

## Information for Support Group Leaders

Project STAR and The Family and Community Support Center at Carolinas Rehabilitation

### ***President's Letter – Sandra Farmer***

Public awareness about brain injury and the need for additional services for people with brain injuries continues to grow at the national and state level. The Brain Injury Association of America (BIAUSA) is spearheading a campaign to alert the public about the lack of funding for cognitive rehabilitation and other services.

The Wall Street Journal published an excellent article entitled "Why Some Patients Get No Help after Brain Injury" that BIAUSA is using to educate local media outlets about the need for funding for rehabilitation. This is just one part of a comprehensive plan to increase the visibility of people with brain injuries.

The News and Observer in Raleigh recently ran a front page story about a young soldier who was severely brain injured in Iraq. The article described how people in his local community in New Bern have rallied together to build a handicap assessable home for the soldier and his young family. The story noted that the military provides for medical care when a soldier becomes disabled but they do not pay for housing and other community supports.

The News and Observer also recently featured a story about Andre Waters a 12 year National Football League veteran who received multiple head traumas during his football career. Mr. Waters later suffered from depression, which lead to his suicide in November. The article discusses studies being conducted at UNC Chapel Hill to determine the long term effects of head trauma in sports.

These articles do not present happy stories but they can help educate the public about the needs for services for people who have sustained a brain injury and eventually lead to increased funding for those services. We need to have more personal stories told so that everyone will understand what it means to have a brain injury.

**Contact Sandra Farmer at the Triangle  
Family and Community Support Office  
of The Brain Injury Association of North  
Carolina**

**1-800-377-1464**

### ***Meet The Board of Directors***

***By: Ana King, Board Chair***

As the new Chair of the BIANC Board of Directors, my goals are to facilitate the completion and approval of a 5-year Strategic Plan that was begun in 2006, to collaborate with the statewide TBI Advisory Council on projects that will benefit both entities, and the brain injury community, and to assure that each Board member participates in activities that will result in the growth and visibility of BIANC. The Brain Injury Association of North Carolina is privileged to have the following persons serving on the 2007 Board of Directors: **Hank Baker** is the parent of an adult son who survived a brain injury. Hank served as Director of Finance for the Board in 2005-06 and has taken an active role in all of BIANC's special events such as the Camp, Golf Tournament, and Walk-and Roll-a-Thon. Hank is a Supervisor of Operations, PSNC ENERGY and a state licensed Plumbing and Heating Contractor. He lives in Raleigh, NC **Bob Burkhardt** is a survivor of traumatic brain injury and co-facilitates the Raleigh Support Group. Having received an MBA, he understands how to run a business profitably and plans to assist BIANC with marketing and advertising. Bob lives in Raleigh, NC. **Mark Eagle** is a survivor of traumatic brain injury. He conducts monthly luncheons for brain injury survivors and family members and advocates for brain injury awareness at public functions. Mark is a financial services professional specializing in long-term care and disability planning and a student in Wake Forest University's MBA program. He lives in Charlotte.

**Sandra Farmer** is President/CEO of BIANC and as such serves as an ex-officio member of the Board. She oversees staff and manages the daily operation of the Association; is responsible for public awareness, program development, membership growth, resource coordination, and financial management. Previous experiences include employment at Cumberland Hospital and Learning Services Corporation. Sandra lives in Chapel Hill.

***Meet the Board continued...***

**Rita Gillis** is the Director of Program Oversight for the BIANC Board. Rita has more than 20 years of experience in brain injury rehabilitation including grant writing, program development, contract management, and clinical supervision. She is the Brain Injury Program Coordinator at the Regional Rehabilitation Center at Pitt County Memorial Hospital. Rita lives near Greenville.

**Flora Hammond, M.D.** promotes the vision of BIANC within the medical community and contributes articles of special interest on brain injury. She also serves on the statewide TBI Advisory Council. Dr. Hammond is the Director of Research and Director of the Brain Injury Program at Carolinas Rehabilitation and principal investigator for the NIDRR Model Systems Project at Carolinas Rehabilitation. She lives in the Charlotte area.

