

All Things Hydranencephaly

Guide for Parents/Caregivers

Publication Provided by:

Brayden Alexander Global Foundation for Hydranencephaly, Incorporated

doing business as

Global Hydranencephaly Foundation, a registered 501c3 nonprofit organization



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“When one's expectations are reduced to zero, one really appreciates everything one does have. “

~Stephen Hawking

Who is Global Hydranencephaly Foundation?

"Aerodynamically, the bumble bee shouldn't be able to fly, but the bumble bee doesn't know it so it goes on flying anyway."

- Mary Kay Ash

About

We are a nonprofit organization incorporated on June 14, 2011 and registered with the Commonwealth of Virginia State Corporation Commission, as well as a foreign entity with the State of Washington. The name Global Hydranencephaly Foundation was adopted as our "fictitious business name" under our parent company: Brayden Alexander Global Foundation for Hydranencephaly, Incorporated for ease of business use purposes. Ultimately, we are a network for ensuring quality of life for the families touched by this rare neurological condition; a parent-run foundation, organized and managed by the following volunteer individuals:

Alicia Harper: Founder, President/CEO

Angela Mason: Vice President, CFO & Director of Marketing

Jessica Zuchowski: Board Secretary & Community Outreach Specialist

Holly Mansfield: Digital Media Specialist & Director of Web Design

Company Overview

Hydranencephaly is a rare neurological condition, knowingly occurring in less than 1 in 10,000 births across the globe with statistics portraying only 1 in 250,000 in the US alone (as of the last statistical predictions made). The condition presents as the absence of the brain's cerebral hemispheres with the existence of excess cerebrospinal fluid in their place. There is no known cause, no cure, and very little optimism available for those diagnosed by medical professionals, so little that doctors most often recommend termination when diagnosed in utero. In the event that diagnosis comes at or after birth, still little to no hope is given for a quality of life worth living.

On July 1, 2008, the morning after Brayden Alexander was born at the University of Missouri: Columbia; he was given this grim diagnosis, a prognosis that stripped all hope for his existence, one that gave him an expiration date of no longer than a year and closer to weeks. By networking with other families with children living quality lives with this condition, his family became believers in the possibilities rather than the medically subjected impossibilities thus bringing this foundation in to existence.

Description

Global Hydranencephaly Foundation's mission and vision statements serve as the inspirational language guiding the efforts of the organization. Together these statements work to establish organizational

behavior plans, guide the decision-making process, and determine the standards for those who represent our name and work effortlessly to build our reputation.

MISSION: 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, life-long 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!"

In effort to carry out this mission, GHF will:

- Provide life-long, individualized support to all family members, as well as care providers, and strive to meet the needs of those individuals as best capable.
- Ensure that children are receiving quality, compassionate medical care without discrimination in all areas of the world.
- Work to dispel medically subjected misconceptions by infiltrating the medical community with experience-based information and real-life, odd-defying stories.
- Develop strong, confident family and care provider advocates through the availability of geographically tailored resources, comprehensive news and information, and the opportunity for effortless sharing of effective care management strategies specific to the unique circumstances encountered by families faced with diagnosis of this rare neurological condition via the heart of our mission: our multi-faceted, optimally structured Family-to-Family Resource Network; and
- Create and maintain credibility with supporters by ensuring every donated dollar is spent for the benefit of the families represented by GHF. Success of this factor is based upon the measure of impact our efforts are having on individuals around the world during specific periods of time.

The business organizational plan displays the value GHF places on community-based awareness campaigns, proper representation, and immediate recognition of its logo and mission in order to strengthen and further develop in the direction of positive change. GHF embraces any opportunity for continuous growth thorough collaborative partnerships with like-minded organizations and reputable community businesses.

Goals: As GHF awaits receipt of their 501c3 tax exemption status, it is undetermined when contributions will be tax deductible. Donations to Global Hydranencephaly Foundation are utilized as support for the individualized support programs for those families faced with a diagnosis of hydranencephaly.

Contributions are utilized for:

Direct individualized support services such as shipment of durable medical equipment donations, purchase of general care items necessary to assist with family needs based on varying circumstances.

- Incorporation fees and business licensing charges.
- Printing and distribution of educational information about hydranencephaly, awareness campaigning flyers, patient advocacy packets, medical treatment facility brochures, business cards, and more.
- Website and domain charges and associated fees.
- Memorial gifts for families upon losing their child.
- Establishment of fundraising events and awareness campaigns in communities across the globe.
- Growth and development of projects to support our mission and ultimately our families.

In keeping with the mission of our foundation, we will expand upon our current level of awareness and gain greater strength through advocacy; giving individuals reason to...

"Believe in the Impossible"

General Legalities and Information

Recognized by the State Corporation Commission of the Commonwealth of Virginia as a Nonprofit Corporation on June 14, 2011 and authorized to transact business subject to all Virginia laws applicable to the corporation and its business. We are a registered 50(c)(3) nonprofit organization. Our foundation began doing business as Global Hydranencephaly Foundation in December 2011 for ease of use and greater distinguishability, under the parent company of Brayden Alexander Global Foundation for Hydranencephaly, Incorporated. The logo, to include: Bennett Buzz-Bee, globe, guardian butterflies, "Global Hydranencephaly Foundation", and <http://www.hydranencephalyfoundation.org/> become registered trademarks of GHF as of August 2013.

What is Hydranencephaly?

From Wikipedia, the free encyclopedia; written by founder and president, Alicia Harper, and submitted by Global Hydranencephaly Foundation (current as of December 2013):

Hydranencephaly is a condition in which the brain's [cerebral hemispheres](#) are absent to varying degrees and the remaining cranial cavity is filled with cerebrospinal fluid.^[1]

Hydranencephaly (or hydroanencephaly)^[2] is a type of [cephalic disorder](#). These disorders are congenital conditions that derive from either damage to, or abnormal development of, the fetal nervous system in the earliest stages of development in utero. Cephalic is the medical term for “head” or “head end of body.” These conditions do not have any definitive identifiable cause factor; instead generally attributed to a variety of hereditary or genetic conditions, but also by environmental factors such as maternal infection, pharmaceutical intake, or even exposure to high levels of radiation.^[3]

This should not be confused with [hydrocephalus](#), which is an accumulation of cerebrospinal fluid in the ventricles.

In [hemihydranencephaly](#), only half of the brain is filled with fluid.^[4]

Usually the cerebellum and brain stem are formed normally, although in some cases the cerebellum may also be absent. An infant with hydranencephaly may appear normal at birth or may have some distortion of the skull and upper facial features due to fluid pressure inside the skull. The infant's head size and spontaneous reflexes such as sucking, swallowing, crying, and moving the [arms](#) and [legs](#) may all seem normal, depending on the severity of the condition. However, after a few weeks the infant sometimes becomes irritable and has increased [muscle](#) tone ([hypertonia](#)). After several months of life, [seizures](#) and [hydrocephalus](#) may develop, if they did not exist at birth. Other symptoms may include visual impairment, lack of growth, deafness, blindness, spastic quadriplegia ([paralysis](#)), and intellectual deficits.

Some infants may have additional abnormalities at birth including seizures, [myoclonus](#) (involuntary sudden, rapid jerks), limited thermoregulation abilities, and [respiratory](#) problems.

Still other infants display no obvious symptoms at birth, going many months without a confirmed diagnosis of hydranencephaly. In some cases a severe hydrocephalus, or other cephalic conditions, diagnosis is misdiagnosed.

Causes

Hydranencephaly is an extreme form of [porencephaly](#), which is characterized by a cyst or cavity in the cerebral hemispheres.

