

Information for Support Group Leaders

SupportLink, a newsletter to assist brain injury support group leaders, is published by Project STAR at Carolinas Rehabilitation. Project STAR also provides services for the Brain Injury Association of North Carolina Family and Community Support Office in Charlotte.

This Issue:

Page 1
BIANC Update

Page 2
Advisory Council
SupportLink Email

Page 3
Advocacy Today

Page 4
Upcoming Events

Page 5
Regional Updates

Page 6
BIANC Update

Page 7
Camp Carefree Photos

Page 8
Grasshopr Updates
News Update

Page 9
BIANC Membership Form

Page 10
Websites

Brain Injury Association of North Carolina Update ***By Sandra Farmer, President***

The Brain Injury Association of NC's mission is to offer help, hope and a voice to people with brain injuries and their families in NC. In order to accomplish our mission we need to let our elected official in Washington know about the need for services in our state. The best way for BIANC to have a voice at the federal level is to support the work of the Brain Injury Association of America (BIAA).

The **Brain Injury Association of America** is located in Bethesda, Maryland just outside of Washington, DC. This allows the BIAA staff to be available to meet with elected officials on a regular basis to advocate for legislation that affects people with brain injuries across the country.

Some of the legislative achievements in 2009 include:

- Established the Council of Brain Injury Alumni and launched a pilot Self-Advocate Empowerment Program, to provide training and support to individuals with brain injury who wish to lobby their congressional representatives,
- Lobbied congress in support of the Veterans Healthcare Authorization Act, allowing service members to access care from non-VA providers
- Collaborated with the Defense Centers of Excellence on the Real Warriors Campaign to de-stigmatize brain injury; worked with Operation Never Forgotten on military public service announcements;

BIAA also strives to improve treatment and care by professionals who work in the field. Some of their accomplishments in that area include;

- Created a Research Council with the goal of establishing a research endowment; recognized Young Investor Michelle C. LaPlaca, Ph.D. for her development of the Display Enhanced Testing for Cognitive Impairment and Traumatic Brain Injury (DETECT) system
- Translated federally-funded TBI Model System research findings from professional journal articles into user-friendly abstracts that have been down loaded more than 200,000 times
- Published Conceptualized *Brain Injury as a Chronic Disease*, a position statement discussing the disease-causative and disease-accelerative consequence of traumatic brain injury.

These are just a few examples of the work that the Brain Injury Association of America does to help people with brain injuries in America. The Association is a very small organization with less than a dozen employees but they work very hard to represent the people that they serve.

We are pleased to have the President of BIAA, Susan Connors, as the keynote speaker for our annual conference on October 29, 2010 in Cary. If you would like to learn more about our national organization please join us at the conference. You can learn more about the event at www.bianc.net.

Sandra Farmer

You can contact Sandra at sandra.farmer@bianc.net or by phone at 1-800-377-1464.

Governors Advisory Council on Brain Injury

Are you keeping abreast of what is going on in North Carolina in the quest for improved services and support for persons with brain injury? It is important that support group leaders stay informed about the various efforts that affect group members. Minutes of meetings can be found on the North Carolina Department of Health and Human Services brain injury webpage <http://www.ncdhhs.gov/mhddsas/tbi/index.htm>.

There are currently two survivor positions on the council, which need to be filled. One representative is needed from the central part of NC and one from the eastern region. Applicants should be able to attend four meetings per year in Raleigh and be willing to serve on committees and participate in other assignments as needed. If you know of someone who is interested, please have them contact Linda Herbert at lbherbert@windstream.net

SupportLink E-mail

SupportLink often receives emails from support group leaders asking for information. The email below is from a group leader.

E-Mail

I am looking for some social opportunities for my group. A lot of the members do not have an opportunity to get out and mingle with other people. What are some of the things other groups do for entertainment? I might also mention that transportation is a problem for most of us. We are pretty rural so our options are limited. We mostly have to depend on family members for transportation when we go places.

SupportLink Response:

That is a tough one. A lot of groups have the same challenge. The most innovative solution I have heard is from the Concord group. They have a pot-luck supper at their meetings. Everyone brings a dish and socialize during the meal prior to the meeting. Bowling outings or movie nights are a way some groups spend time out and about in the community. One thing that can make these types of outings work is consistency. Schedule them on the same day, at the same time each month and give the group members plenty of notice so they can arrange transportation or make any other arrangements that will enable them to participate. It might also be helpful if you can identify a few family members, or group members who drive, who could volunteer to provide transportation for those who cannot arrange it otherwise.

