



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

Brain Injury Family and Community Support Offices

North Carolina has a lot going on in the area of brain injury. There are ongoing efforts to improve supports and services for persons with brain injury as well as in the areas of education and awareness. One key support for persons with brain injury is The Brain Injury Association of North Carolina.

The Brain Injury Association of North Carolina (BIANC) provides resource and referral information through four Family and Community Support Offices (FCSOs) across the state. The offices, located in Raleigh, Charlotte, Asheville and Greenville, can provide persons with brain injury and their families with information and help direct them toward the appropriate service or agency to meet their need. There is also a Brain Injury Resource Office located in Winston Salem.

Staff at the four Family and Community Support Offices are well versed in available resources and have years of experience working with brain injury survivors and their families. They use this experience to determine what referrals best fit the needs of those who contact the FSCO.

The main office of BIANC is in Raleigh and houses the Central North Carolina FSCO. In addition to resource and referral information provided through the FSCO, BIANC provides other supports for persons with brain injury.

Visit the BIANC website at www.bianc.net for additional information.

If you have questions, or need information, you can contact your regional Family and Community Support office.

Asheville	866-890-7801
Charlotte	877-962-7246
Greenville	800-691-3115
Raleigh	800-377-1464
Triad Volunteer Center	
	336-882-1911

Hot Wheels.....



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 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 van conversion process. Persons with mobility difficulty 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!**



Think Green

Save a Tree . . .

Several years ago, when Project STAR started to publish SupportLink, we had a distribution list of only several dozen. The most appropriate way to get the newsletter out was to mail it to those we had identified as caregivers for family members with brain injury. Since that time, the distribution list for the newsletter has continued to grow and now exceeds 350 recipients.

While, for many people, the mailed hard copy of CareNotes may be the best option, we now also have the option of sending it electronically through an email distribution list.

There are many advantages to the electronic email version, the greatest of which is environmental. For each edition, we use approximately 2000 sheets of paper, 380 envelopes and about \$160 in postage. The electronic version uses no paper, unless those who receive it choose to print it, no envelopes and delivery is free through email.

Would you like to receive CareNotes via email? If you would like to be added to the electronic distribution list please let us know by sending us an email. Just write Electronic CareNotes in the subject line and email it to peggy.philbrick@carolinashealthcare.org Your email address will not be shared with others and will only be used for CareNotes or other caregiver information.

You can find the current and archived editions of CareNotes on the Brain Injury Association of website at www.bianc.net



Congratulations Hinds' Feet Farm

Hinds' Feet Farm has announced that both the Huntersville and Asheville Day Programs have earned national accreditation from the Commission on Accreditation of Rehabilitation Facilities (CARF), which sets high standards for programs in the rehabilitation service delivery system. Hinds' Feet Farm has achieved a 3 year accreditation from CARF under the classification of Community Services: Community Integration.

Having achieved this prestigious accreditation reiterates the quality of the innovative program that Hinds' Feet offers to persons with brain injury in the Asheville and Charlotte areas.

CARF describes community integration programs as programs designed to help persons to optimize their personal, social, and vocational competency to live successfully in the community. Persons served are active partners in determining the activities they desire to participate in.

Community integration provides opportunities for community participation of the persons served. CARF defines the scope of these services based on the identified needs and desires of the persons served. A person may participate in a variety of community life experiences or interactions that enhance their ability to live successfully in their home community.

Congratulations on a job well done!

For additional information on Hinds' Feet Farm visit their website at www.hindsfeetfarm.org or contact Will DeGrauw at 704-992-1424

Caregivers and Loneliness...something to share

Caregiving can be required on different levels. Some caregiving is as simple as random oversight or minimal assistance with bill paying or self-care, while other caregivers provide hands on care that requires total assistance, or somewhere in between.

For those who provide the highest level of caregiving, it can be an exhausting, demanding, stressful, and all-consuming task, but often the most difficult thing a total care caregiver faces is loneliness and social isolation.

