



Information and support for families of children with Hydranencephaly

HYDRANENCEPHALY NEWSLETTER

DECEMBER 2007



...that their light may always shine.

Light a candle for all children who have died.
Second Sunday in December
7 PM Around the Globe

THE COMPASSIONATE FRIENDS WORLDWIDE CANDLE LIGHTING ®

National Children's Memorial Day happens every year on the second Sunday of December and is observed internationally. Families around the world light candles at 7 p.m. in their corresponding time zones. As candles burn down in one time zone, they are lighted in the next, creating a 24-hour wave of light that encircles the globe. This remembrance ceremony provides the world with lit candles for an entire 24 hour period in order to honour the children we have lost, the children who lived and died, and who, even in death, continue to matter.

This year's National Children's Memorial Day is on December 9

Remembering Our Children



Heather: Jan. 18, 2001-March 2, 2007

While Heather was alive and healthy, the trait I admired most in her was her hard work. She would do 45 minutes of physical therapy and keep going all the way through. (When she was sick, she would sleep or pretend to sleep to get out of it.)

She put up with a lot of things from therapies, but tried really hard and better than anyone could have expected.

Kirsten Anne: Aug. 5, 2002-Nov. 19, 2006

I think the thing I admired most in Kirsten was her stubbornness. I still have no idea where she acquired that trait ☺. I guess to phrase it in a positive light, it would be her determination. Kirsten always knew what she wanted and when she wanted it. She would do her best to make sure everyone else also knew. Sometimes it was her various sounds and intensities when she wanted attention or a toy; even to the point of learning to say UP and MOM. Sometimes it was drifting into her "Ghandi" mode of complete non-resistance in order to avoid PT. In any case, she created her own language in order to communicate.



What was her greatest accomplishment? When she learned to color and did every one of her invitations to her 4th Birthday party. Actually, I'm wrong. Kirsten Anne's greatest accomplishment was ignoring the doctors and deciding to live as long as the Lord permitted.



Elizabeth: Jan. 17, 1989-Nov. 12, 2006



^ Elizabeth's ^ best trait was Smiling. That little " Gooberhead " would smile through the most intense pain and not bat an eye at it. She managed to keep us happy with that. Her accomplishment was PT and OT. She would try her hardest and every visit she would do

one thing that PT/OT would ask her to do. I guess if I broke it down it would have to be holding someone's finger real tight. That was her way of holding hands. Being here with us was the best accomplishment of all. I smile when I remember her holding someone's fingers, she would smile.

Kayda: Dec. 2, 1988-June 23, 2000

Kayda's best trait was how she used her hands. They were always up and exploring. When she first started using them I thought I was imagining it. Looking back at pictures now I see them always up and reaching for things or just plain moving them. In pictures taken during her last couple of months her hands are still.



Her biggest accomplishment was how she listened to stories and knew if you'd put on a story that had more than 1 tape. If you did that at night she'd stay awake until the entire book was done. I don't know how she knew, but she did. I tested her quite a few things.

Paul: July 26, 1993-May 14, 2003



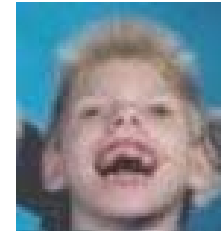
What you remember most about him : His smile and laugh. . . . I miss that the most. I come home from a bad day and there he was, waiting in his recliner. He was so tired but wouldn't nap until he heard me come through the door, there it was, the biggest grin ever- it just washed my day away! I remember one car

ride in particular. Free fallen by Tom Petty came on the radio, for some reason Pauli thought it was the funniest song in the world and belly giggled through the song! Today when I hear that song I don't know whether to cry or laugh my head off. . .

His "greatest accomplishment". His life was his greatest accomplishment. He live 9.5 incredible years! He proved every person who doubt he'd live, wrong. He fought so many illnesses, enjoyed school, baseball, bowling, traveling. . . . and just being a little boy! He loved life for what is was. He knew no evil. . . .

Chris: Sept. 23, 1988-Feb. 1, 2003

What I admired most about Chris was his ability to be happy all the time. And his best accomplishment was his ability to put a smile on everyone's face. He was everyone's ray of sunshine.



