



STATE OF WEST VIRGINIA
DEPARTMENT OF HEALTH AND HUMAN RESOURCES

Earl Ray Tomblin
Governor

Karen L. Bowling
Cabinet Secretary

MEMORANDUM

TO: Newborn Intensive Care Unit
Pediatric Providers

FROM: Kathy Cummons, M.S.W.
Office of Maternal, Child and Family Health
Division Director, Research, Evaluation and Planning
Newborn Screening Program

ISSUE DATE: April 23, 2015

RE: Procedure Change in the Follow-up of Abnormal Cystic Fibrosis
Mutation on Newborn Screen

EFFECTIVE DATE: May 1, 2015

Effective May 1, 2015, the West Virginia Bureau for Public Health, Office of Maternal, Child and Family Health, Division of Research, Evaluation and Planning, Newborn Screening Program is establishing a change in the procedure for follow-up of abnormal Cystic Fibrosis (CF) results identified on the Newborn Screen (NBS). Previously, the primary care physician (PCP) was responsible for ensuring that the child was scheduled for a sweat chloride and once results were obtained, the PCP was notified of the CF status and need for appropriate genetic counseling.

The Newborn Screening Advisory has determined that a change in this procedure is needed to ensure that the appropriate follow-up occurs for every abnormal CF on a NBS. The new procedure will be in the **COMMENT** portion of the abnormal NBS and will now read:

Comment that will now appear on the Lab Mailer:

Cystic Fibrosis: Please notify this family that an abnormal CF mutation was detected on the Newborn Screen and that further diagnostic testing is needed. Please tell the family that a copy of the Newborn Screen has been forwarded to a Certified CF Center, either WVU Pediatrics of Charleston or Mountain State Cystic Fibrosis Center in Morgantown. A team member from the certified CF center will contact the family to schedule a sweat chloride and obtain the necessary follow-up.

It will be the responsibility of the PCP to contact the patient's family as soon as the abnormal screen has been received and inform them that a representative from the CF Center will contact them about scheduling the appropriate follow-up. **Please note your office will no longer be responsible to schedule a sweat chloride.**

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The NBS follow-up RN will forward a copy of each abnormal CF NBS to the certified CF center, based on the patient's geographical location. A CF center representative will contact the family and make arrangements to schedule the patient for a sweat chloride. When the results have been obtained, the patient will be scheduled to meet with a physician from that CF Center for a treatment plan and genetic counseling. Once a final diagnosis has been determined, the NBS follow-up nurse will be notified and will send a copy of the documentation to the PCP for the patient's medical records.

Questions regarding this procedure may be directed to the Newborn Screening Program at 304-356-4448.

Thank you for your assistance to ensure prompt and adequate follow-up care.

cc: Anne Williams
Christina Mullins
Sharon Cibrik
Raheel Khan
WVU Pediatrics of Charleston
Mountain State Cystic Fibrosis