

Information for Support Group Leaders

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

BIANC TODAY

From Past Chairman of the Board,

Marilyn Lash

The first thing you may see above is a change in my title. Let me fill you in on what has been happening.

There are two very important groups working to improve services and supports for persons with brain injuries and their families in NC. The first group is the Board of Directors for BIANC. The Chair is elected by the Board for a term of 1 year. Upon completing my first year, I was reelected for a second year which is due to end this December.

The second group is the Traumatic Brain Injury Advisory Council for NC. Members are appointed by the Governor, the President of the Senate, and the Speaker of the House of Representatives. The legislation states that the Chair of the Board of the Brain Injury Association of North Carolina has a position on this Council.

I have been working with the Board and the Council since January 2005. I was also elected Vice-Chair of the Advisory Council in 2005. With my term as Chairman of the Board of Directors scheduled to end soon, this meant that I would also be leaving the Advisory Council.

I was asked to continue my work with the Advisory Council as a family member. However, this means that I can not wear "two hats at once." I can not be on the Council as a family member and as Chair of BIANC.

So after talking it over with our Council Chair, Sharon Rhyne, and BIANC officers Sandra Farmer, Anne King (Vice Chair) and Elsie Siebelink (Program Chair), they felt it was most important for me to continue with the Advisory Council. So I have resigned as Chair of BIANC.

The Board of BIANC is very strong now. Anne King will step up as Interim Chair to complete my term through December and I will continue to work closely with her. So while I may not carry the official title for these next few months, I will continue to work hard with the Board and the Council to build a better future for all who have been touched by the trauma of brain injury.

From the BIANC President,

Sandra Farmer

The Brain Injury Association of NC is pleased to announce that we will be opening a new Family and Community Support office in Asheville on October 1st. Karen Harrington, whose son has sustained a brain injury, has accepted the position of community support coordinator for the new center. Ms. Harrington has been a strong brain injury advocate for several years and will be an excellent resource for people with brain injuries and their families. The office will be located at Community Care Partner's outpatient clinic and we are very excited to be able to provide more community support and resource development to western North Carolina.

As most of you know, BIANC's Camp Carefree was held in Stokesdale on September 22nd through 24th. We had a tremendous number of applications for camp and unfortunately we were not be able to accommodate everyone who applied due to space limitations. There is another camp planned for the spring and those who missed this camp will have first preference for the spring camp. We are also working with the Victory Junction Gang Camp in Randallman to help facilitate a week long summer camp for children with brain injuries and other neurological disorders.

The 12th annual Brain Injury Association Golf Tournament was held on October 2nd at North Ridge country club in Raleigh. Carolina's Rehabilitation in Charlotte was the title sponsor for this year's tournament. Carolina's Rehabilitation has been a leader in brain injury treatment and research for many years and we are honored to have their support.

The Brain Injury Association's yearly open board meeting will be held on October 7th in Greensboro. Anyone who is interested in brain injury causes is welcome to attend. Please contact our Raleigh office at 1-800-377-1464 for additional information.

Thank you,
Sandra Farmer

Contact Sandra by phone at 1-800-377-1464

Camp Carefree...Mind Matters

The weather was great and enthusiasm high as those who attended camp enjoyed a weekend of fun filled activities. The full capacity enrollment stressed the chef and his staff but no one left hungry. Activities included the traditional Friday Night Dance, where everyone got a chance to meet and greet old friends and make new ones.



May I have this Dance?

Saturday morning found everyone ready for a full day of group activities, including team building, outdoor survival, arts and crafts, and water sports. There was also the opportunity to go fishing. Mike Massey was available to handle the “yucky” worms and give lessons on fly rod casting. Although retired from Vocational Rehabilitation, Mike still volunteers each year at BIANC Camp. It takes commitment to volunteer to play with worms! The catch of the day was approximately three inches long but that did not deter the dedicated fishermen.

