



CARE NOTES

A Newsletter for Family Caregivers of Persons with Brain Injury

We are excited to offer another edition of Care Notes...it is our goal to offer articles of interest, special information, and tips that will be appealing and relevant for brain injury survivors and caregivers in our area.

With summer quickly approaching, this publication includes information pertinent to summer as well as general topics ... Have a safe, enjoyable Summer – happy reading!

CAMP CAREFREE Annual BIANC Retreat



September 17-19, 2010
Stokesdale, NC

A weekend retreat camp providing fun and fellowship for brain injury survivors, family members and friends!

Activities may include:

- * Cookout
- * Fishing
- * Canoes
- * Crafts
- * Games
- * Horseback Rides
- * Music
- * Dancing
- * And much more!

Deadline for applications: August 17, 2010

Availability on a first-come first-served basis ...
sign up now!

For More Information contact BIANC:
(800)377-1464
www.bianc.net

ANNUAL SUMMER PICNIC

Saturday, June 19th

For brain injury survivors



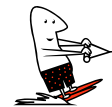
Location: Lake Norman YMCA
21300 Davidson St., Cornelius, NC

Time: 12:00 p.m. - 4:00 p.m.

Cost: Free. Bring a dish-to-share if possible. Monetary donations graciously accepted

Activities: Water skiing* and boating available (be there by 12 to register). Family members/friends may also participate based on space availability

What To Bring: Swimsuit, towel, sunblock, lawn chair (if you would like to sit near the lake).
Family & Friends Welcome!



Adaptive water skiing and boating provided by the Adaptive Sports and Adventures Program (A.S.A.P.) at Carolinas Rehabilitation.

* All levels of physical ability can adaptive water ski. In order to water ski, you must sign a waiver and demonstrate you can turn over in the water.

For more information contact
Barbara Westphal at 704-547-1563

DO YOU HAVE AN EMERGENCY EVACUATION PLAN?

In 2008, 3,320 people in the U.S. lost their lives, and almost 17,000 people were injured as a result of a fire; 84% of those injuries and deaths occurring at home. Everyone has an obligation of preparedness regarding a possible fire in the home.

However, as there are more than 43 million Americans with a disability, and due to special circumstances of their individual disability, individuals should take special steps to ensure their safety in the unforeseen event of a fire. People with disabilities are more than 50% as likely to die in a fire as non-disabled.

As a result, the National Fire Protection Association (NFPA) has developed an *Emergency Evacuation Planning Guide for People with Disabilities* to provide general information, criteria, and tips regarding fire safety for the disabled and their caregivers. The *Guide* provides expert information to assist people with mobility, visual, hearing, speech, and cognitive disabilities and outlines four elements of evacuation including notification, way finding, use of the way, and assistance that are extremely important.



The website also has a *Personal Emergency Evacuation Planning Checklist* to review each step and identify specific criteria based on the individual's needs. General fire safety tips include:

- * Ensure your home is equipped with smoke alarms— change batteries and test on a regular basis
- * Adapt fire safety plans to the specific needs of your loved one needing special assistance
- * Review the fire safety plan and participate in practice drills regularly with everyone involved
- * Keep a telephone and emergency numbers in reach at all times
- * Have a fire extinguisher accessible at all times
- * Notify emergency providers in advance regarding any special needs at your address

- * Add ramps or modify doorways to make an escape easier for people that are mobility impaired
- * Consider sleeping on the ground floor of your residence for people that are mobility impaired
- * Provide a picture book which visualizes drill procedures in case of emergencies
- * Ensure provisions are in place including special locks or latches and other alternative devices that can be easily utilized based on the special needs of the individual
- * Assure a buddy system is in place in the work environment in case of emergencies

For information and/or to download the *Emergency Evacuation Planning Guide for People with Disabilities* and *Personal Emergency Evacuation Planning Checklist* refer to the NFPA website at www.nfpa.org or go to www.firesafety.gov for additional information regarding fire safety with specific guidelines for people with disabilities and their caregivers. Always call **911** for the quickest response to a fire or any emergency!

The above article contains information provided by the National Fire Prevention Association (NFPA), the Centers for Disease Control and Prevention (CDC), the Consumer Product Safety Commission, and the U.S. Fire Administration.

