

Children with Hydranencephaly do have many health challenges and may have more severe effects from colds and the flu, but many of the children remain illness free for years at a time.

7. Children with Hydranencephaly don't feel pain.

In our recent survey 88% of the children are reported to feel pain. At this time, the popular theory of pain is that in order to feel pain, the cortex is necessary. However, we know that isn't necessarily true. We did have a couple of Drs. Interested in trying to prove that our children do feel pain, but we've not heard anything from them in a few years.

8. Children with Hydranencephaly will not grow.

Again, we have no statistics to prove this but, all it takes is to look at the pictures of the children in their stories. (<http://www.hydranencephaly.com/raysofsun.htm>) to realize that this is not true. Some of the children have been thought to require growth hormone shots in order to grow but I don't think any have actually had them. Some of the children may end up being shorter than the average person but they are certainly able to grow. My daughter (and many of the children) actually had trouble with being over weight much of her life.

9. Children with Hydranencephaly will never smile.

From a parent: "What a hoot. I think the smile is their trademark." In our recent survey 77% of the children are reported to smile. In most of the children though they smile and laugh frequently when they're feeling well. Kayda's smile could light up a whole city.

10. All children with Hydranencephaly are blind and deaf

82% of the children hear
60% see at least some of the time

11. The only movements a child with Hydranencephaly makes are reflexes.

This is hard to prove at this time. Although it is clear to anyone who knows or sees a child with

Hydranencephaly will realize that it is not true. The children are very aware and have purposeful movements. We all have pictures of our children moving very purposefully especially when playing in their "little rooms" or play areas.

12. They will add nothing to your life...They will be a constant burden to you, your spouse, your family....

Again, there are no statistics to support this. But, I know that the majority of the families, although sad at the struggles they and their children have, wouldn't give up their child for anything. And, I've had many who have lost a child, say that they would do it again in an instant.

13. Children with Hydranencephaly don't have seizures as they don't have the part of the brain (cortex) that triggers seizures.

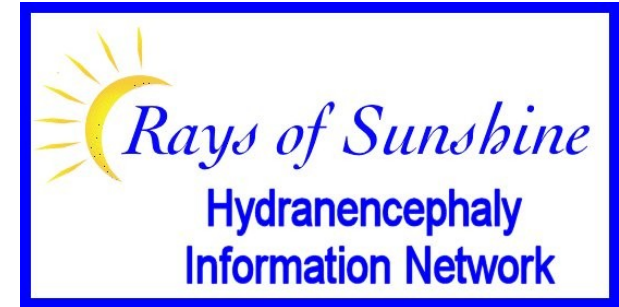
At this time, most testing, and medications for seizures focus on seizures that originate in the cortex. So, often our kids will never have a seizure that is picked up on an EEG or other tests. But, 72 % of the children do have seizures. It has been explained to me that our kids seizures originate in the brain stem. That is why it is often hard to control their seizures with standard anticonvulsant medications.

14. You should find and stick to one doctor.

This is wrong. You should search and search until you find a doctor who feels the same way about your child as you do! Many of us have had multiple Doctors for their children. It is in your child's best interest to have a Doctor that shares your philosophy on them and their care.

This pamphlet is one of a series of pamphlets about Hydranencephaly. To see more pamphlets please email Barb at angelbearmom@shaw.ca

Other Pamphlets include:
When Your Child Has Hydranencephaly
Hydranencephaly The "Facts" According to Parents
Frequently Asked Questions About Hydranencephaly
#s 1-7



Myths About Hydranencephaly

Information is the Key to Hope

This brochure contains statements that most of us hear at one time or another about our children. I have also included the information that we've acquired over the years from families that say that these statements may not always be true. Remember, we are just parents and our evidence is anecdotal. Much of the information on our children that is in this document was gotten through 3 "studies" done by the families of children with Hydranencephaly over the course of several years, and also from letters sent to the Hydranencephaly mailing list. For more information on the "statistics" in this document please see: <http://www.hydranencephaly.com/researchresults.htm>

<http://hydranencephaly.com>

1. He or she will be a vegetable (officially called Permanent Vegetative State): This is one of the most frequent statements and assumptions made about a child with Hydranencephaly.

