

**ACQUIRED BRAIN INJURY
NETWORK NEWS
July 1, 2009—2009/#07
Survivors and Family Members
Building Lives of Meaning, Joy and Value**

Greetings!

Thanks to the donors and volunteers who make our mission possible!

A list of our 2009 donors to date will appear in the August newsletter. Also a riveting story—Divine Intervention—about the sequence of events that saved a life.

A big thank you to the PMHCA Harrisburg Conference volunteers: Erikka Johnston, Barbara Svitila, Sharon Bass, Alison Irving, Jean Hendrick, Gerry Nikolaus, Kathie Winters, Carroll Rottmund, Marie Killian, & Kelly Capos. Very grateful!

Thanks also to attendees at our Inglis Foundation Award ceremony on June 25th: Kimberly Byrd, Barry Childress, Barb Dively, John Dively, Maureen Neve, Peggy O'Neill, Dan Rohrback, Steven Rooney, Madelaine Sayko, & Pat Strenk.

All are welcome at the July 12th Potluck and our July 23rd phone discussion. Also, info table helpers are needed August 4th.

Barb Dively

**PLEASE ASK YOUR
LEGISLATORS TO JOIN THE
BRAIN INJURY CAUCUS**

SENATE—6 Members

Andy Dinniman, Stewart Greenleaf
Sean Logan, Jane Orie, John Pippy
and Gene Yaw

HOUSE—5 Members

Co-Chairs Bill Kortz & Dick Stevenson
with Matt Bradford, Denny O'Brien,
and Tina Pickett.

**For contact information, please go to:
www.legis.state.pa.us**

ABIN-PA EVENTS

**Board Meetings, Potluck & Newsletter
Mailings in Lansdale.
For Info(215) 699-2139.**

Sun. July 12, 2-4pm—Board Mtg. **TC**
4-7pm—**Summer Potluck**—for
Survivors, Families & Friends—
Please RSVP with who's coming
and what you are bringing.

Thu. July 16—7pm GSRH Allentown

Thu. July 23—7pm TeleSupport Mtg **TC**

Help Your Doctor Understand

Tue. July 28—1-3pm Newsletter Mailing

Tue. Aug. 4—Franconia Take Back Nite

Sun. Aug. 16—2-4pm Board Mtg **TC**

Tue. Aug. 25—1-3pm Newsletter Mailing

Sun. Sep. 13—2-4pm Board Mtg **TC**

**TC means a Teleconference:
1-218-486-1300, Password 127105**

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**SUPPORT GROUP FOR
JEFFERSON COUNTY?**

Dan Spinda

I very much enjoy the newsletter every month.

I especially liked Denise's article about being in a wheelchair and being ignored when you can't speak, even though she graduated from college after her accident - and I had tears in my eyes after reading it.

I have to drive three hours to get a prescription for pain medication because local doctors are afraid of losing their medical licenses in case the pain medication is misused.

I really need my pain medication. I was going 55 miles an hour and hit a tree head on. I was life-flighted to Pittsburgh.

I got out of the hospital to go home to help my mother because I was the only one taking care of her. She took care of me while I was little, so I was taking care of her while I was working full time. The Area Agency on Aging sent helpers, but eventually I did have to put her in a nursing home and after a while she passed away.

I am interested in starting a brain injury support group that would be meeting at a church in Falls Creek PA. If you are interested in helping or attending, please call me at 814-503-8158.

**CHOOSE GRATITUDE
AS YOUR ATTITUDE**

**NEW BROCHURES
ON WEBSITE**

BRAIN INJURY BASICS
Injured cells mean signaling failures that cause cognitive, physical, emotional and behavioral problems.

**DOMESTIC VIOLENCE
LEADS TO BRAIN INJURY**
About 66% of victims have a brain injury so counselors must be prepared.

RESOURCES

ABIN-PA Brain Injury InfoLine
1-800-516-8052
BIAPA Brain Injury Resource Line
1-866-635-7097
Brain STEPS—school children
1-724-944-6542
DOH Brain Injury Help Line
1-866-412-4755
Disability Rights Network
1-800-692-7443
Housing—PHFA www.phfa.org
1-717.780.3988
PA Head Injury Program
1-717-772-2762
Pennsylvania Health Law Project
1-800-274-3258
Special Education Consult Line
1-800-879-2301
Waiver Help Line—CommCare, etc.
1-800-757-5042

I Flunked Dog Obedience Class By Pat Strenk

I had a goal in mind, to give back what I turned down while in rehab due to a Traumatic Brain Injury, a visit from the dogs.

