

Project STAR at Carolinas Rehabilitation

SUPPORT LINK

Fall 2008

Information for Support Group Leaders

Brain Injury Family and Community Support Office at Carolinas Rehabilitation

All Groups-Great and Small

Recently, a new group leader, asked Project STAR, about how to keep support group members engaged, and what type of speakers and other programs would benefit the group. Our answer was the usual, *“every group is different, and the group will define it’s self over time”*.

Another questions posed by this person, new to brain injury and new to support group leadership, caused us to realize that it had been a long while since we addressed the very different nature of brain injury support groups across the state. From “Pot Luck Dinners” for fifty or more people, to “one on one” support provided on an as needed basis, each of the groups can meet the need of those involved.

When we make the statement that a group will define it’s self over time, we do so based on years of watching groups develop, each evolving over time to fit the shape of the community it serves. As groups form, and persons with brain injury and their families share their needs and concerns, group leaders can gain an idea of what type of programs and speakers would best suit the needs of the group, by just listening to the discussions.

Bigger is not always better when it comes to support groups. Larger groups, while usually offering more in the way of social contacts and different programming options, offer less of an opportunity to address the more personal support that some people with brain injury and their families need. Similarly, small groups may not appeal to many long-term survivors who have long since adapted to life after their injury and want the social networking that a larger group offers.

It boils down to what members of the group need, and as groups form and grow, they will constantly adjust and define themselves by the needs of the group members.

Program content can also pose a challenge for group leaders. Finding programs that can offer good information and speakers who can engage the group takes time and effort, especially since most groups meet on a monthly basis.

Programs need not be brain injury specific. Persons with brain injury have the same

need for general information as persons without brain injury, so presentations from community resources can be informative and helpful.

Sometimes it is necessary to be resourceful in order to find agencies and people who are willing to attend a meeting and share information. Amazingly, most agencies and service providers seldom say “No”. It may take some work to arrange a time when they can attend a scheduled meeting, but by planning ahead, this is usually manageable. Below are some tips on where to look for programs for your group.

- Public service providers, such as the fire department, police department and utility department can offer valuable tips and useful information about safety.
- Public officials, such as Mayors, City Council Members, County Commissioners or other legislators can address how to communicate with lawmakers and can offer insight into how local government works.
- Advocacy agencies can give information on how to advocate for services.
- Emergency Management personnel for the county or city where the group meets can offer information on what to do in case of weather emergencies or other natural disasters.
- The Department of Social Services can discuss programs that benefit persons living in the community and may be able to offer information on volunteer opportunities.

One of the best ways to refresh your memory about what is available in your area is to Google your County on the internet. There is a wealth of information provided on most county websites with links to agencies and businesses in the county. These websites can be used to access a vast array of service providers and community services. What better way to find speakers?

Let us hear from you.

Do you have ideas to share with other support group leaders? All contributions are appreciated.

Contact us at 704-355-1502 or 1-877-962-7246.

Brain Injury Association of North Carolina Update

By Sandra Farmer, President

The Brain Injury Association staff has worked hard to update our resource directory which is designed to help people find services for individuals with brain injuries in North Carolina. We have made our best effort to identify providers and agencies that specialize in caring for persons with brain injuries. The new BIANC resource book will be given to the families of patients who are being discharged from hospitals with brain injuries, to service agencies and to individuals that request them from our office. It will also be available on our website www.bianc.net

We hope that the resource directory will be helpful to families trying to find services for their loved one. Unfortunately, we know that there are not adequate services to meet the needs of all of the people with brain injuries in NC. We struggle everyday to give the best resource information to the hundreds of people who call our offices seeking help, but often there is no appropriate help.

The only way that new services will be provided is for us to work together to educate our elected representative about the needs of persons with brain injuries.

Please consider joining **ALSTARS**, Alliance of Legislators and Survivors Together Achieving Responsible Services. **ALSTARS** will be an advocacy group made up of families, people with brain injuries and professionals across the state who work to provide outreach and education efforts to state and federal representatives about brain injury.

If you would like to learn more about **ALSTARS** please call the Brain Injury Association office at 1-800-377-1464 or go to our website at www.bianc.net.

Thank you,
Sandra Farmer

UPCOMING EVENTS

Camp Carefree

October 3-5, 2008
Stokesdale, NC

For additional information contact
BIANC at 1-800-377-1464

Statewide

Support Group Leaders Meeting

Saturday, October 4, 2008
Stokesdale, NC

For additional information contact
BIANC at 1-800-377-1464

BIANC Open Board Meeting

October 5, 2008
Stokesdale, NC

For additional information contact
BIANC at 1-800-377-1464

Beyond Tomorrow

Planning for the Future

October 10, 2008

Pathways Auditorium
Gastonia, NC

A one day workshop designed to help family caregivers plan for the time when they can no longer provide care. This workshop provides information on record keeping, financial planning, guardianship, and other important considerations.