Although the exact cause of hydranencephaly remains undetermined in most cases, the most likely general cause is by vascular insult such as stroke or injury, intrauterine infections, or traumatic disorders after the first trimester of pregnancy. In a number of cases where intrauterine infection was determined the causing factor, most involved toxoplasmosis and viral infections such as enterovirus, adenovirus, parvovirus, cytomegalic, herpes simplex, Epstein-Barr, and syncytial viruses. Another cause factor is determined to be monochorionic twin pregnancies, involving the death of one twin in the second trimester, which in turn causes vascular exchange to the living twin through placental circulation through twin-to-twin transfusion, causing hydranencephaly in the surviving fetus.^[5] One medical journal

reports hydranencephaly as an autosomal inherited disorder with an unknown mode of transmission, where an unknown blockage of the carotid artery where it enters the cranium causes obstruction and damage to the cerebral cortex.^[2]

As a recessive genetic condition, both parents must carry the asymptomatic gene and pass it along to their child, a chance of roughly 25 percent. Despite determination of cause, hydranencephaly inflicts both males and females in equal numbers.

Though hydranencephaly is typically a congenital disorder, it can occur as a postnatal diagnosis in the aftermath of meningitis, intracerebral infarction, and ischemia (stroke), or other traumatic brain injury.^[6]

Diagnosis

Diagnosis may be delayed for several months because the infant's early behavior appears to be relatively normal. **Transillumination**, an examination in which **light** is passed through body tissues, can be used to diagnose hydranencephaly. An accurate, confirmed diagnosis is generally impossible until after birth, though prenatal diagnosis using fetal ultrasonography (ultrasound) can identify characteristic physical abnormalities that exist. Through thorough clinical evaluation, via physical findings, detailed patient history, and advanced imaging techniques, such as angiogram, computerized tomography (CT scan), magnetic resonance imaging (MRI), or more rarely transillumination (shining of bright light through the skull) after birth are the most accurate diagnostic techniques.^[2] However, diagnostic literature fails to provide a clear distinction between severe obstructive hydrocephalus and hydranencephaly, leaving some children with an unsettled diagnosis.^[6]

Preliminary diagnosis may be made in utero via standard ultrasound, and can be confirmed with a standard anatomy ultrasound. This sometimes proves to provide a misdiagnosis of differential diagnoses including bilaterally symmetric schizencephaly (a less destructive developmental process on the brain), severe hydrocephalus (cerebrospinal fluid excess within the skull), and alobar holoprosencephaly (a neurological developmental anomaly). Once destruction of the brain is complete, the cerebellum, midbrain, thalami, basal ganglia, choroid plexus, and portions of the occipital lobes typically remain preserved to varying degrees. Though the cerebral cortex is absent, in most cases the fetal head remains enlarged due to the continued production by the choroid plexus of cerebrospinal fluid that is inadequately reabsorbed causing increased intracranial pressure.^[5]

Occurrence

This condition possesses isolated occurrences, affecting less than 1 in 10,000 births worldwide^[5] and officially classifying hydranencephaly as a rare disorder by affecting fewer than 1 in 250,000 in the United States.^[7]

Prognosis

There is no standard treatment for hydranencephaly. Treatment is symptomatic and supportive. Hydrocephalus may be treated with surgical treatment of a **shunt**, which often grants a much better prognosis and greater quality of life. It is important to remember that, just as typically developing children, those with hydranencephaly are unique with varying degrees of abilities^[8].

The prognosis for children with hydranencephaly is generally quite poor. Death often occurs in the first year of life,^[9] but other children may live several years. The oldest known child living with hydranencephaly is 33 years old (as of August 2013)^[10].

Medical text identifies that hydranencephalic children simply have only their brain stem function remaining, thus leaving formal treatment options as symptomatic and supportive.^[5] Severe hydrocephalus causing macrocephaly, a larger than average head circumference, can easily be managed by placement of a shunt^[3] and often displays a misdiagnosis of another lesser variation of cephalic condition due to the blanketing nature of hydrocephalus.^[5] Plagiocephaly, the asymmetrical distortion of the skull, is another typical associated condition that is easily managed through positioning and strengthening exercises to prevent torticollis, a constant spasm or extreme tightening of the neck muscles.

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Does my child have Hydranencephaly?

Disclaimer: This information is not intended to be used for the diagnosis or treatment of a health problem or as a substitute for consultation with licensed medical professionals. The following is retrieved from the textbook source, "The Official Parent's Sourcebook on Hydranencephaly" By James N. Parker, M.D. and Philip M. Parker, Ph.D., editors; shared with written permission from ICON Group International, Inc (ICON Group) for distribution to parents and care providers.

From GHF: The following includes of list of all cephalic disorders, many of which walk hand-in-hand in some circumstances and in others often are misdiagnosed as one or another. In cases of Hydranencephaly, most often it goes diagnosed as severe hydrocephalus; partly as the condition of Hydranencephaly is deemed incompatible with life and therefore overlooked as a possibility, and partly as research and information on this rare neurological condition is limited. You may find many medical professionals who have never heard of the condition, which proves both frustrating and confusing to parents and caregivers alike.

Cephalic Disorders: Overlapping and Fine Lines

Cephalic disorders are congenital conditions that stem from damage to, or abnormal development of, the budding nervous system. Damage to the developing nervous system is a major cause of chronic, disabling disorders and, sometimes, death in infants, children, and even adults. The degree to which damage to the developing nervous system harms the mind and body varies enormously. Many disabilities are mild enough to allow those afflicted to eventually function independently in society. Others are not. Some infants, children, and adults dies, others remain totally disabled, and an even larger population is partially disabled, functioning well below normal capacity throughout life.

These conditions often overlap; therefore below you will find a listing of the different types of cephalic disorders with their medical descriptions:

Anencephaly: neural tube defect that occurs when the head end of the neural tube fails to close, usually between the 23rd and 26th days of pregnancy, resulting in the absence of a major portion of the brain, skull and scalp. Infants with this disorder are born without a forebrain. The remaining brain tissue is often exposed, not covered by bone or skin. These infants are usually blind, deaf, unconscious, and unable to feel pain. Although some individuals with anencephaly may be born with some brainstem, the lack of cerebrum permanently rules out the possibility of even gaining consciousness. Approximately 1000 to 2000 American babies are born with anencephaly each year, more often in females than males, and is one of the most common disorders of the fetal central nervous systems.

Colpocephaly: an abnormal enlargement of the occipital horns, the rear portion of the ventricles of the brain. This enlargement occurs when there is an underdevelopment of lack of thickening of the white matter in the posterior cerebrum. Colpocephaly is characterized by microcephaly, abnormally small head and limited cognitive function. Onset generally occurs between the second and sixth months of pregnancy, and often misdiagnosed as hydrocephalus.

Holoprosencephaly: characterized by the failure of the prosencephalon (embryo's forebrain) to develop. During the fifth and sixth weeks of pregnancy, the normal development of the forebrain and face takes place. In HPE, there is a failure of the forebrain to divide in to left and right hemispheres, causing defects in the development of the face and in brain structure and function. There are varying degrees of HPE: alobar, the most serious form in which the brain fails to separate at all; semilobar, in which the hemispheres slightly separate; and lobar is the least severe where the brain is quite nearly normal. Some facial defects range from cyclopia (one eye) to the most common cleft lip.

Hydranencephaly: cerebral hemispheres are absent and replaced by sacs filled with cerebrospinal fluid (find full definition in previous chapter of this publication).

