



*Information and support for families of
children with Hydranencephaly*

Hydranencephaly Newsletter November 2007

This is the first edition of what I hope will be a monthly newsletter for anyone who has, knows of, or is interested in a child with Hydranencephaly. It's purpose is to share information on the various aspects of Hydranencephaly as well as to show case our beautiful children. Much of the information presented in the newsletter will originate from the Hydranencephaly Mailing list or group which is hosted by

Question of the Month:

Q: Ruth Anne, grandmother to Carly age 12: I know many people have talked about how Baclofen increases seizures in kids that already have them. Is that affect as bad if the child gets Baclofen via a pump?

A: Lisa and Noah: I believe that because with the pump you don't need as high of a dose of baclofen the risk of more seizures is less with the pump, than with the oral med. Noah has so many seizures (an average of about 4-10 a day) that we have no idea really if the baclofen is increasing them or not. Even if it was we would not take him off it as the seizures are mild and don't affect him too much and the benefits of the baclofen making him a lot looser and relaxed is worth it.

A: Sarah G. and Emmie: Emmie is on Baclofen and seems to be doing ok... she isn't having any extra seizures, but I am seeing that is it wearing it off sooner than what I would like. Emmie will be getting her Botox shots next month and I am hoping along with this low dose of Baclofen will help her not to be so tight. I do think each child is different and you wont know what works unless you try it.

A: Jasia & Grace: Our Grace has a baclofen pump she has had it for 4 yrs, it has helped with her spasticity which was so bad. The dose that is given into the spine via the pump is in micro grams very small doses it should not effect seizures. When Grace was on oral baclofen before the pump she was on an adult dose that's when you get more side effects, we didn't have seizure problems. The trial dose is given into the spine from what I remember it could be a bigger dose but I think it is still very small.

What our survey says:

26 children were said to have tried Baclofen, of those only 5 reported an increase in seizures from it.

Information on Baclofen

What is baclofen?

Spasticity is a motor disorder characterized by tight or stiff muscles that may interfere with voluntary muscle movements. Baclofen is a muscle relaxant medication. It is commonly used in adults to decrease spasticity related to spinal cord injuries or multiple sclerosis. Baclofen is also used to treat children who have cerebral palsy.

Why is intrathecal baclofen preferred over oral baclofen?

Baclofen can be taken orally (by mouth in pill form) or delivered intrathecally (as an injection in the spine). Oral baclofen causes side effects that may limit its usefulness, especially when prescribed for children. Of the oral baclofen delivered throughout the body, only a small portion goes to the spinal fluid where it is needed to work.

With an intrathecal delivery system, baclofen is delivered right to the target site in the spinal cord. Because the intrathecal system continuously delivers baclofen in small doses directly into the spinal fluid, there are fewer and less severe side effects than that seen with the oral medication.

For the entire article go to:

<http://www.clevelandclinic.org/health/health-info/docs/0300/0369.asp?index=4590>

Older Child of the Month

Noah has had a big year this year, with starting full time school, and turning 6! He attends a mainstream school 4 days a week, and a special school one day. He has a full time aide at school and the kids love to have him and the teacher has had to set up a roster for the kids to help Noah as there was often an argument about who's turn it is to help him! He gets to go swimming twice a week during school, which he loves and it helps him to relax a lot. At school he has been working a lot on his vision and this has improved immensely over the past year. He has just begun working with a head switch and this is a long term goal - that he will activate things with the switch more.

Noah's health has been fairly good during the year, and he has only missed about a week of school all up because of illnesses. We recently discovered that his adenoids have grown back after having them out 14 months ago, and they need to be removed again. We hope once they have been removed that his health will improve again. We are very blessed in that Noah hasn't been in hospital for over 3 years now - except to get his tonsils and adenoids out. Before that he had been admitted 35 times!

Overall it has been a good year, and we are looking forward to Summer in Australia!!

Do you have an idea or question you'd like to see answered here: contact Barb at: angelbearmom@shaw.ca



Noah

November Birthdays

Ben: 11/2/01
Drew: 11/4/99
Cookie: 11/27/95
Rose: 11/27/05
Gabby: 11/28/93

November

"Sadaversaries"

(birthdays & anniversary dates for those who have died)

Nicholas: 8/24/04-11/3/04
Chelsea: 11/9/00-2/17/01
Joshua C. 11/10/99-9/18/01
Aaliyah: 10/29/03-11/10/06
Belen: 5/22/99-11/11/05
Elizabeth: 1/17/89-11/12/06
Luke: 10/12-11/12/00
Kirsten B. 10/14/98-11/13/06
Joshua R.: 3/25/00-11/14/03
Teal: 6/12-11/14/98
Morgan: 8/20-11/14/04
Christian: 11/15/98-5/16/07
Kirsten W.: 8/5/02-11/19/06
Robbie M.: 11/18/95-10/27/03
Amelia: 11/19/04-2/27/05
Maddison: 11/22/01-6/5/04
Brandon: 11/23/00-3/3/01

Younger child of the Month

Breanna was born on April 6, 2007 at 6:44 in the evening. She looked just like every other baby when she was born into this world. I didn't know that she was different until she was 5 weeks old and we went for a CAT scan because her head was a little on the small side. A couple weeks later I was told that she has Hydranencephaly. Today Breanna is 7 months old and is SO happy and loves to be talked to and played with. Some people think that she's younger than she is both other than that no one really can tell her from other babies at times. She has been a wonderful light in my life and all those around her



Coming Next Month:

- International Children's Memorial day
- Tribute to our "angels"
- Tips on toys and Christmas gifts for our kids.