



Missouri Department of Health and Senior Services

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Director



Michael L. Parson
Governor

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Implementation of SMA screening in Missouri

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 Spinal Muscular Atrophy (SMA) on all Missouri newborns.

SMA is a progressive neurodegenerative disease that affects the motor nerve cells in the spinal cord which impedes the ability to sit up, walk, swallow, and in the most severe cases, breathe. It is the leading genetic cause of death for infants, affecting approximately 1 in 6,000 - 11,000 infants nationally. The U.S. Food and Drug Administration recently approved a promising new treatment for infants with SMA. Infants who are diagnosed before exhibiting symptoms, and who receive treatment have achieved unprecedented milestones such as sitting, standing, and walking. Newborn screening for SMA is nationally recommended and was added to the Recommended Uniform Screening Panel (RUSP) by the Secretary of Health and Human Services in 2018.

Beginning January 2, 2019, all newborn screening samples received by the Missouri State Public Health Laboratory (MSPHL) will be screened for SMA. 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 to the SMA follow-up program manager, a Public Health Senior Nurse trained in coordinating the confirmatory process with the primary care physician and health care specialist. During this implementation phase, SMA 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 testing phase to make you aware that all newborns will be tested for SMA beginning January 2, 2019. If a high risk screening result is detected, the physician of record will be put in contact with a specialist with experience in the confirmation and treatment of SMA so that the family can benefit from early detection and treatment during this newborn screening implementation phase.

If you have questions or comments, please contact: The Newborn Screening Program at 573-751-6266.

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