

# NEWBORN SCREENING NEWSLETTER MAY 2014



## Annual Update of Newborn Screen Coordinator Information

### Please find included in this fax transmission the following information:

- Newborn Screening Hospital Profile for 2014
- Hospital Based Newborn Screening Coordinator Responsibilities
- NBS Guidelines for Very Low Birth Weight and NICU Newborns
- Literature and Forms Requisition
- Newborn Screening Metabolic Kit Order Form
- Letter of Correction Form

### Additional Resources

- Ohio Department of Health Laboratory Newborn Screening website  
<http://www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx>
  - Instructions & form for ordering newborn screening kits & brochures
  - Instructions for collecting and shipping NBS kits
  - "Why Must My Baby be Screened?" in foreign languages
  - Information and form for Religious Objection to newborn screening
  - Ohio Administrative code governing newborn screening
  - Directory of NBS Hospital Coordinators
  - Archive of newborn screening newsletters
  - Links to additional resources about newborn screening

### eReports

Newborn Screening Coordinators are encouraged to obtain an account to access eReports for prompt access to newborn screening results. Instructions for obtaining an account were listed in the March 2014 newsletter. Please contact newborn screening at 1-888-634-5227 if you have questions.

Bureau of Public Health Laboratory  
8995 East Main St, Bldg 22, Reynoldsburg, OH 43068  
Ph: 1-888-ODH-LABS ; 614-466-2278  
Email: [odhlabs@odh.ohio.gov](mailto:odhlabs@odh.ohio.gov)  
<http://www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx>

Bureau of Public Health Laboratory  
Newborn Screening Program  
8995 East Main Street, Bldg 22  
Reynoldsburg, OH 43068-3342  
Phone: (888) ODH-LABS / (888) 634-5227  
Fax: (614) 644-4648



John R. Kasich, Governor  
Lance D. Himes, Interim Director of Health  
Tammy Bannerman, Ph.D., Laboratory Director

CLIA ID#: 36D0655844  
www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx

## Newborn Screening Hospital Profile for 2014

Please complete and return via fax by **June 30, 2014** to **(614) 644-4648**. Please Print.

**Date Form Completed:** \_\_\_\_\_

**Facility Name:** \_\_\_\_\_

**Mailing Address:** Attn: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
City OH, Zip Code

**Telephone Number:** ( ) \_\_\_\_\_ **Ext:** \_\_\_\_\_

List the best number for contacting your facility 24/7 with abnormal NBS results or with questions regarding samples

**Fax #:** ( ) \_\_\_\_\_ **Is this a HIPAA secured fax?**  Y  N

List the best number for faxing your facility's NBS results and information about NBS program updates

**Newborn Screening Coordinator:** \_\_\_\_\_  
Name Title Unit Shift

**NBS Coordinator's Telephone Number:** ( ) \_\_\_\_\_ **Ext:** \_\_\_\_\_

**NBS Coordinator's Email Address:** \_\_\_\_\_

**Quality Assurance Coordinator:** \_\_\_\_\_  
Name

**Quality Assurance Coordinator Telephone Number:** ( ) \_\_\_\_\_

**Quality Assurance Coordinator Email Address:** \_\_\_\_\_

**Nurse Manager of Birth Center or Nursery:** \_\_\_\_\_  
Name

**Nurse Manager's Telephone Number:** ( ) \_\_\_\_\_

**Nurse Manager's Email address:** \_\_\_\_\_

**Person responsible for ordering kits:** \_\_\_\_\_ **Phone:** \_\_\_\_\_  
Name

**Does facility have a written protocol for tracking newborn screening specimens?**  Y  N

**Does facility have a written process**

Y  N

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**for tracking newborn screening results?**

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CLIA ID#: 36D0655844  
[www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx](http://www.odh.ohio.gov/odhPrograms/phl/newbrn/nbrn1.aspx)

## **Hospital Based Newborn Screening Coordinator Responsibilities**

1. Perform Quality Assurance Activities”

- a. Establish a protocol to assure that every baby born at or transferred to the facility is appropriately screened
- b. Maintain a log to document that newborn screening specimens are collected, shipped, and results are returned to facility
- c. Maintain adequate inventory of blood collection cards
- d. Establish a protocol for monitoring demographic data, blood collection quality, and timeliness of specimen submission
- e. Implement blood collection protocols (based upon screening program guidelines) for:
  - i. RBC Transfusion
  - ii. TPN administration
  - iii. Early discharges
  - iv. Facility transfer
  - v. Premature / Extended stay babies
- f. Establish a physician/parent notification process for use when a specimen is unsatisfactory or additional screening is required
- g. Establish a process to assure timely receipt of newborn screening results on all babies screened