Loneliness can cause a myriad of health issues, many of which can have long-term consequences. Caregivers are often reluctant to share their feelings, especially something as personal as emotional needs, thus the emotional side of caregiving is rarely discussed. Whether due to reluctance, on the part of the caregiver, to discuss anything that may appear as a weakness, or because of the natural instinct people have to avoid “sticky personal conversations”, even those closest to the caregiver may be unaware of the emotional rollercoaster caregivers often ride.

If a caregiver is asked, “What can I do to help?” often the answer is “Nothing, I have it covered”, or something to that effect. That may be true at the onset of long-term caregiving, but over time, filling the role of hands-on caregiver can take a toll. What may start as a supported or shared caregiving effort can quickly become a one-person show. Friends and families may continue to be involved for a while, but as the permanence of the need and the ongoing daily demand of caregiving become apparent, they gradually drift back to their own lives, with little or no awareness of the toll long-term caregiving can have on the individual providing most of the care.

In many cases, family and friends are very unaware of how disconnected and lonely a caregiver can become. There are many reasons for this, but a very common one is that the caregiver fails to acknowledge how all-consuming caregiving can become, even to him or herself, and when help is offered, brushes the offer off as not being sincere or just making conversation.

People need people, that is a given. People are social beings, some more than others, but connectivity to family, friends and community is an important part of our mental wellbeing. Without these connections and interactions, a caregiver can quickly begin to feel isolated and depressed and develop a deep sense of loneliness. Caregivers are at high risk for mental and physical health problems and are less likely to care for their own health than the general population.

If you are a caregiver, you have a responsibility to yourself as well as to the loved one you care for. If you do not care for yourself, you will lessen your ability to provide care over the long haul. Making use of offered help can make a lot of difference in the wellbeing of the caregiver.

If someone asks how he or she can help, assume they mean it and take advantage of the chance to do a little “self-care”. Make copies of the list below and put them on the refrigerator, and when someone ask “What can I do to help?” make the assumption that they are sincere and give them a copy the list, or even better make your own list!

Cut Here

You asked me What You Can Do to Help

- **Provide some Respite:** Visit with the person I provide care for while I have some “ME” time.
- **Bring lunch and stay to eat with me:** Don’t just drop off lunch or dinner, sit and talk with me while we share the meal.
- **Call me once a week just to catch up:** You don’t have to talk long, just bring me up to date on what is going on in the outside world and with those mutual people in our lives.
- **Take me out to a movie:** When someone is available to fill in as caregiver, I would like to see a movie that is not on its 15th rerun on Lifetime Movie Network.
- **Arrange a night out once a month:** Arrange alternate caregivers so I can go out to dinner or to a theater or sporting event occasionally.
- **Come over and play cards or board games with me:** Having something to do besides watch TV would be great. Arrange for a game night once in a while.
- **Set up 3 or 4 way calls so that I can feel part of a conversation:** Having a random conversation with a group friends or family is something I would love to do. Just make sure it is at a time when I am available to enjoy it without interruptions.
- **Arrange for me to have time to pursue my hobby:** I would like to get involved in some of the things I used to do.

Annual Brain Injury Survivors Retreat



Join the Fun at Camp Carefree
The Brain Injury Association of
North Carolina
Presents

“Life is an Adventure”
September 17, 18 & 19
Stokesdale, North Carolina

Camp Carefree is for persons with brain injury and their families. The camp is ADA accessible and activities are designed to provide fun for everyone. For additional information contact BIANC at 800-377-1464 or visit the website at www.bianc.net Space is limited so register today!

Pictures from past retreats:



COME CELEBRATE THE SEASON

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

CHRISTMAS CELEBRATION 2010

THE 14TH ANNUAL CHRISTMAS CELEBRATION

WILL BE ON

SATURDAY, DECEMBER 4

11:00 AM UNTIL 3:00 PM

AT

SILER PRESBYTERIAN CHURCH

WESLEY CHAPEL, NC

There will be



Lots of Food



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 own 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

Caregivers as Enablers...the wind beneath their wings

The word enable has gotten a bad rap, and maybe, in some cases, that rap is justified. The term is used to describe those who turn a blind eye to negative behaviors or choose to support the poor choices of others. Whether by accepting the situation as the status quo, or contributing the situation by offering monetary support or making excuses, they enable negative and often detrimental conduct.