First, I needed a dog. After scanning the pet ads in the paper, I thought I found the perfect one for me. The ad said this dog was housebroken, good with kids, etc, etc. Perfect, I thought. How soon I was reminded what my Husband always says, "If it sounds too good to be true, it usually is."

I went to see this pup, 9 mos. old Mya, a Border Collie/Red Husky mix, who turned out a bit larger than I anticipated. She was on the high end of the MEDIUM range, but she absolutely loved me. She was all over me. The owner said that she never saw the dog react this way before as she had me on the floor. I thought, "Wow, she really, really likes me!"

OK, next step, how to tell my Husband who I told earlier, "I'm only going to look." Find an obedience class, quick! I had never been to one before, but I found a beginner's class and "I was a beginner" so...I signed us up.

Once at class in this huge gym type room, there were maybe 25 dogs with their handlers standing in a very large circle. We were to follow the directions of the instructor teaching us the very basics. In the beginning, we all fared about the same, some got it, some didn't.

But as the weeks passed and everyone's dog behavior improved, I continually fell behind never being able to physically and mentally keep up to the commands myself, let alone for Mya to follow. We did fine practicing at home, but keeping up in class was different.

Completely devastated by my inability to follow group directions, I abruptly left the class with Mya one night in tears 2 classes shy of completing the course. We... flunked out.

That was almost 10 years ago.

MOVIE REVIEW—JAMES BURKE

I just finished watching the movie *The Diving Bell And The Butterfly*, which I borrowed from the library. Winner of a Golden Globe for best picture of the 2008 and nominated for 4 academy awards, it is a French foreign language film. It is a moving portrait of Jean-Dominique Bauby, who suffered a devastating stroke at age 43, and couldn't speak or move any appendage. He manages to write a book about his injury and life, using nothing more than one blinking eye. Much of the movie takes place in the character's mind and memories, and is beautifully filmed. After watching this movie, I feel very fortunate, having the outcome from my injury that I did. The movie also gives one the hope and aspiration to follow your dreams, no matter what obstacle is in your way. [For a short video on the film, go to: <http://www.reelgood.tv/reelgoodreviews.php?id=36>.]

**Interactive Metronome and Vital Stim
By James Burke**

I had Interactive Metronome and Vital Stim, for 2 days per week for three weeks. I noticed improvement but since insurance only pays for vast improvement, both therapies were cut.

I actually found Interactive Metronome a little frustrating. As I remember it, you had to keep time using your left and right side. You had sensors on your hands and feet. The computer kept records of how accurate you were, down to a tenth of a second. When you were close to the right timing you heard a high whistle. If you were off, you heard a low hum. The whistles didn't inspire me, but the hums disappointed me. I improved some, but didn't do very well.

Vital Stim is a therapy where electrodes are placed on muscles that haven't been used in awhile, causing them to work. The electricity it gives can be a little jarring at first, as it feels a little like pins and needles, but you quickly adjust to it. While your muscles work, it retrains your brain. It was being used on my speech and left hand. One time when I returned home, my mouth suddenly felt different, normal! I was by myself, but tried some talking. It was much clearer and easier to understand to my ears. This was only the second time, where my speech sounded great, almost pre-accident like. The first time was actually only 6 months post accident. Unfortunately, by the next time I saw my therapist, my speech had reverted back. Without having any great changes to show my insurance, this therapy was also ended.

I honestly, did see changes using both therapies. They were small, but I did notice them. I saw even more improvement using Vital Stim. I only wish that both treatments were not ended so quickly. Perhaps even greater improvements would have then been attained.