**Marian Hartman** is the Director of Public Policy for the BIANC Board. She retired as Branch Head of Community Capacity Building for Developmental Disabilities Services in 2003 where she was responsible for developing program standards, policy manuals, and legislative strategies in support of community service expansion. She is currently a private contractor and wrote the most recently funded HRSA TBI grant. Marian lives in Cary, NC.

**Linda Herbert** is the parent of an adult son who survived TBI. She currently serves as Secretary to the Board, is on the Education and Training Committee, and has initiated a project with a state legislator to secure a specialized license plate to increase public awareness and funding for TBI. Linda is a Special Education teacher and lives in Columbus, NC

**Jaime Hoose** assists BIANC with fundraising projects and facilitates the Raleigh Support Group at Wake Med. Since graduating from college in 1998, she has been employed as a Recreation Therapist at various hospitals in the Southeast. She has implemented wellness programs and is very interested in quality of life issues. She currently works at Wake Med and is also a student. Jaime lives in Raleigh, NC.

**Grey Powell** is a survivor of traumatic brain injury. As an attorney, Grey is interested in helping the Board with legal research, and has engaged the N.C. Bar Association in a collaborative effort to help NC establish a Trust Fund. He is currently employed by the Governor's Advocacy Council on Persons with Disabilities (GACPD) as the coordinator of federally funded TBI Protection and Advocacy Grant. Grey lives in Raleigh, NC.

**Katherine Taber** has been actively involved in creating teaching and reference materials for healthcare providers with a major emphasis on normal and altered brain function and has an interest in helping BIANC develop materials for professionals, survivors, and family members. She is a neurobiologist employed by the W.G. Hefner Veterans Administration Medical Center in Salisbury. She lives in the Salisbury area.

**Jerry Villemain** is chairing BIANC's 5-year Strategic Planning Committee. He has an interest in partnerships between providers and families and utilizing his knowledge of public/private funding and regulatory issues to assist BIANC. He has served on BIA Boards in two other states and worked for two nationally known brain injury service providers before starting his own company, Residential Options, in Chapel Hill in 2006. Jerry lives in Carrboro, NC.

**Michel Weaver** is Chair-Elect for the BIANC Board. He is interested in the integration of training and service delivery and an aggressive public policy agenda that benefits persons with brain injury. He has assisted BIAs in three other states and has been involved in service delivery in various specialty program settings. He currently directs the Learning Services Neurobehavioral Institute in Creedmoor. Michel lives in Raleigh, NC.

**Sandie Worthington** has a passion for the social and recreational needs of persons with brain injury and uses that passion to organize and direct BIANC's camps. She has been a co-advisor to the Eastern NC Support Group, is a Certified Brain Injury Specialist Instructor and served on the Education and Training Committee. Sandie was previously employed at the Regional Rehabilitation Center at PCMH and is current owner of Worthington Farms, Inc. in Greenville. She lives in Greenville, NC.

**MARCH IS BRAIN INJURY  
AWARENESS MONTH**

**Brain Injury Awareness Information Kits are now available on the Brain Injury Association of America web site. You can order your free kit by logging on to the website at:**

**[www.biausa.org](http://www.biausa.org)**

**Plan your group activities now. Creating awareness of brain injury is the key to improving services and opportunities for those with brain injury.**

## **The Faces and Facts of Brain Injury in North Carolina**

*by Marilyn Lash - Vice Chair, NC Traumatic Brain Injury Advisory Council*

This is the title of a new TBI Fact Sheet just developed by the NC Traumatic Brain Injury Advisory Council. We hope that you will use it to raise public awareness and educate legislators about the effects that a traumatic brain injury can have on the life of a child, adolescent, adult or elderly person.

As you know, a traumatic brain injury can happen to anyone. It can be your mother, brother, child, or grandfather. But what we all share in common is the knowledge that a traumatic brain injury is a turning point in the life of an individual and a family. The numbers are important but they tell only part of the story. This Fact Sheet is just a beginning.