*****If other support group leaders have ideas to share please email them to us at peggy.philbrick@carolinashealthcare.org**

Brain Injury Family and Community Support Offices
Asheville 1-866-890-7801
Charlotte/Project Star 1-877-962-7246
Greenville 1-800-697-3115
Raleigh 1-800-377-1464

You can contact the Family and Community Support Office nearest you for resource information, or visit the BIANC website at www.bianc.net

Advocacy Today Support Groups as Advocates

Needs or wants?It depends on who you ask

Needs and wants are descriptive words that can be used in a variety of ways, and often are viewed as somewhat interchangeable, but they are not interchangeable when making a statement regarding the “**needed**” services, funding or supports for someone with brain injury. A person who has a vested interest in the outcome of the advocacy effort will most definitely refer to the things for which they are advocating as needs, whereas an observer or unvested party would refer to those things as a wants.

Examples of these would be - Jim, a parent who needs help with in-home care for a child with brain injury may approach a legislator and advocate for support in securing the “**needed**” service, while Betty, a person who is aware of the advocacy effort, but not personally involved, may refer to those things Joe is advocating for as “wants”. In this type of situation, the defining line in the perception of needs as opposed to wants depends totally on the role of the person who is advocating.

The role support groups can play in advocacy can make a great difference in educating communities, legislators and individuals about the importance of providing “**needed**” support for those living with brain injury. As stated in past editions of SupportLink, there is strength in numbers and North Carolina has approximately 40 brain injury support groups with a collective membership that numbers in the hundreds. If each group does one advocacy event per year, the impact can increase legislative awareness of brain injury and the difficulties that persons with brain injury and their families face in daily life.

As a Support Group Leader, you can help your group plan a legislative action event to advocate for brain injury. While this may not be one of the standard responsibilities of group leaders, the position offers the opportunity to make a difference. The tools to make an emphatic and meaningful impression on the legislators representing your area are already in hand. It all comes down to making the effort to help group members, individually or collectively, make contact with their representatives and provide them with materials that can be left with the legislator to reemphasize the points made. Not all group members will have the ability to independently contact legislators or put together a presentation, but by assisting them or assigning someone else within the group to help them, you can help them be effective advocates.

While there is no brain injury specific legislation on the table at this point, the goal should be to educate the local representative about brain injury and the difficulties that persons with brain injury face daily, and what the “**needed**” services and supports are.

Some things to keep in mind as you reach out to legislators in your community are listed below.

- **Visit in person** - It isn't easy to forget a face. Put the faces of brain injury in front of the elected official, so they will recall the faces when brain injury is discussed.
- **Be persistent** – If you cannot reach them to schedule an appointment or you get an excuse why they cannot meet, continue to pursue it until you get the meeting.
- **Be prepared** – Know ahead of time what you want to present and take supporting information with you to leave with the legislator for his/her later reference. Ask them to share the information with colleagues.
- **Be brief and to the point** – Legislators are very busy. Make sure you state your case in concise terms in the shortest amount of time possible, thank the legislator for listening and leave.
- **Send a follow-up letter or email** – Legislators who take time to meet face to face with constituents deserve to know that their effort is appreciated. Make sure you properly thank them for their time and for hearing you out.

To find out whom the legislators representing your are, visit the following websites:

North Carolina General Assembly <http://www.ncga.state.nc.us/>

US Congress <http://www.house.gov/>

US Senate <http://www.senate.gov/>

As you talk with your group about the “**needed**” advocacy effort and the importance of educating legislators on the “**needs**” of persons with brain injury, perhaps the best way to phrase it would be that “**we want what we need**”, and that we “**need what we want**”. Perhaps those words are interchangeable after all!!

Upcoming Events



**Brain Injury Association of North Carolina
2010 Symposium
October 29, 2010
One Eleven Place
Cary, NC**

For additional information, contact BIANC 1-800-377-1464.

BEYOND TOMORROW

Planning for the Future

Wednesday, November 10, 2010

**9am - 3pm in the Seymour Auditorium at CarePartners
69 Sweeten Creek Road
Asheville, NC**

A workshop for caregivers and families who have wondered what would happen if they were no longer able to care for their family member, or what would happen to them when they 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.