AN ABIN-PA POLICE BROCHURE FOR EVERY OFFICER

Ellen Solt suggests the following script: "I am calling on behalf of a nonprofit organization, ABIN-PA. They are extending an educational opportunity to all law officers across the state—police officers, detectives, sheriffs and state police officers. So, I would like to know how many law officers you have—so I can provide a brochure for each of them, that they can reference and use. Would it be convenient for me to drop the brochures off directly to you? This is a very useful tool for the officers to have. The brochure is very clear and concise and offers some very good suggestions. This way, the officers can keep the brochure in mind and reference it as needed." **If you can help, call 800-516-8052.**

Survive with Pride

RESOURCES FOR PARENTS

Brain STEPS: Intermediate Units across the state have created volunteer teams trained to help schools plan services for children with brain injury. Contact EaganBrown@biapa.org.

Disability Rights Network: Provides the special education information previously provided by the Educational Law Center. Call 800-692-7443 for intake. Go to www.drnpa.org for fact sheets on many aspects of special education.

Elks Home Service Nurses Program: Free services described at www.paelks.com/files/Homeserv.htm (scroll down). For a list of the nurses and the areas they cover, click on Home Service Nurses under the picture of the car. For services, call Program Director, Patricia O'Connor, RN, at 814-781-7860 pato@ncentral.com.

Rehabilitation: This article, "Children with Brain Injury" by Ronald C. Savage, Ed.D., explains that only 2% of disabled children may get the rehabilitation they need. Read this article at: http://www.tbi.org/library/html/children_with_tbi.html

Special Education Consult Line: Free service from the PA Department of Education to help parents understand their rights under special education laws. Call 800-879-2301 from 8-4.

Special Kids Network System of Care: A partnership of local service providers, coalitions and community groups helping to serve children with special needs and their families. Call 877-986-4550 or TTY 1-877-986-5432 to reach a SKN System of Care Coordinator.

Special Kids Network Information & Referral: Call 1-800-986-4550 or TTY 1-877-232-7640 for a trained Information and Referral Specialist who will connect you with services in your community. Call Monday through Friday from 8:00am to 8:00pm, and Saturday from 9:00am to 3:00pm. Type "PA Special Kids Network" to reach the website with this list of possible services: 1) "Education and Training such as independent living skill, Braille instruction and family resource libraries. 2) Health Care Products such as adaptive clothing, assistive technology, standing & walking aids. 3) Support & Advocacy such as parent support groups, education and legal advocacy. 4) Social Services & Counseling such as family and individual counseling, hospice care. 5) Therapy such as equestrian, occupational, physical, play, speech. 6) Recreation and Leisure provides individuals with disabilities with accessible recreational activities such as athletic programs, camps, wheelchair accessibility, hearing, vision, speech and behavioral accommodations."

Special Needs Coordinator Unit in Harrisburg: Call 800-521-6860 or 717-705-8220 to help arrange brain injury rehabilitation under Medical Assistance through the Special Needs Coordinator of your child's physical health managed care provider.

**FOR BENEFITS FOR AGE 18+—PERFORM INTERNET SEARCHES ON:
PA DPW INDEPENDENCE WAIVER....PA DPW OBRA WAIVER
PA DPW COMMCARE WAIVER....PA DOH HEAD INJURY PROGRAM**

Newsletter Sign-Up, Donations & Tributes

ABIN-PA is dedicated to increasing public awareness about acquired brain injury and to providing support, education, information, advocacy and other services for individuals with acquired brain injury and their families.

DATE: _____ NAME: _____ PHONE: _____

STREET: _____ CITY: _____

STATE: _____ ZIP: _____ COUNTY: _____ SURVIVOR: _____ FAMILY: _____ OTHER: _____

EMAIL: _____

DONATION: Amount \$ _____ Check # _____ Monthly: _____ United Way: # 45813

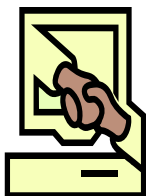
IN HONOR OF (Name): _____ (Reason): _____

(Address): _____

IN MEMORY OF (Name): _____ (Family contact): _____

(Family address): _____

The official registration and financial information of the Acquired Brain Injury Network of Pennsylvania, Inc., may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.



ACQUIRED BRAIN INJURY NETWORK OF PENNSYLVANIA, INC.

2275 Glenview Drive, Lansdale PA 19446-6082

215-699-2139 InfoLine: 800-516-8052

info@abin-pa.org, www.abin-pa.org

PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.