Iniencephaly: combines extreme retroflexion (backward bending) of the head with severe defects of the spine. The infant tends to present short, with a disproportionately large head. Diagnosis is immediate at birth as the face is flexed upward, with the skin of the face connected directly to the skin of the chest and the scalp to the skin of the back; the neck is generally absent. Most individuals with iniencephaly also have anencephaly, cephalocele (protruding cranial contents from skull), hydrocephalus, cyclopsis, absent mandible (lower jaw bone), cleft lip and palate, cardiovascular disorders, diaphragmatic hernia, and gastrointestinal malformation. This condition most commonly presents itself amongst females.

Lissencephaly: characterized by microcephaly and the lack of normal convolutions (folds) in the brain, thus lissencephaly means “smooth brain”. Symptoms may include unusual facial appearance, difficulty swallowing, failure to thrive, and severe psychomotor delays, with anomalies of appendages. Developmental progress is varied dependent upon severity.

Megalencephaly: also called macrencephaly, is a condition in which there is an abnormally large, heavy, and usually malfunctioning brain. This condition affects males most often, and presents itself either at birth or early years.

Microcephaly: is the existence of a smaller than average head circumference, stemming from a wide variety of conditions that cause abnormal growth of the brain, or chromosomal abnormalities. Despite the small head circumference, the face continues to grow, thus this condition becomes more apparent as the child grows.

Porencephaly: the existence of cysts or cavities in the cerebral hemisphere, usually the remnants of destructive lesions but sometimes the result of abnormal development; occurring either before or after birth.

Schizencephaly: characterized by abnormal slits, or clefts, in the cerebral hemispheres; and is a form of porencephaly. Bilateral clefts, slits on both sides, present with developmental delays. Unilateral clefts, slits on only one side, may be affected primarily on one side of the body. Individuals oftentimes also display signs of microcephaly, hemiparesis (one-sided paralysis), quadriplegia (all four extremities affected with paralysis), hydrocephalus, seizures, and reduced muscle tone (hypotonia).

Acephaly: is complete absence of the head, generally a parasitic twin attached to an otherwise intact fetus.

Exencephaly: the brain develops outside the skull, generally displayed as anencephaly in early pregnancy

Macrocephaly: larger than average head circumference, from enlarged brain or hydrocephalus in many cases.

Micrencephaly: small brain

Octocephaly: total or virtual absence of the lower jaw, often displayed with holoprosencephaly, and is considered lethal as it severely compromises the fetal airway.

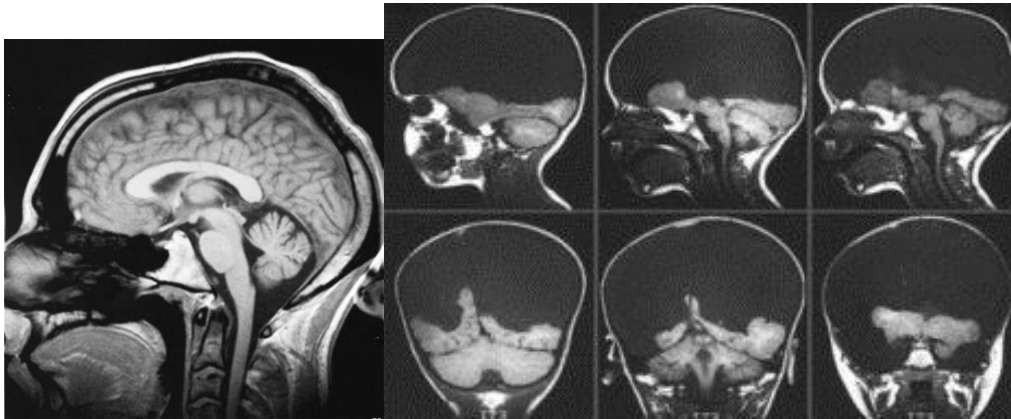
Brachycephaly: premature suture fusion of the top and sides of the skull, causing a shortened front-to-back diameter of the skull

Oxycephaly: premature closure of all sutures, the most severe of deformities of the skull classified as craniostenoses.

Plagiocephaly: premature fusion of one side of the skull; characterized by an asymmetrical distortion (flattening of one side) and is a common finding at birth and may be the result of brain malformation, a restrictive intrauterine environment, or torticollis (a spasm or tightening of neck muscles).

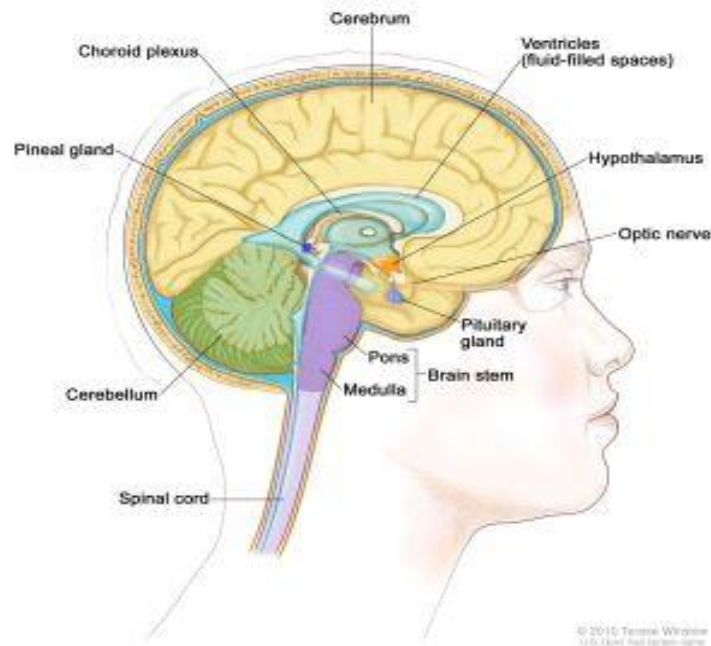
Scaphocephaly: premature fusion that displays as a long, narrow head

Trigonocephaly: premature fusion that displays as a triangular forehead and closely set eyes



Healthy Brain MRI scan

Various Hydranencephalic Brain MRI Scans



How to Manage in the Medical World

One of the most life-altering conversations you can have with another individual is one in which you are told as a parent that your child will not survive. Whether this prognosis is given during pregnancy, at birth, or months thereafter; the information can put your mind in a fog and be difficult to process and cope with. Please be prepared to hear this prognosis at some point in time during initial diagnosis, and often throughout the life of your child as well. Understand that this prognosis is a possibility, though the certainties are unpredictable. Your child may very well die in utero, at birth, or shortly thereafter; however, that could happen to any child. Place your focus on the possibilities that exist and make an effort to not worry over the things that may or may not happen, but haven't happened yet. In the meantime, you will have to rely upon those doom and gloom medical professionals to help you provide your child with the best quality of life possible; with you as the guiding voice for your child.

“Life is an opportunity, benefit from it.

Life is beauty, admire it.

Life is a dream, realize it.

Life is a challenge, meet it.

Life is a duty, complete it.

Life is a game, play it.

Life is a promise, fulfill it.

Life is sorrow, overcome it.

Life is a song, sing it.

Life is struggle, accept it.

Life is tragedy, confront it.

Life is an adventure, dare it.

Life is luck, make it.

Life is too precious, do not destroy it.

Life is life, fight for it.”

~Mother Teresa

Treatment Options:

Treatment of hydranencephaly is symptomatic and supportive; therefore below you will find some common conditions that also often correlate with a diagnosis of hydranencephaly:

Asthma/Reactive Airway Disease: Sometimes the terms "reactive airway disease" and "asthma" are used interchangeably, though not always the same thing. RAD is a more generalized term that does not prompt a specific diagnosis, more generally for respiratory issues with an unknown cause. Accurate testing for asthma is generally impossible before the age of 6, therefore early childhood generally brings the label of RAD prior to eventually receiving a diagnosis of asthma. Oftentimes a preventative pharmaceutical regimen will be prescribed to inhibit complications.