For additional information or to register contact: Karen Harrington 1-866-890-7801

Annual Holiday Celebration

11:00 am – 3:00 pm

Saturday, December 4, 2010

Siler Presbyterian Church Fellowship Hall

6301 Weddington-Monroe Road

Wesley Chapel, NC 28104



For additional information, contact Peggy at 704-355-4354 or Project STAR at 704-355-1502

Do you know of an event of interest to persons with brain injury and their families? Let SupportLink know and we will share the information. Contact your local Family and Community Support Office with the information or email us at peggy.philbrick@carolinahhealthcare.org.

From East to West...happenings across the State

Down East

By: Sandie Worthington

What a great weekend we had at the Annual Brain Injury Survivors Retreat! The cabins were full, we had the best volunteers ever, and there were so many activities to participate in. We were all worn out by Sunday. We had great representation from all over the East, including Goldsboro, Greenville, Morehead City, New Bern, and Washington. Hopefully next year even more will be able to attend.

Greenville had its first new Support Group meeting in September with a total of 13 participants. We would love to see all of you at the October Meeting. The group will meet on Monday, October 11, from 6:30 to 8:00 pm in the Rehab Classroom of the Regional Rehabilitation Center at Pitt County Memorial Hospital. Mark White and Jen Moynihan are the leaders of this group. Please come and join us!!

South Central

BY: Peggy Philbrick



The Charlotte Area Brain Injury Association, the Union County Brain Injury Support Network and the Lake Norman Support Network hosted the annual summer picnic in June at Lake Norman YMCA. Fun was had by all enjoying burgers and hot dogs and boating and adaptive waterskiing provided by Carolinas Rehabilitation's Adaptive Sports and Adventures Program (A.S.A.P). Group members from Asheville, Boone, Charlotte, Union County, Rowan County, Concord, Lake Norman, and Gastonia attended. We would like thank Barbara Westphal for organizing the event, Sylvia Whitmire for set-up and keeping the food line moving, Ken Smelter for the photos and the Adaptive Sports and Adventure Program at Carolinas Rehabilitation for the water sports. This event grows each year and continues to be a highlight for families and survivors alike.

The Concord and Salisbury groups are working with BIANC to try to bring a Walk & Rollathon to the area in 2011. The group hopes that other groups in the region will join in and make it a huge success. For information, contact Margaret Love. Luv3@ctc.net

The Union Group has started preparations for the Holiday Celebration. A fundraiser is planned for October 17th. The event will once again be held on the first Saturday of December in Wesley Chapel, NC.

The celebration is open to anyone who wants to attend. Last year people from Wilmington to Asheville attended.

Out West

by: Karen Harrington

Once again we hit the road rolling on our way to the Annual Brain Injury Survival Retreat with a van full of excited people! There were seasoned attendees as well as new ones anxious to see what all the fuss was about. They were not disappointed. We had a wonderful weekend filled with dancing, boating, horseback riding and relaxing. As always, saying goodbye on Sunday was a tearful event but everyone vowed to return next year. If you happen to make your way to the mountains this fall please look us up - we'd love to have you visit!

Does your group have upcoming events or reports of things you have done? Let SupportLink know and we will include your news in the next edition. Contact us at 704-355-1502 or 1-877-962-7246 or email us at peggy.philbrick@carolinashealthcare.org

BIANC Central

BY: Susan Fewell

Greetings from Susan Fewell at "Headquarters" of the Brain Injury Association of NC in Raleigh. Please help to encourage all your support group members to be BIANC members! BIANC appreciates your service in your community and always wants to hear from you how we can help. Just as a reminder, the BIANC newsletter, Starting Point, and the Support Link and Care Notes newsletters are also on our website on the [News](#) page. www.bianc.net

We hope you are doing well as summer comes to an end and we head into Fall and Winter. We were so glad to see many of you at Camp Carefree in September and appreciate those who could attend our Statewide Support Group leader training meeting at the camp. Each group serves a diverse population, from the newly injured to older injures. It is a challenge to find speakers and programs that are meaningful to all. We discussed barriers, such as transportation, that keep folks from attending our groups. Some groups struggle to maintain membership and are constantly seeking new ways to get the word out in the community. As we mail newsletters to all our rehab hospital contacts this month, we are including the list of support groups in their packets so they can help inform their patients. BIANC will work on a speakers list and set up an email 'list serve' to help keep communication going between groups. We will try to get information out to leaders earlier when events are coming up. We hope to see everyone at Camp Carefree next year. We depend on volunteers and community partners to make it a success. A special thanks for Debbie Jones, Support Group leader from Morehead City, for bringing her church bus and offering a ride to many survivors 'down east'. Karen Harrington, in Asheville, was able to borrow the Hind's Feet Farm Day Program Bus and offer transportation from her area.

