

Hydranencephaly 2010 survey report

This survey was conducted by a survey which was hosted by an online survey company from March 2010-March 2011. A total of 106 families (children) participated. Of those participants, 84 (79%) were children who were still alive, and 22 (21%) had died. The age of the mothers varied from 39 (39%) who were in their teens, 26 (26%) 20-25, 24 (24%) 26-30, and 10 (10%) who were over the age of 30.

Health issues

83 (78%) of the children had hydrocephalus. Of those 83, 80 (96%) required shunts. 57 (54%) of the children were said to have respiratory problems. 13 (12%) have tracheostomies, 32 (30%) use a Bipap machine and 14 (13%) use a ventilator. No questions were asked on this survey regarding other respiratory problems. 13 (12%) have Diabetes Insipidus. 12 (11%) have Hypothyroidism. 75 (71%) are said to have problems controlling their temperatures. Answers to the question as to what a child's normal temperature was were varied. The majority of the children's temperatures tend to be on the low side.

Seizures/consciousness

84 (79%) were said to have absences where they became unaware and unresponsive for periods of time. 23 (26%) did this frequently, 52 (60%) occasionally, and 12 (14%) rarely.

87 (82%) have seizures. 33 (31%) have "coma" incidences where they sleep most of the time for several days.

Feeding

70 (66%) of the children have feeding tubes. The answers to the question as to how old a child was when he/she got the tube were greatly varied. 21 (20%) of the children eat by both tube & orally, 36 (34%) orally and 49 (46%) eat only by tube. 55 (52%) have been diagnosed as aspirating. 61 (58%) have Gastroesophageal Reflux Disorder (GERD).

Physical/Orthopedic issues.

51 (48%) are said to have high tone (tight), 49 (46%) have mixed tone and 6 (6%) have low tone (floppy). 40 (38%) have had a subluxed (partly out) hip, 31 (29%) have had a dislocated hip, 33 (31%) have scoliosis, and 26 (25%) have Kyphosis (hunched back).

41 (39%) have used Baclofen for spasticity. 14 (17%) of the children had increased seizures with Baclofen. But the number of answers in this question were over the number who had used Baclofen. So these numbers aren't necessarily accurate as to how many children have an increase in seizures when taking Baclofen.

General aspects:

76 (72%) of the children are described as being happy, 21 (20%) as being quiet, 7 (7%) as being irritable, and only 2 (2%) as not being able to tell their mood. Of those above the age of 1, during that first year 16 (18%) were described as being happy, 12 (13%) as quiet, 60 (67%) as being irritable and only 1 (1%) as not being able to tell what their mood was.

96 (91%) of the children are aware of their surroundings. 31 (30%) can see, 19 (18%) don't see, 37 (36%) see sometimes, and in 19 (18%) the parents can't tell if their child can see. 97 (92%) can hear, 5 (5%) can't hear and in 4 (4%) the parents aren't able to tell if their child can hear.

Music Questions:

These questions were asked at the request of Bjorn Merker. The answers to "how was this shown?" are varied and are included in full with each of the questions.

84 (79%) show a liking for listening to music. The ways this is shown include, smiling, laughing, looking, calming down and many other reactions. 71 (67%) show a preference for one kind of music over another. The way this was shown was similar to the previous question and the detailed responses are included at the end of this report.

Summary

In summary, we now have more information on some of the issues children with Hydranencephaly face and how they respond to their surroundings. There have been several other surveys conducted over the years. Some were much more detailed. A comparison of these results will be done at a later date. This survey had the most participants.

Demographic Information:

1. Children who participated in survey:

	Number	Percent
Living	84	79%
Deceased	22	21%
Total	106	100%

2. Mother's age

	Number	Percent
Under 14	1	1%
15	1	1%
16	11	11%
17	6	6%
18	12	12%
19	8	8%
20-25	26	26%
26-30	24	24%
Over 30	10	10%
Total	99	99%

- None were 14

Summary of mother's ages

	Number	Percent
Teenage	39	39%
20-25	26	26%

26-30	24	24%
Over 30	10	10%
Total	99	99%

Health Issues

3. Does/did your child have hydrocephalus

	Number	Percent
Yes	83	78%
No	23	22%
Total	106	100%

Does/did your child have a shunt?

