

# ACQUIRED BRAIN INJURY NETWORK NEWS

September 1, 2010—2010/#09

*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](http://www.abin-pa.org)

## Greetings!

Did you grow anything to eat this year? This was our very best year for raspberries, then blackberries, and finally Concord grapes.

We apologize if you missed issues of the newsletter due to the postal service. For missing issues, check the website. To bypass the post office, ask for email delivery. We are happy that our local post office has requested an investigation on our returns.

Good news—the TBI Advisory Board has formed a Children's Task Force (page 2).

Essential info—brain biochemistry requires 3 months to return to normal following a concussion or sub-concussion (page 7).

25 volunteers are starting work on our second Peer Manual, this one for providers—and work has begun on setting up our 6 table top displays, using our new laminator.

Thank you as always to our volunteers and our donors including employee matches this month from SAP in memory of Laurie Nolan. See page 6 to learn about Laurie's life.

PA's federal Mental Health Block Grant report will mention the Mercer report and brain injury training in the Children's Bureau.

Watch out for those falling leaves!

**Barb Dively**

## ABIN-PA SCHEDULE

**Board Meetings (Phone in!)** Sundays 2-4pm on 9/12, 10/10, 11/7, 12/12. Lansdale or call 1-218-862-1300, PassCode 127105.

**Newsletter Mailing Parties** Tuesdays 1-3pm on 9/7, 10/5, 11/2, 12/7. Lansdale. Need 10.

## Legislative Alerts

### PASS SPORTS CONCUSSION BILLS

Representative—House Bill 2060

Senator—Senate Bill 1241

### PASS ADULT PROTECTIVE SERVICES BILL

Senate Bill 699—passed

Representative - pass the Senate Bill!

*To find your legislators, enter your zip code at [www.legis.state.pa.us](http://www.legis.state.pa.us).*

## PROGRAMS

Sat Sept 18—Pat Strenk & Barb  
“Changing Your Brain for the Better”

Frederick Mennonite Community

Jan Morris 610-754-7878 x 109

Sat Sept 25—Pat Strenk & Barb

The Peaceful Living Fall Conference

Souderton Mennonite Church

Register: <http://bit.ly/PLHAPIIConf>

Sat Oct 24, 8-11 am—Info table

5K DASH Against Domestic Violence

Upper Gwynedd Township Park

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PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.

## PEER TO PROVIDER GROUP

This project has begun. Thanks to our volunteers: Dave Burkhardt, Tom Byrnes, Anna Marie Childress, Barb Dively, Michel Florijn, Jean Frey, Corinne Gries, Meta Keating, Barbara Kindon, Steph Knarr, Cindy Lally, Helen Love, Maureen Neve, Joan Nolan, Dorene Pasekoff, John Pistorius, Dan Rohrback, Madelaine Sayko, Sue Schmidt, Pat Strenk, Ladona Strouse, Peggy Vietro, Terri Wernly, Cathie Wright, and Don Zeigler.

## I HAD A DREAM

By Anna Marie Childress

I had a dream and that wonderful dream was that all health care workers understood brain injury...well, even just a little.

My experience, however tells me that most physicians, including neurologists, do not. A very recent experience with one physician I've been seeing for ten years left me nearly speechless.

I walked into his office, we spoke a bit as to how I've been feeling and he brought up the fact that I seemed fine. I didn't need a walker, though I have gait problems, and he didn't see any sign of brain injury. There was nothing wrong with me.

I am on the CommCare Waiver and have a Community Integration Specialist who assists me at most medical appointments. She is able to take notes, interpret what has been said or instructions the doctor gives and reminds me of issues I may be having medically or emotionally. Had I been alone, I would have explained to him again what brain injury can do.

I pray that enough knowledge of brain injury be taught to those in medical schools, those who are already 'in the field', nurses, EMT's, paramedics and all those we should be able to trust with our health care so we are treated with the dignity we deserve. ABIN-PA is on the road to bring this knowledge to all.

## TBI ADVISORY BOARD CREATES CHILDREN'S BRAIN INJURY TASK FORCE

On Thursday, August 5th, PA's TBI Advisory Board created a cross systems Children's Brain Injury Task Force after a compelling presentation by Jane Keim (The Children's Institute, the Brain Injury Association of Pennsylvania), Brenda Eagan Brown (BrainSTEPS), Dahl Krow (the Children's Bureau of the Office of Mental Health & Substance Abuse Services) and Barb Dively (ABIN-PA). The Task Force will be chaired by Jane Keim.

