

This 2009 version of the **BIANC Resource Book** is intended to be a resource guide for individuals with brain injury, family members of people with brain injuries, and professionals who serve people with brain injury. We need your help and input in keeping it current and up-to-date.

The Brain Injury Association of North Carolina supports no particular clinic, rehabilitation program, or practitioner nor does it judge the merits of individual treatment programs. The Association assumes no responsibility for the treatment choices or progress of a person within a program. Rather, the Association strives to make the resources known so that persons with brain injury and their families can make informed choices. The Board of Directors and volunteers shall be free of all liability, joint or several, arising out of their association with the Brain Injury Association of North Carolina.

**It is the choice of each individual to utilize
services and supports described within this Resource Book.**

The Resource Book is based upon information gathered from contacts with survivors, families and resource providers. It will be continually updated on our website, www.bianc.net. If you know of resources that should be added to this Resource Book or if you would like to submit information on your organization, contact us at:

BIANC
PO Box 10912
Raleigh, NC, 27605

Send corrections or updates to: bianc@bianc.net
Call **1-800-377-1464** or **919-833-9634** or Fax **1-919-833-5415** at the BIANC Raleigh office.

About the Brain Injury Association of North Carolina

The Brain Injury Association of North Carolina (BIANC) is a statewide organization dedicated to providing education, outreach, prevention, advocacy, and support services to persons affected by brain injury, their families, and the general public. Founded in 1982 by the families of individuals with brain injuries and health professionals, BIANC is a nonprofit 501(c)(3) organization funded by tax-deductible donations, memberships, sponsors, grants, contracts, and fundraising events such as our annual Golf Classic.

The association maintains a central office located in Raleigh and Regional Support centers located in Charlotte, Greenville, High Point (Triad Volunteer Office), and Asheville. Each office maintains a resource room and library of articles, books, and brochures that we encourage you to visit and borrow or copy information that is helpful to you, or we can mail to you. BIANC has printed materials such as quarterly newsletters, skill packs for hospital staff and families, and this Resource book. BIANC shares these materials with support group leaders, rehab and hospital contacts and those who request information.

Our Mission

BIANC's mission is to offer help, hope, and a voice for brain injury survivors and their families.

Our Goals

- Promote the welfare of people with brain injuries in all stages from point of injury to community re-entry
- Increase public and professional awareness of brain injuries through training and support activities.
- Provide resource information for individuals with brain injuries and their families.
- Promote programs providing rehabilitation and long term care for individuals with brain injuries.
- Provide educational and prevention programs about brain injury.
- Support legislation to increase services for persons with brain injuries.
- Encourage and assist with the formation and support of local brain injury support groups.
- Serve as the coordinating organization for statewide network of local brain injury support groups.
- Increase social and recreational opportunities for survivors and encourage fitness and wellness

Information & Education Services Offered...

Family Help Line for Information & Referral: 1-800-377-1464, bianc@bianc.net

- Raleigh Office 1-919-833-9634 susan.fewell@bianc.net
- Greenville Office **1-800-697-3115** sandie.worthington@bianc.net
- Charlotte Office 1-704-355-1502 peggy.philbrick@carolinashealthcare.org
- Asheville Office **1-866-890-7801** karen.harrington@bianc.net

Brain Injury Volunteer Resource Center

- Triad Office 1-336-687-4702 peggy.nelson@bianc.net

The Brain Injury Association of NC has four Family And Community Support Centers and one Brain Injury Resource Center to serve North Carolina. The family helpline is a starting point for individuals seeking assistance. We maintain information on rehabilitation and residential services, psychologists, neuropsychologists, attorneys, school counselors, etc. who are familiar with brain injury and use this information to refer families to appropriate services.

www.bianc.net or www.ncbraininjury.net

Our web site provides current news & events, important legislative information, contact information for resources, listing of NC support groups, and links to other brain injury resources and web sites around the country dealing with issues pertinent to the brain injury community. This Resource Book is available and will be updated regularly on our website until next printing.

Brain Injury Symposium

The annual symposium provides the latest updates about brain injury research, prevention efforts and support programs for professionals serving people with brain injury. Members receive information about trainings scheduled by BIANC.

Certified Brain Injury Specialist Training (CBIS): A national certification through BIAA

The Brain Injury Association of North Carolina offers training to professionals who work with persons with brain injuries. The trainings are held across the state. For more information contact us at 800-377-1464. BIANC has Certified BI Specialist Trainers to provide the training and certification exam.

