



*DID YOU  
KNOW....*

- That our brains have amazing plasticity and are capable of creating new connections and pathways to make up for ones that have been interrupted
- The Dandy-Walker Alliance is on Facebook
- Everyday a child with Dandy-Walker accomplishes something they were told they'd never do

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# *The Dandy-Walker Alliance Newsletter*

VOLUME 1, ISSUE 2

JUNE 2009

## *Your Alliance at Work*

### **Awareness is on the rise!**

As we wrap up spring and move into the summer months our thanks goes out to so many families who helped raise awareness for Dandy-Walker. Many of you wrote to your elected officials and at last count there were at least 10 states this year that had official Dandy-Walker & Hydrocephalus Awareness months!!! What an awesome accomplishment, we obviously have a large group of very dedicated families in our community! Now for the next step, proclamations are good only in the year they are issued, so as we move towards 2010 this drive will shift gears and requests will begin to be made for executive orders vs. proclamations, which don't expire year to year and will make the May of every year Dandy-Walker & Hydrocephalus Awareness month! On another awareness note later this year the first every Dandy-Walker Alliance Walk/Run will take place in Alabama. Keep an eye on our website, we will post more details and information as it becomes available.

## **Welcome Corlette Todd & Kathy Kitchen!**

As the Dandy-Walker Alliance grows so does our need for volunteers. Most recently Corlette Todd and Kathy Kitchen have joined us by volunteering to be Directors of Relations in their respective countries. Having contacts in different regions of the world is such a valuable asset to our organization. Services differ from country to country and having these ladies on board give us the resources to better help more families all over the world.

Kathy, mother of two, remembers how alone her and her husband David felt when her youngest was diagnosed with Dandy-Walker during her pregnancy. Their doctors gave them a very grim prognosis and after struggling with how to move forward they decided to start doing everything possible to give their daughter a fighting chance. Today she is a happy little two year old, who is doing all the things the Doctors said she wouldn't. After discovering the Dandy-Walker Alliance Kathy shared her desire to help others going through the same thing. We welcome her as our Canadian point of contact for families there.

Corlette and her family hail from Australia, where they are raising two sons. Their oldest with Dandy Walker Syndrome. Earlier this year they were able to come to the United States, they had planned on attending a conference for Dandy-Walker families but unfortunately it was cancelled. Already having their plane tickets they made the trip anyway and one of their many stops was Washington DC, where they were able to spend some time with Eric Cole and his family. After learning more about the Dandy-Walker Alliance Corlette volunteered to be our liaison in Australia.

We are thrilled to have both Corlette and Kathy helping us as we strive to provide information, education and support to individuals and families affected by Dandy-Walker worldwide!

Contact information:

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Kathy Kitchen-Director of Relations, Canada  
[Kathy.kitchen@dandy-walker.org](mailto:Kathy.kitchen@dandy-walker.org)

# Achievements!

Everyday someone with Dandy-Walker does something that they were most likely told they'd never be able to accomplish. We think its important to share these inspiring stories with everyone so that even on days that aren't so great we don't lose sight of the possibilities. Congratulations Samuel & Kate!!

Who would have thought when we received the news that our son had Dandy-Walker Syndrome or when the neurologist told us that our son would never have an IQ out of single digits, that five years later we would be celebrating his Pre-School Graduation? As a parent, you are always proud when your child achieves a major milestone, however, there certainly was an extra little twinkle in our eyes, let alone our hearts, when Samuel walked towards his teacher in his cap and gown and received his diploma. He also received several other achievement awards too!

My hope for all of you out there is that you continue to work hard and strive for your goals. Don't let the negative comments about your child get you down! We're all here to serve a purpose and all of our Dandy-Walker children have purpose! As our Alliance continues to grow strong, together we will educate the world about Dandy-Walker and stamp out those who say our children can't and won't!

Samuel's Father



Samual Pre-School Graduation 2009

Kate Dekoski is getting ready to start her Sophomore year at Delta college in Michigan. Born with Dandy-Walker & Hydrocephalus she's had more than her fair share of surgeries and challenges, but like so many others in our community she has rose above it all and is well on her way to pursuing a career in nursing. Instead of dwelling on her own medical issues she spent much of the past year taking the lead role in having Michigan declare a Dandy-Walker and Hydrocephalus Awareness month. Between being a full time student and her political endeavors she uses her "spare" time to help her grandparents with their farm and works with some of her professors at school on special projects. Somewhere in all of this she managed to find the time to secure a scholarship this year from the Hydrocephalus Association! Way to go Kate, we can't wait to see what other great things are in store for you!

## New Organization dedicated to helping children with Hydrocephalus



Michael & Kim Illions aren't new to the world of hydrocephalus, their 3 year old son was born with the condition. Like so many of us do, they set out to learn as much as they could. Along the way they were moved to get involved, they wanted to advocate for their son and for a better solution. The current treatment for Hydrocephalus is over 50 years old and has an alarming failure rate. With an incidence rate of as many as 1 in 500 Hydrocephalus is a fairly common condition.

