

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 Resource Center in Charlotte.

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Brain Injury Association of North Carolina Update

By Sandra Farmer, President

I would like to thank all the support group members, friends and families who turned out to help with our annual Walk and Roll-a-thons and the Ride for the Rock cycling event. We had over 900 attendees across the state who either attended a Walk and Roll-athon or the Ride for the Rock. We met our goal of raising over \$60,000 to help us better serve the people of NC who live with the effects of a brain injury. Your efforts and dedication allow us help educate more people about the needs of individuals living with a brain injury and also to help improve and expand services in our state.

We have good news about the results of our advocacy efforts at the Federal level. Hard work by the Brain Injury Association of America and other brain injury advocacy groups resulted in renewal of the Federal TBI act with a small increase in funding from \$9 million to \$10 million dollars in spite of the need to reduce the national budget. Karen Harrington from the Asheville office and I traveled to Washington during March and met with several of our elected representatives who pledged their support for the TBI Act. Senator Kay Hagan, Representative Heath Schuler and Representative Walter Jones all indicated that they would protect the money allocated for brain injury and we greatly appreciate their support.

At the state level we are working hard to support passage of several key bills this session including one for a TBI Medicaid Waiver, a sports concussion bill and a bill to expand services for the military service members. It looks like the Gfeller-Waller bill which promotes the development of an athletic concussion safety training program and concussion safety requirements for interscholastic athletic competition will pass this session. This bill will help prevent and manage concussions which are a form of brain injury in our student athletes. The NFL, NHL, Carolina Panthers, Carolina Hurricanes, USA Baseball, the NC Athletic Trainers Association and the NC High School Athletic Association all support the bill and each of these organizations can help us increase awareness about the causes and consequences of brain injury.

It will be a greater challenge to obtain passage of the TBI Waiver bill and the Military Service bill because they both require the legislature to provide funding for their programs. The current economic conditions will make it difficult for new programs to be funded so we need to be certain that our elected officials are aware of the needs of people with brain injuries in North Carolina. The TBI Waiver Bill is now being reviewed in the NC Senate and we need to let our Senators know that we need additional funding to implement the Waiver. Personal stories about the need for care are the best way to help the legislators understand why we need additional funds. I want to thank each of you who have already contacted your representatives for the Senate and to encourage everyone else to call and/or email their Senators at www.ncleg.gov and ask them to support and fund the TBI Medicaid Waiver House Bill 355.

Thank you for all of your efforts to make North Carolina a better place for people with brain injuries.
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

The Governors Advisory Council has been hard at work on trying to establish a brain injury Medicaid waiver which would allow flexibility in the services provided to persons with brain injury. This is a major undertaking on several fronts, involving many people and steps. You have been urged to contact legislators about this and as events unfold, your help in advocating with legislators will be even more important. Stay tuned for more information.

SupportLink E-mail

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

E-Mail

My group is losing the location where it has met for many years. Not only is it a good location for the meetings, it also has snack machines so refreshments have not been necessary. We need to look for another location, but in our community there is really not much to find. No one has room at their house and the churches with meeting space are mostly booked. The times they can offer will not work with our meeting times. Any suggestions?

SupportLink Response:

Many groups meet at hospitals and some at area agencies, such as the offices of service providers or the LME for their area. You may want to contact some of the physicians and some of the agencies to see if they have space or suggestions for where you may find space for your meetings. Brainstorming with group members to come up with people and agencies to contact could also be a way to come up with ideas on how to find a new location.

Changes are often hard, but can be a positive thing also, if properly framed. It is important to be flexible and think outside the box. It may be necessary to look at changing meeting times if the group is agreeable.

