



Connecticut Newborn
Diagnosis & Treatment Network



Pediatric Primary Care Providers and Hospital-Based Medical Providers,

The **Connecticut Newborn Diagnosis and Treatment Network (The Network)** is a statewide network funded through the CT Department of Public Health. Established at Connecticut Children's Medical Center, and in partnership with Yale New Haven Hospital, the Network will respond to all reports of infants who have a newborn screen that flagged out of range. The Connecticut Newborn Screening (CT NBS) Program at the State Laboratory will continue to call an infant's primary care provider (PCP) or hospital-based medical provider (HBMP) with an out of range result, and will either request a repeat heel-stick specimen or report the result to the Network for further follow up.

In coordination with the infant's PCP or HBMP, the Network will begin the diagnostic work-up, and provide support to both the family and health care team. If an infant confirms positive for a disorder, the Network will coordinate treatment and long-term follow-up care for the condition identified, working with PCPs, hospitals and specialists statewide. Finally, the Network has established a registry for measuring, tracking, and reporting of disorder specific outcomes from birth to age 21.

Upon receipt of an out of range result, a Network Coordinator will:

- Contact the infant's PCP or HBMP to obtain some brief information about the baby and to discuss next steps.
- Consult with the appropriate specialist, place follow up lab orders or make recommendations for lab orders (when appropriate) and/or schedule an appointment if necessary.
- Notify your practice of recommended follow-up.

The PCP will still be responsible for:

- Contacting the family to notify them of out of range results, and communicate the need for diagnostic testing.

The network is working to develop tools to assist PCPs in communicating this information to families.

Through integration between EPIC, the Network's electronic health record, and Quest Diagnostics, Network coordinators will now be able to directly view lab results for the majority of infants who need additional testing, reducing the need for frequent faxes and phone calls.

Please note the following phone numbers:

- **Connecticut Newborn Screening Program at the State Laboratory:** (860) 920-6628 or dph.nbstracking@ct.gov
 - Please continue to direct questions about NBS blood-spot specimen collection, results of repeat heel stick screening, Connecticut's NBS panel, NBS waivers, and requests for NBS laboratory reports to the Connecticut Newborn Screening Program at the State Laboratory.
- **To Order Newborn Screening Blood-Spot Specimen Cards:** (860) 920-6674.
- **The Connecticut Newborn Diagnosis and Treatment Network (The Network):**
 - Phone: (860) 837-7870
 - Fax: (860) 837-7871
 - **Effective immediately**, please direct all calls related to follow-up after an abnormal newborn screening result, or care of the infant with a confirmed diagnosis, to the new Network. Network coordinators are available Monday-Friday from 8:30-4:30pm to provide support to families and healthcare professionals.

Please do not hesitate to contact us. We look forward to working together to help make this a smooth process for both families and healthcare providers!

Sincerely,

A handwritten signature in black ink that reads "Karen Rubin, M.D." The signature is fluid and cursive, with "Karen" and "Rubin" connected and "M.D." in a smaller, more formal script.

Karen Rubin, Program Sponsor

The Connecticut Newborn Diagnosis and Treatment Network

Phone: (860) 837-7870

Fax: (860) 837-7871