Newborn screening improvements in Arkansas

Newborn screening is a public health activity carried out in every state in the nation and in nearly all developed countries. Newborns are screened to identify conditions that are present but not clinically evident in the newborn period. Early identification and subsequent treatment of selected disorders can prevent permanent mental or physical damage, or death in affected children. The goal of newborn screening is to identify newborns who have clinically unapparent rare but treatable syndromes. This can prevent the occurrence of developmental impairments, delayed physical growth, severe illness and death.

Newborn screening has been under scrutiny by public health officials since a November 2013 article was published in the Milwaukee Journal Sentinel. The article reported that thousands of hospitals throughout the country are late in sending newborn blood samples to state labs that perform the screening tests. The Journal Sentinel analyzed nearly three million newborn screening tests from hospitals across the country to determine how long it took for newborns’ samples to reach state laboratories. The newspaper began its investigation after learning that a newborn Arkansan experienced significant developmental delay from an easily treatable condition because the hospital where she was born delayed sending her blood sample for testing. The newborn was critically ill by the time her blood sample reached the state lab, five days after it was collected. It took an additional three and a half weeks for the abnormal test to be returned to the treating physicians.

The Arkansas Department of Health’s (ADH) laboratory tests newborn blood samples for 28 genetic disorders, providing an invaluable snapshot of information about the newborn’s health. The American Academy of Pediatrics recommends that blood specimens be collected after the newborn is at least 24 hours old. A specimen collected prior to 24 hours of age can be used to screen for some disorders but is not reliable for amino acid disorders, cystic fibrosis, hypothyroidism and several others. Analyses of screening results suggest that a specimen taken on the second day of life is suitable for all testing. This small delay allows testing to be performed only once and has minimal effect on the outcomes of the condition of interest.

The American College of Medical Genetics recommends that newborn screening samples arrive at a lab for testing no more than three days after they are collected, with a five-day maximum elapsed time between birth and the availability of test results. With some of these abnormal conditions, a newborn baby often appears healthy at birth, becoming extremely ill within days. If not treated, it can lead to disability or death within a few weeks.

The Arkansas State Board of Health’s Rules and Regulations Pertaining to Testing of Newborn Infants purpose is to assure that all Arkansas newborns have the opportunity to be screened for genetic metabolic conditions.
illnesses. For healthy infants born in medical facilities, the optimum time for blood specimen collection is 24 to 72 hours after birth. The collected specimen should be submitted to the ADH’s Public Laboratories in Little Rock within one business day, (previously 48 hours) of collection.

In Arkansas, the newborn screen is collected between 24 and 72 hours after birth. Blood samples from the newborn are collected by pricking the heel of the baby and collecting drops of blood on a piece of filter paper. The blood sample should be sent to the state lab within one business day. That means the next working day for the lab, such as when a state holiday coincides with a weekend.

The ADH laboratory tests newborn blood samples for 28 genetic disorders, providing an invaluable snapshot of information about the newborn’s health. Some health disorders may cause serious lifelong damage within the first five days of life. The earlier the lab processes the tests, the sooner families can be notified of health concerns, and can consult with their physicians about further testing or treatment.

Hospital and public health officials in many states, including Arkansas, have pledged to end delays by changing processes and improving how newborn blood samples get to state labs. Arkansas offers a courier service to transport blood samples from county health units to the ADH lab at no charge to hospitals. Hospitals also have the option to utilize overnight delivery services. Recently the ADH lab added Saturday hours of operation for newborn blood samples.

STATEWIDE EFFORTS ARE WORKING

In January 2014, the Arkansas Department of Health, Arkansas Medicaid Services (AMS), Arkansas Foundation for Medical Care (AFMC), Arkansas Hospital Association, and Arkansas birthing hospitals began a coordinated effort to reduce newborn screening delays in Arkansas. Leveraging the innovative and successful Arkansas Medicaid Inpatient Quality Incentive (IQI) program, AFMC and AMS developed two newborn screening quality measures. These measures both challenge and incentivize Arkansas hospitals to reduce the time between taking newborns’ blood-screening samples and sending them to the ADH lab in Little Rock.

Newborn screening specimen collection and submission requirements from the Arkansas Board of Health were the basis for development of the IQI newborn screening quality measures. The two quality measures are:

- Newborn Screen 1 (NBS-1): Timely Collection of Newborn Screening Specimen
- Newborn Screen 2 (NBS-2): Timely Submission of Newborn Screening Specimen

These quality measures will complement ongoing efforts in birthing facilities to examine their current process for collection and submission of the newborn blood sample and enhance their ongoing quality improvement efforts. Each facility must determine the best approach that will meet its needs and that will assist the facility in reaching established targets.

Since Nov. 2013, the ADH reports that Arkansas’ hospitals have increasingly reduced the time it takes to deliver newborn blood samples to the public health lab for testing. From July through September 2014, about 50 percent of newborn blood samples collected at Arkansas hospitals arrived at the state laboratory within the department’s target time span of 48 hours. Arkansas hospitals are working hard to achieve the more stringent 48-hour target. Many hospitals in Arkansas have addressed and eliminated issues with collection and delivery of newborn blood samples.

Time is critical, and the newborn screening process is a team effort. Hospital physicians, nurses and related staff take care of newborns. Newborns’ blood specimen samples are typically drawn from the baby before it is released from the hospital. After blood specimens are sent to the state lab for testing and the results are obtained, the ADH sends the test results to the physician for follow-up. The physician can then advise and assist families in finding the right resources and the right team of specialists to get the appropriate treatment. Getting the right treatment, which starts with timely collection and testing of blood samples, makes a great difference in affected infants’ chances for a healthy outcome.

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REFERENCES