Cerebral Palsy: This is an umbrella term that covers most neurological conditions that affect nervous system functioning. All children with hydranencephaly have some level of CP, even if not formally diagnosed.

Constipation: Also walks hand-in-hand with neurological conditions. Add the likelihood of children with hydranencephaly taking anticonvulsants for seizure control, the lack of mobility exhibited, and the limited diet; you will battle constipation more often than nearly every other complication.

Diabetes Insipidus: This is a condition in which the kidneys are unable to conserve water, which means an excessive urine output and higher sodium levels in our children. Management is possible with medical intervention.

Epilepsy/Lennox Gastaut Syndrome: Seizures, often without a known cause or even confirmation via EEG, are another common symptom of children with hydranencephaly. Lennox Gastaut is another diagnosis you may hear in conjunction with the severe epileptic spells that our children display, with small periods of undetected or even non-existent seizures scattered amongst longer periods of seizures activity. Seizures are most generally controlled with a combination of pharmaceuticals and other complementary/alternative interventions.

Failure to Thrive/Feeding Concerns: Various feeding complications present themselves during the lifetime of children with hydranencephaly. Concerns are generally managed with placement of feeding tubes and/or intensive feeding therapies.

Hydrocephalus: This is the build-up of cerebrospinal fluid within the cranial cavity. Many, but not all, children with hydranencephaly also have hydrocephalus. Medical intervention most often comes in the form of shunt placement to assist with draining of the fluid to decrease pressure and growth in head circumference for children.

Irritability: Most children prove to be most irritable during the first year of life, calming immediately upon the arrival of their first birthday. Causes are generally unknown, but could be related to muscle spasms and oftentimes reflux.

Spasticity: This is the increased tone, or rigidity, of the muscles. Oftentimes this limits the already limited mobility and purposeful movement possibilities for children, though therapy and pharmaceutical intervention have proven successful and management.

Thermoregulation Malfunction: Oftentimes children with hydranencephaly will have difficulty maintaining a safe and healthy temperature. Before you worry yourself over this issue too much, keep in mind that your child is unique and it is important to learn their baseline temperature before comparing it to a "typically" developing child. It is not unusual for a hydran-child's baseline temperature to be 93-95, with temperatures dipping in to the mid-high 80's at times as well. This is hypothermia by medical definition, but children do not always show sign of distress or create reason for concern under these circumstances.

Help in Finding a Successful Care Team

Partnering with Your Child's Doctor:

- Open communication is essential with full disclosure of your child's symptoms and history. If this isn't possible, or your doctor does not agree with the care plan you hope for your child, find another. Doctors work for their patients, not the other way around. If you need assistance in finding positive support, we are happy to help advocate for you.
- Maintain up-to-date records for prescriptions, over-the-counter medications and/or supplements, etc
- Ask as many questions as necessary to understand the information given to you, bring a list
- Take notes, draw pictures; whatever you need to understand the overload of information you will be receiving. Again, if your child's doctor does not have the time to be thorough and ensure you understand, make it a priority or find another doctor who can.
- Research and educate yourself as much as you're able to in the realm of hydranencephaly and related conditions. You are your child's voice, and with limited knowledge and resources on the condition, you are responsible for many hours of independent research outside of the doctor's office. Be armed with the facts when you go to appointments; but maintain an open-mind to information that may be new to you. Together you both should have your child's best interest as a goal.

Specialists You May Need to Start With (this list is by no means, conclusive, as every child has individual needs):

- Neurology (neuro): this is a must as hydranencephaly is a neurological condition; frequency of visits will depend upon complications from the condition related to care that the neurologist provides: seizures, spasticity, neuromuscular concerns, spine malformations such as scoliosis, etc.
- Neurosurgery: may not be necessary in many cases, unless hydrocephalus becomes an issue; if you suspect your child is in discomfort or detect the circumference of their head increasing, please demand a consult with neurosurgery for further evaluation.
- Endocrinology (ENDO): in cases that hormonal concerns arise: diabetes, thyroid, growth, etc.
- Ophthalmology (OPHTH): for obtaining eye glasses to strengthen the muscles of the eyes or managing general health of your child's eyes
- Gastroenterology (GI): to manage constipation, feeding issues, reflux, and any other complications with the stomach and/or intestinal tract.
- Pulmonology (PULMO): for management of respiratory issues
- Developmental Pediatrics (DEVPEDS): specialized treatment and assessment for children with developmental delays
- Ear, Nose, and Throat (ENT): any conditions associated with ears, nose, throat: apnea, swallowing, etc.
- Home Health/Hospice: care in the home for those needing long-term nursing care; hospice for terminal patients.
- Orthopedics: combat bone concerns; most often with hips and legs; also bracing and positional equipment prescriptions.
- Physical Medicine/Rehabilitation: obtaining braces, orthotics, and therapeutic services; also durable medical equipment such as bath chairs, mobility devices, etc.

Your Medical Rights: your child has the right to:

- Receive adequate medical care
- Know the roles of all caregivers
- Obtain health information that you understand
- Maintain control over decision-making

- Incorporate family members in care and receive visitors
- Have respect shown for their wishes; or yours as the parent
- Have their medical information remain private unless you elect for it to be released

Do Not Resuscitate order (DNR): One misunderstood piece of paperwork you may be presented with upon diagnosis of hydranencephaly is the DNR. This paperwork, when signed, lets hospital staff and emergency medical personnel know that CPR is not requested as intervention with cardiac arrest. This does not limit other treatment, only in instances where CPR may be necessary to revive. This decision is a personal one, and can also be revoked at any time should your initial decision change.

Helpful Resources to Begin With:

Division of Health and Family Services: Every county has one and the services they provide vary from state to state. This is a great place to start in order to find a list of resources your child, and family, may qualify for.

Early Intervention (EI): provides support and guidance to children with developmental limitations and their families. You can find your local program, as each state has individualized name and establishment, by contacting your local health department, elementary school, or searching the National Dissemination Center for Children with Disabilities (NICHCY) at: <http://nichcy.org/state-organization-search-by-state>.

Hospital Social Services: If diagnosis is made while you and your child are in the hospital, ask to be assigned a visit with the hospital social worker who will provide you with localized resources and help you find the support you need.

Social Security Income (SSI): assists financially based upon household income. Find out more at your local social security office, by calling 1-800-772-1213, or contacting your hospital social worker for assistance in applying for benefits.

Medicaid: is a jointly funded, federal/state health insurance program that your child will be eligible for based upon disability. This program is included within your application for SSI, or you can contact your local health department or department of family services for independent application.