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

For additional information on The Brain Injury Association of North Carolina and to see what events are planned please visit the Association website at www.bianc.net

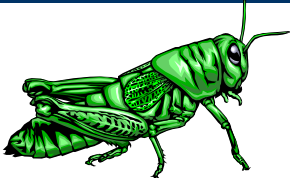
Brain Injury Association of NC Resource Centers	
Asheville	1-866-890-7801
Charlotte	1-877-962-7246
Greenville	1-800-697-3115
Raleigh	1-800-377-1464

You can contact the Resource Center nearest you for resource information, or visit the BIANC website at www.bianc.net

Advocacy Today Support Groups as Advocates

Over the past several editions of SupportLink, we have urged support groups to contact and meet with their local legislators. That is even more important now that there have been several bills introduced with brain injury as a focus. Remind the legislators who represent you that brain injury is important and that you expect them to support legislation favorable to brain injury. Visit the websites below, identify your representatives, and make contact with them. Remember putting a face on brain injury can go a long way in securing support for legislation that will benefit persons with brain injury.

North Carolina General Assembly <http://www.ncga.state.nc.us/>
US Congress <http://www.house.gov/>
US Senate <http://www.senate.gov/>



FROM BIAA on Grasshopper?

New Action Sheets from BIAA

BIAA has made advocating at a national level easier by placing “Action” sheets on their website. The sheets can be downloaded and used as tools when talking to legislators about brain injury issues.

Often persons with brain injury and family members do not know how or what to advocate for brain injury programs or services. These sheets state the position of BIAA on some critical issues and why the issue is important.

One sheet encourages membership in the Congressional Brain Injury Taskforce, a bi-partisan caucus made up of over 120 members of Congress. The task force states its mission is “to further education and awareness of brain injury and support funding for basic and applied research, brain injury rehabilitation and the development of a cure”. BIAA has developed a sheet that can be shared with legislators to encourage them to participate in this task force. North Carolina has only two of thirteen members of Congress on the Brain Injury Task Force: Congressman David Price and Congressman Walter Jones. Neither of the North Carolina Senators is on the taskforce, even though it is open to members of the Senate. The sheet can be mailed or emailed to representatives to urge them to join the task force. Consider asking your group members to contact their representatives and encourage membership.

Other sheets address “Increased Access to Care for Individuals with Brain Injury” and “Sustaining and Bolstering TBI Act Programs”. BIAA counts on grassroots advocates to show members of Congress how important brain injury is to their constituents. These sheets help make that easier.

To locate and download the sheets, go to the Brain Injury Association of America website at www.biaa.org and click on Advocacy and Government Affairs.

Upcoming Events



**ANNUAL SUMMER PICNIC
SATURDAY, JUNE 18, 2011
12:00 PM until 4:00 PM
Lake Norman YMCA
21300 Davidson Street
Cornelius, NC**



Come join in the fun. Lots of food, water activities including water skiing, boating, and a great time to greet and catch up with old friends and meet and make new ones.
For additional information or to make reservations contact Barbara Westphal at 704-547-1563

Camp Carefree Brain Injury Survivors and Family Camp Stokesdale, North Carolina September 16-18, 2011

Registration Forms are now on the Brain Injury Association of NC website at www.bianc.net

Register early as space is limited!



Photos from Camp
2010



Brain Injury Association of North Carolina Symposium October 27 & 28, 2011

Watch for additional details www.bianc.net or contact Shawn Chase at 1-800-377-1464



**Christmas Celebration 2011
December 3, 2011
Wesley Chapel, NC
Watch for additional information**

Recently the Brain Injury Association of NC asked group leaders and advocates to participate in a survey. Thank you to those who participated. Below are the Results. We hope to use the results to better support our group leaders!

BI Support Group Leader Survey: May 2011

30 Support Group leaders/advocates completed the on-line Support Group Leader survey.

1. Do you feel your support group has benefited from being included in the network with BIANC offices and other support groups and support group leaders around the state?

YES 100% NO 0%

Please describe benefits to your group. (Responses are summarized below)

Information to share. Good resources for severe TBI patients. More military references. Support with group events. Newsletters sent for group members. The updates and information sent and email distribution list are great. Insight on new and better ways to benefit the group. Working on the Walk & Rollathon demonstrated that our group can work together to achieve a successful goal. Helps us to be informed about changes and things that are going on. We have a close bond with other support groups in our area-BIANC has a presence. We benefit from the participation of Sandie Worthington from the local BIANC chapter office. Having contact with the network helps to keep everyone "in the loop". Ideas for meeting content. I get good ideas for speakers and I love to visit other groups.