Brain Injury 101 Training & Information Sessions and Workshops for Families

BIANC staff are ready to provide training sessions for LME staff/service providers serving brain injury. BIANC sponsors “Into the Future” Workshops for family members to learn about resources for planning.

Annual Family and Survivor Camp Week-end and Regional Recreation Events

BIANC encourages wellness and exercise and social interactions. Call for details: 800-377-1464

Support Services Offered...

Support Groups

BIANC encourages and assists local support groups in start-up activities and provides leadership training for support group leaders throughout the state. Currently there are over 40 support groups across the state. BIANC sends quarterly newsletters to support group leaders, along with event and training opportunities. Grants are offered to local support groups for advocacy and wellness and recreational events. See Section E for information on a support groups in your area.

Advocacy and Service Coordination

Staff serves on interagency committees that help improve services for persons with brain injury.

Advocacy committees/organizations we participate in include:

- *Partners in Policymaking* – leadership training for parents and self-advocates
- *DD Consortium* – a coalition of statewide consumer, advocacy, and service organizations working to improving the quality of life for persons with developmental disabilities
- *The COALITION*

Prevention Programs

BIANC is committed to supporting efforts to prevent brain injuries.

- *Brain Minder Buddies* – a program for preschool and elementary students to promote the importance of taking care of your brain – wearing a helmet (collaboration with the Pilot Club of Raleigh, a service club for brain related disorders).
- *Walk & Roll-athon* – this event is to raise awareness and educate the public about brain injuries and how they can be prevented.
- *Joggin' for Your Noggin' 5k Run* – to raise awareness, to educate the public on prevention and to encourage the benefits of exercise.

Membership/Donation Information

You can help the Brain Injury Association of North Carolina continue to promote better understanding, treatment and prevention of brain injuries, and improve the quality of life of those North Carolinians who have survived brain injuries. All donations, memberships, memorials, and commemorative gifts are graciously welcomed. Your membership in the Brain Injury Association of North Carolina includes membership in the Brain Injury Association of America, Inc. (www.biausa.org) and in your local support group.

Membership Rates

- *Basic Membership* \$38.00

Individual with a brain injury or a family member of a person with a brain injury.

- *Courtesy Membership* \$5.00

Individual with a brain injury or a family member with limited funds.

- *Executive Membership* \$100.00

- *Platinum Membership* \$250.00

- *Corporate Sponsorship*

Please Contact us for more information.

If you would like to become a member of the Brain Injury Association of North Carolina, please contact us for a membership application at **919-833-9634** or **1-800-377-1464** (family helpline).

Donations and Memorials

Donations in memoriam or *in honor* of an individual or for a commemorative occasion should be made payable to: **The Brain Injury Association of North Carolina**, PO Box 10912, Raleigh, NC 27605.

BIANC Donations

You can now make donations online on our www.bianc.net website, at the bottom of the front page, through PayPal. After confirmation, BIANC will email your receipt to you and request if your donation is to be designated to someone special.

Registration fees for events can be paid through PayPal too!

Brain Injury Association of North Carolina

Membership Form

Membership in the Brain Injury Association of North Carolina provides an opportunity for **you** to demonstrate your interest in and support for survivors and families in North Carolina. Who should join? **Brain injury survivors, family members, friends, nurses, doctors, therapists, rehabilitation specialists, case managers, attorneys**, other professionals, and **organizations** that work with individuals who have had brain injuries.

Benefits of membership include: discounted registration for events sponsored by the Brain Injury Association of North Carolina, and subscription to the *Starting Point* newsletter. All membership fees to this non-profit organization are tax-deductible.

- **Basic Membership** is \$38 a year. Includes all benefits above. No survivor or family will be denied membership due to finances. A reduced rate is available.
- **Executive Membership** is \$100 a year. Includes the additional benefit of recognition in BIANC's publications.
- **Platinum Membership** includes all of the above benefits, as well as a certificate suitable for framing and recognition on our website, which receives over 3000 visitors each month, for \$250 each year.
- **Corporate Sponsor Programs** are also available. These include all of the above benefits plus advertising space in BIANC publications including newsletters, website and this Resource Book, and at BIANC sponsored events and fund-raisers. Contact BIANC for more information.