Global Hydranencephaly Foundation Resources:

A more complete, comprehensive list of information on hydranencephaly and caring for a child with hydranencephaly is available on our information Web site: www.hydranencephalyfoundation.org

Our foundation home site can be found at: www.hydranencephalyfoundation.org

Network with other families across the globe who have been touched by a diagnosis of hydranencephaly for a loved one via Facebook at the Global Hydranencephaly Foundation Family-to-Family Resource Network: www.facebook.com/groups/hydran.families

Network with other families across the globe who have lost a child given a diagnosis of hydranencephaly via Facebook at our Hydran-Angels group: www.facebook.com/groups/hydran.angels

Follow our foundation page on Facebook at: www.facebook.com/globalHYDRANENCEPHALYfoundation

Follow us on Twitter: www.twitter.com/hydranencephaly

Catch a glimpse into the real lives of children living with hydranencephaly through videos on our YouTube channel: <http://www.youtube.com/user/GlblHydranFoundation>

Are you on Pinterest? We are: <http://pinterest.com/alnichole0619/global-hydranencephaly-foundation/>

Resource Organizations:

**obtained via a listing at NINDS; GHF is currently the only organization providing up-to-date published information and/or resources for families faced with a diagnosis of hydranencephaly*

National Organization for Rare Disorders (NORD)

PO Box 8923
New Fairfield, CT 06812-8923
203-746-6518
800-999-6673
www.rarediseases.org

The March of Dimes Birth Defects Foundation

1278 Mamaroneck Avenue
White Plains, NY 10605
914-428-7100
888-MODIMES (663-4637)
www.modimes.org

Association of Birth Defects in Children

930 Woodcock Rd.
Orlando, FL 32803
407-245-7035
800-313-ABDC (2232)
www.birthdefects.org

NINDS Brain Resources and Information Network (BRAIN)

PO Box 5801
Bethesda, MD 20824
800-352-9424
www.ninds.nih.gov

Neuroscience for Kids

An online resource containing clear, concise explanations
<http://faculty.washington.edu/chudler/neurok.html>

The Arc

500 East Border Street
Suite 300
Arlington, TX 76010
800-433-5255
<http://thearc.org>

Children's Brain Diseases Foundation

350 Parnassus Avenue
Suite 900
San Francisco, CA 94117

GHF Regional Resource Contacts by State/Country

These individuals, all of which are parents/caregivers to a child with hydranencephaly, so graciously volunteered to be contact points in order to assist with local resources and information to families who can benefit from more regionally specific information. Please report any issues you have contacting these individuals to us at the email address listed here. Also for general information, we encourage you to email us at President@HydranencephalyFoundation.org or to connect via our Family-to-Family Resource Network on Facebook.

States: Contact Name, Email Address, Personal Phone

Alabama:
Alaska: Teri Sweigart, lagirlinak@hotmail.com, 907-741-1959
Arizona:
Arkansas: Amber Pollard, pollard0808@gmail.com, 870-582-1395.
California: Kimberli Bartlett, Dbh20ski@yahoo.com, 919-719-4005
Colorado: Jerry Lynn Carroll, Callmebeautiful89@yahoo.com, 719-963-4507
Connecticut:
Delaware: Janice Johnson, starlightwell@mchsi.com, 302-537-0521
Florida: Dymond Williams, williamsroyalty86@gmail.com, 941-462-8530
Georgia: Brad and Amy Gibbs, Agrymol@gmail.com, 404-449-2368
Hawaii: Rene Elliott, ReneeMT@sbglobal.net, 310-530-7318
Idaho: Devoney Wolfe, dwolfeywoman@gmail.com, 208-944-4426
Illinois: Barbara Fuller, b_fuller_83@yahoo.com, 309-945-5799
Indiana: Jennifer Bauer, jgabbybauer@gmail.com, 513-646-3962
Iowa: Shanna Schmidt, smarie282191@gmail.com, 712-294-4785
Kansas: Jessica Roberts, jessicaroberts25@yahoo.com, 913-244-5041
Kentucky: Jennifer Bauer, jgabbybauer@gmail.com, 513-646-3962
 Juliet Priest, julietlr71@hotmail.com, 859-991-5161
Louisiana:
Maine:
Maryland: kmjones_1989@yahoo.com, 410-240-9939
Massachusetts: Katie Cone, kccone.28@gmail.com, 413-306-8668
Michigan: Sarah Garcia, godsittlereignbow@comcast.net, 517-902-2779
Minnesota: Katie Wright, kathryn.wright@live.com, 218-220-8185
Mississippi:
Missouri: Ali Harper, alinicholeharper@gmail.com, 573-280-2412
Montana:
New Hampshire:
New Jersey: Jessica Zuchowski, je_si_ka@live.com, 609-353-1012
New Mexico:
New York: Paula Kelwaski, ce-ce_spazz06@hotmail.com, 716-720-6480
North Carolina:
North Dakota:
Ohio: Jennifer Bauer, jgabbybauer@gmail.com, 513-646-3962
 Haylee Megison, bugsleep92@yahoo.com, 614-507-3836
Oklahoma: Brooke Nixon, bnixon0205@yahoo.com, 918-208-8581

Pennsylvania: Holly Mansfield, mom2eth_n_cole@yahoo.com, 717-880-4155
Arlaina Tusing, arlkid@yahoo.com, 724-448-8259

Rhode Island:

South Carolina: Ali Harper, alinicholeharper@gmail.com, 573-280-2412

South Dakota: Desiray Paxton, desiraynelson@yahoo.com, 605-280-2761

Tennessee:

Texas: Angela Mason, mason8TX@gmail.com, 832-799-2371

Utah: Sue Quaid, quaid14@aol.com, 435-830-6399

Vermont:

Virginia: Ali Harper (southern), alinicholeharper@gmail.com, 573-280-2412

Washington: Ali Harper (Puget Sound area), alinicholeharper@gmail.com, 573-280-2412

Jennifer Armerding (north-western), jarmerding@comcast.net, 360-393-1498

West Virginia: Ashley Delancey, danielproper@yahoo.com, 304-917-5928

Wisconsin: Donna Kalmon, bkdk@tds.net, 715-745-2979

Mary Schneider, verymary@somtel.net

Wyoming:**Global**

Belfast, Northern Ireland, UK: Avril Osbourn, avrilosbourn@hotmail.com, 02890 500420

Plymouth, England, UK: Charlotte Stephens, charlotte_stephens00122@hotmail.co.uk, 781-258-9723

Alberta, Canada: Patricia Wheatley, pjwheatly@Shaw.ca, 403-251-9855

County Kerry, Ireland: Cara Galvin

Australia: Lisa King, lisaking@hotmail.com, (03) 6339 3748

Humacao, Puerto Rico: Gladys Flecha, gfd2361@yahoo.com, 787-240-5626

Quezon City, Philippines: Profx Alfanta & Farrah Conda, conda_farah16@yahoo.com, 09054022889

Safed, Hazafon, Israel: Hannah Levi, nahalevi@gmail.com

New Zealand: Patrice Crawford, Graeme_patrice@xtra.co.nz, 027 268 7739 or 0064 3 9814133

Helpful Terms & Definitions

These terms may or may not be included in this particular publication, but can be used as a reference when researching Hydranencephaly and similar conditions independently through other resources. You will especially see this jargon while filing through medical notes.

Abducens Nerve: Cranial nerve originating from the surface of the brainstem; moves the eye.

Ablation: Removal or destruction of tissue.

Acromegaly: Disorder marked by progressive enlargement of the head, face, hands, feet, and thorax, due to the excessive secretion of growth hormone.

Action Potential: Electrical “all-or-none” impulse which transmits information within the nervous system.

Afferent: Neural information flowing from the outer areas to the more central areas of the nervous system.

Agonist: Chemical that behaves like a neurotransmitter and increases the effect of one.

Amphetamine: Synthetic central nervous system stimulant.

Amplitude: Size or magnitude of electrical signal or sensory response.

Amygdala: Brain structure included in the limbic system; controls emotion, memory and fear “the warning center”

Analgesia: Loss of ability to feel pain.

Analogous: Resembling or similar in some respects, as in function or appearance, but not in origin or development

Anesthesiologist: Physician who administers pain-killing medications during surgery.

Anoxia: Total lack of oxygen supply.

Antagonist: Neurotransmitter blocking chemical.

