RESOLUTION 14-19

Title: Addition of Spinal Muscular Atrophy to the Michigan Newborn Screening Program

Introduced by: Emma Frost for the Medical Student Section

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Referred to: Reference Committee D

House Action: **APPROVED**

Whereas, the Michigan Newborn Screening Program is a public health initiative required by state law to identify rare but serious disorders that require early treatment[1], and

Whereas, newborns in Michigan are already screened for 56 disorders[1], and

Whereas, the current complete screening, including follow-up and coordination of confirmatory testing for those who test positive, is administered at a cost of $130.36 per child, currently included in the newborn nursery charges and most often covered under the patient's insurance or via program fee waivers in cases of financial hardship[1], and

Whereas, each year over 250 Michigan babies, or one in every 400 to 500 children, who undergo the newborn screen are found to be positive for one of the aforementioned screening conditions[1], and

Whereas, the prevalence of spinal muscular atrophy (SMA) is 1-2 per 100,000 with an incidence of 1 in 6,000 to 1 in 10,000 live births, making this one of the most common rare diseases[2,3], and

Whereas, in 2018, the Secretary of the Department of Health and Human Services (DHHS) and the Advisory Committee on Heritable Disorders in Newborns and Children updated the Newborn Screening Panel recommendations to include SMA[4,5], and

Whereas, Indiana, Kansas, Massachusetts, Minnesota, Missouri, New York, and Utah include SMA in their newborn screening panel, and many other states are taking steps towards its addition on their panel[6,7], and

Whereas, the loss of SMN1 is essential to the pathogenesis of all types of SMA and the absence of SMN1 exon 7 is 95 percent sensitive and 100 percent specific for the presence of SMA[2], and

Whereas, the different types of SMA range in age of presentation, with type 1 presenting in the first six months of life and being commonly fatal before two years of age, and must be differentiated from other causes of the hypotonia and respiratory issues[8,9], and

Whereas, SMA is the most common genetic disorder linked to infant death worldwide[10], and

Whereas, as of late December 2016 nusinersen (Spinraza) was approved by the FDA, an intrathecal injection given 4 times in the first 60 days and once every 4 months thereafter[11] , and

Whereas, nusinersen has been shown to be effective in 40 percent of patients where there was previously only supportive care as a treatment option, and those patients have been able to achieve motor milestones, with decreased rates of permanent assisted respiration and mortality especially when started earlier in the course of the condition[11,12], and

Whereas, early detection of and implementation of new treatments for SMA promote previously unachievable improvements in outcomes for affected patients; therefore be it

RESOLVED: That MSMS advocate for the inclusion of spinal muscular atrophy in the Michigan Newborn Screening Program.

WAYS AND MEANS COMMITTEE FISCAL NOTE: $25,000 or more as this resolution directs MSMS to engage in governmental advocacy.

Relevant MSMS Policy: None

Relevant AMA Policy:

Standardization of Newborn Screening Programs H-245.973
Our AMA: (1) recognizes the need for uniform minimum newborn screening (NBS) recommendations; and (2) encourages continued research and discussions on the potential benefits and harms of NBS for certain diseases.

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[1] "Michigan Newborn Screening Questions and Answers." Michigan Department of Health and Human Services. https://www.michigan.gov/mdhhs/0,5885,7-339-73971_4911_4916-233319--,00.html. Accessed February 6, 2019.
[2] D'Amico et al. "Spinal Muscular Atrophy." Orphanet Journal of Rare Diseases. 2011; 6:71. doi: 10.1186/1750-1172-6-71.
[3] "A worldwide study into the prevalence and incidence of spinal muscular atrophy." Treat-NMD Neuromuscular Network. http://www.treat-nmd.eu/downloads/file/meetings/2016/WMS2016/Prevalence%20and%20Incidence%20of%20SMA-Ingrid%20Verhaart.pdf. Accessed February 6, 2019.
[4] "Evidence-Based Review of Newborn Screening for Spinal Muscular Atrophy (SMA): Final Report." Human Resources and Services Administration, March 13, 2018. https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/reports-recommendations/sma-final-report.pdf. Accessed February 6, 2019.
[5] Azar, Alex. Secretary of Health and Human Services, June 2, 2018. https://www.hrsa.gov/sites/default/files/hrsa/advisory-committees/heritable-disorders/reports-recommendations/final-sign-azar-response-sma.pdf. Accessed February 6, 2019.
[6] "Newborn Screening Status for All Disorders." NewSTEPs. https://www.newsteps.org/resources/newborn-screening-status-all-disorders. Accessed February 6, 2019.
[7] "Kansas Adopts SMA Newborn Screening as Several Other States Move Closer to Adoption." Cure SMA, 2018. http://www.curesma.org/news/state-nbs-update-fall2018.html. Accessed February 6, 2019.
[8] "Types of SMA." Cure SMA. http://www.curesma.org/sma/about-sma/types-of-sma/. Accessed February 6, 2019.
[9] Prior TW, Finanger E. "Spinal Muscular Atrophy." GeneReviews, February 24, 2000. https://www.ncbi.nlm.nih.gov/books/NBK1352/. Accessed February 6, 2019.
[10] Mammas IN, Spandidos DA. "Spinal muscular atrophy type I and the dual role of viruses: An interview with Professor Basil T. Darras, Professor of Neurology (Pediatrics) at Harvard Medical School." Exp Ther Med. 2018;15(4):3673-3679. doi: 10.3892/etm.2018.5884.
[11] "FDA approves first drug for spinal muscular atrophy." Food and Drug Administration, December 23, 2016. https://www.fda.gov/newsevents/newsroom/pressannouncements/ucm534611.htm. Accessed February 6, 2019.
[12] Wurster CD, Ludolph AC. "Nusinersen for spinal muscular atrophy." Ther Adv Neurol Disord. 2018; 11:1-3. doi:10.1177/1756285618754459.