



January 27, 2022

RE: Senate Bill 242

Dear Senators:

I am a Professor of Genetic Medicine and Neurology at the Johns Hopkins School of Medicine writing in support of Senate Bill 242. I have been an active researcher in the field of X-linked Adrenoleukodystrophy (ALD) for over 25 years.

Adrenoleukodystrophy is a devastating neurologic disease that affects boys between the ages of 3-10 years of age. Early and appropriate monitoring is lifesaving and the resources to provide this care is readily available here in Maryland. Given this need for detection and surveillance, a methodology for newborn screening was developed at the Kennedy Krieger Institute in Baltimore in 2006 and we demonstrated its efficacy in 2010 in 5000 newborns in Maryland born at three area hospitals.

Based on this work, ALD newborn screening began in New York in January 2014.

Adrenoleukodystrophy has since been added on February 17, 2016 to the Recommended Uniform Screening Panel (RUSP) and at this time over 25 states are actively testing babies. I have personally assisted numerous state programs throughout the country with the implementation and development of follow-up programs.

Despite this history of development in Maryland and its presence on the RUSP, newborn screening is still not available in Maryland. This despite an internationally recognized center of expertise right across the street from the state laboratories and multiple attempts to advocate for this to be advanced.

It is negligent to ignore the clear recommendations of the RUSP and not provide timely initiation of this opportunity to every infant in this state. A child born in Maryland should be afforded the same opportunities for diagnosis and care provided children in Pennsylvania or D.C., two neighboring regions which are already screening for this condition. We should also be forward-looking and insist that other conditions as they meet the rigorous standards of the RUSP be added to our newborn screening panel in two years' time.

Sincerely yours,

A handwritten signature in black ink that reads "Gerald V. Raymond, MD".

Gerald V. Raymond, M.D.
Professor of Genetic Medicine and Neurology
Johns Hopkins School of Medicine