2. BIANC (Brain Injury Association of NC) has a website at www.bianc.net with information about brain injury and a specific section on support groups. Have you used the website for information for your group or yourself? (Check any that apply)...

I have not found helpful information on website	0%
Visit website often - found helpful information	26.7%
Visited website a few times - found helpful information	53.3%
Never visited website	16.7%
I recommend website to others	43.3%

What have you found helpful on the website? What would you like to see on the website?

The resource guide, mostly. Community resources. Info related to brain injury. Event listings. Information on yearly conference

Current resources and research. I print out BIANC membership forms and any upcoming events to share with group members. I direct individuals to the Resource Directory on a regular basis. I plan to visit website in the near future. Good ideas for speakers. I like the way it keeps us informed. Would like to know what other support groups are doing & what activities are they participating in.

Website provides updates on events and information about resources. I would like to see more suggestions for activities

Info on events is always current and very helpful. Easy links to BIAUSA and other sites, events and newsletters, Resource book, links.

3. BIANC has a quarterly newsletter, Starting Point, mailed to members. Each support group is mailed 15 copies to share with their group members each quarter. The Starting Point is also on the BIANC website. Is your group receiving these newsletters?

Yes - I receive them and share with group	80%
Yes - Someone receives them and shares with group	10%
No - I have not seen any newsletters at group meetings	3.3%
I don't know	6.7%

What articles or information have you enjoyed or found useful in the Starting Point?

Articles about aspects of BI. Stories about people highlighted. All of it. Info on how to get in touch with NC Legislators, Federal Rep. & Senators. Personal stories and resources are most helpful. Articles focusing on rehabilitation and coping as adult with ABI.

I encourage individuals to become members of BIANC so many receive the newsletter already. My suggestion is handing out these in Dr. Offices, Hospitals, Conferences. None so far. Informational info. Personal stories are interesting. Knowing who supports BIANC is always good to know. Survivor writing, articles by professionals in NC. Pictures.

4. Is the information in the Starting Point useful to you and to your group members? (Check all that apply)

Always has useful information	60%
Sometimes has useful information	36.7%
I do not find the newsletter helpful	0%
I do not have time to read the newsletter	0%
I do not receive the newsletter	3.3%

What articles or information would you like to see in the Starting Point?

More personal stories from individual support groups. More info to help survivors and families. Articles from professionals.

I think info is not relevant to older survivors but leans toward children, teens, sports. I like the message from. How to help with inter-personal relations. More articles to supplement the ads. More survivor stories and information on living with brain injury (especially like series by physicians or psychologist). More research and useful tips for helping those with brain injuries or motivational.

5. SupportLink is an electronic newsletter which has been emailed (or mailed) to support group leaders and advocates quarterly. SupportLink is also posted on the BIANC website. Have you found the SupportLink newsletter helpful to you in your role as support group leader?

Always has useful information	43.3%
Sometimes has useful information	20%
I do not find the newsletter helpful	0%
I do not have time to read the newsletter	3.3%
I do not receive the newsletter	33.3%

How has Support Link been helpful to your group?

It's a great resource but the file size is large and I have had trouble printing it in the past. Has a lot of good info and how we can contact BIANC and the National Brain Injury Group. I distribute this newsletter at our monthly meetings. Everyone likes the newsletter and takes a copy. Chocked full of great info, Inspiration and news. Good information on upcoming events

6. Care Notes is the newsletter which has been created for Caregivers.

I receive Care Notes and always find it helpful	38.5%
I sometimes find helpful information	14.4%
I do not find Care Notes helpful	0%
I do not have time to read Care Notes	3.8%
Do not receive Care Notes	42.3%

What have you found helpful in Care Notes?

