

[Your Name]

[Your Address]

[City, State, ZIP Code]

[Email Address]

[Phone Number]

[Date]

[Representative's Name]

[Office Address]

[City, State, ZIP Code]

Dear [Representative's Last Name],

My name is [Insert your Name] and I am a constituent of the [Your District] in [Your State]. I am writing to you today to express my deep concern about the challenges faced by PDCD families, including mine. My [son/daughter/Grandchild/niece/nephew/friend] was born with Pyruvate Dehydrogenase Complex Deficiency (PDCD), a condition that has forever altered the trajectory of [her/his] life and countless others like [her/him]. I implore you to join our fight to make a life-changing difference.

PDCD is a genetic disorder that affects the breakdown of carbohydrates. There is currently no cure for PDCD however there is a treatment. Children with PDCD need to immediately begin on a Ketogenic diet to prevent permanent brain damage, seizures, disabilities, and death. A few facts about PDCD that are extremely important to note: 50% patients with PDCD are currently undiagnosed! 80% of our patient population is DeNova, meaning not inherited. PDCD is more common than ALS yet it lacks the same funding and awareness, 1 in 40,000 has PDCD.

The reason for my urgent appeal is to shed light on a matter that directly affects the lives of hundreds of children and families across our state and the entire nation. Specifically, I am seeking your support to bring more awareness for PDCD, increase funding for PDCD research, and help us in our fight to include PDCD in the National Newborn Screening program.

Allocating more funding for PDCD research would significantly benefit PDCD families by improving treatment options, deepening our understanding of the condition, offering hope for a cure, fostering a

supportive community, increasing awareness, providing access to clinical trials, and empowering advocacy efforts. This investment holds the potential to enhance the lives of affected individuals and their families, offering them better care, increased opportunities for participation in cutting-edge treatments, and a stronger voice in advocating for their needs.

Incorporating PDCD into the National Newborn Screening program is a pivotal stride we must take. The inclusion of this condition would facilitate early diagnoses, enabling timely interventions that can substantially enhance the well-being and overall quality of life for these young lives. Moreover, this move would spotlight PDCD on the medical map, catalyzing vital research, resource allocation, and a surge of support for the families bearing its weight.

Here is a link to read many children's stories with PDCD <https://www.hopefordcd.org/pdcd-heroes>

Collectively, the stories of these families amount to an astonishing 56 years and 10 months – equivalent to 20,757 days of struggle. That's over two decades during which children and their families endured the lack of appropriate treatment and support. For each one of those days, children suffered through seizures, lactic acidosis, metabolic strokes, significant developmental delays, and hypotonia. Tragically, hundreds of cases have resulted in a parent's worst nightmare: death. If PDCD had been included in the newborn screen, parents could have embarked on appropriate treatment from day one, rather than unknowingly subjecting their newborns to treatments that were harmful.

These resilient families have shared their heart-wrenching stories, striving to raise awareness about PDCD and advocating for desperately needed change. Our children need someone beside their parents and family members fighting for them. Future families who will receive the diagnosis of PDCD need you, even if they do not yet realize it. Will you, Representative [Representative's last name], be the champion these innocent children deserve?

Not only will this help children and families obtain a very important diagnosis however it will save states money on medicare. The Everylife Foundation conducted a study that shown that "in terms of medical costs and productivity loss in the pre-diagnosis years is between \$86,000 and \$517,000 per patient cumulatively for the years of delay"

I urge you to seize this opportunity to transform lives and pave the way for a brighter future for those grappling with PDCD. Your involvement can make an immeasurable difference and stand as a beacon of hope for these families who are desperately in need of it.

Thank you for your time, consideration, and the potential impact you can have on this crucial matter.

Sincerely,

[Your Name]