It is the personal stories of how your life has been touched and changed by a traumatic brain injury that have the greatest impact. Whether you are speaking at your Rotary Club, church group, school or business, it is your face and personal story that make the facts come alive. Your story is what people will remember. So we are asking you to consider how you can become a spokesperson and help educate others. We encourage you to use this TBI Fact Sheet with your presentation.

Here are some of the disturbing facts about TBI in NC during 1999-2004.

- ✓ The number of deaths from TBI has been rising.
- ✓ Five people died from a TBI each day in 2004.
- ✓ People with TBI are in the hospital for fewer days but the costs are higher.

For copies of the new fact sheet, contact one of the Brain Injury Association of North Carolina Family and Community Support Centers.

### ***New Resources available from BIANC***

*By: Susan Fewell, Community Outreach Coordinator*

The Brain Injury Association of NC has recently printed a Resource book with sections on rehabilitation and residential services, advocacy, legal services, support groups. It also lists all of the LME's, Vocational Rehabilitation offices, neurophysiologists and much, much more. Thanks to a grant that BIANC recently completed with the Office of Emergency Medical Services, materials such as the Resource book, a book on brain injury, and a laminated hand-out on Emergency Facts for Brain Injuries have been purchased in sufficient supply to send to all new and renewing BIANC members during 2007.

In January of 2007, BIANC enrolled 41 new members. We hope to enroll everyone in the local support groups across the state so that we can all work together as one organization. Currently, BIANC offers complementary memberships to individuals or families who have been treated at hospitals across NC in trauma/emergency services departments and to those 'graduating' from rehabilitation programs. BIANC feels that it is important to get information on resources, brain injury and the fact that sometimes symptoms can be delayed out to survivors and families as soon as possible. With the complementary membership, BIANC sends out the same information package a regular member currently receives: A membership card, 4 newsletters each year from BIANC (Starting Point), a letter with information on their closest support group(s), and LME locations, a resource book, a book on Brain Injury, a card on Emergency Facts for BI, and a Skill Pack. Through the year, members receive information and discounts for participation in Camps, training sessions or special activities such as the Walk & Roll-a-thons.

An individual membership is \$38. Options for \$100 and \$250 and Corporate Sponsorships are available for businesses or hospitals who want to support BIANC. No survivor or family is turned away. A reduced rates of \$6 is available for persons with brain injury or family members who cannot pay the regular membership fee.

You can become a member of BIANC by sending your name, address, and telephone number along with a check to BIANC PO BOX 10912, Raleigh, NC 27605

### **Brain Injury Association of North Carolina Family and Community Support Offices**

**Raleigh**  
**1-800-377-1464**  
**Greenville**  
**1-800-697-3115**  
**Asheville**  
**1-886-8907801**  
**Charlotte**  
**1-877-962-7246**

**Visit the website for BIANC at**  
**[www.bianc.net](http://www.bianc.net)**



## *Sharing the Load...*

### *Encouraging involvement to support sustainability*

The decision to start a support group is often easily made, but few who undertake the task go into it with a good insight into what the leadership roll can entail.

Each support group within our state is unique; defined by the needs and interests of those who participate. Most groups evolve over time and form their own methodology of meeting the needs of group members. The one thing that is consistent in all groups is the work that goes into planning and scheduling meetings, keeping the group running smoothly and staying on top of resource information, and that in many cases, most, if not all, of the work involved falls on the support group leaders.

Each support group is filled with members who have talents that can be used within the support group. Delegation of tasks and involvement of support group members in the meeting creates ownership of the group and a willingness to divest time and energy into it. Involvement of support group members in the meeting ensures sustainability of the group beyond the life of the “facilitator” and strengthens the group dynamics.