Things I did not or have not thought about. I distribute this newsletter at our monthly meetings. Caregivers and survivors of brain injury take a copy. To learn about what helps others

7. How would you prefer to keep in communication with BIANC offices and other support group leaders?

Yahoo group or message board for SG leaders	16, 7%.
Monthly Teleconference calls Noon - 1pm	20%
Monthly Teleconference calls 5:00-6:00pm	6.7%
Annual State Support Group Leader training at Camp Carefree	33.3%
Regional Support Group Leader trainings	56.7%
List Serve via Email	56.7%
Monthly email blasts/Email me with any information	86.7%

How would you like to communicate with other support group leaders or BIANC?

The teleconference calls did not have very much participation. It is easier to communicate via email. Meetings or possibly Skype conference calls would be helpful. I think the current system works. Trainings. email

8. If you attended any of the Support Group leader trainings in the past, did you find them helpful?

Found training very helpful	60%
I attended training but did not find it helpful	6.7%
I have not attended any training events	33.3%

What training would you like to have to make your group more meaningful?

Learning about programs that are entertaining and beneficial. How to get more people interested in attending meetings.

At our January Triangle support group meeting we welcomed chiropractor Dr. Patrick Gallagher. Dr. Gallagher contacted us at BIANC before Christmas about wanting to present to our group. He practices a chiropractic technique called "atlas orthogonal" which deals with alignment of the C-1 vertebrae. Dr. Gallagher has a practice in Apex and one in Goldsboro, and he is currently treating several patients at ReNu Life in Goldsboro with good results. Dr. Gallagher is a survivor himself, having been involved in a motorcycle accident at the age of 17 without a helmet.

Our February meeting was an open discussion forum, and we had a big turnout. We discussed the upcoming Walk & Roll-athons, and walked everyone through how to organize teams for the Walks, as well as how to register themselves and family. I helped answer questions from SG members including Walk locations, expected turnout, and info on the 5k adjoining the Raleigh Walk. We also began talking about Camp coming up in September. As a wrap up, I explained the "Widgie Method" of fundraising. Our top fund raiser for the state, Mr. Widgie Kornegay of Rocky Mount, has a "method" that he uses, and with his permission, I explained the "don't take no for an answer" approach to our group!

Our March meeting was led by Susan Fewell and Abby Levinson, a BIANC volunteer who has done a wonderful job for us! They talked about the current Walks going on in the state. Mr. Jonathan Shores of Raleigh was the featured guest speaker, and did a wonderful job talking with fellow survivors!

The April meeting was one of the best meetings that I have attended yet and was a discussion on memory and tools to aide memory. Group attendees had some great ideas for methods of remembering everything from names to birthdays to daily tasks, and the info will be featured in our upcoming *Starting Point* newsletter!

For our May meeting, we were happy to have Ms. Ann Cralidis, a doctoral candidate in Communication Science and Disorders at UNCG. Ms. Cralidis spoke with the group on the effects of working memory on verbal fluency after TBI. The group enjoyed her talk and had some great questions and feedback for her.

Camp is Coming up Soon ...spread the news!

Camp planning is well underway. The Camp Committee is busy working out every detail to make sure that Camp Carefree is as much fun as always. No detail is too small for the committee to discuss and detail. Whether it be safety, food, golf carts, and even the music for the Friday Night Gala, the committee is taking steps to insure that even the smallest item is handled.

We are proud to announce that the cooks will return and the food should be good, as well as plentiful. IQUOLIOC will once again be on hand to make the activities fun and safe for all who want to participate, and the horses will be there for riding. Crafty people will oversee the craft venue.

All that is left is for you to spread the word. Encourage group members to register early as the space is limited.

Brain Injury Camp at Camp Carefree 2011

September 16-18, 2011

Reserve your spot NOW!