After spending a couple of years working with other Hydro-

cephalus organizations they saw a need, a need to cater specifically to children with Hydrocephalus and their issues-The Pediatric Hydrocephalus Foundation was born. Their goals are simple, find a better treatment and even a cure. Along the way they want to help families with the challenges they encounter in raising a child with Hydrocephalus.

They have set out to accomplish this by raising money to support research, and to raise awareness. Its only been a few months since they formed this non-profit organization and already they have a resolution in the House of Representatives -HR373, which calls for a National Hydrocephalus Awareness Month. Currently they have secured 10 co-sponsors, but in an effort to educate the law makers on Capitol Hill and to gather additional co-sponsors they are planning a trip to Washington DC, where

they will spend the day visiting Congressmen and explaining why this is such an important issue.

Because their organization is comprised completely of volunteers they have very little overhead and close to 100% of the money they raise will go directly to accomplishing their goals.

We, at the Dandy-Walker Alliance, look forward to working with the Pediatric Hydrocephalus Foundation in the future on projects that are mutually beneficial to both organizations goals.

Visit them on the web at:

[Www. Hydrocephaluskids.org](http://www.Hydrocephaluskids.org)

Or contact them at:

Tel: 732-634-1283

Fax: 847-589-1250

**Advocacy**

**Alert:**

**Hydrocephalus**

**affects as**

**many as 90 %**

**of children**

**with Dandy-**

**Walker. Please**

**call or write**

**your**

**Congressman**

**to encourage**

**them to**

**support and co**

**-sponsor**

**HR373.**

## Visit us on YouTube!

The internet is a valuable resource for many of our families. You can find just about anything your looking for with a few key strokes these days. In an effort to increase our visibility on the world wide web we've recently launched our very own YouTube channel. Starting with one video, our picture montage of many of the children we've

come to know with Dandy-Walker . Recently we've added other videos including congressional testimony, personal stories and media interviews! We have also bookmarked a few interesting videos we've run across that shows how CFS flows through the brain. We'll add more as we find things we



think are relevant. Come visit us on YouTube at :

<http://www.youtube.com/user/DandyWalkerAlliance>



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**We are an all-inclusive organization comprised of individuals directly and indirectly affected by Dandy-Walker sharing a collective interest in educational, informational activities and supporting non-partisan research to increase public awareness of the congenital birth defect Dandy-Walker. We also support all efforts to determine the cause(s), find the cure and to ameliorate the effects of Dandy-Walker. We believe that by making findings available to families affected in an organized and accessible way and by disseminating the direct and indirect outcomes of translational research we can more swiftly move the results from the bench to the bedside in a safe and expeditious manner.**



[www.dandy-walker.org](http://www.dandy-walker.org)

## Spotlight on....Bill

Bill is one of the most pleasant, inspiring people I've ever talked to. It was obvious to me in the few times we spoke that he cares much more about the world around him and his community than himself. During our conversation we talked about some of the things going on in the Dandy-Walker community, when I mentioned research projects he said, "Where do I sign up?" When he heard we are working on getting proclamations in all 50 states he said, "Who do I write to?", but when Bills Doctor told him he had Dandy-Walker, his reaction was much less emotional, he wasn't concerned or scared, he'd lived with this all his life without ever knowing it and giving it a name was rather uneventful to him. Bill is in his 50s and wasn't diagnosed with Dandy-Walker till about a year ago when he had an MRI for an unrelated issue. With the medical technology

available today there is a whole older generation of Dandy-Walker patients getting diagnosed later in life almost by accident. These individuals may have had various struggles during life without ever having any idea they had Dandy-Walker. Growing up in a family with 4 other children he says he always felt "different", he often had headaches and never really had much of an appetite. Although he accelerated in subjects like History and English he had some struggles with Math and Science. That didn't hold him back academically, today he holds a Masters Degree in Political Science and History. He devotes much of his time to helping others; he volunteers in his Synagogue and spends time helping to feed the hungry. He is a musician in his own right and plays 5 musical instruments as well as

composing his own music. Bill is a man of hope; he truly believes what we do today can make a better tomorrow, not just for himself but for everyone. It was just that philosophy that motivated him to write to his Governor, Pat Quinn of Illinois, requesting that May be proclaimed Dandy-Walker & Hydrocephalus awareness month. Thanks to Bills efforts Governor Quinn did exactly that and we can add Illinois to our list of states that have granted such requests!

*The Dandy-Walker Alliance Newsletter would like to highlight a different person in each of its Newsletters. If you'd like to share your story please send a picture along with your story to: [Comments@Dandy-Walker.org](mailto:Comments@Dandy-Walker.org)*