

# THE Challenge!

Brain Injury Association of America

Fall 2008

Volume 1, Issue 6

## CARE GIVING:



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Periodicals postage is paid at Vienna, VA 22181

Send address changes to:

*THE Challenge!*  
1608 Spring Hill Rd., Suite 110  
Vienna, VA 22182

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Publication designed by Eye to Eye Design Studio  
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## From My Desk

Susan Connors, President/CEO  
Brain Injury Association of America

The summer after my mom died, my stepdad Ernie was hospitalized for a series of strokes and other ailments—including a broken heart. Like so many others, he was discharged from the hospital with the surgical site from his pacemaker still oozing.

Rather than send Ernie to a nursing home, my sister (a saint by any definition) brought him to live with her. While she took care of the B's (blood, bladder and bowels), I attended to the P's (prescriptions, payers and paperwork). That summer I gained a new appreciation for caregivers.

A year later, in June 2006, the Brain Injury Association of America held its first caregivers' conference in more than decade. This June, we hosted a second gathering that was so successful, we dedicated THE *Challenge!* to the topic. Inside this issue you'll find details and pictures from the conference and a great article summarizing research on caregiving in brain injury. We shine the spotlight on the California BIA, one of our newest affiliates.

As always, a report on our public policy work is included and we proudly recognize and thank our individual donors and corporate sponsors—they provide the gas for BIAA's tank!

PS – Ernie is now healthy and living independently. In fact, he traveled to Europe this summer!

## Contents

- 2 ..... National Brain Injury Caregivers' Conference
- 3 ..... Easing the Burden of Caregiving
- 7 ..... Honor Roll of Donors
- 9 ..... Advocacy Update
- 13 ..... Help for Family Caregivers
- 15 ..... Spotlight: CALBIA
- 18 ..... State Affiliate Listings

2008

## NATIONAL BRAIN INJURY CAREGIVERS' CONFERENCE

*By Mary Reitter, CAE, Brain Injury Association of America*

Caregivers from across the country gathered at the Westin hotel in Dallas for the Brain Injury Association of America's National Brain Injury Caregivers' Conference. The caregivers came to share their challenges and triumphs, learn more about brain injury and support one another.

Keynote speaker Lee Woodruff opened the conference on Friday, June 6, 2008, by describing the experiences she and her husband, Bob Woodruff, have had since his injury in Iraq. She acknowledged that her family has accessed services and supports that should be available to everyone but are not. Lee emphasized the vital role that laughter plays in the recovery process.

Greg O'Shanick, MD, delivered the afternoon plenary, which covered medical issues after brain injury. Breakout sessions on Friday afternoon included concussion/mild TBI lead by Thomas Kay, PhD; substance abuse lead by John Corrigan, PhD; and what happens in the military after TBI lead by Sarah Wade. The day's educational program closed with a riveting panel discussion in which Sarah Wade described her wish that someday patients would move seamlessly between military and civilian care while John Corrigan expressed hope that awareness of TBI resulting from the war would not end once service members return home.

On Friday night, attendees were treated to a welcoming reception that featured delicious food and plenty of networking. Old friends greeted one another with hugs and smiles while bonds were forged among new caregivers. A book signing by Lee Woodruff and Carolyn Rocchio held earlier in the day also brought attendees together.

Michael Howard, PhD, opened the Saturday morning plenary session, which focused on managing the stress and depression that caregivers experience. Morning breakouts included Janet Tyler, PhD, and Julie Peterson-Shea on school issues; Lisa Silver on TriCare; and Tim Feeney, PhD, offered a very informative session on behavioral self-regulation. Richard Bonifigilo, MD, and Mike Davis, CBIS presented a plenary session about the long-term consequences of caregiving.

In a plenary session on Saturday afternoon, James Mikula, PhD, discussed psychosocial issues for the whole family. The first set of afternoon breakouts featured a panel presentation by Peggy Keener and Faye Eicholzer described brain injury through the eyes of a parent and spouse, respectively, Laura Schiebelhut on military legislation; and Carolyn Rocchio on practical strategies for day-to-day living. The second set included Penelope Suter, OD, on visual changes; Tina Trudel, PhD, on navigating VA services; Linda Wilkerson and Janet Tyler, PhD on school transitions; and Brandy Reid and Kellie Manderfeld from Pate Rehabilitation on vocational options.

(Continued on pg. 8)



*Planning committee members Julie Peterson-Shea, Peggy Keener and Lisa Silver welcomed Sarah and Ted Wade at the registration desk.*



*Lisa Silver and Lee Woodruff paused for a picture before Lee's opening keynote.*



*Greg O'Shanick, Carolyn Rocchio, Sarah Wade, John Corrigan, and Tom Kay responded to audience questions in an "open mike" session at the end of the day.*

# EASING THE BURDEN OF CAREGIVING

By Jennifer LaPlante,  
Brain Injury Association of America

Caregiving for persons with traumatic brain injury is an unexpected and often long-term dedication of one's self, time, and resources to the enhancement and maintenance of a care recipient's physical, cognitive, and emotional wellbeing, as well as assistance with activities of daily living. Caregivers largely experience increased bouts of depression, anxiety, stress, and other psychological and emotional problems as a result of their role as a caregiver (The Essential Brain Injury Guide; Chronister & Chan, 2006; Florian & Katz, 1991; Allen, Linn, Gutierrez, and Willer, 1994). Other negative effects of being a caregiver include taking on the financial responsibility for the care recipient, either in part or in whole, a loss of personal time, a decrease in social activities, and feelings of guilt. However, there are also positive effects of caregiving that are often overlooked by clinical studies, such as mastery of tasks and satisfaction with one's own quality and competency as it pertains to caregiving.