Currently, children with brain injury are not identified or provided with rehabilitation when receiving publicly funded services in the mental health, mental retardation, juvenile justice, physical health or Children & Youth systems. You can help educate primary care physicians, psychiatrists, and neurologists and primary care physicians to recognize brain injury and refer for rehabilitation to reverse cognitive dysfunction. Go to [www.cdc.gov](http://www.cdc.gov) and search on "brain injury tool kit" to order a free educational packet for your doctor.

## ABIN-PA MISSION

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.

## UPDATE YOUR PROFILE

To get the newsletter by email or change your name, address or phone, contact [updater@abin-pa.org](mailto:updater@abin-pa.org).

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)

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



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It's no wonder why Ride-Away customers remain so loyal – **Superior Support!** Ride-Away – America's #1 provider of modified vehicles for people with disabilities.

## **DISABILITY INCLUSIVE CONGREGATIONS**

Encourage your congregation to join the disability movement. Share your disability resource materials, ask for a congregational disability advocate, and ask for a disability committee to address special needs.

Pat Strenk of our board serves on her church disability committee and also with Peaceful Living, the interdenominational movement for inclusive worship. Pat and Barb Dively will speak at the Peaceful Living conference. They also provided information to Courtney Smith, founder and leader of the Links of Love disability ministry at another church.

For inclusive worship information, go to:  
www.accessibilitynetwork.net  
www.adnetonling.org and  
www.peacefulliving.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 [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's Benefits  
[www.pbpp.state.pa.us](http://www.pbpp.state.pa.us)  
[1-800-563-6399](tel:1-800-563-6399) and [1-800-233-2339](tel:1-800-233-2339)
- Defense & Veterans Brain Injury  
[1-814-255-8601](tel:1-814-255-8601)
- 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
- Parent to Parent - Mentoring  
[1-8880727-2706](tel:1-8880727-2706)
- Resources for Daily Living—Inglis  
[www.easiresources.org](http://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](http://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)

**NEW COUNSELING PROVIDER UNDER COMMCARE**

**By Jill Parisi**

Jill Parisi Counseling Associates (JPCA) has just become approved to provide counseling through the CommCare Waiver.

Jill is a licensed social worker and long time disability advocate. Her personal experience with disability, combined with her professional background, maximizes her effectiveness in dealing with complex issues.

JPCA is located in Harrisburg and offers supports coordination and cognitive and behavioral therapy services for individuals and families who have been affected by traumatic brain injury. A large portion of people affected by brain injury do not respond to traditional treatments or time restraints based on goals and behavior modification. Instead a caring, compassionate and patient therapist who utilizes a strengths-based approach based on the individual's interests is key to maximizing healing. The brain is a much more likely to heal itself through enjoyable, pleasurable activities not restricted by time and behavior regimented goals.

JPCA is currently accepting new clients who are receiving services under the CommCare waiver, as well as the Independence and OBRA waivers. Call 717-526-6987 or email: [jillparisicounseling@yahoo.com](mailto:jillparisicounseling@yahoo.com).

**ATTENTION CONSUMERS**

**There is a NEW Attendant Care Provider in the Lehigh Valley!**

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**PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.**

**DANNY'S MIRACLE**

By Daniel F. Rohrback, Jr., rohrstar@comcast.net

I don't know if you all know, but I was just in the hospital for 5 months with an abscess from breaking my tail bone 7 years ago. Since then, I often complained about pain in my rear end, but in 2007 my doctor CAT scanned it, found nothing, then x-rayed it and found a hairline fracture. He told me to lie on my side for 3 weeks and it would feel better. I did that and it felt better. Then in 2009, my rear end started to swell up and hurt like you could not believe. I woke up during the night with a 105 fever and was rushed to MossRehab at Elkins Park where my doctor was on staff.

Three weeks later I was transferred to Albert Einstein Medical Center where they took me in for major surgery. What they had to do was stop my stool from getting into the wound because that's what was giving me the infections. So they gave me a temporary colostomy bag that would be reversed after my wound heals up. That was on July 28, 2009. Here it is 2010 and I still have a hole 2 centimeters wide. I went from 6 centimeters to 2 and it took a year's time. What I have learned is that instead of taking pain pills to get rid of the pain, I'm going to investigate much more.

I will still need to go in and have everything reversed, but I'll be back to normal thanks to the surgeon. I feel the best respect for the surgeon because he told me that, with the fever I had, he almost lost me on the table during the operation. So, besides the prayers from everybody, I feel there was somebody looking out for me.

