

Myths About Hydranencephaly

The following are 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>

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, oculophalic, 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:

88% of the children are aware of their surroundings at least some of the time.
79% are aware of objects
48% have a favorite toy or 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:
48% of the children can touch or manipulate items
17% can pick up and hold items
93% of the children hear
75% see at least some of the time

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/our_rays_of_sunshine.htm or to Part 1 in the book: Caring For Your Child With Hydranencephaly

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C. No evidence of language comprehension or expression

45% of the children understand some or much of what is said to them. 17% were too young at the time of the questionnaire.

10% of the children say one or more words.

For example:

Carly says "Hey!", "Yea" for 'yes', "Uh-uh" for 'no' (all done with a good Southern drawl. She uses these words consistently and with REAL meaning :) Actually, she uses body language, facial and eye expressions to further emphasize her point. (In other words, she makes sure we understand what she's trying to tell us!)

She also has her own 'names' for each one of us. They're all distinctly different. She says these names for the right people consistently. When we say, "Call Christopher" she then says her name for Christopher out loud just like we would do to call someone that's in another room. It's fascinating to watch her look towards the other room and anticipate them coming through the door. (Usually with a loud squeal). This has been true as long as we can remember. She's almost 9 years old.

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 72 children we know of who have died only 3 definitely 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.

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4. Children with Hydranencephaly die before the age of 1

Of the 91 children living at this time (April 2004) 85 children are currently over the age of 1. At this time we have 3 who are over the age of 20 and a number over the age of 10.

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

There are no "statistics" to prove this, but to the best of our knowledge 100 % of the children know the difference between family members and strangers. In some children the reaction is very slight, such as setting off a ventilator alarm if mom doesn't respond quickly when she comes home, or having a seizure if handled by a stranger. But, most of the children show very clearly that they know their families and friends.

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

In our most recent study (2003), 60 % of the children have never had bacterial or viral pneumonia, 62% have never had aspiration pneumonia, 45% have never had ear infections, and, 81% have never had tonsillitis.

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.

We have no statistics that will prove this. But all families report that their children feel and express pain like any other child does.

At this time (April 2004) a couple of Doctors in the US are considering doing a study on our children and their pain responses. 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. And, finally we seem to have found some Doctors who agree with us and are willing to look into it further.

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/our_rays_of_sunshine.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." To the best of my knowledge all children have smiled at least a few times in their lives. 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

93% of the children hear
75% 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.

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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, 75 % 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.

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