

23 June 2020

Dr. John Hellerstedt, Commissioner  
Texas Department of State Health Services  
PO Box 149347  
Austin, Texas 78714-9347

Dear Dr. Hellerstedt,

The Newborn Screening Advisory Committee (NBSAC) recommends that the Department of State Health Services (DSHS) or another state agency provide financial compensation to newborn screening physician consultants who provide critically important but uncompensated services in support of the Texas Newborn Screening Program.

As you know, the NBSAC advises the Texas DSHS on strategic planning, policy, rules and services related to newborn screening and additional newborn screening tests. The Committee was mandated by [House Bill \(HB\) 1795](#), 81st Texas Legislature (2009), relating to newborn screening and the creation of the advisory committee. HB 1795 is also known as “Greyson’s Law” in memory of Greyson Morris.

In 2019, the NBSAC responded to a request to remedy a perceived disparity: that certain Texas physicians – those holding a primary specialty certificate in Clinical Biochemical Genetics, as specified by the American Board of Medical Genetics, a member board of the American Board of Medical Specialties – are not fairly compensated for their work on behalf of the State of Texas. This work consisted of responding to numerous telephone calls from primary care providers to provide clinical guidance after results from the Texas Newborn Screen fell out of the expected range. Texas Newborn Screening Program routinely directs primary care providers to seek such advice via ACT Sheets, or ACTion sheets, the national standard in newborn screening programs.

Newborn screening, one of the nation’s most successful public health programs, prevents extraordinary hardship, suffering, and expense by diagnosing conditions before symptoms. Texas now screens for 56 conditions. Newborn screening clinical care coordination program staff consult with medical specialists throughout the state. When the newborn screening results are abnormal or out of range, families are referred to one or more of recommended specialists for their infants to receive further testing.

A by-product of success, however, is the generation of some false positive newborn screening results, each of which must be treated at the outset as potentially a true positive. The determination if a particular newborn has true disease falls upon the shoulders of various specialists, not just biochemical geneticists but also pediatric endocrinologists, hematologists, immunologists, neurologists, and pulmonologists. These consultants must immediately respond

to phone calls from primary care providers to help make the right decisions, order the right tests, and make the right referrals for that baby.

The Newborn Screening Program has vetted medical specialists who qualify, by virtue of their training, board certification, availability, and agreement, to serve as consultants. The metabolic genetics consultants have traditionally handled the majority of the increasing burden of phone calls, but the number of calls and their complexity has dramatically increased as new tests are added, to the extent that a significant portion of work hours are now devoted to fielding these important phone calls about out-of-range results from primary care physicians. In our deliberations, however, the NBSAC recognized that an equitable policy response should clearly incorporate consultants across the spectrum.

The committee, based on our current knowledge and experience, recommends that consultants be financially supported for pre-clinical work addressing out of range newborn screens in Texas. We recommend that an analytic process be put in place to develop a funding strategy. Options to consider would potentially include policies related to telemedicine funding, use of our existing Benefits Program, an increase in newborn screening fees, or other available mechanisms. The logistics of this support program needs to be transparent and straightforward as minimizing undue burden on the consultants is also important for our healthcare system.

Your decision to decisively provide this critical support for newborn screening consultants will ensure that the State of Texas will continue to leverage the power and public health benefits of the Texas newborn screening system without causing undue burden to our public health infrastructure. As always, the NBSAC thanks you for your tireless work for Texas public health.

Respectfully,



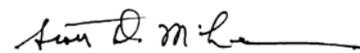
Alice K. Gong, MD

Chair, Newborn Screening Advisory Committee



Michael E. Speer, MD

Vice-Chair, Newborn Screening Advisory Committee



Scott D. McLean, MD

Chair, Consultants' Fees Subcommittee



July 14, 2020

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Chair, Newborn Screening Advisory Committee

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Scott D. McLean, M.D.  
Chair, NBS Consultants' Fees Subcommittee

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Dear Dr. Gong, Dr. Speer, and Dr. McLean:

Thank you for your letter dated June 23, 2020, regarding the Newborn Screening (NBS) Advisory Committee (Committee) recommendation to provide financial compensation to newborn screening physicians and other medical consultants for pre-clinical services related newborn screening. The work of the Committee has been instrumental to the Department of State Health Services' NBS Program for many years and the input and expertise contributed by its membership is highly valued.

We recognize that as the state's ability to screen for and identify newborns with heritable conditions expands, the need for specialty consultation has also increased; the work that these physicians provide is important to Texas families and the state's health care system. The NBS Program is exploring what can be done to address your recommendation, including leveraging existing programs and identifying available unobligated funds to meet this need.

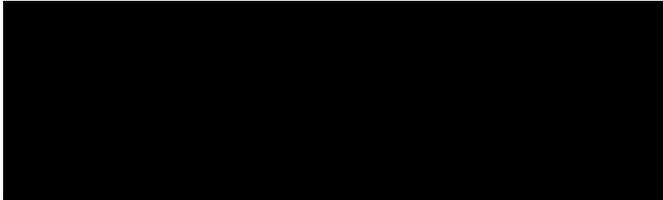
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Thank you for the important work the Newborn Screening Advisory Committee continues to do on behalf of the newborns in Texas. If you have further questions, please contact Dr. Manda Hall, Associate Commissioner of Community Health Improvement, at [REDACTED] or by e-mail at

Sincerely,



John Hellerstedt, M.D.  
Commissioner