Date: July 2, 2014

To: Hospital Administrators, Newborn Nursery Managers, Neonatal Intensive Care Units (NICU), Special Care Nurseries, Primary Care Providers, Wisconsin Academy of Family Physicians, Wisconsin Chapter of the American Academy of Pediatrics, Wisconsin Guild of Midwives, Wisconsin Hospital Association, and Wisconsin Medical Society

From: Karen D. McKeown, RN, MSN
State Health Officer and Administrator
Division of Public Health

Re: Emergency Rule Issued to Add Critical Congenital Heart Disease to Newborn Screening

The Wisconsin Department of Health Services (DHS) has added, by emergency rule, screening for Critical Congenital Heart Disease (CCHD) by pulse oximetry (POX) to the Wisconsin Newborn Screening Program’s panel of conditions. Every infant born in a hospital is required to have CCHD screening prior to discharge. Babies born out of hospital are also required to be screened. This rule will go into effect once it is published in the Wisconsin State Journal, which is expected to occur on Thursday, July 3, 2014.

Why is it important to screen for CCHD?
CCHD requires prompt diagnosis and treatment for the best outcome. Babies with undetected critical congenital heart defects are at risk for death or significant disability.

What do I need to do if I am a hospital or birth facility, NICU or special care nursery, or a home birth provider and I am not currently screening?

- Visit Wisconsin SHINE (Screening Hearts in Newborns) Project’s website (http://wisconsinshine.org/) for information on how to appropriately screen newborns, including a screening tool kit. The Wisconsin SHINE Project, a collaborative effort of the University of Wisconsin School of Medicine and Public Health, the Medical College of Wisconsin, Wisconsin DHS, and Wisconsin State Laboratory of Hygiene, facilitates implementation of universal screening for CCHD. If further assistance is needed, SHINE on-call personnel can be reached through the UW page operator at 608-262-2122.

- The Wisconsin SHINE Project provides the following assistance:
  - POX screening information.
  - Standardized protocols for CCHD screening in the well-baby nursery and NICU.
  - 24-hour technical assistance for questions about screening policy or procedure.
  - Staff and parent education materials.
  - Information on screening results reporting.

- Contact the Wisconsin SHINE Project Hotline on-call personnel at 608-262-2122 anytime:
  - A baby Fails the pulse oximetry screen for CCHD.
  - A baby is born who has known or suspected CCHD.
  - A baby does not have a newborn blood screening card where pulse oximetry screen results can be recorded.
How should a hospital or birth facility, NICU or special care nursery, or a home birth provider report results for the pulse oximetry screening for CCHD?

- Report CCHD screening results on the newborn screening blood card. Screeners should mark PASS, FAIL, or NOT TESTED and fill in time and date of POX screening.
- Reporting of CCHD results should NEVER delay the submission of the blood card.
- For infants with pulmonary disease requiring treatment with oxygen:
  - Photocopy newborn screening blood card before collecting newborn blood screen and mark “not tested” on newborn screening blood card.
  - When pulmonary disease and need for oxygen resolves, screen infant and record results on photocopy of newborn screening blood card.
  - Send the photocopy of newborn screening blood card with CCHD screening results to the Wisconsin State Laboratory of Hygiene.
- For a baby that does not have a newborn blood screening card where pulse oximetry screen results can be recorded, contact the Wisconsin SHINE Project Hotline on-call personnel at 608-262-2122.

What do I do if I have an infant that FAILS the pulse oximetry screening for CCHD?

- Assure that the infant receives a complete clinical evaluation to assess for the cause of hypoxia, and begin treatment as indicated.
- Consult established neonatal intensive care and pediatric cardiology referral centers for further and ongoing care of the newborn.
- Contact the Wisconsin SHINE (Screening Hearts in Newborns) Project (http://wisconsinshine.org/) on-call personnel at 608-262-2122.

If an infant passes the pulse oximetry screening, are all forms of significant neonatal heart disease excluded?

Not all significant congenital heart disease will be excluded by pulse oximetry screening; clinicians should continue to consider the possibility of heart disease in infants based on the clinical scenario.

What do I do if I have an infant with a known or suspected CCHD?

- Proceed with care as in the past.
- For program quality assurance, please report all such cases to the Wisconsin SHINE program on-call personnel at 608-262-2122.

What do I need to do if I am a primary care provider for a newborn?

Know the results of the newborn screening tests (blood, hearing, and POX for CCHD). If you do not have results for the POX screening for CCHD, contact the hospital of birth, if the infant was born in a hospital; or for out of hospital births, contact the birth attendant for the screening result.

Where can I get additional information?

The Wisconsin SHINE Project has developed educational materials for hospitals and out of hospital and health care providers regarding recommended screening protocols, equipment selection, and other information to support the implementation of CCHD screening. These materials are available at http://wisconsinshine.org/. Included on the website are an online learning module and video tutorial. Information for families is available in English and Spanish at http://wisconsinshine.org/families/.

You can also visit the DHS website for information regarding the Newborn Screening legislation changes at www.dhs.wisconsin.gov/health/children/newbornscreening/Updates.htm.

If you have questions for the Department of Health Services, contact Sharon Fleischfresser, MD, MPH, Medical Director of the Wisconsin Children and Youth with Special Health Care Needs Program at Sharon.Fleischfresser@wisconsin.gov, 608-266-3674; or Timothy Corden, MD, Chief Medical Officer for the Bureau of Community Health Promotion at Timothy.Corden@wisconsin.gov, 608-266-5818.