

ACQUIRED BRAIN INJURY NETWORK NEWS

May 1, 2010—2010/#05

Survivors and Family Members Building Lives of Meaning, Joy and Value

InfoLine: 215-699-2139, 1-800-516-8052. Fax: 215-699-5139

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

Greetings:

So many milestones in April!

About 150 people attended our PA Legislative Brain Injury Caucus. Committee **Brain Injury Rally in the Capitol Rotunda** on April 20th. Thank you!

Our **Leadership Training** in Philadelphia and Pittsburgh went well—you can still call in to register for Sat. May 8th in **Camp Hill**.

A new volunteer, Katherine Alvarez, is translating our brochures into **Spanish!**

Thanks to Terri Wernly, Lisa Kohut, Melissa Hill, John Dively, and Erikka Johnston, our website has a **rehab facility search feature**.

Looking ahead, this is the last month of our **Inglis Award year**—an amazing year!

Our **summer potluck** is on June 13 at 4pm at Dively's. Please RSVP and bring food to share. Friends and family are welcome.

At the end of June, Pat Strenk, Anna Marie Childress, Corinne Gries and I are presenting a workshop on the Peer to Peer manual at the **BIAPA conference**. See you there!

Wishing you a wonderful Spring!

Barb Dively

ABIN-PA SCHEDULE

Leadership Training 5/8 Camp Hill.

Board Meetings Sundays 2-4pm on 5/16, 6/13 (Potluck), 7/11, 8/8, 9/12, 10/10, 11/7, 12/12. **All in Lansdale or phone in.** (PH:1-218-862-1300, PassCode 127105)

Newsletter Mailing Parties Tuesdays 1-3pm on 6/8, 7/6, 8/3, 9/7, 10/5, 11/2, 12/7.

★ **INPUT NEEDED FROM** ★
★ **PARENTS OF CHILDREN** ★
★ **WITH BRAIN INJURY IN THE** ★
★ **MENTAL HEALTH SYSTEM** ★
★
★ "OMHSAS is gathering input for the "Call for
★ Change," a strategic plan for quality, effective
★ behavioral health services for children and
★ their families. This effort is similar to the
★ successful Call for Change that earlier helped
★ transform the adult system....
★
★ We are seeking the input of organizations and
★ individuals that have insight into strengths and
★ weaknesses of the children's behavioral
★ health system. One means of gathering input
★ is to ask for a written response to the following
★ two questions:
★
★ 1. What is your overall impression of the
★ publicly funded system of children's
★ behavioral health services in Pennsylvania?
★ 2. What are the areas for improvement?"
★
★ NOTE: Please send your comments to
★ info@abin-pa.org and I will forward them to
★ the Office of Mental Health and Substance
★ Abuse Services. You will also be able to
★ comment on a draft of their plan. Barb Dively
★
★*****

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ABIN-PA MATTERS

BOARD MEETING LOCATION—Back to Lansdale until further notice. Come in person or call in if you can't get to Lansdale.

FUNDRAISING EVENTS—watch for news of our fundraising plans—we will need your help and we plan to have fun!

GOVERNMENTAL AFFAIRS—the Office of Mental Health and Substance Abuse Services is reaching out to the brain injury community to help design a service system for children with traumatic brain injury.

NEWSLETTER SUBSCRIBERS—We are now up to 680 and rising quickly. Soon we will be ready to offer the newsletter by email as an Adobe pdf document.

VOLUNTEER HOURS RECORDED—Did you know that Erikka Johnston records your volunteer hours in our on-line database? If you are volunteering at home, you can enter your own hours or email them to Erikka at erikkajohnston@gmail.com. The database was designed by John Dively.

HELP NEEDED FOR FOUR INFO TABLES

June 14-17, 2010, King of Prussia,
9pm-5pm, Speaking for Ourselves.

June 18, 2010, Harrisburg 8am-5pm
PA Mental Health Consumers.