Information shared in contributed articles does not necessarily reflect the opinions of Project STAR or Carolinas Rehabilitation. Websites and other information sources are intended to be used at the reader's discretion and inclusion in this publication is not intended as an endorsement or recommendation.

Ombudsman Program... ... getting the word out

As part of a Health Resources Services Administration (HRSA) Grant, received by North Carolina Department of Health and Human Services-Division of Mental Health, Developmental Disabilities and Substance Abuse Services, BIANC is charged with creating, and making sustainable, a network of volunteer ombudsmen for persons with brain injury. The role of these ombudsmen is to mentor, support and, when necessary, assists persons with brain injury and their families to navigate through the maze of services and other obstacles that can follow a brain injury.

Volunteers for the ombudsman program have attended three days of training to learn about services and supports for persons with brain injury, and coupled with their own experiences, as either a survivor of brain injury or a family member, gives them a unique perspective that may not be available elsewhere.

Not all ombudsman volunteers offer the same types of support. Some may offer service facilitation, guidance and community linkage, while others may offer peer support and social support. As the network of volunteers grows, so will the ability to support those who need help navigating life after brain injury.

As a caregiver, you are in a position to help ensure that persons with brain injury have access to the ombudsman program. Often, in the months or years following a brain injury, persons with the injury and/or their families reach out to a support group for help, information and support, but, sometimes the need is beyond what the group can offer. At such a time, a referral to the regional Brain Injury Family and Community Support Office (FCSO) for information and support may be needed. If the situation warrants more hands-on involvement than the FCSO staff can provide, referring them to BIANC to connect them to a brain injury ombudsman may be a good option.

Not all situations will need to be referred to an ombudsman. In many cases the staff at the Family and Community Support Office may be able to give the needed information and guidance. When the person with brain injury or family member contacts their regional FCSO they should first speak with a staff member and give the details of the type of situation they need assistance with. Based on the individual need and the ability of the FCSO to help the person, he/she maybe referred to an ombudsman.

It is important to realize that there are situations where involving an ombudsman would not help solve the situation. Ombudsmen are volunteers, and while they have received training to help them learn the steps necessary to facilitate connection with appropriate services and community based programs, they have no ability to secure or expedite any service or benefit. What they do offer is a wealth of personal experience, that when coupled with the ombudsman training can often help survivors and families avoid mistakes and wasted effort.

You can contact your regional Brain Injury Family and Community Support Office to be put in touch with an ombudsman in your area.

Brain Injury Family and Community Support Offices:

Raleigh	1-800-377-1464
Asheville	1-866-890-7801
Charlotte-Project STAR	1-877-962-7246
Greenville	1-336-882-1911

SUMMER IS ALMOST HERE ...

Keep the following tips in mind when planning your vacation when traveling with someone requiring special accommodations:

- * Involve everyone in the planning process
 - * Choose your destination wisely
 - * Lots of careful pre-planning
- * Incorporate down time to avoid fatigue
 - * Structured daily activities
- * Ensure you have all needed meds/supplies
 - * Get the doctor's OK prior to traveling
- * Include planned breaks in your travel time
 - * Enjoy Your Vacation!!



READING continues to be a favorite pastime for many people. Not only is reading a great way to learn new information, tips, and ideas, regarding a favorite subject or hobby ... it is a wonderful way to daydream through the creative works of countless authors.

Unfortunately, it can be inconvenient, expensive, and sometimes impossible to visit the bookstore each time you would like to read a new one.

In addition, for many people, it can be difficult to actually read the book due to vision problems, physical impairments, and other issues than can hinder your reading abilities.

A convenient alternative is online books. Due to the popularity, more publications are being offered in audio format. They are easily downloadable onto music players or onto your computer where you can listen to them anytime. Some sites that we found easy to navigate with a diverse genre include:

www.audible.com

www.ebooksonus.com

www.talkingbooks.org

www.freebookdirectory.com

Pet therapy helps patients heal

FOR ANIMAL LOVERS, BEING

away from their pet during inpatient rehabilitation stays can be difficult. Pets like dogs and cats have been proven to have a calming effect on people and can make even the worst day seem bearable.

Knowing the positive effects pets can have on our patients, Carolinas Rehabilitation started an animal assisted therapy program in 2009. Baker, a Labrador/golden retriever mix, was brought in to help patients meet their therapy goals. Every day, Baker works with both adult and pediatric patients, bringing a smile to the faces of all who he encounters.