**WHAT NUTRITIONAL SUPPLEMENTS WORK FOR ME**

By Tom Carroll

Over the years we have heard many accounts of how different alternative medicines have helped with brain injuries. Well, I believe that I am using the ultimate alternative medical method.

In May I celebrated 25 years since my Brain Injury and decided to give my rehabilitation another try. My Brain Injury caused mostly physical deficits, so I got a new Exercise Therapist, signed up for proper walking lessons, but most importantly started on Electric Life Nutritional Supplements.

My father who is 86 years old and plays cardio type tennis two or three times a week, has been using it for 18 months and claimed the effects were great for him. He paid for my 90 day trial of these supplements. The results have been fantastic. I was 27 years old when the car accident that caused my brain injury occurred and this gave me back that energy I had when I was 27.

I said this was the Ultimate alternative medicine because we were always taught that the body is chemically based, but in fact it is electronically based. It is all explained at <http://tomc.electricle.net> and you can click on "CONTACT" for your questions. There is a quote on the webpage which reads "Nutrition the way Nature intended it". All I know is it works for me.

**2009 Annual Report & 2010/2011 Newsletter/Web/Ad Packages**

Our newsletter circulation has risen from 453 in December 2009 to 760, and our website has had 14,450 visitors to date. Rates below include October 2010 through December 2011. Call 215-699-2139 or email [info@abin-pa.org](mailto:info@abin-pa.org) for details. JPG of ad required. Dark copy extra.

Sponsorship	Newsletter 15 Issues	Web Archives	2009 Annual Report	Homepage Link 15 months	Value
Diamond	1/4 page ad	Yes	Yes	Yes	\$2,690
Platinum	1/8 page ad	Yes	Yes	Yes	\$2,095
Gold	1/4 page ad	Yes	Yes	No	\$1,190
Silver	1/8 page ad	Yes	No	No	\$595

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## Laurie A. Nolan—1970-2010

Laurie A. Nolan of Wayne, formerly of Lansdale, died Monday, May 24, 2010 at Abington Health-Lansdale. She was 40. Born March 30, 1970 in Abington, Laurie was the daughter of Joan Nolan and the late Kevin Nolan of Lansdale.

Laurie was a 1988 graduate of North Penn High School where she was active in the Marching Band and Key Club. She attended Penn State University and obtained a Bachelor of Science degree in Elementary Education in 1992. Soon after graduation, she began a long and successful career in business software implementation at SAP America, located in Newtown Square and Walldorf, Germany. She held a variety of prominent positions during her many successful years at SAP, eventually working her way up to a role as Vice President. In November of 2008, while still working for SAP, Laurie completed her MBA (highly commended) from the University of Mannheim.

Laurie was an avid traveler who welcomed the opportunity to visit anywhere new. She liked to hike, bike and ski with friends in locations around the world, including Italy, Singapore and even Antarctica. She had been to every continent and had developed a true appreciation for the diversity this world has to offer.

In addition to being a successful businesswoman, Laurie also was generous with both her time and money. She contributed to many charities, including Big Brothers and Big Sisters, believing it was important to share what she had with those in need. She was always there for her many friends, who were an important part of her life. It was through their help, and the help of her family that she was able to courageously battle and overcome brain cancer in 2009.

Laurie's Funeral Mass was held May 27th at St. Stanislaus Catholic Church in Lansdale. In lieu of flowers, her family requested donations to the Brain Injury Network of Pennsylvania. So many donations have been received from Laurie's many family members, friends and colleagues in the United States and Germany, that ABIN-PA's Board requested this newsletter article about Laurie's life as a way of expressing their appreciation.

### ANY MOTHERS FOR JUSTICE?

Please contact ABIN-PA if you are interested in working for brain injury rehabilitation in the prison system. Did you know that 25-87% of those in prison have had one or more brain injuries? Did you know that brain injury rehabilitation works? Did you know that the state funds brain injury rehabilitation? Do you think that the police, prisons, prosecutors, and defense attorneys should divert offenders into treatment just as they do for those with drug addictions or mental illness? Contact ABIN-PA if this is your issue.

### ABIN-PA BROCHURES

#### ANNUAL REVISION

All brochures were revised this year and can be printed from the ABIN-PA website.

#### SPANISH TRANSLATION

Thanks to Katherine Alvarez, you will soon be able to print Spanish versions of ABIN-PA's brochures from the website. Katherine is also interested in presenting brief talks on brain injury to Latino communities in the Delaware Valley. Please contact ABIN-PA to request a program or offer your help in reaching out.