November 9, 2010, 11am-2pm, Bucks
County Community College.

April 13, 2011, 11am-2pm, Bucks County
Community College.

ADVERTISING RATES

SIZE	ANNUAL	TO YEAR END
Business Card	\$250	\$25 per month
Quarter page	\$350	\$35 (portrait)
Half page	\$500	\$50 (landscape)
Full page	\$1,000	\$100 per month

PA LEGISLATIVE BRAIN INJURY CAUCUS COMMITTEE

Michael J. Miller, Chair

APRIL 20 LEGISLATIVE DAY—Thank you to everyone who came out. What an exciting time! Hoping everyone is eager for more!

GOVERNMENT TRANSITIONING—This administration is drawing to a close so state employees are leaving and legislators are working on their election campaigns. The caucus will focus on plans for 2011.

NEW REHAB SEARCH ON ABIN-PA WEBSITE

Families and case managers can now research rehab facilities on our website.

This was a big project. Terri Wernly and Lisa Kohut gathered data from the rehab providers. Then, Terri, Lisa, Melissa Hill and I identified the search fields. Next, Lisa, Melissa and I coded the raw data. After John Dively programmed the search engine, Erikka Johnston entered the data.

This search feature allows you to choose an age range and then search for one of 14 categories of services. Categories include:

- General hospitals
- Acute rehab hospitals
- Post-acute rehab hospitals
- Post-acute residential rehab
- Supported living
- Day rehab programs
- Private schools
- Outpatient appointments only
- Community re-entry services
- Office of Vocational Rehabilitation
- Respite
- Long term residential facilities
- Nursing home facilities

THANK YOU TO THE VOLUNTEERS!

**CROCHETED LAP BLANKET
DONATED—PLEASE CONTACT
IF YOU ARE INTERESTED**

A beautiful crocheted lap blanket has been donated by Bob Drucker and will be mailed to the first person requesting it.

The blanket is about 4 feet X 4 feet square and is very carefully made. The yarn is variegated - combining the colors of white, light blue, medium blue and dark blue in a very attractive way.

If you would enjoy having this blanket, or know someone who would, contact ABIN-PA at 1-800-516-8052 or info@abin-pa.org.

RESOURCES

(PDO = "PA Department of")

Brain Injury Help Line—PDO Health
[1-866-412-4755](tel:1-866-412-4755)

Brain Injury InfoLine—ABIN-PA
[1-800-516-8052](tel:1-800-516-8052)

Brain Injury Resource Line—BIAPA
[1-866-635-7097](tel:1-866-635-7097)

Brain STEPS—school children—BIAPA
[1-724-944-6542](tel:1-724-944-6542)

Client Assistance Program for
OVR & CIL Complaints
[1-888-745-2357](tel:1-888-745-2357)

Consumer Protection—PA Atty. General
[1-800-441-2555](tel:1-800-441-2555)

Crime Victim Benefits—PDO Corrections
[800-322-4472](tel:800-322-4472)

Disability Rights Network
[1-800-692-7443](tel:1-800-692-7443)

Domestic Violence Hotline—Nat'l
[1-800-799-7233](tel:1-800-799-7233)

Head Injury Program—PDO Health
[1-717-772-2762](tel:1-717-772-2762)

Health Law Project—Public benefits
[1-800-274-3258](tel:1-800-274-3258)

Managed Care—Health Insurance
[1-888-466-2787](tel:1-888-466-2787) PDO Health

[1-877-881-6388](tel:1-877-881-6388) PDO Insurance
Resources for Daily Living—Inglis

www.easiresources.org
Self-Determination Housing Project
[1-877-550-7347](tel:1-877-550-7347)

Special Ed Consult Line—PDO Educ.
[1-800-879-2301](tel:1-800-879-2301)

National Volunteer Programs
www.nationalservice.gov

Voting Issues—PDO State
[1-877-868-3772](tel:1-877-868-3772)

Waiver Help Line—PDO Public Welfare
[1-800-757-5042](tel:1-800-757-5042)

888-Ride-Away
www.Ride-AwayPA.com

*"(Ride-Away)
knew what to do.
Dave made all the
phone calls to the
VA... saving me
\$25,000!"*
- Steve Hodgkins
(Malden, MA)

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Steve poses here with his Ride-Away
Mobility Consultant, Dave Qualey, of the
Londonderry, NH facility.