	Number	Percent
Yes	80	75%*
no	26	25%*
Total	106	100%

- 80 of the 83 (96%)with hydrocephalus from previous ? had shunts.
- 26, did not have shunts, this includes the 23 in previous ? that did not have hydrocephalus, so 3 of83 (3%) did not need shunts

4. Does your child have respiratory problems

	number	percent
Yes	57	54%
No	49	46%
total	106	100%

Does your child have a tracheostomy?

	Number	Percent
Yes	13	12%
No	93	88%
Total	106	100%

Does your child use Bipap?

	Number	Percent
Yes	32	30%
No	74	70%
Total	106	100%

Does your child use a ventilator?

	Number	Percent
Yes	14	13%
No	92	87%
Total	106	100%

Totals for respiratory problems/issues	Number	Percent
Respiratory problems	57	54%
Tracheostomy	13	12%
Bipap	32	30%
Ventilator	14	13%

5. Does your child have Diabetes Insipidus (problem controlling sodium levels)

	Number	Percent
Yes	13	12%
No	93	88%
Total	106	100%

6. Does your child have Hypothyroidism?

	Number	Percent
Yes	12	11%
No	94	89%
Total	106	100%

7. Does your child have trouble controlling his/her temperature?

	Number	Percent
Yes	75	71%
No	31	29%
Total	106	100%

Answer to the question: what is your child's temperature most likely to be were varied. Most children's temperatures tend to be on the low side.

Seizures/Consciousness

8. Does your child drift off into "absences" (blank stare, unresponsive, etc)?

	Number	Percent
Yes	84	79%
No	22	21%
Total	106	100%

Does this happen

	Number	Percent
Frequently	23	26%
Occasionally	52	60%
Rarely	12	14%
Total	87	100%

9. Does your child have seizures?

	Number	Percent
Yes	87	82%
No	19	18%
Total	106	100%

10. Does your child have "coma" type incidents where they sleep most of the time for several days?

	Number	Percent
Yes	33	31%
No	73	69%
Total	106	100%

Feeding Issues

11. Does your child have a feeding tube (Nasal Gastric, Gastrostomy, Jejunostomy, GJ)?

	Number	Percent
Yes	70	66%
No	36	34%
Total	106	100%

The answers to the open ended question: at what age did your child get his/her feeding tube were varied.

12. Does your child eat:

	Number	percent
Both	21	20%
Orally	36	34%
Tube	49	46%
Total	106	100%

13. Has your child been diagnosed as aspirating?

	Number	Percent
Yes	55	52%
No	51	48%
Total	106	100%

14. Does your child have Gastroesophageal Reflux Disorder (GERD)?

	Number	Percent
Yes	61	58%
No	45	42%
Total	106	100%

Physical/orthopedic issues

15. What is your child's tone?

	Number	Percent
Tight	51	48%
Mixed	49	46%
Loose	6	6%
Total	106	100%

16. Has your child had a subluxed hip?

	Number	Percent
Yes	40	38%
No	66	63%
Total	106	100%

17. Has your child had a dislocated hip?

	Number	Percent
Yes	31	29%
No	75	71%
Total	106	100%

18. Does your child have scoliosis?

	Number	Percent
Yes	33	31%
No	73	69%
Total	106	100%

19. Does your child have Kyphosis?

	Number	Percent
Yes	26	25%
No	80	75%
Total	106	100%

20. Has your child used Baclofen for spasticity?

	Number	Percent
Yes	41	39%
No	65	61%
Total	106	100%

21. Has your child had increased seizures when taking Baclofen?

	Number	Percent
Yes	14	17%
No	69	83%
Total	83*	100%

- Note that the number of 83 is more than the number of children who used Baclofen

General

22. What is your child's general mood?

	Number	Percent
Happy	76	72%
Quiet	21	20%
Irritable	7	7%
Can't tell	2	2%
Total	106	101%

What was your child's mood during his/her 1st year

	Number	Percent
Happy	16	18%
Quiet	12	13%
Irritable	60	67%
Can't tell	1	1%
Total	89	99%

23. Is your child aware of his/her surroundings?

	Number	Percent
Yes	96	91%
No	10	9%
Total	106	100%

24. Can your child see?

	Number	Percent
Yes	31	30%
No	19	18%
Sometimes	37	36%
Don't know	19	18%
Total	103	102%

25. Can your child hear?

	Number	Percent
Yes	97	92%
No	5	5%
Can't tell	4	4%
Total	106	101%

26. Does your child show a liking for listening to music?

	Number	Percent
Yes	84	79%
No	3	3%
Can't tell	19	18%
Total	106	100%

How is this shown?