The following is the generally accepted definition of Permanent Vegetative State:

“The vegetative state can be diagnosed according to the following criteria; (1) no evidence of awareness of self or environment and an inability to interact with others; (2) no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; (3) no evidence of language comprehension or expression; (4) intermittent wakefulness manifested by the presence of sleep-wake cycles; (5) sufficiently preserved hypothalamic and brain-stem autonomic function to permit survival with medical and nursing care; (6) bowel and bladder incontinence; and (7) variably preserved cranial-nerve reflexes (pupillary, oculo-phalic, corneal, vestibulo-ocular, and gag) and spinal reflexes..... A wakeful unconscious state that lasts longer than a few weeks is referred to as a persistent vegetative state. <http://www.thalidomide.ca/gwolbring/pvsilm.htm>

Our Experiences:

A. No evidence of awareness of self or environment and an inability to interact with others:

71% of the children are aware of their surroundings at least some of the time.

38% have a favorite toy and 28% have a security item

B. No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli.

This is a hard point to prove but:

21% of the children can touch or manipulate items

23% give hugs and kisses

80% are comforted more by one person than another

57% show fear or dislike

79% show an interest in music, with 66% showing a preference for 1 type of music over another.

We all have pictures of our children playing very purposefully with toys and using their hands. To see some of the pictures of the children go to: <http://>

www.hydranencephaly.com/raysofsun.htm or to Part 1 in the book: *Caring For Your Child With Hydranencephaly*

C. No evidence of language comprehension or expression

30% of the children understand some or much of what is said to them

12% of the children say one or more words.

For example:

Logan responds to his name and several nick-names we have for him. But if you call him by a different name he doesn't respond.

Malcom also used to reach out his right hand when we would cuddle at night and I would sing to him. I would finish and say "touch Mama's hand if you want more". He would reach and extend his fingers until he touched me and then I would sing again. He repeated this many times.

Another example: Kayda never said any words, yet she was extremely communicative with her eyes and hands. She also loved to listen to taped stories and knew which ones she liked and would fuss if she didn't like the story she was listening to. She also always knew if you put on a book that had more than one tape at night and wouldn't go to sleep until the whole book was done.

The other points in the definition are not in contention

2. It does no good to insert a shunt in a child with Hydranencephaly.

Although it's true that a shunt will not necessarily change the diagnosis or prognosis for a child with Hydranencephaly, there are many reasons that it is entirely appropriate to insert a shunt. In a number of cases, once the shunt is in place and working it has been found that the child has much more brain tissue than previously thought and that the child doesn't have Hydranencephaly at all.

In most cases, though, the diagnosis stays the same. However, increasing intracranial pressure is extremely painful (see myth # 6 if you're told that it

doesn't matter as a child with Hydranencephaly can't feel pain). We know of several children with Hydranencephaly who have had hydrocephalus and were not shunted. One child lived her entire life in a hospital, as it was impossible to care for her with her huge head at home. Others, while not as extreme as this one child, have had problems due to the size of their heads and their discomfort from the pressure. Not all children with Hydranencephaly need shunts but those who do, benefit greatly from them.

3. All children with Hydranencephaly die from pneumonia

Of the 158 children we know of who have died very few died from pneumonia. There are many more causes of death but most remain unknown. Yes, pneumonia in our children is serious, but it doesn't always end in death.

4. Children with Hydranencephaly die before the age of 1

Of 357 children in our database, 157 have died, with 60 dying before the age of 1, 97 over. Of the children still living, 183 are over the age of 1. We have 2 confirmed members who are over the age of 30.

5. A child with Hydranencephaly will never know or recognize their family.

In a recent survey we did, 72% of children know the difference between a family member and a stranger, 67% show that they recognize someone or something. The children show this in many ways, some very subtle but those who know them well recognize their signs.

6. A child with Hydranencephaly will be sick all the time.

In our most recent study (2006), 54% of the children have never had bacterial or 56% have never had viral pneumonia, 62% have never had aspiration pneumonia, 38% have never had ear infections, and, 73% have never had tonsillitis.