A good way to determine how to delegate or begin to involve members in the meetings is to identify what tasks are needed to lead the group. Most meetings involve:

- Reserving or confirming meeting space
- Contacting local media for inclusion in community events notification
- Notification or reminding of group members as to the time, date and location of the meeting
- Arranging a speaker, if one is a part of the meeting
- Arranging refreshments
- Set up of area prior to meeting
- Greeting the members as they arrive
- Facilitation and dissemination of information
- Clean up the meeting space after the meeting

The things listed above reflect what is necessary for each meeting, but does not include other responsibilities that many support group leaders assume, such as maintaining current contact information for group members, staying informed on community resources and opportunities, maintaining educational materials for new members, and many duties as defined by the needs of the group.

Sustainability is one of primary value for all support groups need to strive for. Shared responsibility and leadership can often make the difference between a thriving group that can self sustain and a group that flounders and disbands if the leader is removed.

In this edition of Support Link we will offer tips for sharing responsibility and offer some tools to help support group leaders involve members in the leadership of the group.

The forms below are designed to help group leaders and members look at the talents that each member brings to the support group. Encouraging group members discuss the different responsibilities within the group and asking them to volunteer for task that they feel they are suited for is a good way to help the members of the support group to take ownership of the group.

If you have other ideas that can help support groups grow please share the information with Support Link

Contact Peggy Philbrick at 704-355-4354 or [peggy.philbrick@carolinashhealthcare.org](mailto:peggy.philbrick@carolinashhealthcare.org)

**Brain Injury Support Group  
Contact Information and General Interest Survey**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone Number: (\_\_\_\_) \_\_\_\_\_ Email Address: \_\_\_\_\_

Cell Phone #: (\_\_\_\_) \_\_\_\_\_ Date of Birth: \_\_\_\_\_

**Emergency Contact Information**

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Name: \_\_\_\_\_ Phone Number: \_\_\_\_\_

Please check areas of interest and subjects that you would like to learn about at future group meetings.

- Nutrition
- Exercise/Fitness
- Sleep
- Complimentary/Alternative Therapies
- Humor
- Transportation
- Support Services and Resources/Agencies
- Research
- Advocacy
- Legal Issues
- Stress Management
- Recreational Activities
- "FUN" meeting-with games, prizes etc.
- Volunteer Opportunities
- Thinking Skills and Strategies( memory/attention, etc)
- General Brain Injury Information: List ideas \_\_\_\_\_
- Medications
- Emotions
- Social Security Benefits
- Employment and Return to Work/ Vocational Rehabilitation
- Other Areas of Interest or Issues Impacting You or Your Family

\_\_\_\_\_

## **Brain Injury Support Group Volunteer and Leadership Opportunities**

*There are many volunteer opportunities within a support group. Below are some suggested positions. Each support group is different and will need to determine the best organizational system for its members. Some groups will prefer to combine duties or create other positions.*

### **Group Leader/Facilitator**

- Create meeting agenda
- Leads the group meetings and keeps meeting on track
- Coordinates with volunteers to insure that all duties are being performed
- Attends BIANC Support Group Leader meetings and reports back to group
- Communicates information to the group

### **Assistant Group Leader/Facilitator**

- Assist group leader to insure that all priorities are met
- Performs group leader duties if group leader is unavailable
- Attends BIANC Support Group Leader meetings and reports back to group

### **Treasurer (if needed)**

- Manages the finances of the group and reports to the group at each meeting

### **Meeting Coordinator**

- Contacts group members about time and location of meetings
- Sets up for the meetings
- Handles refreshments
- Insures that clean up is done after the meeting

### **Hospitality Coordinator**

- Greet attendees as they arrive
- Welcome any new members and insure that they complete general information survey and contact information

### **Publicity Coordinator**

- Make sure that information about meeting dates, time, etc. is in local media
- Distribute meeting information to area locations including doctors offices, etc.
- Notifies local media about special events and arranges articles about brain injury when possible

### **Resource Coordinator**

- Provide information to group members about available resources
- Attend local agency meetings when possible and report information to the group
- Organize and maintain a notebook of brain injury resource information

### **BIANC Liaison**

- Maintain communication with the regional Family and Community Support Office
- Provide information for the BIANC Newsletter and Support Link Newsletter
- Attend the annual BIANC Open Board Meeting and report group concerns
- Attend Support Group Leader Meetings

