Dear Practitioner, Laboratory Manager, and Newborn Nursery Manager:

The Missouri Department of Health and Senior Services’ Newborn Screening Program is launching the implementation phase to screen for Mucopolysaccharidosis II (MPS-2), also known as Hunter Syndrome on all Missouri newborns.

MPS-2 is a lysosomal storage disorder caused by a deficiency or absence of an enzyme called iduronate-2-sulfatase (I2S) and is a rare, progressive and debilitating genetic disorder that interferes with the body’s ability to break down and recycle a specific cellular substance. As this cellular substance accumulates through the body’s cells, signs of MPS-2 become more visible. MPS-2 affects approximately 1 in 100,000 to 1 in 170,000 total live births and affects predominantly males. Symptoms may not present at birth, but frequently appear in early childhood and may include delayed development, enlarged internal organs, heart conditions, stunted growth, skeletal abnormalities, and joint problems. The range of symptoms and effect of the disease on individuals varies widely; however, MPS-2 is always progressive and life-limiting.

Beginning November 1, 2018, all newborn screening specimens received by the Missouri State Public Health Laboratory (MSPHL) will be screened for MPS-2. The newborn screening dried bloodspot card collection process will not change, as testing will be conducted using current newborn screening samples. All infants with high risk positive screens will be referred for confirmatory testing at one of the four contracted genetic referral centers in Missouri. During this implementation phase, MPS-2 screening results will not appear on the standard newborn screening laboratory reports provided by the MSPHL. Once more permanent reference ranges can be established through this initial testing phase, laboratory reports will be standardized to contain this information.

The MSPHL is announcing this pilot phase to make you aware that all newborns will be tested for MPS-2 beginning November 1, 2018. If a high risk screening result is detected, the physician of record and baby’s family will be notified by a genetic specialist with experience in the confirmation and treatment of MPS-2, so that the family can benefit from early detection and treatment of MPS-2 during this newborn screening implementation phase. If you have questions or comments, please contact: Tracy Klug, Newborn Screening Manager, 573-751-2662.

www.health.mo.gov

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