Our financial viability is largely dependent upon the generosity of our members. You can help now by becoming a member. Join by completing and returning the membership form below.

Membership Form

- Basic individual membership.....\$38/yr Executive membership.....\$100/yr
 Platinum membership.....\$250/yr Please send Corporate Sponsorship Program info

Name _____ Company _____

Address _____ City _____ State _____ Zip _____

E-mail _____ Telephone _____

I am a: Survivor Family member Professional Military Other

I am a support group member: Yes No Name of Support Group: _____

Card No. _____ Exp: _____ Master Card Visa Check enclosed

Send to: Brain Injury Association of North Carolina PO Box 10912, Raleigh, NC 27605

BRAIN INJURY FACTS FOR EMERGENCIES

Brain injuries are common and may occur from a bump in the head, an unexpected fall, a car crash, a sports related injury, or from an explosion. Brain injuries may also occur during a mass emergency situation involving many people at once.

- It is important to be aware that after a brain injury or concussion, symptoms may not show up for days or weeks after the injury.
- Some of the signs of brain injury are subtle and may be dismissed, especially if there are other injuries at the same time, or a lot of people are involved in the emergency.

Call your doctor or return to an Emergency room immediately for:

- Repeated vomiting
- Double vision
- Slurred speech
- Pupils dilated/different sizes
- Difficulty waking up
- Seizures
- Confusion/changes in behavior
- Numbness in arms/legs
- Severe headaches
- Blood/fluid from ears or nose

If Symptoms continue...

If you notice that symptoms are getting worse in the weeks after the injury, or if you answered YES to any of the following questions, you should get help. Contact your doctor to get appropriate treatment. A Physiatrist (Rehabilitation doctor) or Neuropsychologist may be able to help.

- Personality changes?
- Balance problems?
- Changes in sleep patterns?
- Getting confused?
- Headaches/dizziness/fatigue?
- Increased anxiety/irritability?
- Difficulty with work/school?
- Problems with memory?

For additional information and to locate available resources, contact:

The Brain Injury Association of North Carolina

1-800-377-1464 (Raleigh)

Email us at: bianc@bianc.net

Visit our website www.bianc.net

Asheville
1-866-890-7801

Greenville
1-800-697-3115

Charlotte
1-704-355-1502

High Point
1-336-687-4702

Adapted from “Traumatic Brain Injury Facts: Emergency Medical Services” by NASHIA, “Brain Injury Fact Sheet” by project STAR, Carolinas Rehabilitation, and “Traumatic Brain (Head) Injury Facts” by the Florida Brain Injury Association.

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The Americans with Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) is a law that prohibits discrimination against persons with disabilities. The law protects the basic civil rights of the millions of persons with disabilities throughout the United States. The ADA guarantees people with disabilities the same opportunities as other Americans when it comes to:

Earning a Living: The ADA covers all employment practices, including hiring and firing, raises and promotions, job training, insurance and other benefits. Employers are required to make reasonable accommodations unless doing so would create significant difficulty or expense, as determined by specific guidelines.

Public Accommodations: Public accommodations must be accessible. This includes places that provide food and drink, lodging, entertainment, areas for public gathering, shopping and rental services, recreation or exercise, education, social services, travel and more.

Transportation: The ADA covers traveling by bus or rail. All trains, buses and their stations must be accessible.

State and Local Government Programs and Services: People with disabilities may not be excluded from educational and recreation programs, even if separate programs are available. If a public service operates out of an inaccessible office, it must be moved or provided at another location.

Telephone Relay Services: Telephone companies must provide telephone relay services for persons who use TDDs (Telecommunications Devices for the Deaf) or similar devices at no extra charge.

For more information about what the ADA means for your situation, visit www.ada.gov or call the ADA Information Line at 800-514-0301. The TDD number is 800-514-0383

ALSTARS: WHAT TO DO IF YOU CAN'T GET THE SERVICES YOU NEED

Contact your local Representative or Senator.

Write your legislator a letter about your situation, call them, or go in and meet with them in person. It is important that North Carolinians get the services they need and the more people we have telling them about it, the better chance we have at getting those services that are needed.

Join **ALSTARS** (**Alliance of Legislators and Survivors Together Achieving Responsible Services**) and become part of the team of legislative advocates raising awareness for brain injury.