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

Brain Injury 2008-Unraveling the Mystery

October 31-November 1, 2008
Chapel Hill, NC

www.wakeahec.org

Annual Christmas Celebration

Saturday, December 6, 2008
Wesley Chapel, NC

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

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

TRIAD Resource office

Highpoint 336-687-4702

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

From time to time Project STAR asks individuals involved in Brain Injury in North Carolina to contribute articles for publication in SupportLink. If you have a story to tell or know someone who would like to write an article for SupportLink, please let us know. Input from many sources goes into SupportLink and contributions are always appreciated.

ACCENT ON ADVOCACY VOTE 2008

During election years we hear a lot about healthcare reform from candidates who run on a platform of “making it better” for persons with disabilities. It may be about health insurance for everyone, the development of more consumer driven services, help with prescription medication cost, and the list goes on and on.

Campaign rhetoric can be confusing to anyone, especially those with brain injury. This year, as in most general elections, there are many pitches from local, state and presidential candidates, each promising that he or she can deliver just what we all need. Negative campaigning and self inflating ads, aimed at influencing voters, clog the airways and people get more and more confused about who and what to believe.

As a support group leader, you can help members of your group access the information they may want or need in order to make an informed decision when voting. It is important to remember that how a person votes is a private and personal matter and should be based on the opinion of that individual. Therefore, a support group leader should refrain from sharing his or her personal preferences.

Getting information out to your group members on how to access information on the candidates is a proactive approach to encouraging your group members to express their opinions at the polls . There are many tools available on line that can provide information on the candidates and the issues. Researching these may take a little bit of preparation on the part of the group leader, but in the long run can help group members be responsible voters in November. Here are some things group leaders can do.

- Provide candidate information. There is a complete listing of all candidates on the NC Board of Elections Website at <http://www.sboe.state.nc.us/Default.aspx?s=0> . Website visitors can easily identify their districts and identify the candidates who will represent them area if elected.
- Provide information on how to find out what each candidate is supporting. You can find this information on the campaign home page of most candidates. For example, North Carolina Gubernatorial candidate information can be found on line. For Beverly Perdue go to <http://www.bevperdue.com/> , and information on Pat McCrory can be found at <http://www.patmccrory.com/>
- Local and regional candidate information can be found the same way. Type in the name of the candidate and the office they are running for into a web search engine to see if the information is on line. Providing a listing of candidates and the links to their websites is a good way to help group members learn about the candidates and where they stand on issues of interest.
- The voting records of candidates for state legislator seats can be found on the personal legislative webpage of candidates who have been in office before. How they voted on bills that impact issues the group member supports or disagrees with could be an important factor in deciding how to vote. Homepages for current legislators can be accessed through the NC Legislative Homepage at <http://www.ncga.state.nc.us/> and the past voting records for the US representatives can be located on their personal web pages at <http://www.senate.gov/index.htm>.
- Provide information on how to find the correct voting place and voter status.

It is important that the voices of persons with brain injury and their families be heard. Voting is one way of having voice. Choosing the candidate who supports policies that will benefit and support our personal views is a right and a privilege of each American.

As support group leaders, we can make information available to help our group members exercise the right and privilege of voting by making sure they have the tools that will help them access the information they need to make an informed decision when they vote.

North Carolina

State Board of Elections

As voting day approaches, most people have heard a lot about the candidates and the issues that will bring voters to the poles, but may have received very little information on **how** to vote.

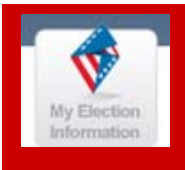
The State Board of Elections is the state agency charged with overall responsibility for administration of the elections process and campaign finance disclosure in North Carolina. It is the only statutory bi-partisan, quasi-judicial supervisory board in North Carolina State government. The Governor of North Carolina appoints the five members of the Board.

The North Carolina Board of Elections website (<http://www.sboe.state.nc.us>) has a wealth of information on the voting process and other useful information for voters. This information may be useful to members of your support group and their families.

Below, SupportLink gives an overview of the website and what you can expect to find there.



Click the “How to Register” icon on the homepage to access information on how to register to vote. This page also addresses voter requirements, early and absentee voting, and other information on how to become a qualified voter, and how to vote in North Carolina.



By clicking on the “My Voter Information”, registered voters can enter their name and birth date to access information on where they are to go to vote. The address of the polling place is given and a link to a map to the location is also provided. You can also view voter eligibility along with personal demographics and past voting history.



“My Polling Place” gives information on the current voting location assignment, if they are unsure of where to go to vote. It also allows visitors to the site to search for other polling places if they have moved. It is important to note that voters must vote at their assigned precinct unless there is a pre-approved exception.