Making a fire can be one way of staying warm. Survival Skills activities included learning how to make a fire in case of an emergency. Each group got to learn the skill and practice what they had learned. Other activities included horse back riding and face painting.



Mike fishes, David Watches

Special Thanks

The Camp Committee

Sandy Worthington (Chairman)

Mary Beth Moore

Tonya Harrison

Darlene Wetzel

Hank Baker

Denise Grant

Registration and Coordination

Donna White, BIANC Raleigh Office

Financial and Other Support

Charles Monet & Associates-Transportation & Shirts

The Chris Calloway Memorial Fund-Scholarships

CreatX-Printing – Shirt Printing

Target, Harris Teeter and Others

Volunteers and Others

Horsepower-Horseback Riding Volunteers

Big Harry and the Blandells- Entertainment

Debbie Leonhardt-Devotional Service

Agnes Moore and Kitty Barringer- Camp Nurses

And to

All of the other Volunteers who did everything from sweeping floors to driving golf carts.

Thank YOU!



Fire!

If you or a member of your support group was unable to attend camp due to the maximum capacity limits and would like to attend the Spring Camp, please contact BIANC to have your name added to the priority list. Those who applied but were turned away will receive first priority for the next camp.

1-800-377-1464

Tracking down resources



What Support Group Leaders are expected to know...

Frequently people attend a support group meeting to get information about where to turn to for resources. They look to the leader of the group for direction and advice. Some groups are facilitated by professionals while others are led by persons with brain injury or family members, but the expectations of group participants is the same; That the group leader know about the available resources and be knowledgeable in the process of how to tap into those resources.

As a group leader, being able to give accurate referral information is important. Often people attend a support group meeting as a first stop or as a last resort, and in both cases being able to access accurate information can have a tremendous impact on the lives of the family and the person with a brain injury.

Becoming knowledgeable on resources can require many hours of research. While other group members may share the experiences they have had in dealing with agencies and searching out resources, often their information can be vague and confusing to those who have only begun to unravel the maze of securing services. It is also important to remember that the key to getting any service is to meet the qualifications required by the provider. Circumstances can vary and not all will qualify for all services, so it is important to give information on what may be available and how to research eligibility on an individual basis. Here are some tips.

Maintaining a file or notebook of referral information is a good method of having the information at hand during meetings. Visit state agency websites and print out the homepage or specific program information that describe the services provided and the contact information for the agency or service. Most sites feature links to pages which gives a description of what services the agency may provide to those who qualify. Below are some of the key agencies that provide services and supports for persons with TBI.

- BIANC is developing a resource guide that list resources across the state www.bianc.net
- Project STAR has a resource guide that covers Mecklenburg and 10 surrounding counties
- North Carolina Division of Mental Health/Developmental Disabilities/Substance Abuse Services www.dhhs.state.nc.us/mhddsas/tbi
- Department of Social Services Programs www.dhhs.state.nc.us/dss/programs/index.htm
- NC Division of Vocational Rehabilitation www.dhhs.state.nc.us/DVR/VRS/consumer.htm
- North Carolina Division of Vocational Rehabilitation Independent Living programs www.dhhs.state.nc.us/DVR/IL/ilhome.htm
- A chart showing Medicaid eligibility guidelines for North Carolina residents www.dhhs.state.nc.us/dma/basocmedelig.pdf
- The United Way local office search page www.UnitedWay.com
- North Carolina Social Security Administration www.ssa.gov
- North Carolina Disability Determination Services www.dds.its.state.nc.us/faqs/default.asp
- North Carolina Governors Council for Persons with Disabilities www.GACPD.com
- The Brain Injury Association of North Carolina Regional Office Information www.bianc.net
- The Brain Injury Association of America www.biausa.org

Prepare, and have available, cards that can be handed out that contain contact information for the agencies and organizations that provide services in the counties your group covers and a brief statement of the types of services that are offered. Some examples of what to include are;

- Division of Mental Health/Developmental Disabilities/Substance Abuse Services
- Department of Social Services
- Health Department
- Housing Authority
- United Way
- Crisis Assistance Programs
- Vocational Rehabilitation
- Any other resources which may offer help in emergency situations.