Don't forget, BIANC has \$200 grants available to our Support Groups to help with an awareness or recreational event that you want to plan. This could be a party for the holiday or an event to raise awareness in your community, T-shirts to advertise your support group or transportation for your group to attend one of the Walk & Roll-athons. Hope to see you there! Send me an email at susan.fewell@bianc.net or give us a call at 919-833-9634 to request a grant. Tell me what you want to do and give me the names of 2 folks in your group with contact information to recommend your project.

Here are some dates for the Spring of 2011 and Brain Injury Awareness month that you may want to put on your calendar for 2011. BIANC is hoping for our best year of attendance at our awareness events. Our events will be scheduled across NC during March and April and each support group can form a team and attend one of the events. There will be pledge sheets and Team packets available by the end of the year which we will send to you.

Event	Date	Town of Event	Park or Event location
Ride for the Rock - A 50K and 100K Bicycle ride	March 6, 2011	Cary, NC	Ride starts at Whole Foods in Cary
Walk & Roll-athon - A Walk for Thought and for Brain Injury	March 19, 2011	Fayetteville, NC	Honeycutt Park
Walk & Roll-athon - A Walk for Thought and for Brain Injury	March 26, 2011	Greenville, NC	Town Commons
Walk & Roll-athon - A Walk for Thought and for Brain Injury	April 2, 2011	Raleigh/Morrisville, NC	Lake Crabtree County Park
Joggin'4 Your Noggin' - A 5k Run for brain injury and A Run for our Troops	April 2, 2011	Raleigh/Morrisville, NC	Lake Crabtree County Park
Walk & Roll-athon - A Walk for Thought and for Brain Injury	April 9, 2011	Asheville, NC	Carrier Park
Walk & Roll-athon - A Walk for Thought and for Brain Injury	April 16, 2011	Greensboro, NC for Triad area	Bur-Mill Park
Walk & Roll-athon - A Walk for Thought and for Brain Injury	To be announced	Concord	To be announced

CAMP RECAP...IT WAS FUN BUILDING MEMORIES..

Photos submitted by BIANC



Thank you to David, Chandler and Taylor White, Barbara Westphal, Natalie Johns, Harvey Montijo, Pam Quinn, Roger and Barbara Abernathy, Wayne Foutz, Norman Carter Terry & Peggy Philbrick and others who jumped in to help in the kitchen.

Water Sports...the Lake was Great!



Party ! Party! Party!



Team Building ... in living color

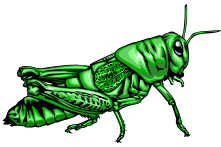


T
R
U
S
T



Special Thanks to the Camp Committee who worked tirelessly for months to put together this awesome experience. A special thank you is due to Donna White and Sandie Worthington, Hank Baker and Susan Fewell. We owe a debt of gratitude to all of the volunteers who dedicated their time and energy to making it work, and most especially to Tammy Cleveland and the IQUOLIOC team for taking the adventure to the next level!

THANK YOU!



FROM BIAA on Grasshopr?

The Brain Injury Association of America (BIAA) works to insure that persons with brain injury, their families and other interested parties stay informed about what is happening legislatively that could impact them.

There are several ways that BIAA accomplishes this. Those who are signed up to Grasshopr will receive updates and alerts when action is needed. This can come in the form of a request to contact your legislators, write letters or other actions needed to insure funding or other things critical to those living with brain injury. If you are not signed up, go to www.grasshopr.com, click on groups and register at the BIAA site to receive the alerts.

If you would like an in-depth look at the position that the Brain Injury Association of America take and would like to review their policy statements you can visit their website at <http://www.biausa.org/policyissues.htm>

Some of the current issues and policy statements have to do with healthcare reform, funding for the TBI act, Medicaid policies and other legislative actions that may affect persons with brain injury. There are informative, easy to read and understand, fact sheets on the BIAA website. The sheets are easily printed and make great handouts for group meetings.

Keeping group members who may not have access to the internet, or who, for other reasons, may not be able access the information is important. As a group leader it may be necessary to offer the information in several ways to make the information accessible to everyone.

Sharing information is also important. Encouraging group members to sign-up for Grasshopr and to visit web pages that contain information that may be of interest is a great way to help group members stay informed.