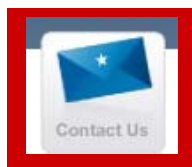


By clicking on “My Election Board”, website visitors can access information on their County Board of Elections. This information includes the name of the County BOE Director, the mailing and physical address of the county office and contact information including mailing address and phone numbers.

Other links included on the NC Board of Elections website can help visitors link to sites on election financing, a voter guide, campaign reports and other information of interest.

By using this website, support group members can find the information they need to get registered to vote, if they are not registered, find out where to go to vote, download absentee and provisional ballots and many other items to make voting easier.

It is important that persons with brain injury and their families feel empowered to vote in this election. As a support group leader, you can share information to help group members locate the information they need to become informed voters, and by all means, if you need additional information you can go to <http://www.sboe.state.nc.us> and click on



Your Voices Were Heard!

By Marilyn Lash, Chair, Statewide TBI Advisory Council

You made a difference! In the last newsletter, I asked for your help to support a request before the General Assembly Legislature for an additional \$1 million for brain injury services. It passed!

These additional funds are now in the 2008-09 budget of the state's lead agency for brain injury services, the Division of Mental Health/Developmental Disabilities/Substance Abuse. This *more than doubles* the total amount of funding for brain injury services in this new fiscal year. These new funds are in addition to the exiting budget for brain injury – increasing the total dedicated funds for brain injury to over \$2 million. This is the first major increase in brain injury funding to the Division by the Legislature in many years.

So thanks, to all of you, on behalf of the Advisory Council. Your voices, telephone calls, visits and letters to legislators have made a big difference. Many times over the past year, I have heard legislators and advocates comment that they are constantly hearing from families, survivors and professionals about the need to improve funding for brain injury services. We are finally on the radar and this is just the beginning!

The Advisory Council just held its fall meeting on Sept 17th and we have laid out an ambitious action plan for 2009. The next big challenge that we face is asking the Legislature to change the state's definition of brain from "traumatic" to "acquired." This would mean that individuals with brain injuries due to non-traumatic causes such as brain tumors, infections, strokes, near drownings, and near strangulations would be included. It won't be easy, but that is our goal.

You will be hearing much more from the Council as we will continue to ask for your help and support. No matter how many detailed reports and budget analyses we do, it is still your personal stories that legislators remember when the important votes come up. Thank you all for what you have done. We look forward to continue working closely with you.

Drive and Educate ... Brain Injury Awareness License Plates

Help raise awareness and show your support by purchasing a Brain Injury Awareness license plate. A portion of the proceeds will go to BIANC to help continue to offer help, hope, and a voice for people with brain injury and their families.



I would like to sell at least 300 license plates. For the License Plate Application go to the Brain Injury Association of North Carolina at 800-377-1464 or download the application online at www.bianc.net.

BIANC will be taking the orders for regular as well as personalized plates. After 300 of the Brain Injury Awareness plates are received by BIANC, the license plate order will be placed with the North Carolina Department of Motor Vehicles. The plates will be date numbered and will be printed in the order they are received.

Payment must be made in advance. Please make out your check payable to BIANC and mail it to BIANC

PO Box 10912
Raleigh, NC 27605

**Getting to know you... Board of Directors of the Brain Injury
Association of North Carolina Profiles
Prepared and contributed by Ana King**

Stephanie McAdams

Stephanie Walther McAdams, M.A.-CCC\SLP received her Master's Degree in Speech Pathology from Western Michigan University. She has been a practicing Speech Language Pathologist for 17 years, specializing in the treatment of adult neurogenic disorders, especially those related to Traumatic Brain Injury and Stroke. For the past 12 years, she has been employed at the University of North Carolina Health Care System in the Rehabilitation and Acute Care settings. She currently serves as the Director of Speech Pathology and Audiology for UNC Healthcare. She is a guest lecturer at the UNC-Chapel Hill graduate Speech Pathology program for classes including "Aphasia", "Cognitive Linguistic Disorders" and "Professional Issues in Speech-Language Pathology". She frequently lectures on topics related to cognitive dysfunction and treatment strategies for individuals with Traumatic Brain Injury.



Stephanie has been a vital member of the BIANC Board of Directors for the past three years. She has served as Director of Education and Training during this time period and brought a wealth of experience to this role after coordinating education and training events on behalf of persons who have suffered strokes. Since joining the Board in 2006, she and a committee she assembled have been responsible for coordinating a number of successful events on behalf of persons with brain injury. A wellness event, *Living Healthy, Living Well After Brain Injury* was attended by 30 participants at the UNC Wellness Center on November 4, 2006. And an open house was hosted by CarePartners in January, 2007 centered around the opening of BIANC's Family Support Center in Asheville.