**Brain Injury Support Group  
Volunteer and Leadership Opportunities**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City:** \_\_\_\_\_ **State:** \_\_\_\_\_ **Zip Code** \_\_\_\_\_

**Phone Number:** ( \_\_\_\_ ) \_\_\_\_\_

**E-Mail:** \_\_\_\_\_

**Cell Phone #:** ( \_\_\_\_ ) \_\_\_\_\_

**How would you like to help with the support group?**

\_\_\_\_\_ **Help with Organizing Meetings —**

\_\_\_\_\_ **Name Tags**

\_\_\_\_\_ **Put out Resource Materials**

\_\_\_\_\_ **Set up Refreshments**

\_\_\_\_\_ **Make Refreshments**

\_\_\_\_\_ **Set up Tables and Chairs**

\_\_\_\_\_ **Help with Clean Up**

\_\_\_\_\_ **Introduce New People to Others**

\_\_\_\_\_ **Arrange Speakers**

\_\_\_\_\_ **Publicity**

\_\_\_\_\_ **Newsletter**

\_\_\_\_\_ **Plan and Organize Recreational Events**

\_\_\_\_\_ **Send out Birthday Cards**

\_\_\_\_\_ **Send out meeting notices**

\_\_\_\_\_ **Help with Weekend Activities/Recreational Events**

\_\_\_\_\_ **Help with Transportation**

\_\_\_\_\_ **Attend Brain Injury Association of NC Events and Update Group**

\_\_\_\_\_ **Other:** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Support Groups Across the State

**Jefferson (Ashe County):** Wylene Taylor reports that the group which was formed in 2006 is doing well and that it continues to meet on the second Tuesday of each month. They had eighteen present at the last meeting and of those present three were teenagers.

**Union County:** Members of **UCABISN** are still recuperating from the Christmas Celebration. All of the “thank you” cards are mailed, extra gift items packed up and stored, and the plans underway for next years Celebration. Mark your calendars for the first Saturday in December. UCABISN will provide lunch for those who attend the Beyond Tomorrow Workshop in March. It seems that “food” is the group “focus”!

The group is starting to explore the formation of a “Coffee Club” and some other specific activities for group members with specific needs and interest.

**Fayetteville:** Ellen Morales reports the following; The **Fayetteville Brain Injury Support Group** has been steadily growing. We have a fundraising activity where we sell beaded bracelets that the members make. We participated in a Craft Fair displaying and selling the bracelets. We are now planning to have the first annual Walk and Roll-a-thon in Fayetteville as part of BI Awareness Month. We will also have a bake sale during the month of March. We are attending the February City Council meeting and the mayor will provide us with a proclamation declaring March to be BI Awareness Month in Fayetteville

**Concord:** Members of the **Concord Brain and Spinal Cord Injury Support Group** are having fun nights of bowling and watching movies. The group meets at Woodleaf Lanes in Salisbury the first Monday of the month at 7:00pm. On the second Thursday of the month they get together to watch movies at the Salisbury Village media room at 6:00pm. Thanks to Abdullah Saleh, for arranging the times and places to get together and socialize and just have FUN! The Group is making plans to mark Brain Injury Awareness Month by having an information table at the Carolina Mall in Concord on a Saturday in March. Also in March, the group will celebrate their fourth anniversary. At our December meeting members brought toys and money to donate to Jimmy Murphey for his annual Christmas dinner. Margaret, Danny, and Chris Love delivered meals on Christmas Day, which was the way our group decided to give back to the community.

**Stanley County:** Margaret Owen of **BITS** reports that at the next meeting on Feb. 20, the group is planning a Pizza Party, a good movie, complete with popcorn and that they will be making brownies. Sounds like fun! The next goal is to raise money so that we can go to camp in April, and will probably hold another yard sale sometime in March.

**Asheville: Smoky Mountain and Teens & Families with TBI** are now meeting together. The meetings are being held at . The new Asheville Family and Community Support Office, located at Care Partners is now open and is staffed by Karen Harrington. To reach Karen you can call the office at 1-866-890-7801.