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Free Cell Phone Service From www.safelinkwireless.com

PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.

OUR CONTRIBUTORS

FEBRUARY 2010

Kay & Gordon Rowe, John & Barb Dively
Bob Drucker, Susan Hartzfeld

MARCH 2010

Kay & Gordon Rowe, Bob Drucker
Denise Westerfer, Julie Flockerzi

APRIL 2010

John & Barb Dively
Bob Drucker, Steph Knarr
*Honoring Zack Fuller for being an Inspiration
from Debbie Baublitz
Happy Birthday to Tommy Hartzfeld
from Susan Hartzfeld*

JACK SCANLAN'S WHY INTERVIEW IS ON-LINE

Go to www.jackwords.org for Jack's two special features. Click on the Picture of Jack and Obama, and that will take you to the WHY website. There, click on the red arrow for his interview or the picture of Jack's Mom for a video that includes a more inclusive story of Jack's life.

The accident was 26 years ago when Jack was sixteen....."He had been an athlete playing high school football and baseball – and his competitive spirit helped him through the grueling rehab process."

After listening to the interview, you can post a comment on the WHY website, Jack's website, or Jack's blog on the WHY site.

ATTENTION CONSUMERS

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**Fighting Back Program
from Joseph Chaitkin**

Our Mission: Our mission is to help the patient develop and maintain mobility, strength and health after a life changing injury or illness once formal rehabilitation is over.

Our Program: Disabilities caused by injury and illness can seem overwhelming. Fighting Back is the bridge for reentry to an active lifestyle. The goal of our individualized rehabilitative exercise program is to help each client attain maximum independence within a community based setting. We accomplish this through one-on-one supervision and an individualized program to meet the patient's special needs. This program ultimately helps the individual gain confidence in a community based program while improving mobility, strength and health.

Our Staff: Since 1987 we have been an organization comprised of health professionals who understand and are committed to patient progress after rehabilitation. We have worked with clients in these situations providing a supportive, motivating environment for people with disabilities.

Program Costs/Scholarships: Fighting Back costs are \$33 for a 25 minute session and \$55 for a 55-minute session. At this stage of recovery most clients are not covered under their health insurance. For those patients who lack insurance coverage or the financial means, we established the Fighting Back Scholarship Program.

The Fighting Back Scholarship Program, was created in 1989 to assist individuals who have suffered a life-changing illness or injury, and are without the financial means needed to participate in a rehabilitative exercise program.

The Fighting Back Scholarship Program's first mission is to provide financial scholarships to be used for individualized exercise rehabilitation. These scholarships are awarded based on financial need to those who have demonstrated the attributes consistent with our mission statement.

Our mission is also to recognize individuals at our Annual Achievement Night who have triumphed over a life-changing illness through their courage, desire to improve, and perseverance.

We are located in the Upper Main Line Area and are willing to train in-home around the area. For more information about Fighting Back call 610-695-9818 and ask for Beth.

CRIME VICTIMS' SERVICES FUND REHABILITATION

OFFICE OF THE VICTIM ADVOCATE 1-800-563-6399, www.pbpp.state.pa.us (left menu)

VICTIMS COMPENSATION ASSISTANCE PROGRAM,S 1- 800-233-2339
(or file online through the PA Commission on Crime & Delinquency website.)

PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.