Anterior: Front.

Anterior Commissure: Small fiber that connects the hemisphere; corpus callosum.

Anticonvulsants: An agent that prevents or relieves convulsions.

Antidiuretic: An agent which reduces the output of urine. Antidiuretic hormone (ADH) is formed in the hypothalamus and stored in the posterior pituitary gland. Its secretion reduces urine output.

Aphasia: Inability to speak or understand verbal language.

Apnea: Cessation of respiration; inability to get one's breath.

Apoplexy: A sudden event. Often used as equivalent to stroke.

Aqueous Humor: Fluid between the cornea and lens of the eye.

Arachnoid: Middle layer of membranes covering the brain and spinal cord.

Arteriosclerosis: Thickening and calcification of the arterial wall with loss of elasticity and contractility.

Arteriovenous: Relating to both arteries and veins.

Arteriovenous Malformation: Collection of blood vessels with one or several abnormal communications between arteries and veins which may cause hemorrhage or seizures.

Astrocyte (astroglia): Cell which supports the nerve cells (neurons) of the brain and spinal cord.

Atrophy: A wasting of the tissues of a body part.

Autonomic Nervous System: Involuntary nervous system, also termed the vegetative nervous system. A system of nerve cells whose activities are beyond voluntary control. Provides neural connections with glands and smooth muscles; divided in to sympathetic and parasympathetic (sometimes the enteric) systems.

Avascular: Non-vascular, not provided with blood vessels.

Axon: The part of a nerve cell that usually sends signals OUT to other nerves or structures.

Bactericidal: Causing the death of bacteria.

Bacteriostatic: Preventing or retarding the growth of bacteria.

Basal Ganglia: Brain areas important for movement: putamen, caudate nucleus, globus pallidus, subthalamic nucleus and substantia nigra.

Bilateral: Having two sides, or pertaining to both sides.

Biopsy: Removal of a small portion of tissue, usually for the purpose of making a diagnosis.

Blood-Brain-Barrier: The barrier which exists between the blood and the cerebrospinal fluid which prevents the passage of various substances from the bloodstream to the brain.

Bradychardia: Slowness of the heart rate.

Bradykinesia: Slowness in movement.

Brainstem: The brain's central core; at the top of the spinal column.

Carbamazepine: An anticonvulsant used to control grand mal and psychomotor or focal seizures.

Cardiovascular: Pertaining to the heart and blood vessels.

Carotid Artery: Large artery on either side of the neck which supplies most of the cerebral hemisphere.

Carotid Sinus: Slight dilatation on the common carotid artery at its bifurcation containing nerve cells sensitive to blood pressure. Stimulation can cause slowing of the heart, vasodilatation and a fall in blood pressure.

Caudal: Toward the tail end; same as inferior, in human anatomy.

Central Nervous System: Brain and spinal cord.

Central Sulcus: Groove in the brain separating the frontal and parietal lobes.

Cerebellum: Part of the metencephalon that lies in the posterior cranial fossa behind the brain stem; important for balance and posture.

Cerebral: Of or pertaining of the cerebrum or the brain.

Cerebral Aqueduct: Connects the third and fourth ventricles.

Cerebral Cortex: Outer layer of the cerebral hemisphere; the gray matter.

Cerebrospinal: Pertaining to the brain and spinal cord.

Cerebrum: The principal portion of the brain, which occupies the major portion of the interior of the skull and controls conscious movement, sensation and thought.

Cervical: Of or relating to the neck.

Chiasm (optic): Crossing of visual fibers as they head toward the opposite side of the brain; for each optic nerve most of the visual fibers cross to the opposite side, some run directly backward on each side without crossing.

Choroid Plexus: CSF producing structures.

Chronic: Persisting over a long period of time.

Cingulate Cortex: Area above the corpus callosum; important to emotional behavior.

Circadian: About a day; used with rhythm to describe bodily schedules.

Cochlea: Inner ear structure; important for hearing.

Coma: A state of profound unconsciousness from which one cannot be roused.

Cone: Structure in the retina; important for color vision and detail.

Consciousness: Sense of awareness of self and of the environment.

Contracture: A condition of fixed high resistance to passive stretch of a muscle, resulting from fibrosis of the tissues supporting the muscles or the joints, or from disorders of the muscle fibres.

Contrast Medium: Any material (usually opaque to x-rays) employed to delineate or define a structure during a radiological procedure.

Convulsion: A violent involuntary contraction or series of contractions of the voluntary muscles.

Coronal Suture: The line of junction of the frontal bones and the parietal bones of the skull.

Corpus Callosum: Large collection of axons connecting the brain's hemispheres.

Cranial Nerves: 12 nerves leaving the brain.

Craniectomy: Excision of a portion of the skull.

Cranioplasty: The operative repair of a defect of the skull.

Craniosynostosis: Premature closure of cranial sutures, limiting or distorting the growth of the skull.

Cranium: The part of the skull that holds the brain.

CT scan - (computed tomography scan): A diagnostic imaging technique in which a computer reads x-rays to create a three-dimensional map of soft tissue or bone.

Cyst: Any closed cavity or sac; normal or abnormal, lined by epithelium, and especially one that contains a liquid or semisolid material.

Diabetes Insipidus: Excretion of large amounts of urine of low specific gravity, inability to concentrate urine.

Diffuse Axonal Injury: Damage to the axons of many nerve cells that lie in different parts of the brain.

Diffuse Brain Injury: damage to the brain that can affect many areas of the brain, often subtly; ex. Diffuse axonal injury and inadequate blood flow.

Dilatation: The condition, as of an orifice or tubular structure, of being dilated or stretched beyond the normal dimensions.

Diphenylhydantoin: Dilantin; anti-seizure medication.

Diplopia: Double-vision, due to weakness or paralysis of one or more extra-ocular muscles

Dopamine: Neurotransmitter; important for movement and behaviors.

Dura Mater: A tough fibrous membrane which covers the brain and spinal cord, but is separated from them by a small space.

Dysesthesia: A condition in which a disagreeable sensation is produced by ordinary touch, temperature or movement.

Edema: An excessive accumulation of fluid generally in extracellular.

Electroencephalography (EEG): The recording of the electric currents developed in the brain, by means of electrodes applied to the scalp, to the surface of the brain, or placed within the substance of the brain.

Electromyography (EMG): Method of recording electrical currents generated in a muscle during contraction.

Embryo: Those derivatives of the fertilized ovum that eventually become the offspring, during their period of most rapid development, i.e., after the long axis appears until all major structures are represented. The developing organism is an embryo from about two weeks after fertilization to the end of the seventh or eighth week.

Encephalization Factor: Brain size in relation to body size.

Endocrine Gland: Furnishes an internal secretion, usually having an effect on another organ.

Endocrinopathy: Abnormality of quantity or quality in one or more of the internal glandular secretions.

Endorphin: Neurotransmitter; important for pain reduction.

Ependyma: Membrane lining the cerebral ventricles of the brain and central canal of the spinal cord.

Epilepsy: Disorder characterized by abnormal electrical discharges in the brain, causing abnormal sensation, movement or level of consciousness.

Epithelium: The covering of internal and external surfaces of the body, including the lining of vessels and other small cavities. It consists of cells joined by small amounts of venting substances. Epithelium is classified into types on the axis of the number of layers deep and the shape of the superficial cells.

Extracellular: Outside a cell or cells.

Facial: Of or pertaining to the face.

Falx (cerebri): Extension of dura matter between the hemispheres of the brain.

Fontanelle: Normal openings in the skulls of infants; "soft spot"

Forebrain: Frontal area of the brain containing the cerebral hemispheres, thalamus and hypothalamus.