For additional information contact Susan Fewell at 1-800-377-1464

Download Application at www.bianc.net

Camp Committee members:

BIANC Raleigh	Susan Fewell
BIANC Asheville	Karen Harrington
BIANC Greenville	Sandie Worthington
BIANC Charlotte	Peggy Philbrick
Camp Director:	Donna White
Pilot Clubs of NC	Dee Ann Stafford
IQUOLIOC:	Tammy Cleveland
BIANC volunteer:	Hank Baker
BIANC Ombudsman	Jennifer Nyland

Taking Brain Injury Awareness Month Seriously...A Group Recap

By: Nadine Cherry, Rowan County Brain Injury Support Group

For the month of March, Brain Injury Awareness Month, the Rowan Brain Injury Support Group chose this year to show support by helping the Concord Brain/Spinal Cord Injury Support Group with the first Walk & Roll-a-thon ever held in this area of the state. After a lot of debate and planning as to whether we could pull it off, the Concord Group decided we would do it. There were over 150 people at the walk which was held at Frank Liske Park in Concord on March 19th. It turned out to be a beautiful day to hold a walk. The actual walk or roll (for those in wheel or power chairs who could make it thru the gravel and rocks) was a lap around the lake.

I was humbled to be chosen by the Concord Group as one of the three people selected to carry the banner. The March winds did not want to cooperate with us, as it was rough trying to keep the banner straight. We were not able to get a good picture of the banner but we have talked about getting together again and see if we can get a better picture of the banner.

We had some great sponsors, plenty of food, entertainment, and activities. Larry Sprinkle, Meteorologist from WCNC in Charlotte was our MC and he did a fantastic job. Our DJ, was Tim Troutman of CHARLOTTEOUTDOORSTAGE.COM. Without hesitation or reservation, I believe I can safely say this will be an annual event for this area of the state.

Mary Sechler and Nadine Cherry, also for March activities, attended the March meeting of PBH Advisory Council Meeting in Salisbury. Martin Foil, Executive Director of Hinds' Feet Farm in Huntersville was the speaker and gave a presentation on Brain Injury. They also attended the Advocacy Group meeting at the Rufty Homes Center, located in Salisbury. Centralina Ombudsman Patricia Cowan led the meeting. A member of the group also attended an outing with Cabarrus County Safe Kids handing out information and answering questions on brain injuries, concussions and about wearing helmets.

Mary and Nadine were each recognized at the Arc of Rowan's annual dinner in March. Each received the volunteer of the year award from the Arc.

After the Walk & Roll-a-Thon was over on their way home Mary & Nadine visited the Pill Drop in Landis which was sponsored by the Landis Police Dept. Officer Brandon Linn accepted the old medicines.

The group again this year received proclamations from the Town of Landis and Rowan County Commissioners declaring March as Brain Injury Awareness Month.

Other activities for the month include speaking about the Rowan Brain Injury Support Group and handing out the group's cards at meetings members attended. Meetings members attended include; Cabarrus Advisory Council Meeting, CIT Steering Committee Meeting, PBH Continuum of Care Meeting, Clinical Advisory Committee Meeting, CIT Continuing Education Meeting, Police & Fire Academy in Charlotte, Western Ridge CFAC meeting in Gastonia, NAMI Conference "Power to Change Minds" in Asheville, Domestic Violence Training sponsored by the Family Crisis Council, attended the open house and toured Daymark in Rowan County, PBH Housing Forum, the car seat and safety check in Cabarrus County, Faith Community Health Promoter's Meeting, CFAC meeting.

The group owes a big thank you to group member, Mary Sechler for all the meetings she attends.



Transitions...a time for change

By; Peggy Philbrick and Shawn Chase

I have always had a love affair with words. From a very early age, words and their varied meanings captured my interest. I would hear or read a word that for whatever reason, would stick in my head. I would look up the word in the dictionary to get the meaning. I would then try to figure out ways to incorporate the word into my vocabulary by creating imaginary scenes in which the word would be appropriate within the scope of a conversation. I would wait until the opportunity presented itself and spring my newly learned word upon whoever I was conversing with. My family and friends tolerated my somewhat unusual “quirk”, but I am sure they were laughing when I walked away. My little secret is...I still do it!

The word for this time is ***Transitions***. I love the word and all that it implies. Life situations, personal, environmental and work, are ever changing and melding the old into new. Everything we do is a part the transition process. Transition is occurring each minute of every day, even if we seldom pause to think about it. Whether it will be a small thing, like completing one task that creates the foundation for the next task, or major life impacting events, transition means that changes are in progress.