**Charlotte Area Brain injury Association:** The Charlotte Group is already making plans for weekend fun throughout 207. The first adventure will be Bowling at Coliseum Lanes on February 24<sup>th</sup>. Plans are underway for the annual cookout, boating and waterskiing event which will be held on a Saturday in June. Anyone involved in any of the brain injury support groups across the state are invited. The more the merrier!!! For additional information on the picnic, contact Barbara Westphal at 704-547-1563 or Sally Rickard at 70355-2620.

**Statesville:** Kim Munroe reports that Surviving Angels Support Group is well into making plans for Brain Injury Awareness Month. These plans include a Brain Injury Education event to be held at a local church on Saturday, March 17<sup>th</sup>. Everyone is invited. For additional information please contact Kim Munroe at 704-528-0399.

*Please send Support Link your Support Group News. [Peggy.philbrick@carolinashhealthcare.org](mailto:Peggy.philbrick@carolinashhealthcare.org) or call Project STAR at 7 04-355-4354*

## ***Coming Attractions***

### **Brain Injury Association of North Carolina**



### ***Walk & Roll-a-thon***

**March 31, 2007**

#### **Five Locations across North Carolina**

**Asheville : Biltmore Square Mall, Asheville, NC**

**Fayetteville: Honeycutt Kiwanis Recreational Park, Fayetteville, NC**

**Triad Area: Triad Park – Kernersville, NC**

**Greenville: Greenville Town Commons, Greenville, NC**

**Triangle Area: Lake Crabtree Park, Morrisville, NC**

***For information on how you and your Support Group can participate in the Walk and Roll-a-Thon nearest you, or to register for one of the walk locations, please contact BIANC at 1-800-377-4354.***

### **THE BRAIN INJURY ASSOCIATION of NORTH CAROLINA**

#### **Camp Carefree at Stokesdale, North Carolina**

A Weekend of camp fun and fellowship for persons with traumatic brain injury and their families hosted by BIANC

**Date: April 27-29<sup>th</sup> , 2007**

**Where: Stokesdale, North Carolina**

The camp site is totally accessible and accommodations include cabins, a dining room and other amenities. Activities include, team building, games, crafts, fishing, paddle boats, horse back riding, archery and others. Cost is \$18 per person for BIANC members and \$20 for non members. Limited scholarships are available by contacting the Brain Injury Association of NC.

**For information regarding registration**

**Call BIANC at 1-800-377-1464**

**Project STAR**  
at Carolinas Rehabilitation  
Presents

**Beyond Tomorrow-Planning for the Future**

A workshop designed to help family caregivers of persons with brain injury begin to plan for the time when the family caregiver can no longer provide care

Have you ever wondered what would happen if you were no longer able to care for your family member, or what will happen to them when you are gone? While many families are able to arrange for the continued in-home care of their loved one, care is not the only consideration that needs to be addressed. Insuring the continuation of government benefits and other factors can greatly impact the future of the person being cared for. If this is a concern for you and your loved one, this workshop is for YOU.

**Professionals will address topics such as:**

Protecting government benefits Record keeping/communication Guardianship Financial planning  
Making long range plans Choosing the right living options

Agencies and Service Providers will be available to share information

**When: Friday, March 9, 2007 Time: 8:30AM – 4:30PM**

**Where: Siler Presbyterian Church**

**6301 Weddington-Monroe Road**

**Wesley Chapel, NC 28104**

There is no charge for attending this workshop but registration is necessary in order to plan for lunch and handouts. To register please use the attached registration form or contact Project STAR at 704-355-1502 or toll free at 1-877-962-7246. Please register no later than February 25, 2007.

Project STAR at Carolinas Rehabilitation is funded in part by the North Carolina Department of Health and Human Services through the Department of Mental Health/Developmental Disabilities and Substance Abuse Services Division.

For additional information, please contact Project STAR at 704-355-1502 or Toll free at 1-877-962-7246