

Dear Dr. _____,

The Michigan Department of Community Health's Newborn Screening Follow-up Program and the Pediatric Endocrinology Medical Management Center at the University of Michigan are interested in follow-up of congenital hypothyroidism (CH) patients at three years of age who had borderline elevations of serum thyroid stimulating hormone (TSH) levels when diagnosed. This survey is intended to inquire about treatment and diagnostic re-evaluation.

Data collected by this survey will be used to determine the rate of transient CH among cases identified by Michigan Newborn Screening. We hope to use these data to inform both diagnostic and treatment standards for CH in Michigan. Your participation in this survey is extremely important and will contribute to our understanding of transient vs. chronic CH.

Please provide the information requested below and return via fax or mail to:

*Newborn Screening and Coordinating Program
Endocrine Follow-Up Office
PO Box 5718
UMMC-MPB, D1221
Ann Arbor, MI 48109-5718
Phone: 734-647-8938
Fax: 734-936-7918*

We sincerely thank you for your participation,

William I. Young, Ph.D., Manager, Newborn Screening Program, Bureau of Epidemiology, Division of Genomics, Perinatal Health and Chronic Disease Epidemiology, Michigan Department of Community Health, P.O. Box 30195, 201 Townsend St., Lansing, MI 48909

Mary J. Kleyn, M.Sc., Newborn Screening Epidemiologist, Maternal and Child Health Section, Bureau of Epidemiology, Division of Genomics, Perinatal Health and Chronic Disease Epidemiology, Michigan Department of Community Health, P.O. Box 30195, 201 Townsend St., Lansing, MI 48909

Chris Hoeft-Loyer, M.S., Newborn Screening and Coordinating Program, Endocrine Follow-Up Office, UMMC-MPB, D1221, Box 5718, Ann Arbor, MI 48109-5718

Diagnostic Verification Survey of Endocrinologists Treating Children Identified by Michigan Newborn Screening as Having Congenital Hypothyroidism and Borderline Thyroid Function

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 or your group's practice providing care for the patient listed in the above table [check one]?

Yes (if yes, proceed to question 2)
 No (proceed to 1.1)

1.1 If no, do you know the patient's current health care provider?

Name: _____

Address: _____

Phone: _____

Fax: _____

2) Is the patient currently being treated for CH [check one]?

Yes (proceed to 2.1)
 No (proceed to 2.2)

2.1 IF on treatment,

2.1.a What is the patient's current CH medication dosage? _____

2.1.b Has the treatment dosage increased over the past 3 years [check one]?

Yes (proceed to question 3)
 No (proceed to question 3)

2.2 IF not on treatment,

2.2.a Why was the treatment stopped?

2.2.b When was the treatment stopped (mm/dd/yyyy)? _____

2.2.c What is your protocol for following up patients after treatment cessation? _____

3) Does the patient have a sibling with CH [check one]? Yes No

4) Has the patient's CH diagnosis been re-evaluated [check one]?

Yes (proceed to 4.1) No (proceed to question 5)

4.1 If the patient's CH diagnosis was re-evaluated, what was the result [check one]?

Diagnosis Confirmed or Diagnosis Not confirmed

4.1.a How did you make your decision to re-evaluate the patient's CH diagnosis?

4.1.b How was the patient's diagnosis re-evaluated [check one]?

Thyroid challenge was conducted by decreasing the dosage of levothyroxine and then evaluating thyroid function (Free T4/ Serum TSH levels).
 Other (specify): _____

4.1.c At what age was the patient's CH diagnosis re-evaluated? _____

4.1.d What is your protocol for follow-up after re-evaluating the CH Diagnosis?

5) If you have not re-evaluated the patient's CH diagnosis, do you plan to do so [check one]?

Yes (proceed to question 6) No (proceed to question 7)

IF you plan to re-evaluate the patient's CH diagnosis,

6) How will you re-evaluate the patient's CH diagnosis [check one]?

Conduct a thyroid challenge by decreasing the dosage of levothyroxine and then evaluating thyroid function (Free T4/ Serum TSH levels).
 Other (specify): _____

6.1 When do you plan to re-evaluate the patient's CH diagnosis?

IF you do not plan to re-evaluate the patient's CH diagnosis,

7) Why do you not intend to re-evaluate the diagnosis [check one]?

- Pre-treatment thyroid scan revealed abnormal thyroid anatomy
- Medication dosage and/or serum TSH levels increased over time
- Lost to Follow-up
- Parental refusal
- Other _____
- _____
- _____