Fovea: Center of the eye's retina; most accurate vision.

Frontal Lobe: Front area of the cortex; involved in reasoning, planning, parts of speech, movements, emotions, and problem-solving.

Gastrointestinal: Pertaining to or communicating with the stomach and intestine.

Gastrostomy: Creation of an artificial external opening into the stomach for nutritional support or gastrointestinal compression.

Genecology: A medical-surgical specialty concerned with the physiology and disorders primarily of the female genital tract, as well as female endocrinology and reproductive physiology

Glasgow Coma Scale (GCS): Neurological scale aiming to give a reliable, objective way of recording the conscious state of an individual for initial review or regular assessment; the outcome scale is the classification of severity of head injury or other neurologic conditions.

Glia (neuroglia): Major support cells of the brain; involved in nutrition and maintenance of the nerve cells.

Globus Pallidus: Part of the Basal Ganglia; cells that lie deep in the brain.

Gyrencephalic: Heavily folded cerebral cortex.

Gyrus: Brain “bumps” separated by fissures.

Hemiatrophy: Deterioration of half an organ or of the body.

Hemiplegia: Paralysis of one side of the body.

Hernia: The protrusion of a loop or knuckle of an organ or tissue through an abnormal opening.

Hindbrain: rear area of the brain; includes cerebellum, pons and medulla.

Hippocampus: Limbic system area; important for memory.

Hormones: Chemical substances having a specific regulatory effect on the activity of a certain organ or organs. The term was originally applied to substances secreted by various endocrine glands and transported in the bloodstream to the target organs. It is sometimes tended to include those substances that are not produced by the endocrine glands but that have similar effects.

Hydrocephalus: A condition marked by dilatation of the cerebral ventricles, most often occurring secondarily to obstruction of the cerebrospinal fluid pathways, and accompanied by an accumulation of cerebrospinal fluid within the skull; the fluid is usually under increased pressure, but occasionally may be normal or nearly so. It is typically characterized by enlargement of the head, prominence of the forehead, atrophy, mental deterioration, and convulsions; may be congenital or acquired; and may be of sudden onset (acute) or be slowly progressive (chronic or primary).

Hydromyelia: Enlargement of the spinal cord due to increased CSF in the central canal.

Hyperacusis: Abnormal acuteness of hearing or auditory sensation.

Hyperesthesia: Excessive sensibility to touch, pain or other stimuli.

Hypertension: High blood pressure.

Hypertonia: Or hypertony, hypertonicity. Increased rigidity, tension, and spasticity of the muscles.

Hypothalamus: Area of the brain that monitors internal environment and balances the system.

Hypotonia: A condition of diminished tone of the skeletal muscles; diminished resistance of muscles to passive stretching.

Induction: Any pathological or traumatic discontinuity of tissue or loss of function of a part.

Infundibulum: Stalk extending from the base of the brain to the pituitary gland.

Intracerebral Hematoma: Blood clot within the brain.

Intracranial Pressure (ICP): Overall pressure inside the skull; a measure monitored with hydrocephalus.

Intraoperative Cisternography: Administration of contrast dye directly in to the ventricles; the brain chambers that contain cerebrospinal fluid (CSF).

Iris: Colored portion of the eye; controls pupil size.

Ischemia: Inadequate circulation of blood generally due to a blockage of an artery.

Labyrinth: The internal ear, comprising the semi-circular canals, vestibule and cochlea.

Lateral: Towards the side.

Leptomeninges: Two thin layers of fine tissue covering the brain and spinal cord (called pia mater & arachnoid).

Leptomenigitis: Inflammation of the above two membranes.

Lethal: Deadly, fatal

Leukodystrophy: Disturbance of the white matter area of the brain.

Limbic System: Brain group important for emotional and other behaviors.

Lissencephalic: Relatively smooth cerebral cortex; opposite of gyrencephalic.

Lordosis: Curvature of the spine with the convex area facing forward.

Lumbar Drain: A device inserted into the cerebrospinal fluid space of the lower back to drain CSF.

Magnetic Resonance Imaging (MRI): Diagnostic imaging test that produces 3-D images of body structures using magnets and computer technology; alternative to xrays.

Malformation: A morphologic defect resulting from an intrinsically abnormal developmental process.

Mandible: The largest and strongest bone of the face constituting the lower jaw. It supports the lower teeth.

Medulla: Area between the pons and spinal cord; responsible for breathing and heartrate.

Membrane: A thin layer of tissue which covers a surface, lines a cavity or divides a space or organ.

Meninges: Three membranes covering the spinal cord and brain; dura mater, arachnoid & pia mater.

Meningitis: Infection or inflammation of the above membranes.

Meningocele: Protrusion of the above membranes through a defect in the skull or vertebral column.

Meningoencephalitis: Inflammation or infection of the brain and meninges.

Meningoencephalocele: Protrusion of the meninges and brain tissues through skull defect.

Midbrain: Middle area of the brain, including tectum and tegmentum; aids in vision, hearing, eye movement, and body movement.

Monotherapy: A therapy which uses only one drug or treatment.

Motor Cortex: Cerebral cortex region that sends impulses to motor neurons from the frontal lobe; coordinates movement

Myelin: Fat-like substances which surrounds nerve fibers creating an insulation.

Myelogram: Xray of the spinal canal with contrast material into the CSF spaces.

Myelomeningocele: Protrusion of the spinal cord and coverings through a defect in the vertebral column.

Myelopathy: Functional or pathologic disturbance of the spinal cord.

Neocortex (isocortex): 6-layered portions of the cerebral cortex; bulk of the cerebral hemispheres.

Neonatal: Pertaining to the first four weeks after birth.

Neural: 1. Pertaining to a nerve or to the nerves. 2. Situated in the region of the spinal axis, as the neural arch.

Neuralgia: Paroxysmal pain extending along one or more nerves.

Neurohypophysis: posterior lobe of the pituitary gland.

Neurology: A medical specialty concerned with the study of the structures, functions, and diseases of the nervous system.

Neuronal: Pertaining to a neuron or neurons

Neurons: The basic cellular units of nervous tissue. Each neuron consists of a body, an axon, and dendrites. Their purpose is to receive, conduct, and transmit impulses in the nervous system.

Neuropathy: Functional or pathologic disturbance in the peripheral nervous system.

Neurosurgery: A surgical specialty concerned with the treatment of disease and disorders of the brain, spinal cord, and peripheral and sympathetic nervous system.

Neurotransmitters: Chemicals that carry information during synapse from one neuron to others.

Nystagmus: Involuntary rapid eye movement; horizontally, vertically or rotary.

Obstetrics: A medical-surgical specialty concerned with management and care of women during

pregnancy, parturition, and the perperium.

Occipital Lobe: Area behind the parietal and temporal lobes; responsible for vision.

Occiput: Back part of the head.

Oligodendroglia: Non-nerve cells (glia) which creates part of the supporting structure of the central nervous system.

Ophthalmology: A surgical specialty concerned with the structure and function of the eye and the medical and surgical treatment of its defects and diseases

Ophthalmoplegia: Paralysis of one or more of the eye muscles.

Oral: pertaining to the mouth, taken through or applied in the mouth, as an oral medication or an oral thermometer.

Papilledema: Swelling of the optic nerve head.

Paralysis: Loss or impairment of motor function in a part due to lesion of the neural or muscular mechanism; also by analogy, impairment of sensory function (sensory paralysis). In addition to the types named below, paralysis is further distinguished as traumatic, syphilitic, toxic, etc., according to its cause; or as obturator, ulnar, etc., according to the nerve part, or muscle specially affected.