BIANC and Project Star are working on some important transitions designed to get information out to group leaders in a more timely manner and to put into place some “new” ways of doing things designed to improve the way we communicate and support our Support Group Leaders.

You recently filled out a survey about the supports that BIANC has provided for group leaders. In many cases your answers were as we expected, but in others areas your answers made us rethink our methods of communicating and providing information to our Support Group Network. (Results from the survey are on pages 5 & 6)

Some of the transitions you will see will include:

- The quarterly SupportLink newsletter will be replaced by electronic information sharing. This transition will help get information to group leaders in a more timely manner.
- An updated Website that will be much more interactive and easier to navigate is being designed and due to go on line soon.
- Quarterly calls to group leaders just to touch base and discuss any concerns or accomplishments.

One other transition that will occur this fall is a personal one for me. In September, I will be retiring. I will be leaving my position with Project STAR and the BIANC Resource Office. I will be transitioning the role of Support Group Liaison to Shawn Chase (more about Shawn later). My role will change from being an employee of Project STAR to that of a volunteer. I plan to volunteer as an Ombudsman and to work as an advocate to improve awareness and access to appropriate services for persons with brain injury. I will continue to serve on the Governors Advisory Council for Brain Injury and will continue to support BIANC in any way I can.

I would like to thank all of you awesome group leaders for all that you do to support those in your community with brain injury and their families. It has been a privilege to work with you. I am excited about my upcoming transition, but it is not without some degree of separation anxiety. On the upside, I am not going away, just “TRANSITIONING”!

Thank You!

Peggy Philbrick

Now a note from Shawn...

“Hello from the BIANC Raleigh Office! I am Shawn Chase, the State Training Coordinator and I am excited about all of the happenings around the state! Part of my position is to reach out to support groups throughout the state, and I have enjoyed visiting different groups in the area since I came on late last year. The Triangle Support Group based here in Raleigh has been wonderful and I look forward to attending every month! I have had a chance to visit the Cary, High Point, and Rocky Mount groups as well, and I have plans on visiting Wilmington coming up in June. As Training Coordinator, I hope to visit as many groups as possible and to meet as many folks as I can! We at BIANC hope to be able to visit every group this year, so please contact me at shawn.chase@bianc.net with any requests for training or questions!

Walk & Roll-a-thons once again a Great Success

Article and photos submitted by; Susan Fewell, BIANC

March was Brain Injury Awareness month once again in 2011 and BIANC helped plan and participated in 5 Walk & Roll-a-thons across NC to celebrate and raise awareness. Events were held during March and April in Raleigh, Greenville, Asheville, Concord and for the Triad area in Greensboro. The Statewide sponsor was Charles G. Monnett, III and Associates, and 27 other Star Partners helped to fund the events. There were 856 participants documented and together with the generous sponsors raised over \$55,000. Our biggest fundraiser was Widgie Kornegay, from Rocky Mount. He used his "don't take no for an answer approach" to gather 300+ donations totaling over \$10,000. Actual expenses for the 5 events were \$11,000 and another \$10,000 was donated in food, drinks, raffle prizes, services and media. How is the money used by BIANC? 62% of funds raised go to client support and 31% is for outreach and education, while only 7% of money goes to administrative costs. BIANC pays for the annual Camp Carefree which costs more than \$10,000 for the weekend retreat, for regional recreational events and provides local support group grants for awareness or fitness projects. BIANC is seeking to expand outreach to military service members and their families, rehab hospitals and services, and nursing homes and our aging population. We are targeting coaches and sports programs and schools to provide education on sports concussion and prevention of brain injuries. We plan to re-print our valuable Resource Book, upgrade our website capabilities and continue to be a voice for all people with brain injuries and their families. The Brain Injury Association of NC extends our deepest appreciation and thanks to each and every sponsor, Pilot club, volunteer, team, display booth and pledge earner who helped to make this possible. Many local support groups and individuals across NC rose to the occasion to make each event memorable and to assist with planning and organization. Thank you!



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.

Project STAR



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.

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