2. Educational activities:

- a. Serve as a contact person and facilitator between the state screening program and the birthing facility staff
  - i. Inform and educate facility staff about new program guidelines and protocol changes (new disorders added to test panel, changes in specimen collection requirements, administrative rule changes and other newborn screening information, as necessary)
  - ii. Disseminate information (newsletters, QA reports, etc.) received from the newborn screening program to the appropriate facility staff (nursing, laboratory, clinicians, QA)
- b. Document competency of blood drawing staff on an annual basis (new and existing staff)
- c. Document competency of staff completing demographic information on an annual basis (new and existing staff)
- d. Maintain adequate supply of “parent” brochures/pamphlets
- e. Establish a dissemination process for the “parent” brochure/pamphlet before the blood collection

3. Collect and report missing/incorrect demographic information requested by the newborn screening program via telephone or fax within an appropriate period (established by the newborn screening program).

4. Establish a procedure for witnessing and recording those parents who refuse newborn screening testing on their baby



## NBS Guidelines for Very Low Birth Weight (VLBW) and NICU Newborns

### Newborn Screening Schedule:

Define VLBW: <1500 gm

#### ➤ Transfusion

1. Pre-transfusion sample
  - Collect pre-transfusion sample even if baby is less than 24 hours of age
  - If baby is older than 24 hours at time of pre-transfusion sample, then the need for additional samples is dependent on the results of the pre-transfusion sample.
2. Post-transfusion sample
  - Collect between 24 hours and 5 days of age if pre-transfusion sample was collected before 24 hours of age.
  - The post-transfusion sample should not be drawn until 24 hours after transfusion
  - If baby is on TPN, post-transfusion sample should not be drawn until 3 hours after TPN has been discontinued
3. If no pre-transfusion sample was collected (or transfusion occurred in utero)
  - Collect an initial sample 24 hours after transfusion.
  - Collect a repeat sample at 30 days\* following the final blood transfusion, **OR** obtain quantitative Biotinidase, IRT, and GPUT 30 days following the final blood transfusion
  - Obtain a hemoglobin electrophoresis or HPLC 60-90 days following the final blood transfusion

#### ➤ TPN or Amino Acid / Carnitine enhanced formula

1. Collect an initial sample between 24-48 hours (if baby has been transfused the sample should not be drawn until 24 hours post-transfusion)
2. The need for additional samples is dependent on the results of the initial sample. If multiple amino acids are elevated on the initial sample, collect a repeat sample 3 hours after TPN has been discontinued

#### ➤ Transport

1. It is recommended that the transferring hospital collect an initial sample prior to transport, even if baby is less than 24 hours of age.
2. The receiving hospital should collect a sample between 24 hours and 5 days of age.

### Follow-up of screening results

#### ➤ 17OHP / CAH positive:

1. Examine baby for signs of congenital adrenal hyperplasia (CAH).
2. If CAH is not suspected based on physical exam, collect a repeat screening sample within 10 days of notice.
3. If CAH is suspected based on physical exam, perform diagnostic 17OHP level.

#### ➤ Thyroid

1. A thyroid panel is recommended at the time of discharge on all Very Low Birth Weight babies regardless of screening results.

### Report all diagnostic results to ODH.

The responsibility for follow-up testing and notification of diagnostic test results to ODH rests with the primary care providers.

\* ODH does not provide normal ranges for children >7 days of age which may generate at risk reports on results otherwise normal for age levels.

# LITERATURE AND FORMS REQUISITION

Ohio Department of Health  
 Bureau of Public Health Labs  
 Newborn Screening Program  
 8995 East Main Street, Bldg 22  
 Reynoldsburg, OH 43068-3342  
 FAX (614) 644-4648

SYMBOL <small>(Column for ODH Use Only)</small>	QUANTITY	ITEM #	TITLE	REMARKS
		O1PT	Why must my newborn be screened?	

Contact Person	Day-time Telephone Number (    )       -
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Send to: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Attn: \_\_\_\_\_

Date: \_\_\_\_\_

<b>For Ohio Department of Health Use Only Do Not Write in this Space</b>
Date Received:
Filled By:
Date Filled:
Order No.

**ODH use only**

Site number
ODH number

## Ohio Department of Health Metabolic Screening Kit Order

**ODH use only**

Order #
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**Order will not be filled if form is not completed in full**

Number of kits requested (\$63.61 per kit)	Total Cost \$
<b>Number of envelopes requested</b> (No charge)	
Tax ID #	
PO #	

**Make Check payable to:**

Treasurer, State of Ohio  
Ohio Department of Health

**Return order form with remittance to:**

Ohio Department of Health  
Accounting Unit – M. S. Kits  
P. O. Box 15278  
Columbus, OH 43215

**Ship kits to:**

Name of individual		
Unit		
Facility name		
Street Address		
City	State	Zip Code
Phone (       )		

For shipping information, call the ODH Warehouse at (614) 752-1365. For all other information concerning your order, call the Accounting Unit at (614) 752-4292.

