

ACQUIRED BRAIN INJURY
NETWORK NEWS
January 1, 2009—2009/#01
Survivors and Family Members
Building Lives of Meaning, Joy and Value

Happy New Year!

Thank you to our wonderful Annual Fund donors—this organization depends on individual donations!

If you haven't had a chance to respond, just hang onto that stamped envelope and send a few dollars when you can.

We also need your help to form a strong new Brain Injury Caucus (box on right).

And, you can help share information with police officers by leaving brochures for them at your local station. Just let me know how many brochures you need. So far, ten of us are reaching 18 stations.

Here's to a wonderful 2009 for all!

Barb Dively

**SUPPORT GROUP Changes:
New Stanton & Elkins Park**

Maria Martin's Westmoreland Brain Injury Support Group left New Stanton and will meet at Panera Bread, 300 Greengate Centre Circle, Greensburg, PA 15601, (724) 552-0399. Meetings are now the second Thursday of each month from 7 to 9 pm. The next meeting is January 15th. For more information, please call Maria at 724-838-1312.

For the new daytime support group at MossRehab in Elkins Park, please call Dan Rohrback at 215-291-4235.

**SENATOR JANE ORIE'S
BRAIN INJURY CAUCUS**

**Please tell your Harrisburg
Senator and Representative
why you care about brain injury
and ask them to join this Caucus.**

**To locate your elected officials,
go to www.legis.state.pa.us. In
the top right hand corner, enter
your zip code + four, then choose
your county.**

**When your legislators appear,
click on their names to get their
email, phone, and address.**

**Please pass your efforts along
to: 215-699-2139 or
info@abin-pa.org**

Please Help !

ALL ARE WELCOME

Sun. Jan. 11th, 2-4pm—Board
Tues. Feb. 3rd, 1-3 pm— Mail Newsletter
Sun. Feb. 8th, 2-4pm—Board

**FOR QUESTIONS or DIRECTIONS:
info@abin-pa.org**

**2008 NEWSLETTER
CORRESPONDENTS**

Tom Carroll
Cheryl Dougan
Sharon Dutkevich
Cindy Honstine
Jeannette Kline
Helen Love
Barbara Martin
Michelle (Denise Patterson)
Pamela Reeves
Dan Rohrback, Jr.
Carroll Rottmund
Madelaine Sayko
Pat Strenk
Terry (Denise Patterson)

Thank you!

**2008 NEWSLETTER
MAILING VOLUNTEERS**

Jeanne Asche
Anna Marie & Barry Childress
Dottie Curtis
Mary Day
John & Barb Dively
Bob Drucker
Michel Florijn
Robin Gane
Jill Griffith
Ann Hagendorf
Joe Neve
Maureen Neve
Kay & Gordon Rowe
Robin Schott
Gerry & Suzanne Slapkus
Pat Strenk
Erik Toye
Karen Walia
Terri, Alyson, Kyle & Natalie Wernly
Marcia Williams
Mary Wunder

Thank You !

**BOARD NOTES
12/07/2008**

Board

Barbara Dively, President, Secretary
Barry Childress, Treasurer
Pat Strenk, Director

Finance Committee

Barry Childress, Chair
John Dively
John Frock

County Education Coordinators

Pat Strenk—Montgomery
Dan Rohrback—Philadelphia

Sponsored Support Group

Westmoreland—Maria Martin

Webmaster

John Dively

Office Assistant

Erikka Johnston

RESOURCES

Acquired Brain Injury Network of PA
1-800-516-8052
BIAPA Brain Injury Resource Line
1-866-635-7097
DOH Help Line & Head Injury Program
1-866-412-4755
Disability Rights Network
1-800-692-7443
Housing—PHFA www.phfa.org
717.780.3988
Pennsylvania Health Law Project
1-800-274-3258
Special Education Consult Line
1-800-879-2301
Waiver Help Line 1-800-757-5042

COMMCARE vs. PHIP—Joe's Mom

I'll introduce myself as "JOE'S MOM". My son was inducted into the world of traumatic brain injury or TBI in 2004. He was in a major motorcycle accident, his skull was removed and he was in a coma for almost 6 months. I had to quit work when the accident occurred, in order to be with him every day, so I had no income for quite a while.

At the time of Joseph's hospital release, I met with the doctors many times to discuss what I should expect. I listened to them concerning the expectations and progress Joseph would go through. Yes, I listened but I truly did not hear what they were saying.

While Joseph was in rehab, I tried to learn as much as I could concerning TBI, but as you all know, you really don't know anything until you live it. Since I was with him every waking hour of his hospitalization and rehab, I thought I knew what to expect but I didn't.

I could not decide on my own to put my son in a facility that deals with TBI so Joseph came home in a wheelchair. I was so thankful that I got him back that I really didn't think about the future. I stayed in the moment, day after day. Teaching him everything just like a newborn. And with the help of God, I did a great job.

