Congreſs of the United States
Washington, DC 20515

July 29, 2025

The Honorable Robert F. Kennedy Jr.
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Kennedy,

In support of the millions of Americans living with rare diseases, we are writing to inquire about the current status and future of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) following reports that your department suddenly terminated the committee in April.[1] The ACHDNC, established by law, has played a vital role in promoting early diagnosis and access to care through its newborn screening recommendations. This legacy compels us to ensure the continuation of this critical initiative and evidence-based policymaking at the federal level.

The U.S. Department of Health and Human Services (HHS) has a long-standing commitment to improving the lives of individuals and families affected by rare and heritable disorders. Originally recognized in 2003 under President George W. Bush and supported across administrations of both parties, the ACHDNC plays a vital role in this mission. As required by law under the Public Health Services Act, the ACHDNC advises the HHS Secretary on evidence-based additions to the Recommended Uniform Screening Panel (RUSP). The RUSP provides essential guidance to states on which devastating diseases and conditions should be included in newborn screening at birth, helping establish a gold standard that promotes consistency and timely access to life-saving interventions for families across the country.

As expressed by 273 organizations committed to improving the health of America's infants and families, the elimination of this committee will have devastating impacts on the delivery of time-sensitive, life-saving care.[2] Without a convening central body, there is no forum for streamlined evaluation and recommendation of which conditions should be added to the RUSP. Our nation's newborn screening infrastructure relies heavily on ACHDNC. By guiding the screening of nearly 4 million newborns annually, the RUSP both saves thousands of lives and improves outcomes for thousands more by enabling early detection of 32 treatable conditions, often before symptoms appear or irreversible harm or death occurs. This progress is directly threatened by your unilateral decision to eliminate the ACHDNC.

We urge HHS to ensure there is no interruption in the core functions that support timely updates to the RUSP. A clear, transparent, and science-informed pathway is indispensable to continue realizing the benefits of research advancements, particularly as new treatments, diagnostics, and screening technologies emerge at an unprecedented pace.

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[1] HHS Scraps Advisory Committee on Newborn Screening, Kennedy axes HHS committee advising states on genetic screening for newborns
[2] Coalition Expresses Concerns About the Elimination of the Advisory Committee on Heritable Disorders in Newborns and Children | Cystic Fibrosis Foundation

By strengthening and improving the ACHDNC and continuously evaluating conditions included in the RUSP, states can avoid duplicative work that adds inefficiencies in the healthcare system. The rare disease community depends on this infrastructure to advance life-saving early diagnosis and access to treatment.

We are concerned about the long-term implications of a gap in this process and respectfully request answers to the following questions no later than August 6, 2025:

1. What led the department to terminate the Advisory Committee on Heritable Diseases in Newborns and Children (ACHDNC)?
2. As the department discusses plans to restructure the ACHDNC, or create a new evidence review process, what will that restructure look like?
3. What are the immediate and long-term plans to ensure continuity in the review and recommendation process for the RUSP?
4. What are the department's plans for proposals that were in process or on track for final review?
5. Are there plans to resume previously coordinated opportunities for stakeholder engagement in shaping a modernized, sustainable approach to newborn screening?

We are committed to continuing progress toward a stronger, equitable newborn screening system that reflects the rapid evolution of science and the needs of patients and families nationwide.

We look forward to your response to collaboratively continue building a framework that aligns with medical progress, reduces preventable chronic disease, and ensures that every child—regardless of geography or socioeconomic status—can benefit from timely, evidence-based screening and care. Thank you for your attention to this important matter.

Sincerely,

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Member of Congress

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