Most of the agencies will come speak to the group if asked. Scheduling speakers from the service providers in your community can help educate your group members on locally available resources and also allow your group to educate service providers about TBI.

BRAIN INJURY SERVICES IN NORTH CAROLINA.... Changes that Challenge

Many families and brain injury survivors are struggling to understand the sweeping changes that the federal redefining of Medicaid laws has caused, and what services would be covered. North Carolina has been fortunate enough to have Traumatic Brain Injury Services housed within the Developmental Disabilities division the Mental Health System (MH/DD/SAS). The transition to other methods of receiving community based services and alternative options for providing needed services for persons with TBI has been greatly enhanced by the Brain Injury Staff at MH/DD/SAS. The staff for Brain Injury includes:

Sandy Ellsworth, Lead TBI Staff / Grant Project Director

Sandy is a member of the Best Practice Team of the DMH/DD/SAS. She has served as staff for Traumatic Brain Injury for approximately one year. Sandy has worked for more than 20 years in DD/MH/SAS in North Carolina. She has served as an Advocate in a Mental Retardation Center, and as a Guardianship Specialist for the Lifeguardianship Program. She has also worked for a provider of residential and program services, holding positions of Director of Quality Improvement, and of Associate Director of Programs.

Having a sister who is a TBI survivor, and a brother with a developmental disability, who has resided with her since he was 13, gives her a personal perspective on the need for services.

She received a Masters of Education in Counseling from the University of Georgia. Sandy is the Lead TBI staff for DMH/DD/SAS and is working with Janice White of the Prevention Team on TBI program and policy.

Sandy presented an overview of how TBI services and funding works in North Carolina at the statewide Support Group Leaders Workshop last fall. Her experience within the DD/MH/SAS has been invaluable to those who were affected by the changes in Medicaid law.

The Division of Mental Health/Developmental Disabilities/Substance Abuse Services has recently received a HRSA (Health Resources and Services) Grant through the US Department of Health and Human Services. The HRSA grant will focus on assessing the training needs of brain injury service providers across the state and developing a regional Family and Community Support Office for the Brain Injury Association of North Carolina in the Asheville area.

Janice White ,Program Manager for Prevention of TBI

Jan obtained her BA in Speech and Hearing Science from the University of Pittsburgh and her Masters of Education in Speech Pathology from the University of Virginia. She has worked as a Speech Pathologist on the brain injury team at what is now

Carolinas Rehabilitation in Charlotte and as a Marketing Representative for Learning Services, a post acute brain injury rehabilitation program in Durham. While at Learning Services she evaluated prospective clients for the program and provided marketing and community education about brain injury. She has also worked as Program Manager for Brain Injury and Spinal Cord Injury at HealthSouth Rehabilitation Hospital in Columbia, SC.

After a number of years working in Long Term Care, Jan is pleased to be back in the field of brain injury. In her role with the State of NC in the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS).While Jan will be working closely with Sandy Ellsworth on matters of policy for the State of NC, Her primary role, is Program Manager for Prevention for Traumatic Brain Injury.

As we all know prevention is the only "cure" for brain injury. Jan will be working with other State agencies such as Public Health, Department of Public Instruction and the Division on Aging, also in the Department of Health and Human Services, to increase knowledge and awareness of brain injury and to develop prevention programs.

Jan states, "This is an exciting time within the Division of MH/DD/SAS as there are now two people working on TBI issues. Although the Division is in reform they remain firmly committed to serving the consumers in the state of North Carolina who have sustained a traumatic brain injury."

If you have questions or ideas surrounding prevention programs please feel free to contact Jan at 919-715-5989.

What is a Local Management Entity?

Services for persons with traumatic brain injury are provided to those who qualify through their Local Management Entity (LME).

