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08/17/22

To Whom it May Concern,

At the Batten Disease Support, Research, and Advocacy Foundation (BDSRA), we have fought for hope for treatments and a cure for Batten Disease. In 2008, Congress passed the original Newborn Screening Saves Lives Act (P.L. 110-204), which established national newborn screening guidelines and helped facilitate comprehensive newborn screening in every state. In 2007, only 10 states and the District of Columbia required infants to be screened for all the recommended disorders. Today, all 50 states and the District of Columbia require screening for at least 31 treatable conditions, as recommended by the Department of Health and Human Services.

While we continue to advocate for treatments for Batten disease, we ask for continued federal support so that when we have approved treatments, early screening and detection can save families precious time and peace of mind. Newborn Screening Saves Lives Reauthorization Act, S. 350 Reauthorizes the Health Resources and Services Administration (HRSA) state grants to expand and improve screening programs, provide educational resources to parents and health care providers, and improve follow-up care for infants with a detected condition.

More than 700 babies born in Ohio are identified with a condition through current newborn screening efforts every year. Not only does early detection allow for the diseases to be managed successfully and at a lower long-term cost saving lives, but also saving state and federal funds. Our CLN2 families are eager to see CLN2 added to the RUSP. The hope placed in Brineura as a treatment has given children with a CLN2 diagnosis a chance to stay with their families a while longer and significantly slows the progression of the disease. When added to the RUSP, it will open doors for families and our Industry partners to explore treatment before the progression of the disease.

It also reauthorizes the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children which advises the Secretary of Health and Human Services on newborn and childhood screening policies and priorities to enhance state health agencies to ensure screening is available to every eligible infant. Includes the evidence-based federal Recommended Uniform Screening Panel (RUSP).

We thank you for your time and are hopeful for your support for S. 350.

In Confidence,

A handwritten signature in black ink, appearing to read "Morgan DeBoth".

Morgan DeBoth
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