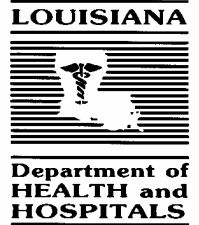




Kathleen Babineaux Blanco  
GOVERNOR

DEPARTMENT OF HEALTH AND HOSPITALS  
OFFICE OF PUBLIC HEALTH



Frederick P. Cerise, M.D., M.P.H.  
SECRETARY

## IMPORTANT INFORMATION ON NEWBORN HEEL STICK SCREENING

May 30, 2006

### RE: **NEWBORN HEEL STICK SCREENING**

Dear Newborn Screening Submitter:

This is to notify you of new improvements and changes to the Louisiana Newborn Heel Stick Screening Program.

#### Five Metabolic Diseases Officially Added to the Newborn Screening Panel with More to Come

Since November 1, 2004, the Louisiana Newborn Heel Stick Screening Program has been performing universal screening for homocystinuria, maple syrup urine disease (MSUD), medium chain AcylCoA dehydrogenase deficiency (MCADD), citrullinemia and argininosuccinic aciduria (ASA) statewide. An amendment to the Newborn Screening Rule (LAC 48: V. 6303) published in the *Louisiana Register* of February 20, 2006, changed the status of this testing from a pilot to an official part of the newborn screening panel.

#### Plans for Further Expansion of the Panel

On August 1, 2006, the Newborn Screening Program will expand to screen for 27 metabolic and genetic disorders. This expansion was recently recommended by the Louisiana Newborn Screening Advisory Committee, and has been requested by many physicians and hospital laboratory directors. The expansion plan is also consistent with proposed legislation (HB 293 of the regular session of the Louisiana Legislature), that will require the newborn screening panel to include testing for the 29 disorders recommended by American College of Medical Genetics, and supported by the March of Dimes and the American Academy of Pediatrics. This panel includes universal hearing screening, which has been mandated in Louisiana since 1999. Testing for cystic fibrosis has been delayed until July 1, 2007, while the Louisiana Office of Public Health (OPH) and the directors of the cystic fibrosis centers work out diagnosis and follow-up protocols.

#### Screening for Congenital Hypothyroidism Using Thyroid-Stimulating Hormone (TSH) Levels

Screening for congenital hypothyroidism by the Louisiana Newborn Screening program has been changed from T4 (thyroxine) to TSH (thyroid stimulating hormone). Screening by TSH will detect the most common forms of congenital hypothyroidism. Less common causes of congenital hypothyroidism, however, will not be detected. Therefore, if congenital hypothyroidism is suspected on the basis of clinical presentation, appropriate examinations and studies should be done.

### Price Increase for the Purchase of a Laboratory Specimen Filter Paper Form Used for Non-Medicaid Newborns and Recall of Old Forms

Pursuant to the increase in services, effective August 1, 2006, the price of the red border laboratory specimen forms used for non-Medicaid patients will be increased from \$18.00 to \$30.00. There will continue to be **no charge** for the blue border laboratory specimen forms used for newborns covered by Medicaid. These two types of color coded forms are available on a cash and carry basis at your nearest parish health unit. Please call the health unit before sending a courier to pick up forms so your order can be ready when they arrive. New forms are in stock now and a recall of old forms will be conducted in the next few weeks. **After July 1, 2006, only 2005 and 2006 lots will be accepted.** The OPH laboratory must conform to all regulations of the Clinical Laboratory Improvement Amendments of 1992 (CLIA), and **specimens submitted on older forms will thus be rejected.** Old forms may be exchanged at your parish health unit. If problems are encountered with this process, call the Genetic Diseases Program Office in Metairie at 504/219-4413.

### The Urgency of Mailing in Specimens and Following up on Positive Screens

Complications for some of the disorders can present within the first week of life. To ensure timely receipt and analysis of specimens, the Newborn Screening Program is now providing courier service (Stat Courier) for the pick up of filter paper specimens at each birthing hospital. If a positive screening result is obtained, the Genetics follow-up staff will notify the submitter and/or the child's primary care physician by telephone and fax. It is very important that if you are notified, follow-up must be initiated immediately and advice on doing so will be given by the Genetic Diseases program follow-up staff.

Submitters other than birthing hospitals should continue to mail the specimens to the OPH Laboratory in Shreveport:

Shreveport Regional Laboratory  
P.O. Box 3561  
Shreveport, LA 71133-3561

### Voice Response System with FAX Capability (VRS) (24-7 Automated Retrieval of Results)

We apologize for the inconvenience of not having the VRS system operating since it was knocked out by Hurricane Katrina. We are pleased to inform you that a new upgraded version of the VRS system is being installed and will be operational by August 1, 2006. A re-registration process will be conducted within the next few weeks.

### Post Katrina Laboratory Arrangements and Future Plans

We are very grateful to the University of Iowa Hygienic Laboratory and their Newborn Screening Program for so rapidly absorbing Louisiana specimens into their operation, and the excellent service provided by them and the Iowa Genetics Program. This arrangement will continue for the foreseeable future. There currently is no definitive timeline for the re-establishment of the OPH laboratory in New Orleans.

### Stay Informed About Newborn Screening Updates

Information on the screening expansion, the recall of forms, the registration for using the VRS and more is available on the new Genetic Diseases Program website at <http://www.dhh.louisiana.gov/offices/page.asp?ID=263&Detail=6302>

Thank you for all of your efforts on behalf of the public health of the children of Louisiana and for your cooperation with the state's Genetic Diseases Program.

Sincerely



Charles Myers, G.S.W.  
Administrator  
Genetic Diseases Program



Stephen Martin, Ph.D.  
Laboratory Director



Louis Trachtman, MD, MPH  
Medical Director  
Genetic Diseases Program



Arthur Hagar, Ph.D.  
Assistant Director, Laboratory