As a member of ALSTARS, you will receive:

- Information on your local Representative and Senator with contact information.
- Updates on new legislation that affects brain injury.
- Making the most of Your Legislative Visit – This handout gives you tips on what to do when meeting with your legislator.
- Brief Tips for Advocates Who are Meeting with a Representative

Another Reason to contact your legislator: Brain injury needs more funding!

Nationally, North Carolina ranks among the lowest for funding of services to help people with brain injuries. The State Lead Agency for brain injury services receives only \$1.3 million in recurring funds to meet the needs of more than 180,000 North Carolinians whom the Centers for Disease Control and Prevention estimates have sustained a brain injury. This figure does not include the injured military service members returning from Iraq and Afghanistan whom the Veterans Administration acknowledges will need access to state services.

Brain injury is preventable, it is treatable and the long term cost of care can be greatly reduced with appropriate services. The majority of people who sustain brain injuries are young adults who can recover abilities and go on to lead productive lives. Many states have developed systems of care that allow persons with brain injuries to receive services that help them reach a maximum level of independence reducing their need for assistance. North Carolina needs to provide programs that include neurobehavioral treatment, crisis services, residential options, day programs, vocational/educational supports and specialized training for caregivers and professionals.

We need YOU to help educate our legislators that resources are not adequate for NC civilians or veterans. BIANC would like to support you in your legislative efforts. If you would like materials or information please call us at 800-377-1464 or email bianc@bianc.net.

Join the ALSTARS

I want to join the ALSTARS!

I want to tell my story or help educate legislators to achieve responsible services for all individuals with Brain Injuries.

Call me _____ Email me _____ or Mail info. _____

Name _____ Company _____

Address _____ City _____ State _____ Zip _____

Email _____ I am a (circle one): Survivor Family Member
Professional Other

Send to: Brain Injury Association of North Carolina, PO Box 10912, Raleigh, NC 27605

Brief Tips for Advocates Who Are Meeting with a Representative

By Grey Powell

- Make an appointment with your representative and be on time for the meeting.
- **Be Prepared:** Know exactly what it is that you want to say to your representative and be able to express it clearly and succinctly.
- **Stay on Message:** Say only things you know to be true and that are relevant to why you are meeting with your representative. Do not get sidetracked by issues that do not pertain to the purpose of your meeting. If you are asked questions you do not know the answer to, “I don’t know.”, is an appropriate response. If possible, offer to find an answer to the question and get back to them. This opens up the possibility of further dialogue between you and your representative.
- **Clearly State Your Wishes:** Make sure your representative knows exactly what it is you would like them to do when you meet. It is a good idea for the last thing you say at the end of the meeting to be a review of what you want your representative to do for your cause.
- **Do Not Assume They Know Anything About Your Issue:** Be prepared to educate your representative about your issue.
- **Do Not Act Confrontationally or Threaten Your Representative:** As much as possible, be positive and friendly. Remember, you are among many others who are trying to persuade them to work on a particular issue. Do not let your actions drown out your message.

You should follow up your meeting with your representative, and anyone in their office you met, with a thank you letter which reiterates your message. If applicable, follow up at an appropriate time to see if your representative has followed through on any promises made to you in the meeting. Most importantly, keep any promises you make to your representative. Your meeting should be part of a continuing relationship you cultivate with your representative and their office.

Remember, you are a part of an overall movement. You do not have to represent all people with brain injuries, just yourself.

General Questions to Ask Service Providers

You have the choice to research potential professionals or supervisors to assure their competence in providing services for persons with brain injury. Do your research when you are choosing providers and professionals with whom to work. Try to interview at least three providers or professionals whenever you make a decision and then choose the best one for your situation. The following list of questions is designed to get you started. You may want to ask more questions relating to the services needed in your particular situation. Some sections in this guide have more specific questions that you may want to ask.

- *How many persons with brain injury with situations similar to my own have you provided services for? What were the results?*
- *What aspects of your educational and training background qualify you to work with persons who have sustained brain injury? Explain your knowledge of government benefits and explain how that will impact the way you handle my situation.*
- *How can we work together to encourage community integration and independence for my loved one or myself?*
- *Can you provide the names and telephone numbers of three references?*

If you find a service provider or professional whom you trust but with little experience with brain injury, help that person learn more about brain injury by encouraging him or her to call the Brain Injury Association of North Carolina to receive information and become a member. If you have any questions during the process of finding competent service providers and professionals, call the Brain Injury Association of North Carolina, **919-833-9634** or **800-377-1464**.