**One Parent's Role in Rehabilitation:
A Proactive Approach Through Divine Guidance
By Stephanie Knarr**

The following is based upon my experience with my son, Christopher. On October 20, 2005, at the age of 14, Chris suffered extensive injuries as the result of a car accident. Injuries to his head included a right intraventricular hemorrhage, an intraparenchymal hemorrhage with a subdural hematoma, a subarachnoid hematoma and cerebral contusions. He also had a broken left arm, a left shoulder wound, an abrasion on his right hand and nerve damage to the right shoulder. He underwent a craniotomy to remove the hematoma and to relieve brain pressure. He remained in a coma for two weeks.

Often following trauma involving a brain injury, caregivers focus on the patient's physical injuries; the need for urgent rehabilitation takes a secondary role if it is considered at all. With Chris I took a proactive approach to rehabilitation as soon as I was able to be with him. It was through prayer that I was given direction to take this role. Through my experience, I recommend that anyone else going through such a situation should consult with a higher power.

The following is the approach that was given to me:

- Begin with familiarizing the patient with the people in the room, the weather outside, the meal you just ate, the events preceding the injury, and idle conversation to trigger memory and recognition.
- Do not allow negativity from any visitors. If you know someone who will be very upset, speak with them first to ensure that only positive interaction will be given when visiting.
- Talk with the patient and use their name. This gets their attention even if you do not get a reaction due to the coma.
- Touch the patient and tell them that you are touching them and who you are.
- Include the patient in conversation realizing the coma will not allow them to respond verbally.
- Do not ask the patient confusing questions, but rather be the one to offer the answers to the loved one.
- Play/sing the person's favorite movie, music, jokes. Read their favorite book.
- If a child, a parent's voice is very important. Give verbal communications and commands. Such as "make your brain heal", "concentrate on pulling out of coma", "rest". The patient can hear much of what is being discussed. My son, Chris remembers pictures that were in his room while he was in a coma and he also remembers verbal commands. He states that he knew he would wake in two weeks. I attribute this to my enforcing the fact verbally that he needed to concentrate on doing so. Know the patient is aware even if he does not appear to respond.

(continued on next page)

One Parent's Role in Rehabilitation (Continued from Page 6)

- Refamiliarize the patient with his or her body. Take your hands and touch different parts of their body, pointing out to the patient the part that is being touched. Tell the patient to concentrate and make the brain reconnect to the body. Depending upon the injuries of the patient you may or may not be able to move parts of the patient's body. When able to move extremities, take their fingers and make them touch their own bodies. Have the patient's fingers touch the patient's hair "this is your hair" and hand to hand and foot to foot and on and on stating right side and left side of the body, over and over, helping the patient reconnect the body with the brain. Instruct visitors to do the same to make use of the valuable recovery time.
- Give a massage. Rub legs, feet, arms, and hands with lotion while talking to the patient and enforcing the body parts being rubbed.
- You may feel this is repetitive. That is good, for then you know you are doing it often. Keep doing it.
- When your patient is being transported out of the hospital to a rehab facility do not stop your own therapy. Continue between the therapy visits that are given at the facility. A child responds better to a parent than to a stranger.
- Be proactive and re-teach your child that which was taught before. Remember that you know your child better than anyone else.

Additional information:

At the time of Chris' injury his prognosis was very poor. When I arrived at the hospital a priest was waiting in a secluded waiting area for me where I was told the accident was very serious. After his surgery I was consulted by the trauma doctor and told that he may not make it through the night. He also said that if Chris did make it through the night he might not ever leave a hospital.

Chris spent two months altogether in the hospital and the rehabilitation facility. Then he underwent the final surgery to replace his bone flap. Next, he had outpatient physical therapy for three months. With occupational therapy we kept running into insurance issues and we decided to do most of it on our own. He began school part-time three months after his accident.

Today he is attending high school part-time to catch up on the three credits remaining for graduation since he missed the majority of one year of high school. He is planning to attend college or a technical school.

Editor's Note: Steph is an ABIN-PA Board Member.

CHOOSE GRATITUDE AS YOUR ATTITUDE

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.

PLEASE REMEMBER ABIN-PA IN YOUR WILL.

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