
  - k.  Internet references given to me to look up on the computer
  - l.  Information that I receive in the mail
  - m.  Information that I look up on the internet on my own
  
- 6.) Were you satisfied with the information that you received about your child's diagnosis? [check all that apply]
  - a.  Yes, I was satisfied
  - b.  No, I would have liked to receive more information from my pediatrician
  - c.  No, I would have liked to receive more information from the endocrinologist (thyroid doctor)
  - d.  No, I would have liked to receive more information from the state Health Department

e.  No, I would have liked to receive more guidance from internet websites

**7.) Whom would you most want to provide you with educational material about your child's thyroid treatment? [choose one]**

- a.  Your child's pediatrician
- b.  Your child's pediatric endocrinologist (thyroid doctor)
- c.  The state Health Department/Newborn Screening Lab
- d.  The American Academy of Pediatrics
- e.  Other (please specify): \_\_\_\_\_

**8.) Was your child started on thyroid treatment for Congenital Hypothyroidism [check one]?**

- a.  Yes
- b.  No (you may stop survey)

**9.) Is your child currently still being treated for Congenital Hypothyroidism [check one]?**

- c.  Yes
- d.  No (proceed to question #11)

**10.) If your child is still being treated, did the doctor ever stop the thyroid medication temporarily to see if it was needed any longer (called a TSH challenge test)? [check one]**

- a.  Yes, but the medication had to be re-started
- b.  No, because the doctor said that it was a permanent thyroid problem
- c.  No, but the doctor is planning to do it
- d.  No, and I do not know if it is planned

**11.) If your child is no longer on thyroid medication, when was the treatment stopped? [check one]**

- a.  Less than 6 months of age
- b.  6 months – 1 year of age
- c.  1 – 2 years of age
- d.  2 – 3 years of age
- e.  Greater than 3 years of age

**12.) Who stopped the treatment? [check all that apply]**

- a.  My child's pediatrician stopped the treatment (proceed to question #13)
- b.  My child's endocrinologist (thyroid doctor) stopped the treatment (proceed to question #13)
- c.  I stopped the treatment
- d.  No one; the prescription ran out
- e.  Other (please specify): \_\_\_\_\_

**13.) If you stopped the thyroid treatment was it because of any of the following reasons? [check all that apply]**

- a.  I did not think my child needed it anymore
- b.  The prescription ran out
- c.  I could not afford the thyroid medication
- d.  I had difficulty arranging for transportation to the pharmacy
- e.  I was unable to get off of work for my child's doctor appointments

**14.) Systematic Notification for Thyroid Testing:** Please indicate the level of benefit to your family if the state Newborn Screening program systematically contacted you when your child reached their 3<sup>rd</sup> birthday for re-evaluation of their thyroid? [check one]

- a.  Extremely helpful
- b.  Somewhat helpful
- c.  Not helpful

**Thank you very much for you assistance and contribution to our efforts to improve  
the Newborn Screening Program!!**