Response table				
Category	Words	Words used in this entry	number	percent
Facial expressions	smiles, smiling, grinning, wincing,	Smile, smiles, smiling	30	29%
Vocal	Laughs, laughing, Cries, coos, cooing, screams, fusses, makes sounds, oohs, yelling	Laugh, laughs, laughing Cry, crying Coo, cooing Fuss yell	12 2 6 4 1	24%
Visual	Looks, looking, tracks	Looks, looking	6	6%
Hand use	Batting, touching,			

	stroking, holding, pushing, picking up, reaches			
Body use	Kicks, Kicking, wiggling, pulling away, startling, calms, head movement, eyes moving, turns toward, moves	Kick, kicking Calms, calming Eyes moving, eyes flickering Turning towards (eyes, head)	4 4 6 6	19%
Auditory	Listens, listening	listens	5	5%
Other common words		Happy, happier Excite, excitement	15 4	18%
Negative reaction	Seizure			
Total			105	101%

detailed responses follow:

- either he stops what his doing and listens
- Smiling or Cooing
- She always got happier and more active. And she loved Birds. She would "talk" to her parakeet.
- just pent attention
- turns his head to the music, smiles
- Smiling, Makes noises
- smiles
- eyes move toward the sound she likes. Mood is quiet and happy. Satisfied look on her face, sometimes little smiles. if its not one of her faves or the music isn't to her liking she gets an icky look starts to fuss a little with irritated looks
- smiles; kicks legs in excitement
- She smiles and goos
- when he likes a tune he will turn toward it and smile, or if he's sitting he will start to sway
- she smiles and laughs and even has music preferences Beyonce is one of her favorites
- calms her down
- smiling and vocalising
- Turn towards noise
- Very Happy smiling
- smiling; giggling; relaxation
- Smiles, Excitement, Contentment
- coos to the music
- he sings along in his roar voice
- Smiled and moved her hands..
- gets quiet as if listening
- When music stops sometimes she wakes up and fusses.
- Increased awareness, turning head towards music, smiling
- Smiles
- may seem calm
- He smiles and gets excited. He often will kind of hum along as if trying to sing.
- Smiles
- fussing will settle with music. Smiles and makes "happy" sounds when music she really likes is played
- he really like harmony and instruments
- starts to smile and "talk"
- Happy smiling reaction
- smile, laugh, or make noise along with the music
- smiles, moving and singing along to the sounds
- she used to calm down when certain music was played
- moving eyes
- irritable until we sing to her, then calms down
- Bella smiles, laughs and kicks her legs. She will also quiet and turn her head to listen to some pieces she likes. She has responded very well to music therapy and now anticipates during certain songs and when she hears her tambourine (object of ref)

- smiled and turned towards sound
- he will laugh out loud
- By smiling, laughing, and singing(make loud noises)
- calming down if crying or smiling and looking for when music is turned on
- his little face would light up, he would smile and look around
- All the time
- making happy sounds smiles
- her eyes would stop flickering for a few seconds when she was listening to the music
- turn to music and quiets to hear it
- smiles, coos, yells like singing with
- Listen carefully and happy
- Some songs calm him when he's fussy, but if we go to another song he's fussy again. If we play the previous song, he calms again.
- opens his mouth like trying to sing - does make noise
- happy
- eyes moved around when she heard music, laughs and verbal noises when it was something she liked, very happy and content with headphones on
- turns head and smiles
- calm, relaxed, attentive
- Smiling, cooing, kicking legs, just plain happy!
- she seems to calm down
- smiles/laughs
- Coos when LOUD music is played
- Sometimes he "sings" along, he becomes more active and happy when music is played. It is was how we first were able to calm him down.
- Calm and happy
- Laughing, kicking legs, happy excitement.
- smiles when piano or flute music is playing
- She starts to rock side to side
- smiling, laughing
- smiles, laughter, calmness
- Smiling and breathing faster
- RADIO
- daily
- his facial expressions and he is vocal
- his eyes turn to where sound is coming from and smiles
- moves head toward music
- quiet sitting laughing
- smiles, turns head, vocalises
- Smiling, gets excited, looks around
- Gets mad if you turn it off
- Eyes lighten up... She stares at the person playing the music
- calm happy
- she smiled when music was played and always laughed when she activated her musical toys.
- Eye movement and head turning
- smiles and looks around shows contentment
- Singing along, smiling, looking toward the sound.
- smiles, and coos

27. In listening to music, does your child show preferences of some pieces (or kinds) of music over others?

	Number	Percent
Yes	71	67%
No	35	33%
Total	106	100%

How is this shown?