Local Management Entities are agencies of local government, area authorities or county programs, who are responsible for managing, coordinating, facilitating and monitoring the provision of Mental Health/Developmental Disabilities/Substance Abuse Services in the catchment area served. LME responsibilities include offering consumers access to services, developing and overseeing providers, and handling consumer complaints and grievances.

To check eligibility for services contact the LME that serves the county where you live. You can find the contact information for LMEs at www.dhhs.state.nc.us/mhddsas/lmedirectory.htm or by phoning 919-715-5989

Below is a copy of the Brain Injury Fact Sheet for DHHS/DD/SAS that can be copied and shared.

Have you had a Traumatic Brain Injury?

What supports are available in North Carolina if you have had a traumatic brain injury?

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) oversees the state's public system of services to persons with mental illness, developmental disabilities and addiction disorders.

The state of North Carolina includes traumatic brain injury (TBI) in the definition of developmental disability.

What Types of Support Are Available?

Do you need someone to help you with?

- Social Security Disability Insurance (SSDI)/Supplemental Security Income (SSI)
- In Home or Community Support
- Residential Options
- Finding a Job
- Transportation
- Finding Services (Case Management)

How Do I Access Support and Services?

In North Carolina support is available for eligible individuals of all ages who have sustained a TBI. Call **919-715-5989** to locate the program nearest you. You may also visit www.dhhs.state.nc.us/mhddsas/tbi for more information.

An intake coordinator will ask questions to determine the individual's needs, urgency and eligibility for services. They may ask for medical records documenting the traumatic brain injury.

Brain Injury Association of North Carolina (BIANC)

To find out about resources, contact the Brain Injury Association of North Carolina (BIANC). BIANC is a statewide non-profit agency. It is committed to making a difference in the lives of persons with a brain injury.

A current listing of brain injury support groups can be found on the BIANC Web site. Support groups across the state offer opportunities to meet others in similar circumstances and learn more about brain injury and helpful resources.

There Are Three Regional Family and Community Support Offices of BIANC across the State of North Carolina:

Family and Community Support Office at Carolinas Rehabilitation

1100 Blythe Boulevard
Charlotte, NC 28203
Phone: 704-355-1502 or 1-877-96-BRAIN

Triangle Family and Community Support Office

P.O. Box 10912
Raleigh, NC 27605
Phone: 919-833-9634 or 1-800-377-1464

Eastern Carolina Family and Community Support Office

202 East Arlington, Suite T
Greenville, NC 27834
Phone: 252-439-1900 or 1-800-697-3115

The Family Hotline with BIANC is 1-800-377-1464 and the Web site is www.bianc.net.

This publication was made possible through a grant from the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services.

Project STAR



Carolinas Rehabilitation

704-355-1502

www.carolinasrehabilitation.org

COME CELEBRATE THE SEASON

**THE CHARLOTTE AND UNION COUNTY
BRAIN INJURY SUPPORT GROUPS
INVITE YOU TO JOIN US FOR**

**CHRISTMAS
CELEBRATION 2006**

**THE 9TH ANNUAL CHRISTMAS
CELEBRATION WILL BE ON**

SATURDAY, DECEMBER 2

11:00 AM UNTIL 2:30 PM

AT

**SILER PRESBYTERIAN CHURCH
WESLEY CHAPEL, NC**

There will be



Lots of Food to pig out on!



Music and laughter and visiting with friends!



Santa has agreed to come!



There will be gifts for everyone!

The Celebration is for persons with brain injury and their families from all across North Carolina. We hope you will attend. For additional information or to request your personal invitation with directions to the annual Christmas Celebration contact Project STAR at Carolinas Rehabilitation. 704-355-1502 or by email at

peggy.philbrick@carolinashealthcare.org



SUMMER FUN

The Charlotte Area Brain Injury Association hosted the annual Summer FUN Day at Lake Norman on June 18th. Members from the Charlotte Group along with members from the Lake Norman, Iredell, Cabarrus Stanly, and Union County groups enjoyed waterskiing, boating, kayaking, and swimming.