Well, Joseph has been on an incredible journey to say the least. But the journey doesn't end just because he can now walk, talk, eat, bath and shave. While the first time he let out a real laugh was amazing, many problems remain.

Unfortunately, Joseph was on drugs at the time of his accident and now he has improved to the point where he somehow manages to get what he wants. Drugs have a terrible effect on his injured brain, causing sporadic, unprovoked violence. It as though he is in a trance. You see nothing but coldness in his eyes. The only thing that takes him out of the dark place he is in is a loud noise or abrupt movement. Not from the person or thing that his actions are aimed towards but from a neutral source.

In the beginning, we got involved with services under the CommCare Waiver. It really was a Godsend at first with outpatient therapy and doctor's appointments. When I was introduced to CommCare, I was also told about the PA Head Injury Program or PHIP. To me PHIP was out of the question. Joseph needed long term care but PHIP is only for one year.

Now, to solve this problem of sporadic unprovoked violence, Joseph needs short term intensive neurological rehabilitation. While this treatment is very expensive, it would be available to him under the PHIP program. Unfortunately, due to new state regulations, Joseph can not file an application to switch to the PHIP program as long as he is on the CommCare Waiver.

I would appreciate hearing from other families facing similar problems. Messages can be forwarded to me through info@abin-pa.org.

**Brain Injury Survival: Now What?
Creating A Personal Therapy Regime —by Annie Miller
Part 1: For the Survivor**

Okay. You have endured the trauma. You have survived.

You've entered the world of brain injury. Now what?

You can't work; you're tired all the time.

There's always doctor appointments.

You might feel lonely, unhappy, and useless.

Perhaps you have not found a therapy program that you are comfortable with.

What program would work for you?

Why not create your own custom made therapy regimen using community resources?

What does your local library offer?

Are there any community volunteer programs?

How about equine therapy, water therapy, or animal therapy?

Could your local church use someone to clean, do odd jobs, or light maintenance?

Could a schedule be created for friends or family members to take you bowling, play pool, or fishing (all great forms of therapy themselves) so you have fun time to look forward to?

What steps do you need to take to create your own therapy program?

- Think; what do you enjoy doing most? Not what you used to do--what would you like to do now?
- What care provisions would you need to do it? Special equipment, supervision, etc.?
- Could you talk to your care provider? Share how you feel and what you would like to do? Ask your provider to help you work things out?
- If you try something, and don't like it...stop; don't get discouraged. Rethink what you are doing, what would make it work better, or try something else.

**THE SELF-DETERMINATION HOUSING PROJECT OF PA—
REGIONAL HOUSING COORDINATOR PROGRAM**

**(CONTACT THE REGIONAL COORDINATOR CLOSEST TO YOU
FOR ASSISTANCE IN SECURING HOUSING OF VARIOUS TYPES.)**

Region 1—Erie to Clarion
VOICES FOR INDEPENDENCE
ERIE, PA
814-874-0064
Suzanne Smith

Region 2—McKean to Clearfield
LIFE & INDEPENDENCE FOR TODAY
ST. MARY'S, PA
814-781-3050
Kelly Valdez

Region 3—Tioga to Sullivan
FUTURES COMMUNITY SUPPORTS
TOWANDA, PA
570-265-3800
Jim Meehan

Region 4—Wayne to Carbon
UNITED NEIGHBORHOOD CENTERS
OF NORTHEAST PA
SCRANTON, PA
570-346-0759
Nancy Perri

Region 5—Lawrence to Fayette
ALLEGHENY COUNTY DISABILITY
CONNECTION
PITTSBURGH, PA
412-350-2791
Joe Elliott

Region 6—Cambria to Franklin
CENTER FOR INDEPENDENT LIVING
OF CENTRAL PA
CAMP HILL, PA
717-731-1900
Howard Ermin

Region 7—Centre to Columbia
CENTER FOR INDEPENDENT LIVING
OF CENTRAL PA
CAMP HILL, PA
717-731-1900
David Drezner

Region 8—Mifflin to York
CENTER FOR INDEPENDENT LIVING
OF CENTRAL PA
CAMP HILL, PA
717-731-1900
Stephen Scanlon

Region 9—Schuylkill to Chester
RESIDENTIAL LIVING OPTIONS
DOWNTOWN, PA
610-518-6242
Drew Passic

Region 10—Northampton to Philadelphia
RESIDENTIAL LIVING OPTIONS
DOWNTOWN, PA
610-518-6242
Mary Vilter

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

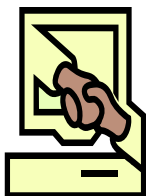
IN HONOR OF (Name): _____ (Reason): _____

(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