



STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH
LANSING

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GOVERNOR

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**Newborn Screening for Cystic Fibrosis
Implementation: October 1, 2007**

Dear Practitioner:

We would like to inform you that beginning October 1, 2007, cystic fibrosis (CF) will be added to the current dried blood spot screening panel of 48 disorders.

Cystic fibrosis is one of the most common autosomal recessive genetic disorders affecting children. It occurs in about 1 in 3,500 white newborn infants, with a lower incidence in other ethnic groups. Although a specific cure for CF is still needed, treatment at specialized Cystic Fibrosis Centers has greatly improved the quality of life for people with CF. The average life expectancy has also increased significantly from less than ten years, when the disease was first identified over 40 years ago, to the current mean above the mid-thirties.

The objective of newborn screening for CF is to identify most affected children and make early referral to a specialty center accredited by the national Cystic Fibrosis Foundation that offers aggressive intervention to allow normal growth and delay the onset of lung disease. Any delay can result in irreversible bronchiectatic changes with dramatic impact on the lungs' vital functions.

The IRT concentration will be used by the Michigan Department of Community Health (MDCH), Newborn Screening Laboratory as the first tier in screening. It will be followed by DNA mutation analysis using a panel of 40 mutations as a second tier screen for infants with an abnormal IRT. Both tiers of the screening test for CF can be run on the dried filter paper blood spots collected as part of current newborn screening procedures. Specimen collection will not change with the addition of CF, i.e. additional samples will not be needed.

We anticipate that each year about 350 Michigan newborns will have a positive CF screen. Approximately **1 in 10** of these infants will have a diagnosis of CF. The majority of the others will be carriers of CF and will not have symptoms of the disease. Infants with a positive newborn screen will require confirmatory sweat chloride testing at a Cystic Fibrosis Center. More extensive genetic testing may be needed for a small percentage of patients. Genetic counselors will be available through the CF Care Centers for patients undergoing confirmatory testing, as well as for those identified as carriers. For children with a confirmed diagnosis of CF, ongoing assessment and treatment at a CF center are strongly recommended.

There are currently five accredited CF centers in Michigan:

- University of Michigan (Ann Arbor), serves as the state's CF NBS Coordinating Center
Phone: (734) 764-4123
- Children's Hospital of Michigan (Detroit)
Phone: (313) 745-5541
- DeVos Children's Hospital (Grand Rapids)
Phone: (877)-391-2345
- MSU Kalamazoo Center for Medical Studies (Kalamazoo) *Phone: (269) 337-6433*
- Michigan State University Cystic Fibrosis Center (Lansing) *Phone: (517) 364-5440*

Prompt communication and interpretation of results with the patient's primary care physician will be provided by MDCH and CF Coordinating Center staff. If you have any questions or concerns, please do not hesitate to contact us at (517) 335-9205 or by e-mail at mdch-newbornscreening@michigan.gov.

Sincerely,

William Young, PhD
Manager, Newborn Screening Follow Up Program