A special thanks to the Adaptive Sports and Adventures Program at Carolinas Rehabilitation and to Barbara Westphal, "official support group activities coordinator" for organizing the event, and to her husband Bill for cooking around 100 hamburgers and 40 hotdogs!

About

Adaptive Sports & Adventure Program

The Adaptive Sports & Adventure Program (ASAP) is part of Carolinas Rehabilitation. The program creates opportunities for former patients of Carolinas Rehabilitation, and other individuals with disabilities, to develop an active lifestyle through outdoor adventures, sports and recreational activities. ASAP participants may choose from a variety of team and individual sports designed to introduce them to an activity at a comfortable level. The program provides resources reflecting their individual choices and skill level.

Programs include; Wheelchair Rugby, Cycling, Wheelchair basketball, Snow and Water Skiing, Swimming, Fishing, Kayaking, Adaptive golf, Track and Field, Wheelchair Tennis, Power wheelchair soccer and others.

For information about becoming involved with ASAP or volunteering contact Carolinas Rehabilitation at 704-355-1062 or call toll free at 1-877-734-2251 or visit www.carolinasrehabilitation.org

WHAT'S HAPPENING?

UPDATES FROM SUPPORT GROUPS ACROSS THE STATE

The Raleigh Triangle Support Group

The Raleigh Triangle Support Group continues to have new members join the group. Several group members are getting ready for camp and looking forward to spending the weekend with other survivors, family members, and friends. The leadership of this group has been provided by a team of folks over the past several months. Dunella Jones has taken responsibility for planning social and community activities for the group members, including a bingo game and a cook-out and afternoon of fun and games at a local park. BIANC board members Bob Burkhardt and Jaime Hoose as well as Monica and Carolyn McGrath have worked together to plan for speakers or activities and to improve communication for group members.

The Charlotte Area Brain Injury Association

Community activities continue to be a focus of the Charlotte group. The group recently hosted a picnic and with games and water sports. (See Summer Fun) Congratulations to Dan and Angela High on the birth of their baby girl!

The Cary Support Group

BIANC sends a great big thank you to Janice Millns for her efforts to start a new support group in Cary, NC during 2006. Janice has now moved to New Bern and will hopefully be getting involved with the support group and the BIANC office in that area. We wish her well in her new location. Dave Baach is to be congratulated for his efforts to keep the group going. Sandra Farmer attended the group in September and pledged BIANC's help with communication and support if there are individuals who want to continue to meet in Cary.

The High Point Support Group

The High Point support group has 7 members going to the fall camp in Stokesdale Sept. 22-24. We are looking forward to the fellowship, meeting new people, as well as making new friends. We have been having our regular monthly meetings with approximately 20 people attending. Our October meeting will focus on fire prevention and our November meeting will be on the topic of seizures and medications. We will have our annual Christmas party in December. Harris Teeter grocery store continues to sponsor refreshments at these meetings.

The UNC Brain Injury Support Group

Karla Thompson reports that The UNC Brain Injury group has been meeting twice a month since March 2006. We now meet on the second Monday of each month, 1-2 pm, and the third Thursday, 7 - 8p.m. Getting the word out about the group has been a challenge, but we have two volunteers, Philip and Travis, who have been working the phones, calling agencies and survivors we know who might be interested. We are having guest speakers at least once a month through December.

Kerr Lake Support Group

Mike Scott reports a new addition to the Scott family. A baby boy! Carter Edward Scott born was born on Friday, August 25 2006 @ 2:46pm., weighing in at 7lbs and 9oz. Mike reports, "Our group has been getting new members and is growing steady. We have talked about the recent challenges of understanding Medicare Part D the confusion with the Prescription Drug Plan, and also, about the changes in insurance across the board, and helping families and survivors to understand the process. Those are the issues which the group has been focusing on."