Response table				
Category	Words	Words used in this entry	number	percent
Facial expressions	smiles, smiling, grinning, wincing,	Smile, smiling, smiles	17	33%
Vocal	Laughs, laughing, Cries, coos, cooing, screams, fusses, makes sounds, ooohs, yelling	Laugh, laughs, laughing Cry, crying, cries Coo fuss	4 7 4 2	33%
Visual	Looks, looking, tracks			
Hand use	Batting, touching, stroking, holding, pushing, picking up, reaches			
Body use	Kicks, Kicking, wiggling, pulling away, startling, calms, head movement, eyes moving, turns toward, moves	Calms Turns, moves head Eyes light up moves	2 2 1 1	12%
Auditory	Listens, listening	listens	6	12%
Other common words		Whine happy	2 4	12%
Negative reaction	Seizure			
Total			52	102%

Detailed responses to this question follow:

- if he doesn't like it he will make noises or move his head
- Country, Grateful Dead, Phish
- he prefers soft music.. hard loud music.. he starts to cry
- Repetitive music that he has heard before.
- smiles if she likes it - cries if she doesn't like it
- same as above except she will be listening more intently, happy. plays with her tongue - sticking it in and out sometimes pretty far.(one of her favorite happy hungry or eating things she does). half of these times she will also coo and smile more & kick
- yells at us until we change the music to what he prefers
- She smiles and laughs
- More laughing and smiling and sometime it sounds like she sings with the music
- she likes loud almost rock music
- Movement, turning toward noise
- He fusses if country, church or show tunes are on.
- With a pleasant/happy affect. Frustration/irritation or no response when he doesn't care for it. He receives both school-based & home-based music therapy. While he enjoys an eclectic mix of music his favorite are very age appropriate (Miley Cyrus etc.)
- Facial expressions, cooing, "talking"
- turns his heads & coos
- the louder and more rhythmic the more frequently he responds. He ignores a lot of music
- She would frown
- grows quiet
- She likes lullabies and mellow music
- Smiles at some, cries at others
- He is quicker to show excitement or hum along if he likes the music.
- Facial expression

- She is responsive through smiling and making happy sounds when music she likes is played. She is unresponsive to music which does not interest her.
- he gets excited
- facial reaction
- happier reaction
- music he like he makes noise, other music he remains quiet
- she used to calm down when certain music was played
- attention span
- she seems to prefer people singing to her rather than recorded music
- Bella no longer enjoys lullabies or nursery rhymes, she will get upset and cry if left to listen to them.
- whether or not he continues to gravitate towards the sound
- If she doesn't like a song she will not react. If it's just ok with her she will smile. If she knows the song or loves the song she will sing
- dislikes very heavy metal music and likes most other music
- She will make whining noises
- doesn't respond
- if she liked it, she'd listen, if she didn't she'd fuss and wouldn't settle at all
- beautiful instruments
- will whine if he doesn't like it. he will smile if he likes it
- more attention to his favorite music
- big smile
- cried when a song came on her ipod that she didn't like until I changed it. Smiled and laughed when her favorite songs came on
- no response to music she does not care for
- "sings" to those she likes, whines to others that she doesn't really prefer
- eye movements
- smiles and perks up
- Listens intently and smiles
- smiles and is quiet...listening?
- general happiness
- calmness, smiles, laughter
- Raising arms up and smiling
- Soft music
- coos, smiles
- he giggles or smiles and vocalizes
- really seems to listen
- if she likes it she smiles and moves her arms and legs . if she doesnt she cries . and stopps cring with song is over or we change it
- laugh or sit quiet
- Happy when hearing other children singing
- Gets mad if you turn to a different type music
- eyes light up, if falling asleep, she wakes
- smiles or laughs
- She liked children's music and would smile and sometimes laugh when her musical bear would play music for her. she did not like rock music; it would make her cry
- Eye movement
- he concentrates more
- likes classical, does not cry when he hears it.