Paraplegia: Paralysis of the lower half of the body.

Parasympathetic nervous system: One part of the autonomic nervous system; response constricts pupils, stimulates salivation, constricts airways, slows heartbeat, etc.

Parietal Lobe: Area behind the frontal cortex; perception of stimuli in touch, pressure, temperature and pain.

Peripheral Nervous System (PNS): All nerves and neurons outside of the brain and spinal cord.

Peritoneal Cavity: Abdominal cavity; placement of the shunt catheter is often placed here.

Phenobarbital: A barbituric acid derivative that acts as a nonselective central nervous system depressant, used as an anticonvulsant.

Pituitary: Gland at the base of the brain which works to regulate the thyroid, adrenals and gonads; “The Master Gland”

Porencephaly: Abnormal cavity within brain tissue; hydranencephaly is a severe case of this.

Posterior: Situated in back of, or in the back part of, or affecting the back or dorsal surface of the body.

Post-ictal: Post-seizure state; altered function and consciousness.

Postnatal: Occurring after birth, with reference to the newborn.

Prefrontal Cortex: Front-most area of the frontal cortex; involved in problem solving, emotion and complex thoughts.

Prenatal: Existing or occurring before birth, with reference to the fetus.

Proprioception: Sensation concerning movements of joints and position of the self in space.

Prosencephalon: The part of the brain developed from the most rostral of the three primary vesicles of the embryonic neural tube and consisting of the diencephalon and telencephalon.

Pseudotumor Cerebri: Higher intracranial pressure without clear structural abnormality.

Psychomotor: Pertaining to motor effects of cerebral or psychic activity.

Pupil: Black part of the eyeball through which light comes through; adjusts size according to level of light.

Quadrantanopia: Vision impairment in one-fourth of the field of vision.

Quadriplegia: Severe or complete loss of motor function in all four limbs which may result from brain diseases; spinal cord diseases; peripheral nervous system diseases; neuromuscular diseases; or rarely muscular diseases. The locked-in syndrome is characterized by quadriplegia in combination with cranial muscle paralysis. Consciousness is spared and the only retained voluntary motor activity may be limited eye movements. This condition is usually caused by a lesion in the upper brain stem which injures the descending cortico-spinal and cortical-bulbar tracts.

Rachischisis: Abnormal congenital opening of the vertebral column.

Radiography: The making of film records (radiographs) of internal structures of the body by passage of x-rays or gamma rays through the body to act on specially sensitized film.

Reflex: A reflected action or movement; the sum total of any particular involuntary activity.

Refractory: not readily yielding to treatment

Retina: The ten-layered nervous tissue membrane of the eye. It is continuous with the optic nerve and receives images of external objects and transmits visual impulses to the brain. Its outer surface is in contact with the choroid and the inner surface with the vitreous body. The outer-most layer is pigmented, whereas the inner nine layers are transparent.

Sclerosis: An induration, or hardening; especially hardening of a part from inflammation and in diseases of the interstitial substance. The term is used chiefly for such a hardening of the nervous system due to hyperplasia of the connective tissue or to designate hardening of the blood vessels.

Seizures: Clinical or subclinical disturbances of cortical function due to a sudden, abnormal, excessive, and disorganized discharge of brain cells. Clinical manifestations include abnormal motor, sensory, and psychic phenomena. Recurrent seizures are usually referred to as epilepsy or “seizures disorder.”

Shunt: A passage or anastomosis between two natural channels, especially between blood vessels. Such structures may be formed physiologically (e.g. to bypass a thrombosis) or they may be structural anomalies. Also a surgically created anastomosis; also, the operation of forming a shunt.

Skeletal: Pertaining to the skeleton.

Skull: The skeleton of the head including the bones of the face and the bones enclosing the brain.

Spastic: 1. Of the nature of or characterized by spasms. 2. Hypertonic, so that the muscles are stiff and the movements awkward. 3. A person exhibiting spasticity, such as occurs in spastic paralysis or in cerebral palsy.

Spectrum: A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. Also the complete range of manifestations of a disease.

Spina Bifida: Congenital defect of the spine; absence of a portion of the spine.

Stenosis: Narrowing.

Strabismus: Eye movement deviation preventing eyes from moving parallel together.

Subarachnoid Hemorrhage: Blood or bleeding into the underneath of the arachnoid membrane; likely cause of trauma or aneurysm rupture

Symptomatic Nervous System: Part of the autonomic nervous system; response dilates pupils, inhibits salivation, relaxes airways, accelerates heartbeat, inhibits digestion, etc.

Symptomatic: 1. pertaining to or of the nature of a symptom. 2. Indicative (of a particular disease or disorder). 3. Exhibiting the symptoms of a particular disease but having a different cause. 4. Directed at the allaying of symptoms, as symptomatic treatment.

Synapse: Functional connection between the terminal of one neuron with the membrane of another.

Syringomyelia: Fluid-filled cavity in the spinal cord.

Tectum: The midbrain’s “roof”.

Tegmentum: The midbrain’s “floor”.

Teratogenic: Tending to produce anomalies of formation, or teratism.

Teratogens: An agent that causes the production of physical defects in the developing embryo; “cancer-causing”

Thalamus: brain cells of the upper part in the brain stem; sensory and motor functions.

Tomography: The recording of internal body images at a predetermined plan by means of the tomograph; called also body section roetgenography.

Tone: Normal degree of vigor and tension; in muscle, the resistance to passive elongation or strength; tonus.

Torticollis: Wryneck; a contracted state of the cervical muscles, producing twisting of the neck and an unnatural position of the head.

Toxin: A poison; frequently used to refer specifically to a protein produced by some higher plants, certain animals, and pathogenic bacteria, which is highly toxic for other living organisms. Such substances are differentiated from the simple chemical poisons and the vegetable alkaloids by their high molecular weight and antigenicity.

Transillumination: Passage of light through body tissues or cavities for examination of internal structures; most often used to correctly diagnose hydranencephaly and its level of severity.

Transplantation: The grafting of tissues taken from the patient's own body or from another.

Ultrasonography (US): The visualization of deep structures of the body by recording the reflections of echoes of pulses of ultrasonic waves directed into the tissues. Use of ultrasound for imaging or diagnostic purposes employs frequencies ranging from 1.6 to 10 megahertz.

Valve: Portion of the shunting system used to regulate flow and direction of CSF.

Vascular: Pertaining to blood vessels or indicative of a copious blood supply.

Vasopressin: Hypothalamus secreted hormone stored in the pituitary; raises blood pressure and increases reabsorption of water by the kidneys.

Ventral: 1. Pertaining to the belly or to any venter. 2. Denoting a position more toward the belly surface than some other object of reference; same as anterior in human anatomy

Ventricle: Cavities of the brain containing CSF; there are two lateral and midline third and fourth.

Ventriculitis: Inflammation or infection of the ventricles.

Ventriculogram: Xray study of the ventricles.

Ventriculostomy: Opening into the ventricles; made by insertion of a catheter.

Ventricular Drainage: Draining of CSF; often when hydrocephalus is present.

Vermis: Middle part of the cerebellum; centered between each hemisphere.

Vertebra: Any one of the 33 bones in the spinal column.

Viral: Pertaining to, caused by, or of the nature of virus.

White Matter: Shiny layer of axons covered in white myelin underneath the cortex.

X-Ray: Electromagnetic radiation used to produce a picture of bone or soft-tissue.

**The above definitions are derived from official public sources including, but not limited to, the National Institutes of Health and the European Union, as well as hardbound resources.*