

NEWBORN SCREENING: ON-THE-SPOT HOME EDITION

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UCLA AREA SERVICE
CENTER (ASC 97)

MEET THE TEAM:

EVA BERMAN, RN, BSN
PROJECT DIRECTOR

MARI SMITH, RNC, MSN
COORDINATOR

BREONNA PRESTON,
MPH, CHES
COORDINATOR

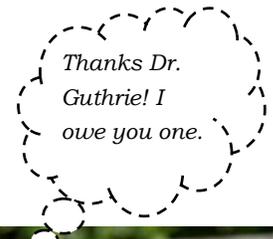
KRISTINA PARKINS,
MPH
PROGRAM SPECIALIST

DIANE PAIETTA
ADMINISTRATIVE
ASSISTANT

NEWBORN SCREENING CELEBRATES 50 YEARS IN CALIFORNIA

For half a century, newborns in the state of California have been tested for various genetic and congenital disorders, trailing the National Program for newborn screening (NBS) by only one year. Thanks to the pioneering efforts of Dr. Robert Guthrie, who introduced the first newborn screening test for phenylketonuria (PKU) in the early 1960's, babies born in California have benefited from early detection and early treatment for five decades. Thousands of babies have been saved from the debilitating and—at times—deadly effects, such as metabolic crises, seizures, failure to thrive, developmental delays, and death, of genetic diseases. The methodology—collecting blood specimens via heel stick

by using a filter paper card—was also inaugurated by Dr. Guthrie in the early '60s and has become the standard technique for NBS specimen collection. Although the California NBS program tested only for PKU in 1966, the panel has progressively expanded, adding hypothyroidism and galactosemia in 1980; sickle cell and other hemoglobinopathies in 1990; and congenital adrenal hyperplasia and a plethora of metabolic disorders in 2005, thanks to the development of tandem mass spectrometry (MS/MS). Now, in 2016, the state of California screens newborns for 80 different genetic disorders and more babies are living longer, healthy lives. A success for public health and a big win for babies and families across the state!



With one heel stick, many abnormalities are caught early. Lives are saved.

SPECIAL POINTS OF INTEREST:

- 50 yrs of newborn screening in California!
- Updated regulations for midwifery providers
- New TRF forms: 30 vs. 31 series
- Quality Improvement: timeliness matters
- Outreach to midwife service providers in 2017

REGULATORY CHANGES NOW IN EFFECT!

Signed into official law as emergency regulations in March 2016, the California Code of Regulations, Title 17, Public Health, now mandates for all midwife service providers to collect a Newborn Screening Test within 12-48 hours after birth for babies born out-of-hospital. Changes in the law also stipulate that the specimen

must be sent to the State Public Health lab the same or next business day (after proper drying time), using a state-contracted carrier, which is currently GSO. Please continue to encourage families to complete newborn screening tests, as early testing and treatment can save their babies' lives. In the event that a parent refuses

testing for religious reasons, please ensure that an official Test Refusal form is signed and sent to CA Department of Public Health, Genetic Disease Screening Program in Richmond.



NEW TEST REQUEST FORMS—31 SERIES

Starting in October 2016, the California Department of Public Health, Genetic Disease Screening Program has issued new Test Request Forms (TRF) for newborn screening & distribution of these new forms—the 31 series—is underway. Although similar to previous forms, key differences exist between the 31 & 30 TRF. For example, on the 31 TRF, there are two fields for provider info: one field in the middle of the form for the *inpatient/ordering*

physician (please place your information here) & another field at the bottom for the *outpatient physician* (please place the baby’s pediatrician or PCP here). This change will hopefully provide sufficient information if the baby needs additional follow-up care once results are released. If a midwife provider wishes to include special notes related to the newborn’s health status, we urge the collector to write this information in the *Comments* field, located to-

wards the bottom right of the 31 TRF. Additionally, if you are using 31 TRFs & a specimen is not collected for whatever reason, please complete the TRF form fields and the *Specimen Not Obtained* field and send the 31 form (with unfilled blood spots) to the lab — this replaces the NBS-NO form. You can leave the date and time collected fields blank on the form. Lastly, please use 30 forms before they expire later this year, in December 2017!

[FYI!]

Does your client have questions about their child’s newborn screening specimens?

Please remind parents that information regarding confidentiality, results, specimen storage, and retrieving specimens after testing can be found **on the back of the pink & blue copies** of the TRF!

IMPROVING TIMELINESS, SAVING LIVES

Now in Year Two of the statewide Quality Improvement (QI) project, ASC 97 continues to emphasize the importance of timeliness in specimen collection and transit. With support from the newly revised state regulations, the QI project comprises of 2 main goals: 95% of initial specimens must be collected within 12-48hrs of life & 85% of all initial specimens must be transported to

the NAPS¹ lab within 2 business days of collection. Even with a smaller number of deliveries as compared to hospitals, midwifery providers are still expected to achieve these goals, thus ensuring all babies the utmost in NBS service delivery. As a follow-up to last year’s survey, the UCLA Area Service Center will be conducting more outreach activities & coordinating site visits to midwifery providers in

2017. This will allow us to engage more with small providers in our Service Area, address any issues or concerns regarding QI goals or newborn screening practices, & provide education on program updates & best practices. Please let us know if you have any specific questions regarding the QI project. We look forward to speaking with you soon & thank you for continuously supporting newborn screening!

“Next to creating a life, the finest thing a [person] can do is save one.” -
Abraham
Lincoln

¹Neonatal and Prenatal Screening

QUESTIONS OR COMMENTS? LET’S HEAR FROM YOU

11726 San Vicente Blvd
Suite 220
Los Angeles, CA 90049

Phone: 310-826-4458

Fax: 310-826-7638

E-mail: newbornscreening@mednet.ucla.edu

Website: <https://www.uclahealth.org/mattel/newborn-screening-program>

Out of NBS materials? Need more forms?

To order official forms, supplies or education materials for newborn screening, call California State Dept. of Public Health at 510-412-1542, fax request to 877-984-9650, or send an email to NBSOrders@cdph.ca.gov