Union County Support Network

The Union Group is beginning the process of planning the Christmas Celebration. The Celebration will once again be held at Siler Presbyterian Church Fellowship Hall in Wesley Chapel, NC. A fundraiser brunch to help with the cost of the party will be held on October 29th, also at Siler.

Surviving Angels of Statesville held it's annual Fall picnic on September 19th at Caldwell Park in Statesville. The group continues to do a lot of community outreach and education for both group members and the community.

Would you like to share what your Support Group is doing with other Support Group Leaders across the state? If your group has done something great or is planning an event that you think would be of interest to other group leaders, please us know. Email the information to peggy.philbrick@carolinashhealthcare.org or phone us at 704-355-4354.

ACCENT ON ADVOCACY

FUNDING...the fight that never ends

As Support Group Leaders, you have been bombarded with e-mails and alerts from advocacy organizations urging you to get your group involved in campaigns to either try to preserve TBI funding or get it increased, both at a federal and state level. There have been successes and there have been failures.

One of the most significant successes has been preserving the federal funds in the TBI Act. These funds provide grants to states for programs that serve the TBI population, and insure that the Centers for Disease Control can continue to support brain injury prevention and education programs.

You will soon start to see information on the campaign to insure these funds into and past 2007. It is important to get your support group involved in these efforts. The impact the stories and experiences of persons with brain injury and their families can have on legislators is an important factor in securing funding.

In North Carolina, one of the most disappointing situations in regards to funding was a legislative bill to appropriate \$2,800,000 from the NC General Fund to NC Department of Mental Health to fund brain injury services got hung up in a committee and did not clear the committee in time to be heard or voted on prior to the legislative recess. These funds would have given MH/DD/SAS the opportunity to greatly enhance brain injury services.

Now is the time to contact your local representatives to discuss the need for additional funding for TBI. They are in recess until January 24th, and while they are still involved in many aspects of their elected offices, such as committees and other duties, they spend more time in their home districts, so are more accessible on a local level. Here are a few tips on communicating the need for increased TBI funds:

- Be short and sweet and to the point. Don't ramble. Be sincere and avoid being emotional.
- Be prepared to be specific about the needs and what they can do to help.
- Offer to speak before committees when bills affecting TBI issues are being considered.

To find information on how to contact your local representative log on to the NC Legislative Homepage at <http://www.ncga.state.nc.us/>
US Legislators <http://www.senate.gov/index.htm>

Tips and Tidbits

Did you know...

The Federal TBI Program's Traumatic Brain Injury Technical Assistance Center offers a quarterly update on what is happening within Federal agencies that can impact services for persons with TBI. The information includes a legislative tracking grid which can be used to follow funding and other legislation. A link to this quarterly update can be found on the NASHIA website at <http://www.nashia.org>

Some Great Websites...

www.familyvillage.com

Family Village is a global community of disability-related resources, this site has links to all sorts of information by specific diagnosis. Check out the Brain Injury resources.

www.caregiver.com

Family Caregiver Alliance offers links to many websites that offer caregiver support and offers a chance to sign up for a weekly online newsletter for caregivers.

www.familiesusa.org

Families USA offers information on legislation and other issues of concern for persons with disabilities.

www.birf.info

Brain Injury Resource Foundation – a site that offers general information as well as information on healthcare services and advocacy issues.

www.headinjury.com

Head Injury Hotline is a site that offers links to many information sites and other resources.

www.tbiguide.com

Traumatic Brain Injury Survival Guide by Dr. Glen Johnson

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

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

Up-coming Events

SUPPORT GROUP LEADERS MEETING

Saturday October 28, 2003

9:00 until 2:00

Carolinas Rehabilitation

1100 Blythe Boulevard

Charlotte, NC

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

**Beyond Tomorrow: Planning for the time when you can no longer provide care
A workshop for caregivers and family members of persons with brain injury
Coming in March 2007, watch for further information**