Become a BIANC Member

If group members would like to become members of BIANC and cannot pay the full membership price, they can join for the \$5.00 reduced rate for survivors and family members. Membership numbers are important as they increase the legislative influence of BIANC. Group members can become a member of BIANC for one year and will receive information from both BIANC and the Brain Injury Association of America.

Below is a membership application form to share with members of your group. For additional information about BIANC membership, contact the Raleigh Family and Community Support Office. 1-800-377-1464



Reprinted from CareNotes 9/25/2010



MV-1 Factory Built Wheelchair Accessible Vehicle

On the 20th anniversary of the ADA (Americans with Disabilities Act), a new American car company unveiled a breakthrough mobility solution. The Vehicle Production Group LLC, presented their accessible car at the National Council on Independent Living Annual Conference in Washington, DC.

The car, expected to hit the market in the fourth quarter of this year, is the first factory built vehicle designed for persons who use wheelchairs and other mobility devices. It will be manufactured in Indiana and is expected to be priced at under \$40,000.

Named the MV-1 ("First Mobility Vehicle") the car features a built in deployable access ramp, a three-foot access door, and seats up to six people. Standard features will include such features as electronic stability control, anti-lock braking system, anti slip floor and ramp surface, a wheelchair restraint track system and adjustable commercial driver's seat. Upgrade features are also available. The MV-1 will be equipped with a Ford 4.6L V8 engine and will be offered in both a traditional gasoline engine or with a CNG (compressed natural gas) fuel system.

The MV-1, offers an alternative to the costly conversion van process. Persons with mobility problems can get involved in the process of designing their own vehicle. By visiting the Vehicle Production Group website www.vpgautos.com, consumers can choose features and custom design their own MV-1.

The MV-1 really is HOT WHEELS!

Update: The MV-1 has a webpage that has video demos and other neat ways to check out the vehicle. Visit the website at <http://www.vpgautos.com> and check it out.

Brain Injury Association of North Carolina

How to Reach Us

Family Helpline

1-800-377-1464

bianc@bianc.net

BIANC has four regional offices:

Asheville

Community CarePartners

68 Sweeten Creek Road

Asheville, NC 28803

828-277-4868 Fax: 828-277-4869

1-866-890-7801

Raleigh

P.O. Box 10912

Raleigh, NC 27605

919-833-9634 Fax: 919-833-5415

1-800-377-1464

Charlotte

Carolinas Rehabilitation

1100 Blythe Boulevard

Charlotte, NC 28203

704-355-1502 Fax: 704-355-9480

1877-REHAB51 (734-2251)

Greenville

P.O. Box 30496

Greenville, NC 27833

1-800-697-3115

Visit our website

www.bianc.net

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, tickets to the annual golf tournament, and sponsorship of campers at the survivor's retreat. 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
 Platinum membership.....\$250/yr

- Executive membership.....\$100/yr
 Please send me an information packet on the Corporate Sponsorship Program

Name

Company

Address

City

State

Zip Code

E-mail

Telephone

I am a: Survivor Family member Professional Other

Card No. _____ Exp: _____

Master Card Visa Check enclosed.

BRAIN INJURY WEB-CONNECT...

Websites about brain injury

www.brainline.org

This site has information on brain injury and features videos and articles that educate about TBI.

www.bianc.net

The Brain Injury Association of North Carolina has state information and coming events as well as links to newsletters and other information

www.biausa.org

The Brain Injury Association of America website offers information on national brain injury events, statistics and links to many other sites

www.cdc.gov

Centers for Disease Control offers statistics and materials that can be used to educate others. Information is free to download or it can be ordered through the site

www.dvbic.org

Defense and Veterans Brain Injury Center offers information for military and veterans with brain injury and their families

www.hrsa.gov

Health Resources and Services Administration offers links to information about health care and resources across the nation.

www.waiting.com

A website that gives a detailed overview of brain injury, from initial injury through reentry into the community.

If you find websites that you would like to share please send us the information. We will include them in Support Link.

Peggy Philbrick 704-355-4354 or peggy.philbrick@carolinashealthcare.org



Carolinas Rehabilitation

Uncompromising Excellence. Commitment to Care.

Contributed articles do not necessarily reflect the views or opinions of Project STAR or Carolinas Rehabilitation, and are wholly the opinion of the contributing author.

828/2010

TBI Project STAR at Carolinas Rehabilitation is funded in part by North Carolina DHHS's DMH/DD/SAS project number 1990