National Organization for Rare Disorders (NORD®)
Rare Disease Centers of Excellence

Robert F. Kennedy Jr.
Secretary, Department of Health and Human Services

Dear Mr. Secretary,

On behalf of the NORD Rare Disease Centers of Excellence (RD CoE), we wish to express our deep concern over the recent decision to dissolve the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) and urge the immediate reinstatement of this important body. The NORD Rare Disease Centers of Excellence, a group of 40 academic medical centers in the US, represents those who care for most of the children in the US who screen positive for these conditions, and as such we know firsthand that newborn screening saves lives.

The ACHDNC has been instrumental in the development of a Recommended Uniform Screen Panel (RUSP) for newborn screening. This was the result of bipartisan and wise leadership of both Republicans and Democrats to address the incredible variability of testing from state to state. The fact that babies were dying based on the zip code where they were born was unacceptable then and is unacceptable now.

The result of that bipartisan work was the creation of a Federal Committee comprised of experts in the field and including numerous important national organizations. This committee, the ACHDNC, has contributed to the development and provided considered evaluation of additional conditions to the RUSP. Since there is an approved and recommended panel, many states have accelerated the pace of addition of all recommended conditions to their panels. This ensures that newborns have the same opportunities to benefit from diagnosis and treatment prior to symptom onset, regardless of the state in which they are born. Thousands of lives have been saved, but there is even more work to do.

The members of the ACHDNC are volunteers who give their precious time because the effort is incredibly important. Not every state has the expertise to perform the careful evaluation necessary to weigh evidence for and against inclusion of additional conditions. The absence of expertise and resources at the federal level will have negative consequences on screen-positive newborns and their families.

Newborn screening plays a critical role in preventing the devastating effects of these diseases. Its preventative approach makes it one of the most effective public health initiatives and aligns with your vision for a healthier America. Until the ACHDNC and the RUSP, each state developed its own panel of conditions and advances were dependent on state level expertise and funding. Now there is a clear standard to which every state aspires. The final decision of whether and when to include a new condition still rests with each state, as it should, but the ready availability of national expertise and the Secretary's review ensure rapid uptake as evidence and knowledge expand.

We strongly urge you to immediately reinstate the ACHDNC so that the essential business of optimizing care for newborns, the most vulnerable citizens of our country, can continue. We would welcome the opportunity to discuss this matter further and collaborate on a path forward. Thank you for your attention to this critical and urgent issue.

On behalf of the **NORD Rare Disease Centers of Excellence Directors**,

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