HIGHLY TRAINED HELPERS

Baker was trained by Canine Companions for Independence® (CCI). CCI is a nonprofit organization that enhances the lives of people with disabilities by breeding, training and providing Labradors and golden retrievers to be highly trained assistance dogs. At 18 months old, each dog begins an extensive training program to master more than 40 commands. The dog is then matched with a professional who assists people with disabilities. Baker



was matched with Carolinas Rehabilitation recreation therapist Kina Atkin, RT .

Baker works with individuals and participates in group therapy to help patients meet their goals. For example, Baker can help spinal cord injury patients learn how to take care of their pets at home. For those without pets, he can help them work on their upper extremity skills. Baker is incorporated into the patient's therapeutic goals, and his work with patients counts as part of their required daily therapy sessions.

THE POWER OF PUPPY LOVE

When wearing his signature blue vest, Baker knows he's on duty. "The best thing about working with Baker is seeing patients' faces light up when he comes in a room,"

says Atkin. "Many times, our patients are tired or sad and don't always want to get out of bed for therapy. But as soon as patients know Baker is coming, they're eager to get up and start the day.

"Baker loves to work," Atkin continues. "Every morning before we leave for work, Baker sits near his vest waiting for me to put it on. As soon as we walk through the door of the hospital, he gets so excited."

Some of the many commands that Baker knows include picking items up off the floor, opening and closing doors or cabinets and fetching items. He also is trained to put his head in patients' laps and hold it there for as long as necessary. The simple act of petting Baker helps to improve patients' coordination.

Since coming to Carolinas Rehabilitation, Baker has been a welcome addition to the recreation therapy staff at Carolinas Rehabilitation. He provides joy to our patients, their families and our team members.

A UNIQUE THERAPY

For more information about the pet therapy program at Carolinas Rehabilitation, Call 1-877-REHAB51.

The article above was written for Within Your Reach, a publication of Carolinas Rehabilitation in Charlotte, NC and reprinted with their permission.

ABOUT CARE NOTES . . .

Care Notes is a newsletter for family caregivers of persons with brain injury. It is published quarterly by Project STAR at Carolinas Rehabilitation. Project STAR also houses one of three Family and Community Support Offices for the Brain Injury Association of North Carolinas (BIANC). The focus of Care Notes is to provide caregivers with useful information on services, opportunities and general items of interest. Sources are provided for articles included in Care Notes. This allows readers to gather more complete information by accessing the sources referenced in Care Notes.

We welcome your thoughts and suggestions. Please feel free to contact Project STAR and let us know what you would like to see included in Care Notes. You can contact us at 704-355-1502 or by email at mary.ruckart@carolinas.org.

THE FOCUS ON REHABILITATION ... AM I FINISHED YET?

Approximately 1.7 million people experience a Traumatic Brain Injury (TBI) each year. Over 230,000 people are hospitalized. No two TBIs are alike. Therefore, the treatment and recovery of each TBI are unique to the individual.

There are multiple phases of treatment and recovery. The acute care phase occurs when a patient initially visits the emergency room and is initially treated for their injuries. This phase involves treatment for life-threatening injuries as many TBIs result in other injuries besides the injury to the brain (i.e., internal injuries, lacerations, broken bones, etc.) due to the nature of the cause of the TBI (i.e., car crash, fall, etc.).

For many TBI survivors, the next phase of treatment and recovery includes rehabilitation. During this phase, a team specializing in the treatment of TBI including neurologists, physiatrists, physical therapists, occupational therapists, cognitive therapists, speech pathologists, and others evaluate the extent of brain damage and areas of the brain where the injury occurred. Based on these findings, they coordinate a comprehensive rehabilitation program for the unique requirements of the patient. This program usually includes cognitive therapy and speech therapy with a focus on cognitive functions including memory, speech, attention, executive functioning, and decision making. It also includes physical therapy and occupational therapy; focused on learning to regain use of and/or



compensate for physical impairments including sitting up and/or standing, followed by retraining of fine motor skills (i.e., eating, brushing teeth, dressing, and writing).

The overall goal of rehabilitation is to improve the patient's ability to function at home and in society. When a patient returns home, many require a caregiver's assistance in some capacity. Usually at this stage, patient and family are attempting to settle into a new routine which is challenging for everyone involved. During this stage, the TBI survivor's difficulties can be impacted further by denial/reality of their brain injury, onset of additional changes in personality and behavior, social difficulties, and many other life-altering challenges.