**December
"Sadaversaries"**

(birthdays & anniversary dates for those who have died)

- Tanner: 3/8/00-12/1/01
- Emma: 4/8/06-12/1/06
- JD: 12/1/99-3/13/03
- Kayda: 12/2/88-6/23/00
- Kirsten: 3/13/91-12/2/05
- Rebekah: 8/8/03-12/3/03
- Angelina: 10/5/05-12/4/05
- Aiden: 10/12/04-12/5/04
- Michael: 9/12/95-12/5/02
- Daniel: 12/7/95-1/9/05
- Brianna: 1/22/03-12/8/03
- Lara: 2/23/06-12/10/06
- Preston: 12/13/99-1/22/07
- Katie: 12/20/85-3/20/04
- Isaiah: 12/22/97-10/17/04
- Dameon: 6/24/02-12/20/03
- Matthew P.: 5/24/00-12/30/02

What are some of the best toys for a child with Hydranencephaly?

TJ Bear, an animated storytelling teddy bear, it's Jeremy's favorite little buddy!

Many of the children love TJ Bear. Here's Noah with his.



Leap Frog's learning toy, called Little Tad

http://www.leapfrog.ca/dofindproductid=huglearntad_caen

OMG.. Sean is OBSESSED with this toy.....It sings songs to you... Says a few different things, Plays night time music, lights up.... I LOVE IT!!! And more importantly HE DOES!!!

The best toy I found was the Personalized Leap Frog. You can record anyone's voice into it and set it for prompts or commands. It starts off by saying hello to the child and it goes from there. To operate it, just lightly push on the Frog's feet or hands and it speaks.. I got it a Walmart for less than \$35.00 2



Tiny Love - Jittering Julie

by East Coast Nursery

http://www.amazon.co.uk:80/East-Coast-Nursery-94042-Tiny/dp/B00006JZE8/ref=sr_1_1?ie=UTF8&s=toys&qid=1195465750&sr=8-1



Tiny Love® Musical crib/cot mobile

http://www.mothercare.com/gp/product/B000JFD9B8/sr=1-3/qid=1195465836/ref=sr_1_3?ie=UTF8&mcb=core



Glo Puppy

Ethan's favorite toy in the whole world has been his glo puppy since he was only a few months old. It is his comfort item. This link is to the larger one but the smaller is half the price. There is a bear, monkey and puppy. He still gets just as excited over it as he used to. Of course I had to include a pic of Ethan and Puppy. I just took it like two minutes ago since my son doesn't like to sleep at night anymore. *Cool green scarf not included with purchase:)

http://www.amazon.com/Glo-Bear-Five-Different-Light/dp/B000C7NRA6/ref=pd_bbs_sr_1?ie=UTF8&s=toys-and-games&qid=1195483792&sr=8-1



Junior really likes Spidey dog (one of those toys that can be plugged into a ipod, mp3 or cd player and lights up and moves to music, there are lots of different ones)



One of the best toys we ever got for Noah was the Musini made my Neurosmith. It senses vibrations and plays music in time with the vibrations. You can adjust the sensitivity. Everytime Noah would even more a little bit near it, it would start playing music. If he stopped moving, it stops

playing music. It has different types of music and you can buy extra cartridges with more music on it. We love it.

One website I found it at is <http://www.amazon.com/Carlen-Enterprises-Musini-MagicSensor/dp/B000065CKT>



Bella and her space blanket



There is a toy called interactive Elmo. It comes with a cd and a USB port and you plug the elmo into the computer and use this program to add there name, b-day , what there favorite foods, and song etc. It is great. When you turn it on it says Good Morning "Brandon" (or whoever) lets play. It can also be a switch toy. I have seen it turned into one. I hope this helps you. Brandon loves it.



December Birthdays

- Emily T.:12/1/02
- Kaylee: 12/1/05
- Layla: 12/1/05
- Mason: 12/3/01
- Sean: 12/11/06
- Trevor: 12/24/01
- Chrissy: 12/26/00
- Brendan: 12/27/97
- Crystal: 12/28/86
- Ethan: 12/28/00
- Cassie: 12/31/96

May your Christmas be merry & bright

