



The Dandy-Walker Alliance Newsletter

VOLUME 1, ISSUE 1

MARCH 2009

DID YOU KNOW....

- Our website has had as many as 100,000 visits in a single month!
- We have recently partnered with the University of Chicago regarding genetic testing
- Our website has been translated into 18 different languages around the world

INSIDE THIS ISSUE:

- Meet our Scientific and Medical Advisory board 2
- New Resources for Families 3
- Awareness Update 3
- Research Corner 3
- Spotlight on.... 4

Your Alliance at Work

2008 Was a Great Year for Dandy-Walker

A lot of the things that we do here at the Dandy-Walker Alliance aren't always visible to many of you. As we wrapped up 2008 we couldn't think of a better time to share some of the progress that has been made in our efforts to promote research and advocacy for Dandy-Walker patients. Throughout this newsletter you'll find many different accomplishments that have been made starting with this publication. This is the first of what we intend to make a periodic publication for our organization. We hope in the future to be able to publish newsletters throughout the year to keep everyone up to date on the latest developments in our progress to advocate and educate on behalf of Dandy-Walker patients everywhere. In closing we would just like to thank everyone who visits our website and helps us in our endeavors. Without all of you we wouldn't have been able to make the impact we have over the last few years. Keep a look out for more good things in the future!

Dandy-Walker has a Voice!

House Resolution 163 was introduced in 2007 to the House of Representatives by then, Congresswoman Heather Wilson, from New Mexico. The resolution calls for Congress to support the much needed research, public and professional awareness and education for Dandy-Walker and Hydrocephalus. We were proud to be part of what became an awesome grass roots effort that had 105 co-sponsors when it was passed in Congress on June 26th. Only a few short months later, in September, it was also passed unanimously in the Senate. Many of you wrote your representatives asking them for support and it paid off! Thank you all for supporting this important piece of legislation! You can view the full text of the resolution and videos of testimony on our website:
www.Dandy-Walker.org

Have you seen the new Dandy-Walker Alliance Awareness Wristband?

Earlier this year the Dandy-Walker Alliance in conjunction with Awareness Products Online, designed and produced the first ever Dandy-Walker awareness wristbands. These wristbands are a great way to show your support and spread the word about Dandy-Walker!



Go to http://www.wristbands4awareness.com/dandy_product_info and get yours today!



Having a
Scientific and
Medical Board in
place helps us
get you the most
up to date and
accurate
information
available

Meet our new Scientific and Medical Advisory Board

In 2008 the Dandy-Walker Alliance created a Scientific and Medical advisory board. These professionals donate their time to the Dandy - Walker Alliance to serve as our experts in the scientific and medical areas of our organization. Without their valuable input we wouldn't be able accomplish much of what we do. Our sincere gratitude and thanks to them for serving on our board.

William B. Dobyns, MD, PhD
*Professor of Human Genetics,
Neurology, and Pediatrics
University of Chicago, Chicago, IL*

David A. Fowler, PhD
*Division of Health Assessment and
Consultation
Agency for Toxic Substances and
Disease Registry, Atlanta, GA*

Marjan Huizing, PhD
*Head, Cell Biology of Metabolic
Disorders Unit
Medical Genetics Branch
National Human Genome Research
Institute
National Institutes of Health*

Giorgio Kulp, MD, FAAP
*Metropolitan Pediatrics, Bethesda,
MD*

Kathleen Millen, PhD
*Associate Professor, Department of
Human Genetics
University of Chicago, Chicago, IL*

John S. Myseros, MD, FACS, FAAP
*Associate Professor of Neurosurgery
and Pediatrics
Children's National Medical Center,
Washington, DC*

Seth D. Norrholm, PhD
*Assistant Professor
Department of Psychiatry and Behav-
ioral Sciences
Emory University School of Medicine*

Kenneth N. Rosenbaum, MD
*Director, Center for Prenatal Evaluation
Center for Neuroscience and Behavioral
Medicine
Children's National Medical Center,
Washington, DC*

Billie Lou Short, MD
*Chief, Division of Neonatology
Children's National Medical Center,
Washington, DC*

Asha Subramanian, MD, MPH
*Assistant Professor, Department of
Family Medicine
Georgetown University Medical Center,
Washington, DC*

