



Summer 2011 Newsletter

Newborn Screening Program
 Area Service Center
 Rady Children's Hospital San Diego
 Servicing San Diego, Orange, Riverside &
 Imperial Counties



NEWBORN SCREENING SUCCESS STORY A PARENT'S PERSPECTIVE:

Volume 4, Issue 1
 Summer 2011

When you find out you're going to be a parent, all you can hope for is a healthy and happy baby. The day we had Skyler was the happiest day of our lives.

We knew about the Newborn Screening process, but, of course, we never truly thought that anything would come back positive.

When he was 5 days old we were informed that he needed further testing, and on day 7 we found out that he

was born with Phenylketonuria (PKU). It was a shock to us, and we felt like we had gotten the wind knocked out of us.

As we started researching and talking to specialists, we realized we are blessed that the Newborn Screening caught this. Our son has the opportunity that so many people before him didn't have, because he is able to be treated from the age of infancy.

As long as his diet is consistent and his blood is checked regularly to make

sure he doesn't have high phenylalanine levels, he has the same likelihood as any other child to grow up as an intelligent, full-functioning human being.

We are so thankful that his PKU was caught early, because, as such a happy, joyful child, he is now able to share that with the world.

By Robin Fox



Skyler



You can order the following supplies by email: NBSOrders@cdph.ca.gov, by faxing this form to 877-984-9650 (system), or by calling either 310-412-1542 or 888-NBS-4887 (888-677-4228)

Newborn Screening Form:	Quantity
Test Request Form: CDPH 4408 (08-09) SRS-1 (2)	
Parental Request for Missing Newborn Screening Test Results (NBS-MR): CDPH 4559 (08-07)	
Biogenic Report of Newborn Screening Specimens Not Obtained (NBS-NO): CDPH 4439 (08-07)	
Notification of Registration of Birth Which Occurred Out of a Licensed Health Facility (NBS-OH): CDPH 4460 (01-09)	
Newborn Screening Test Refusal (NBS-TR): CDPH 4419 (08-10)	
Factores de Participación Para Padres/Padres (NBS-TR): CDPH 419 (08-10)	

Important Information for Parents About the Newborn Screening Test (IIP):	Quantity
English / Spanish	
Cambodian	
Chinese	
Esperanto	
Vietnamese	
Armenian	
Farsi	
Hmong	
Laotian	
Russian	
Tupelo	

Facility Name: _____
 Shipping Address: _____
 Contact & Phone #: _____

Internet Address: www.cdph.ca.gov
 Genetic Disease Screening Program, Newborn Screening Branch,
 850 Marina Bay Plaza, P.O. Box 999, Richmond, CA 94804 510-412-1502

ORDERING NBS SUPPLIES

Do you need Newborn Screening Supplies such as:

- Test Request Form
- NBS-MR (Missing Results)
- NBS-NO (Not Obtained)
- NBS-OH (Out-Of-Hospital)
- NBS-TR (Test Refusal)

English and Spanish • IIP's (Important Information for Parents) booklet
 These can be ordered via phone (510-412-1542), fax (877-984-9650) or email NBSOrders@cdph.ca.gov.

Complete and send-in the [Order Form](#) and supplies will be quickly received.





THE IMPORTANCE OF COMPLETING AN NBS-NO (NOT OBTAINED) FORM

The completion of the NBS-NO form is a critical step of the reporting process when an infant is discharged from care without obtaining a Newborn Screening Test. A NBS-NO form must also be completed in the following special circumstances:

- when an infant expires
- when an infant is transferred to another facility

- NBS test refusal by the parent*
- Other (hospital error, NBS performed outside CA State Program, etc.)

After completion, the NBS-NO form should be mailed promptly to the address designated on the form.

Once a NBS-NO is received by Genetic Disease Screening Program (GDSP), all untested in-

fants are referred to the Newborn Screening Area Service Center for appropriate follow-up.

For more information, please call your Area Service Center at (858)966-8708.

Delays in testing result in delays of treatment

*NBS-Test Refusal (NBS-TR) form must also be completed.

NEWBORN SCREENING CONTACT INFORMATION

LOCATED AT:

7920 Frost Street, Suite 302
San Diego, CA 92123

MAILING ADDRESS:

3020 Children's Way
Mail Code 5116

San Diego, CA 92123

TOLL FREE: (800) 793-1313

PHONE: (858) 966-8708

FAX: (858) 966-8709

www.rchsd.org/newbornscreening

nbs@rchsd.org

Call for Results*Information*Question



HEPP REPORT EXPLANATION

The Hospital Evaluation Performance Profile (HEPP) report has been developed to provide the facilities with feedback on their newborn screening performance. This report is produced quarterly and sent to each Facility/Midwife. It monitors both the completion of the NBS Test Request Form (TRF) and the adequacy, timing and transport of the Newborn Screening Test. Future newsletters will explain different items on the report and the purpose for collecting the data correctly.

Total Screened 84		Total above Cut-Off 4	
Missing Demographic Data	Number	Hospital Percent	State Cut-Off
Missing Birth Date Count			0.0%
Missing Birth Time Count			0.2%
Missing Birth Weight Count			0.2%
Missing Gender Count			0.2%
Missing Ethnicity Count	1	1.19%	1.0%
Missing Mother's Zip Code Count			1.0%
Missing Collection Date Count			0.0%
Missing Collection Time Count			1.0%
Missing Mother's Maiden Name Count			1.0%
Missing Mothers DOB Count			1.0%
Missing Mother's SSN Count	1	1.19%	4.0%
Missing Medical License No. Count	10	11.90%	3.0%
Missing RBC Transfusion Before Collection Count	2	2.38%	0.2%
Missing Feeding Since Birth Count	1	1.19%	2.0%
NBS Inadequate Collection Process Count			0.5%
NBS Inadequate Handling and Transport Count			0.5%
NBS Inadequate Spec Card/TRF Issues Count			0.8%
NBS Inadequate Misc Count			0.5%
Test Done < 12 Hours			0.1%
Test Done > 6 Days			0.5%
Transit Delay Count > 5 Days	2	2.38%	2.40%
Average Number of Transit Days	2.01		
NBS Corrected EM Count	1	1.19%	0.0%
NBS Unexplained Early Count			0.2%

Demographic Data Item	Purpose	Observed Errors	Correct Completion of Field
Birth Weight	Aid in interpreting results for Metabolic and Endocrine tests	Left blank, or used lbs. & oz. instead of grams	Use grams as reported on birth record
Facility Name and Code	To identify the specimen and ensure the NBS results are reported to the collecting/submitting facility	One or both fields are left blank or filled in incorrectly	Record correctly and clearly both the name of the facility and unique code
Medical Record Number (MR#)	Correctly identifies newborn and it aids in obtaining additional information for follow-up	Left blank, or used incorrect MR# (such as the mothers or other newborn's information)	Enter correct alpha – numeric identification code used by facility & HIM dept.
Nursery Type	Gives information about the newborn's clinical status for follow-up and identification where the specimen was collected	Left blank or filled in incorrectly	Select NICU or Regular Nursery/Family Centered Care (FCC)/Rooming in. Other refers to the lab, PICU, birth service provider, etc.