Brayden Alexander Global Foundation for Hydranencephaly, Inc.
Dba Global Hydranencephaly Foundation
760 San Diego Loop
Jemez Springs, New Mexico 87025

To Whom it May Concern:

It has come to my awareness that you have a child in your care that has been given a diagnosis of hydranencephaly, or that presents with the absence of the cerebral hemispheres to a great degree which would prompt the potential diagnosis of such. Thank you for allowing us to make your acquaintance in this capacity.

Let me first introduce myself: My name is Ali Harper. The first time I heard the word hydranencephaly was when my own son, Brayden Alexander, was diagnosed after birth via MRI in June 2008 at Columbia Regional Medical Center in collaboration with University of Missouri: Columbia. This was only after many weeks of my pregnancy having been encouraged to terminate by neonatologists and neurologists. I was led to believe that my decision to continue my pregnancy was a selfish one and that I was bringing a child in to this world to suffer in pain, mercilessly, and to cause my family more pain in his loss. They were sure he would be still-born, if he survived to term at all; but instead he was born via emergency c-section and had very obvious severe hydrocephalus, but was otherwise doing well: breathing on his own, eating as he should, regulating a tolerable body temperature, not showing any signs of seizures or muscle spasms, nor seizures. Yet our doctors continued to give me a long list of things he would never accomplish. They encouraged myself and my family to leave him in the hospital to live out his days, and when that wasn't received well, they sent him home on hospice with a prescription for morphine to administer when he cried, a prescription that I later discovered was to aid in his passing. Their recommendation for care was for me to join a child-loss support group.

Despite being set up for failure, Brayden's journey was not as the medical community anticipated it to be. He was doing well, yet they refused to place a shunt to treat his severe hydrocephalus. When I advocated strongly for it, they reluctantly agreed and removed him from hospice – a difficult decision it was to abandon the support we had received from that program. Nonetheless, he received his shunt when he was just over 1 month old and it changed his life – no, it SAVED his life. That child, MY child lived, loved, and thrived for 4 years, 4 months, and 15 days until he unexpectedly died at home from respiratory failure. Yes, the medical professionals told us he wouldn't survive - but, he didn't only survive: HE LIVED.

He lived a life where he had begun to learn to communicate with augmentative and alternative communication devices, was gaining mobility with a gait trainer, was attending a preschool program where he was learning and making friends, was active in physical therapy, occupational therapy, speech therapy, hydrotherapy and hippotherapy. Not to mention, that long list of medically subjected impossibilities we had been delivered – he had checked them all off his to-do list: eating semi-independently, breathing independently, smiling, laughing, making friends, recognizing his loved ones, vocalizing a handful of words, showing true emotion, making purposeful movements, being a community member, traveling and exploring almost daily, and living his best life.

I share this because I didn't have a support system. I was fortunate that I did find a small email group of information that led me to a few other families across the globe who had children living with this condition that I had been told was impossible to live with. Together with a couple of these parents, we created Brayden Alexander Global Foundation for Hydranencephaly in 2011 – a registered 501c3 nonprofit organization that provides individualized family resources and support services from the moment of diagnosis until forever. Currently in our database are more than 700 families in more than 30 countries. I must add that I do not have a medical degree, but rather hold a Bachelors in Special Education. I have a heart for the population of human beings that are believed to not have the same capabilities as society would deem "norm" and have done enough research on hydranencephaly to be able to consider myself an expert on this diagnosis specifically. I respect that you are an expert in your field of study as well, however I also acknowledge the serious lack of information in medical text in regards to life with hydranencephaly vs the condition being deemed "incompatible with life" and this is what concerns me.

And with that, I want to conclude with an awareness of the possibilities that do exist for children delivered this diagnosis. Too often in my years, since 2008, on this journey have doctors delivered a death sentence rather than a plan to support a quality of life worth living. The treatment for hydranencephaly when diagnosed in-utero should not be abortion. The treatment for hydranencephaly when diagnosed in infancy should not include morphine and "slow codes". I hope, instead, that we can work together, with the families facing this diagnosis for their loved one, to provide every opportunity for their child to thrive and grow with support and equality in healthcare when intervention is necessary.

Thank you for your time and I hope to hear from you!

Sincerely,

Ali Harper
Founder, Chief Family Advocate & Executive Director
Global Hydranencephaly Foundation
www.ghf.life
"Believe in the Impossible!"