Stephanie and her committee identified a need for professionals serving individuals with TBI to have access to continuing education opportunities. Through collaborative efforts with the NC Speech and Hearing Association (NCSHA) and AHEC, a TBI presentation was included at the NCSHA annual conference during March, 2007. And then in November, 2007, a 2-day statewide TBI Conference - *Brain Injury 2007: Where We've Been, Where We're Going* - was attended by 130 professionals and providers at the Friday Center in Chapel Hill.

The success of this conference prompted the committee to organize a second statewide conference which will be held October 31 - November 1, 2008 at the Friday Center. The conference, *Brain Injury 2008: Unraveling the Mystery* will include sessions on sports-related concussions, diagnostics breakout sessions, sessions on grief, loss and advocacy, and the challenges of coordinating services to families of military service men and women. This year's conference will feature an evening reception at which time several individuals will be honored for their efforts on behalf of people with brain injury.

In addition to coordinating training events, the Education and Training Committee has been exploring options for online, self-study modules which would be supported by the BIANC website.

When Stephanie is not busy with the responsibilities of her full-time job or the BIANC Board of Directors, she enjoys remodeling projects and spending time with family and friends....including her two cats, Everest and Bobo.

From my observations, Stephanie is enthusiastic and passionate about everything she does. I asked her if she had a philosophy that she lives by that she would be willing to share with the readers. Here is what she said:

"Life is short, so live your passions. Love the work you do each and every day."

Karen McCulloch

Karen McCulloch joined the BIANC Board of Directors in January, 2008 and is its newest member. Her 18-page curriculum vitae provided the Board with more than enough evidence that she is a well-educated, well-published, and much sought-after teacher and public speaker in her field of Physical Therapy and Human Movement Science who would be a real asset to the Board.

She received a B.S. in Physical Therapy from the University of Florida where she was a National Merit Scholar; an M.S. in Physical Therapy from the University of Alabama at Birmingham;

and a PhD in Human Movement Science from UNC-Chapel Hill.

Karen knew she wanted to be a PT when she was in 9th grade and worked as a candy striper at the local hospital in a small town in Tennessee. She did a clinical rotation at Spain Rehabilitation Center in Birmingham (part of the TBI Model Systems research program) and from there she was hooked. She's known that she'd rather work with survivors of brain injury than any other group.

During the early part of her career, which began in 1984, Karen worked as a physical therapist in a large rehabilitation center and did home health care. One day in 1987 she drove over for a job interview in Atlanta with the Director of a new community re-entry program in Durham, NC – Randy Evans (for whom our memorial golf tournament is named). She agreed to move to NC to coordinate the PT program for Learning Services in Durham and enjoyed 5 years of the best PT job ever, where she got to work with clients in the community on recreational and exercise activities that were important to them.

In 1993, she moved over to UNC-CH to be a student coordinator and to begin teaching, but continued to provide consultative services to Learning Services. Since completing her PhD, she has served as a researcher and educator in residential and distance education programs at UNC-CH. In this role she teaches students who are Physical Therapists earning an additional degree. Karen is excited that one of these students is planning a project that is based on BIANC's need for a wellness program.

Karen is very interested in how balance is affected by attention. She has done several studies of older adults and people with brain injury to understand how thinking and balance influence risk of falls. She has co-authored 27 publications, made 54 conference presentations, delivered 14 lectures within the academic community, and currently teaches 7 courses. She has been a research advisor, book and journal reviewer, and professional journal editor.

Karen is a member of the American Congress of Rehabilitation Medicine Brain Injury Interdisciplinary Special Interest Group. She is also an active member of the American Physical Therapy Association Neurology Section, where she co-founded the Brain Injury Special Interest Group in 1990 and currently serves as the Director of Education.

"I've spent much time in professional service outside the state on issues related to brain injury – so I'm very happy to be able to serve on the BIANC Board and give some of my time a little closer to home. The current health care climate makes it harder for people with brain injury to get care they need. Being involved with the BIANC Board in advocating for changes in funding and care in the state of NC is important."

Karen, her husband, two children, two cats, and big garden live in Hillsborough, NC.

TRIAD Brain Injury Resource Office Opens

Contributed by: Kitty Barringer

The new Traumatic Brain Injury Resource Center has been steadily progressing since its Open House was held on July 31. This center hopes to provide avenues of information as well as means for survivors, caretakers and providers to be more informed about TBI and its serious effects on individuals as well as society at large.

The High Point brain injury support group applied for a grant from the state association and donated the funds to the support of the new facility. There are ongoing projects planned for the coming months. The support group continues to meet each month with an average attendance of 25-30 people, New member join the group at interval throughout the year.

You can contact the Resource Center at

Triad Brain Injury Resource Center



Carolinan 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.