GHF is a registered 501c3 tax exempt nonprofit organization—EIN: 45-2113600

We are 100% volunteer driven and functioning on 100% donations.

Your contributions are greatly appreciated. Consider donating in one of the following ways:

~Via mail to the address below
~Via our website address below
~Directly through PayPal at President@HydranencephalyFoundation.org

Thank YOU!

Primary Mailing Address:
PO Box 1150
Seabeck, WA
98380-9800

Phone: 573.280.2412
Web:
www.hydranencephalyfoundation.org
Email:
President@HydranencephalyFoundation.com

Brayden Alexander Global Foundation for Hydranencephaly, Incorporated

Doing Business As:

Global Hydranencephaly Foundation

Mission Statement:

The Global Hydranencephaly Foundation is a family driven nonprofit organization dedicated to providing families faced with a diagnosis of hydranencephaly, the opportunity to help their child live the quality of life he or she deserves. The family-to-family resource network is the foundation of this mission; an ideally structured, multi-faceted community for the dissemination of invaluable information, sharing of effective care management strategies specific to the unique circumstances a family faced with diagnosis of this rare neurological condition may encounter, and individualized, lifelong support. Emphasis is placed on the development of empowered parent advocates, strengthened by availability of comprehensive information, geographically tailored resources, and a confident awareness of the rights children have to quality, compassionate care without discrimination. We embrace the opportunity for continuous growth through the expansion of additional collaborative partnerships with like-minded organizations and reputable community businesses. Through community-based awareness campaigns and the planned infiltration of the medical community, we aim to conquer the misconceptions that exist surrounding this diagnosis and portray a clearer picture of the possibilities that exist for these children; giving multiple reasons to

"Believe in the Impossible!"

hydranencephaly

(hi-dran-en-sef-uh-lee)

WHAT IT IS

Hydranencephaly is a congenital condition in which the brain's cerebral hemispheres are absent to varying degrees and the resulting empty cranial cavity is filled with cerebrospinal fluid. Hydranencephaly (or hydroanencephaly) is one of several types of cephalic disorders. These disorders are congenital conditions that derive from either damage to, or abnormal development of, the fetal nervous systemn the earliest stages of development in utero. Cephalic is the medical term for "head" or "head end of body." This particular rare neurological condition, an extreme form of porencephaly, occurs after the 12th week of pregnancy, after the brain has begun developing.

This condition does not have any definitive identifiable cause factor. As with all cephalic conditions, there is an obvious interruption in normal development of the nervous system. A traumatic occurrence of sorts, resulting in prenatal stroke, is believed to be the primary cause of hydranencephaly. Some possibilities include: intrauterine infection, environmental exposure to toxins, vascular insult of another nature, and twin-to-twin transfusion. Some researchers have also suggested the possibility of a genetic component, though only one case has been documented in which a family has been presented this diagnosis for more than one child.

Global Hydranencephaly Foundation provides individualized support and advocacy services to families facing a diagnosis of hydranencephaly for a child in their life; regardless of what stage of the journey the family is on.

WHAT THIS MEANS

The prognosis for a child born with hydranencephaly is presented as very poor: death in utero, within weeks, or no longer than a year. While some children given this diagnosis may not survive past their first birthday, each case is unique and there are a growing number of cases where children can defy this prognosis and live several years. The oldest individual with a confirmed case of hydranencephaly celebrated his 33rd birthday before his passing.

Oftentimes diagnosis is made in utero to some degree, though often inaccurate or unconfirmed until birth. In other cases, diagnosis is delayed for several weeks or even months since the infant appears developmentally normal at birth. As the child matures, delays become much more apparent. In extremely rare cases, damage causing hydranencephaly can occur in infancy following infections such as meningitis, stroke, intracerebral hemorrhage, and traumatic brain injury.