The Merriam-Webster's online dictionary defines the word "enable" as "to provide with the means or opportunity or to make things possible, practical, or easy", and while this can apply to any situation where support and assistance is provided, it takes on a totally new light when applied to those who "enable" through caregiving.

Persons with brain injury often credit their spouse, parents or other family members as being instrumental in their ability to thrive after their injury, and research has clearly shown that family support makes a tremendous difference in the recovery process. As early as 1988, the late Mitchell Rosenthal, PhD, a renowned expert in brain injury, who at his death was the Chief Operating Officer for Kessler Medical Rehabilitation Research and Education Corporation cited family involvement as a critical determinant in the ability to achieve success in the rehabilitation of a person with brain injury. (Journal of Head Trauma 1988-3(4) 42-50)

Family caregiving "enables" many things, which can include the ability to live at home, participate in the community, and be successful in returning to work or other pre-injury activities.

At a recent support group meeting, a brain injury survivor credited his wife as being "his guide" through his recovery. He talked about how she had refused to let him give up when he found it difficult to walk, how she refused to let him get caught up in feeling sorry for himself, and stated that what amazed him most was her unwavering belief in his ability to regain life as it was before his injury. He stated that even when she was dealing with his incontinence, anger and frustration and was facing financial difficulties, she never failed to be his coach and cheerleader. Her determination and support has enabled him to recover well enough to return to work.

Caregivers are often facilitators who enable the person for whom they provide care to receive needed medical care or community supports. They enable by advocating for, and insuring that physical, medical and personal needs are met. Making sure that these needs are met is a vital part of caregiving. This is an example of enabling that helps improve the reputation of the word enable. Many persons with brain injury would be unable to secure this on their own.

Caregivers can be encouragers. They offer support and applaud achievements. Belief in the ability to achieve can become a self-fulfilling prophecy. Just as a good baseball coach can take an inept eight year old and enable him to become a star player, a good caregiver can enable a person with brain injury to achieve their maximum potential. Many times the accomplishments exceed what many would have thought possible.

A lot of songs have been written attributing the support and encouragement of someone else as a key factor in enabling personal success, none more appropriate than a Grammy winning tune penned by Jeff Selbar and Larry Henley and made famous by Bette Midler. The song, which was used as a feature song in the movie "Beaches", is about selfless support that enables the success of another, the type of enabling support caregivers can provide in the lives of a loved one with brain injury. They can truly be described, as the brain injury survivor at the support group meeting described his wife; "She really is, just like that song says, "The Wind Beneath My Wings"."

HELP Wanted...help plan a Family Brain Injury Conference

Have you ever looked over a conference brochure and thought, "This is good information, but it is just not the information I need"? Often that is the case, especially with the focus of many conferences being education for professionals, with family and survivor information secondary to that focus.

Carolinas Rehabilitation, through the Carolinas Brain Injury Model Systems Project has spent the past several years looking at relationships and family issues after brain injury, and has learned that are many topics about which families and persons with brain injury need information.

After looking at research information, a list of possible topics for the conference was compiled. However, as the conference committee was discussing the topics, it became apparent that it is **YOU, the families and survivors of brain injury**, who should guide the selection of the content of the conference.

Enclosed in this edition of CareNotes you will find a postcard survey that lists possible topics for the conference sessions. Please take just a minute of your time and complete the survey. Tape the open end, stamp it, and mail it back to the Conference committee. Your feedback is valuable. Now is your chance to help design a conference especially for families living with brain injury.

Thank you in advance for your feedback.

Carolinas Rehabilitation Model Systems Conference Committee



Carolinas Rehabilitation

Uncompromising Excellence. Commitment to Care.