As many who have had or cared for someone with a TBI know all too well, the stages of recovery and progress following injury are unique for each TBI survivor, yet challenging in many areas for all involved. It is critical for those assisting in care giving responsibilities to be aware of the multiple challenges and issues facing the patient and entire family. However it is also important to know that that research has shown TBI survivors can continue to make improvements in their physical

and cognitive abilities for many years following their TBI. In addition, there continue to be changes in behavior, personality, increased potential for substance abuse issues and other physical/ psychological transformations and challenges for years after the initial TBI.

Based on these findings, it is very important for the TBI survivor to have routine evaluations, to continue therapies that fit their individual needs, and to continue to be involved in support groups and/or other activities which benefit TBI survivors and their caregivers and families for years post injury.

Throughout North Carolina, there are rehabilitation hospitals offering outpatient programs including physical and psychological evaluations, and continued therapy programs for physical, occupational, speech, and vocational therapies. In addition, there are over 35 TBI support groups (go to www.bianc.net for a listing) and a variety of programs and activities (i.e., parks and recreation, therapeutic horseback riding, day programs) available in your area. Contact your local Family and Community Support Office for resources (go to www.bianc.net to locate your regional office).

Our goal is to assist in the continued journey of life after TBI for the survivor, their caregivers, and their family!

In each CareNotes we like to introduce a new resource or tip to readers ...

... **Hinds' Feet Farm (HFF)** ... is a unique entity dedicated to serving persons living with brain injury. Their mission is to maximize the post injury potential of persons living with brain injury through integrated, person-centered, post-rehabilitation, community-based programs, allowing members to pursue meaningful activities while developing a sense of belonging. HFF has locations in Huntersville and Asheville. For more information call (704) 992 - 1424 or go to www.hindsfeetfarm.org.

Rehabilitation in NC ...

Carolinas Rehabilitation (CR) - is part of Carolinas Healthcare System – with CR-Main located adjacent to Carolinas Medical Center (CMC) in Charlotte. This location has 172 beds for acute rehabilitation, as well as an outpatient department. In addition, there are over 10 outpatient CR facilities throughout the region. For more information call (704)355-3558 or (877)REHAB51 or go to www.carolinasrehabilitation.org.

CarePartners Rehabilitation - is located in Asheville, NC. This 80-bed facility offers inpatient and outpatient services. They also have over 5 outpatient area locations. For more information call (828)274-2400 or go to www.carepartners.org.

New Hanover Regional Medical Center (NHRMC) Rehabilitation – consists of a 60-bed inpatient rehabilitation facility on the NHRMC campus in Wilmington. There are also 2 outpatient rehabilitation centers in the area. For more information call (910)343-7835 or go to www.nhhn.org.

Cape Fear Valley Rehabilitation Center (CFVRC) – a 78-bed facility on the campus of Cape Fear Valley Medical Center, located in Fayetteville, NC. CFVRC provides inpatient and outpatient services. For more information call (910)615-4000 or go to www.carefearvalley.com.

DO YOU NEED HELP WITH YOUR PHONE BILL? DO YOU HAVE A CELL PHONE? IMPORTANT INFORMATION!

In this day and age everyone needs a telephone – this is especially true if you have special mobility needs or other special consideration needs. It is a difficult time economically for many people. The good news is that there are programs available to people who qualify. We have outlined three phone programs that are free or discounted based on the program and the individual's qualifications.

Lifeline – this is a federal program that provides qualified consumers with a discount on monthly charges for their primary home phone line. The



amount of discount is based on income. If you as a consumer receive federal assistance (i.e., Medicaid, SSI, etc.) you usually qualify. For more information go to www.lifeline.gov.

Link Up – is also a federally funded program that lowers the cost eligible consumers pay for installation/set up of new phone

service in their home. The amount of discount is based on income. If you already receive federal assistance (i.e., Medicaid, SSI, etc.) you generally qualify. For more information, go to www.Lifeline.gov.

SafeLink Wireless – this government supported program provides a free cell phone and limited air time for eligible consumers based on income - you generally qualify if you participate in a federal assistance program (i.e., Medicaid, SSI, etc.). For more information go to www.safelinkwireless.com.



Carolinas Rehabilitation

Uncompromising Excellence. Commitment to Care.