



April 15, 2025

The Honorable Robert Kennedy, Jr.  
Secretary of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Kennedy:

The Association for Diagnostics & Laboratory Medicine (ADLM) urges you to reinstate the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which plays an indispensable role in our nation's efforts to detect, diagnose, and treat asymptomatic babies with serious medical conditions. Left undetected and untreated, these disorders lead to premature death or lifelong disability.

As a panel of medical experts, ACHDNC was responsible for assessing the evidence to ensure that screening tests for a disorder are accurate, and that effective treatment is available. If the advisory group endorsed testing for a condition, and the Department concurred, it was placed on the Recommended Uniform Screening Panel (RUSP) – a registry used by states to determine which disorders to screen.

The service provided by these volunteer experts was invaluable to the localities, but more importantly the parents and their baby. Many states do not have sufficient resources to evaluate these life altering tests on their own. The Department and the ACHDNC filled that void, helping to improve, and in many instances, save the lives of children.

For example, Phenylketonuria or PKU, is an inherited disorder that, if left untreated, can result in long-term cognitive disabilities. However, through early diagnosis and a modified diet, these babies grow to be adults with no limitations on what they can achieve. Everyone benefits from the availability of testing for this condition and the 37 other conditions included in the RUSP.

The current federal-state partnership has been critical to expanding newborn screening. In 2007, only 10 states and the District of Columbia tested for all of the disorders on the RUSP list. By 2025, all states offered testing for at least 30 of the 38 conditions. The lives of approximately 15,000 children are improved annually by newborn screening. The Department and ACHDNC, in partnership with the states, have been instrumental to this success.

ADLM strongly recommends that you reinstate ACHDNC and allow it to continue its work on behalf of our nation's parents and children. If the Department decides not to restore the advisory panel, we suggest that you provide guidance on how (1) new conditions/tests will be evaluated for efficacy in the future and (2) what process will be used to update the list of disorders that should be screened? The absence of ACHDNC creates a significant gap within newborn screening that must be addressed.

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ADLM is a global scientific and medical professional organization dedicated to clinical laboratory science and its application to healthcare. Many of our members are medical experts in the pediatric field who generate and evaluate the evidence that is often used to decide whether a test for a disorder is sufficiently accurate to include in a screening panel. One of ADLM's primary missions is to improve the quality of care for our vulnerable populations, such as our children.

We look forward to working with you on this important issue. If you have any questions, please email Vince Stine, PhD, ADLM's Senior Director of Government and Global Affairs, at [vsstine@myadlm.org](mailto:vsstine@myadlm.org), or Evan Fortman, MPA, ADLM's Manager of Government Affairs at [efortman@myadlm.org](mailto:efortman@myadlm.org).

Sincerely,

A handwritten signature in blue ink, appearing to read "Anthony A. Killeen".

Anthony A. Killeen, MD, MSc, PhD  
President, ADLM