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Dr. John Hellerstedt, Commissioner
Department of State Health Services
1100 W. 49th Street
P.O. Box 149347, MC 1920
Austin, Texas 78714-9347

Re: Funding Newborn Screening for New Conditions

Dear Commissioner Hellerstedt:

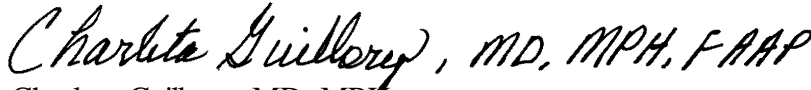
On behalf of the Texas Newborn Screening Advisory Committee, we wish to respectfully recommend that the State consider developing a funding mechanism for conditions that have been added to the Recommended Uniform Screening Panel (RUSP) since 2015. These conditions include X-linked Adrenoleukodystrophy (X-ALD), Glycogen Storage Disease Type II (Pompe) and Mucopolysaccharidosis Type I (MPS-1). In addition, it is anticipated that Spinal Muscular Atrophy (SMA) will be recommended for addition to the RUSP in February 2018. The Committee respectfully recommends that the State establish a permanent funding mechanism to support newborn screening for the above conditions and all conditions that are added to the RUSP in future years.

Newborn screening is a highly effective public health program saving the lives of thousands of babies nationwide every year. In 2016, the Texas program found 925 confirmed cases of the 53 conditions screened by blood spot prior to onset of symptoms; thus, allowing families to get early treatment for their babies. Unfortunately, since we have not added X-ALD, Pompe, and MPS-1 screening to our program, we were not able to detect the approximately 10 cases of Pompe, 4 cases of MPS-1, and 8 to 20 cases of X-ALD that are estimated to occur each year. If we do not add SMA screening after it is added to the RUSP, we will miss 40 to 65 cases each year. As you know, SMA, the most common genetic cause of infant mortality, is an autosomal recessive disease caused by a genetic defect in the SMN1 gene that encodes SMN, a protein necessary for survival of motor neurons. These babies may appear healthy initially, but will deteriorate with system-wide muscle wasting leading to death. The current funding mechanism for the Texas Newborn Screening Program does not allow the start-up costs of a new test to be passed on prior to the implementation of that test.


The Texas Newborn Screening Advisory Committee supports the inclusion of X-ALD, Pompe, MPS-1 and SMA screening into the state's newborn screening panel because there is documented medical benefit to the affected infant with early detection and treatment. We appreciate your consideration and hope we can count on your support. We look forward to

working with you to ensure that all Texas babies are given the best chance at a healthy start in life. Thank you for your dedication and commitment to the health of Texas families.

Sincerely,


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