



Research Study Referral

The Division of Pediatric Endocrinology at the UMass Memorial Children's Medical Center is conducting a research study to determine whether infants with Down syndrome need to be screened at more frequent intervals during the first year of life for thyroid disorders.

Thyroid hormone is **critical** for brain development in the first three years of life. Early diagnosis and treatment of thyroid disorders in **all** infants can optimize neurodevelopmental outcomes.

This study involves screening for thyroid disorders with either a heel, toe or finger stick blood sample at 2 and 4 weeks of age, and monthly thereafter for the first 12 months of life. For convenience, these blood samples can be done at your pediatrician's office. If your infant is diagnosed with a thyroid disorder, then treatment will be started promptly.

Criteria

- Newborn with Down syndrome (≥ 30 weeks gestation)
- Age < 6months of age

Parent(s)/ Guardian(s) Name:	
Contact Phone:	
Referred By:	

- The privacy law, Health Insurance Portability & Accountability Act (HIPAA), protects individual identifiable health information (Protected Health Information, or PHI) that belongs to you or your child. The privacy law requires you to sign an authorization (or agreement) if you want your provider to give this completed form to the researchers of the study entitled ***Should Infants With Down Syndrome Be Screened More Frequently For Thyroid Dysfunction?*** The researchers will then contact you and provide you with information about the study.
- You do not have to sign this Authorization. If you decide not to sign the Authorization, it will not affect your treatment, payment, or enrollment in any health plans, or affect your eligibility for benefits.

If you sign the Authorization, you understand that:

- You have the right to revoke the Authorization by sending a **written** letter to Penny Feldman, MD, 55 Lake Avenue North, Worcester, MA 01655 to inform her of your decision.
- If you revoke this Authorization, the researchers may only use protected health information already collected for this research study.
- If you revoke this Authorization, your protected health information may still be used and disclosed if you have an adverse event.
- Any disclosure carries the potential for re-disclosure. Once your provider releases your PHI, it may no longer be protected by the HIPAA privacy rule.
- The Authorization has no expiration date.
- You will receive a signed copy of this Authorization for your personal records.

If you have questions about the research study, please contact: Penny Feldman, MD, at 508-334-7575.

THE FOLLOWING INDIVIDUAL HAS READ AND UNDERSTANDS THE ABOVE STATEMENTS AND AUTHORIZES THE DISCLOSURE OF THE INFORMATION REQUESTED ABOVE

Signature of Parent/Legal Guardian	Date
Name of Parent/Legal Guardian (Printed)	

Include a description of the legal guardian’s authority to represent the child:

Fax Completed Form to 508-856-3123.
 If you are interested in learning more about this study please call *Penny Feldman, MD*, at 508-334-7575.
Compensation provided for each visit.