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PRESS RELEASE

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Sen. Testin Works with Wisconsin Rapids Family to Update Newborn Screening Program
“Collin Cushman’s Law” Would Add Krabbe Disease to List of Disorders Screened for in Wisconsin

Madison, WI – When Kevin and Judy Cushman brought their son Collin home from the hospital, he seemed like the perfect baby. Over the next nine months, Collin developed normally. He learned to wave and smile, and by all accounts, he was a happy baby – but all that changed.

At nine months, Collin regressed; he became irritable and stiff. It took four months to get the diagnosis – globoid cell leukodystrophy, a rare disorder that impacts the central and peripheral nervous systems more commonly known as Krabbe disease. Kevin and Judy were forced to provide around the clock care and come to grips with the fact that their son had been handed a slow-moving death sentence. Collin passed away in January of 2019.

Things could have been different. While Krabbe has no cure, detection of the disease at birth enables parents to seek treatment for their children, who are then able to live longer, fuller lives. On Monday, Senator Patrick Testin (Stevens Point) introduced legislation with Representative Todd Novak (Dodgeville) to add Krabbe disease to Wisconsin’s newborn screening program.

“Scientific advancements and new treatments have brought hope to families of children with Krabbe, but early detection is key,” said Senator Testin. “By adding Krabbe to our newborn screening program, we give these kids a fighting chance.”

Collin’s father Kevin spoke about what newborn screening could mean for families with a child afflicted with Krabbe.

“When it comes to your child you never want to hear ‘rare and terminal illness,’ but that’s what we heard when we got the diagnosis for our son, Collin,” said Kevin Cushman. “The only thing we could do was make him comfortable and watch him regress. We want to bring hope to families before it’s too late for their child. Newborn screening is the one way to save a child born with Krabbe when parents aren’t aware they are carriers of the disease.”

The bill will circulate for co-sponsorship in the legislature through Wednesday, March 3rd, 2021.

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