**PLEASE PHOTOCOPY AND DISTRIBUTE TO ALL WHO ARE INTERESTED.**

## THANK YOU TO OUR CONTRIBUTORS

- JUNE** John & Barb Dively, Bob Drucker, Corinne Gries, Kay & Gordon Rowe,  
*In Memory of Laurie Nolan* from Margaret Anderson, Linda Brooks, Jacqueline Fitzpatrick, Peggy Frankenfield, Stefan Goetting, Danielle Giorgetti, Anita Granoff, Barbara McEvoy, Sue Metzger, Gerald Rigney, Rose Mary Saylor, Elaine Seiler, Kristine Sholly, Audrey Stevenson, Marie Trgovac, Mary Zagorzycki and from Laurie's Mannheim EMBA Class of 2008: Barbara Althoff-Simon, Guiliana Angonoa-Doehnert, Carston Bähr, Timo Baumann, Xavier Chapuis, David Dixon, Andreas Döhrn, Andreas Flach, Peter Flensberg, Tatiana Gillitzer, Isanthe Heberger, Nicole Höhn, Bernd Junginger, Sven Jungmann, Torsten Kunz-Aue, Joe Lewis, Ali Mabrouk, Sarah Marinoni, Raquel Martin, Ralph Schubert, Carsten Schulz-Schaffnit, Jochen Scholten, Matthias Seiler, Kai Stenzel, and Mirko Strube.
- JULY** Thomas Carroll, Jim Cox & Erikka Johnston, Sue Scott Dolan, Bob Drucker, Sherri Herschfeld, Kay & Gordon Rowe, Elizabeth Schaffner, Denise Westerfer, Carol Zapiec  
*In Honor of Stephanie Bailes* from Kim Wolfe for living every day with a smile!  
*In Honor of Kyle Ghilyard* from Marta Bivins for accepting and embracing his disability!  
*In Memory of Laurie Nolan* from Nancy Brincheiro, Danielle Giorgetti, Barbara McEvoy, Nanci McGonigal, Val & Judy Nolan, Stacey Nunn.  
*In Memory of Anne Frock Olson* from John and Carol Frock.
- AUGUST** Barry & Anna Marie Childress, John & Barb Dively, Bob Drucker, Gordon & Kay Rowe, Mike & Denise Westerfer.  
*In Memory of Laurie Nolan* from the SAP Matching Gift Program.
- SEPTEMBER** Bob Drucker, Sally Kneipp, Karl Thaler.

## RECOVERY TIME FOR CONCUSSIONS & SUB-CONCUSSIONS

On January 4, 2010, Dr. Bennett Ormalu, co-founder of the Brain Injury Research Institute, testified at a House Judiciary Committee field hearing in Detroit that, due to the effect of concussions and sub-concussions on the developing brain, "...a child who plays football may be precluded from attaining the full capacity of his cognitive and intellectual functioning as an adult."

Both concussions and sub-concussions cause Chronic Traumatic Encephalopathy or CTE, a unique type of dementia. CTE is detectable by tissue technology on autopsy but not by CT scan or MRI. Public attention has been focused on the symptoms of concussion, but sub-concussions do not necessarily result in symptoms that can be observed. Unfortunately, sub-concussions are tens to hundreds of times more common than concussion and also cause memory loss, mood disorders, and major depression.

To allow accurate diagnosis and sufficient recovery time in concussion and sub-concussion, Dr. Ormalu urged Congress to develop diagnostic tests for the protein and peptide bio-markers that appear from one to three hours post injury and disappear three months later. He believes that these biomarkers are more precise than neuropsychiatric testing because they indicate whether brain biochemistry has returned to normal. ([www.braininjuryresearchinstitute.org](http://www.braininjuryresearchinstitute.org), search on "Congressional hearings")

Dr. Ormalu also testified on February 1, 2010, at a Congressional hearing in Houston, that players under age 18 who experience a concussion should sit out for three months before returning to football in order to lower their risk of irreversible brain damage. (Sports Section, USA Today, February 2, 2010). While neuropsychiatric symptoms on sports concussion palm cards may resolve in minutes or hours, brain biochemistry requires three months to return to normal. The brain should be normal before another hit.

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(Address): \_\_\_\_\_

IN MEMORY OF (Name): \_\_\_\_\_ (Family contact): \_\_\_\_\_

(Family address): \_\_\_\_\_

**Make check out to ABIN-PA and mail to: ABIN-PA, 2275 Glenview Drive, Lansdale PA 19446.**

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  
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