Eric R. Trumble, MD
Neurosurgeons for kids, Orlando, FL

Marcie Oser Wertlieb, MD
*Medical and Surgical Ophthalmology,
Laurel, MD*

Do you have a suggestion?
We'd love to hear from you!
Drop us a note at:

Dandy-Walker Alliance
4422 Clearbrook Lane
Kensington, Maryland 20895

Or E-mail us at:
Comments@Dandy-Walker.org



New Resources for Families



One of the most difficult things in life is to find out there is something wrong with your unborn baby or child. There are so many unanswered questions, so many unknowns, it's a very

Families Matter: Your not alone

scary time. We hear from families all the time in this very situation and we remember exactly how they feel. One of our goals has been to try and help untangle the web of questions we all went through in the beginning of our journey into the world of Dandy-Walker. In the past year we have created a brochure with information and

resources for families that can be mailed out or downloaded directly from our website. We also created the Dandy-Walker Alliance blog. Reading about other families experiences are a great way to learn more about Dandy-Walker. Our blog was created to give you a place to share and learn from each other and has been a great success!

Visit our blog at:

www.Dandy-Walker.org/blog

*One person
can make a
difference! Get
in touch with
us and we'll be
happy to show
you how you
can help!*

Awareness Update

In May of 2008 the State of Maryland led the way, to what we hope someday to be a nationwide awareness day, when their Governor Martin O'Malley proclaimed the first official Dandy-Walker and Hydrocephalus Awareness month! This year the Governor of Nebraska, Dave Heineman, will join the cause and proclaim May

2009 Dandy-Walker and Hydrocephalus Awareness month there. We have a goal, to sooner than later, get all 50 states to make similar proclamations. These proclamations are a great tool to promote awareness in any community and can have almost any kind of event focused around them. For more information on how to

get your state involved contact Terri.Eldridge@dandy-walker.org.



Research Corner

It looks like research into Dandy-Walker is becoming a little higher on some priority lists! In the last five years the National Institute of Health has more than tripled the number of grants it has funded for Dandy-Walker research!!! This is awesome news for those of us that hold a interest in

advances to finding a cause and better treatment for Dandy-Walker. Both the University of Chicago and University of California San Francisco are conducting on going research projects especially in the field of genetics and how they relate to brain malformations. Some of these projects are open to

volunteer participants. Additional information is available by clicking the Federally funded clinical trials link on our website.





4422 Clearbrook Lane
Kensington, Maryland 20895

DC Office: +1 301 919 2653

FL Office: +1 321 446 0349

NE Office: +1 217 239 9999

Toll Free:

+1 877 DANDYWALKER

(+1 877 326 3992)

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.



Spotlight on....Tesla

Meet Tesla Michelle. Tess was born in May of 2007 having been diagnosed in utero a few days earlier with moderate Hydrocephalus. When her mom went into early labor she had to be air lifted to a trauma center to deliver. The specialist on staff there was less than hopeful since Tess had Hydrocephalus but her head wasn't enlarged-he was concerned about the "amount of actual brain matter" in her head. The morning after she was born a MRI was done and that's when we first heard the term Dandy-Walker. The Neonatologist on staff said if anything she'd be a little clumsy. No further explanation. Her Hydrocephalus was stable and didn't require any intervention at the time and after 5 days in the NICU let her come home. Well her journey has encompassed a bit more than "a little clumsy", she has some delays and receives PT, OT & ST

through early intervention. Last summer, right after her first birthday, she had an ETV to relieve pressure from the Hydrocephalus. She also has seizures but they are controlled pretty well with medicine. Even with all of that the most important thing anyone should know about Tess is that she is a happy, loving, playful little girl. She is our little football baby, she loves going to games and watching all the excitement. She can crawl, and sit on her own and right before Christmas took her first steps, she's still a little wobbly but she never quits trying. It may take her a little more work than most of us to do things but she gets there in her own good time. She is such a little people person, nothing makes her happier than when everyone she loves is home and playing with her. She is the love of our life and

has taught us more than we'd ever hoped to learn in our lifetimes.

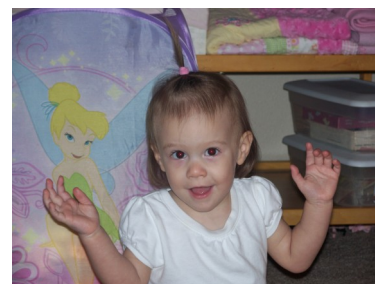


Photo: Tesla Michelle –Summer 2008

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