## TRENDS

The last few decades have seen a large shift from formal institutional care to informal home and community care (Friedman, 2007). The good news about this shift is individuals with significant needs have a higher degree of freedom and a sense of individuality. The bad news is that it places more economic and temporal constrictions upon change to caregivers. Changes in personality, behavior, and an increase in physical limitations are common consequences for individuals who sustain brain injuries (Hanks et al., 2007; Ergh, Rapport, Coleman, & Hanks, 2002). Families who must cope with these changes in a loved one experience an increased incidence of anxiety and mood disorders as well as trouble with social adjustment (Hanks et al., 2007). High levels of depression, anxiety, burden, trouble sleeping, and problems with marriage, finances, drugs (including alcohol), and mental disorders are prevalent among caregivers (Chronister & Chan, 2006). Many models, scales, and tests have been created to measure stress, burden, and satisfaction among caregivers.



Researchers typically focus on the negative effects of caregiving since these are what cause the most concern. Measures of familial, psychological, social, life satisfaction, and health-related concerns are used to determine the levels of stress associated with caregiving (Chronister & Chan, 2006). Since a significant group of caregivers does not report that caregiving is a derogatory factor in their lives, researchers associate increased levels of satisfaction and mastery with decreased levels of burden.

## EMOTIONAL/PSYCHOLOGICAL/ PHYSICAL WELL-BEING

Studies on well-being of caregivers and individuals with brain injury vary because of a large variety of different scales and measures and a small number of studies that contain both clinical and self-report data. However, surveys and self-report data can be used effectively to measure certain aspects of a person's health and well-being. On one survey, many caregivers responded that they felt a sense of hopelessness when taking responsibility for the care recipient. More than 42% of caregivers did not feel that they had a choice in taking on their role, and greater than 10% said that no one would be able to provide the person with care if he or she were unable to give care (DeFries, 2007). While some caregivers benefit from either group or individual therapy, other approaches may be necessary to decrease or eliminate the negative effects of being a caregiver. The stress on time and resources coupled with physical and emotional exhaustion can wear down even the most dedicated caregivers.

In a 2002 study, Ergh et al., found the best predictors of family dysfunction are the caregiver's perception or sense of social support and the neurobehavioral,

neuropsychological, and functioning of the care recipient. The study found that the number of years post injury was also a predictor of family dysfunction as was whether or not the care recipient was truly aware of the degree to which he or she was impaired. Although some of these factors cannot be altered or easily changed, it is evident from research that social support is important to the psychological well-being of caregivers.

Erin DeFries gives some particular statistics about caregivers in the 2007 Conference Proceedings of the Family Caregivers Alliance. In a survey of 895 caregivers, caregivers reported better general health than non-caregivers. These data, however, were contradicted when both the caregivers and the non-caregiver groups were asked to report the number of days they had experienced bad health in a month's time. Caregivers reported an average 4.3 days of poor health as opposed to the general population's report of 3.0 days (DeFries, 2007). A reason for this difference in perceived health and actual health could be the caregiver's proximity to the care recipient, whose impairments, by comparison, make the caregiver perceive his or her own health problems as not worthy of reporting.

A recent study indicates that problem-solving training is effective in reducing both stress and dysfunctional problem-solving styles among caregivers of care recipients with brain injury (Rivera, Elliott, Berry, & Grant, 2008). The researchers found that caregiver depression was positively correlated with burden, negative orientation to problem-solving, and physical symptoms, while depression was negatively associated with life satisfaction. These results mean that as levels of caregiver depression increase so do levels of burden, negative orientation to problem-solving and the manifestation of physical symptoms. Conversely, as caregiver depression rises, life satisfaction decreases. The study showed that caregivers receiving problem-solving training reported significant decreases in depression, health complaints, and in dysfunctional problem-solving (Rivera et al., 2008).

The authors of the study acknowledge the difficulties in self-report data. Interestingly, they also point out that the study is the first to show beneficial effects of problem-solving training on participant health complaints. Because their study was the first of its kind, one may assume that although the study has limitations, much may be learned from perfecting problem-solving training as a prospective way of easing the emotional, psychological, and physical effects of caregiving on the caregiver.

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## FINANCIAL BURDEN

Emotional, psychological, and physical effects are the primary manifestations of the burden of caregiving. However, a variable that contributes greatly to all aspects of distress is the financial burden caregivers face in accepting the responsibility for long-term care recipients with brain injury.

Medicaid has remained a primary source of financial help for patients whose condition requires long-term care. As much as 47% of Medicaid funding goes toward long-term patient care (Friedman, 2007). However, Medicaid allowances are susceptible to funding cuts and eligibility varies from state to state, making financial burdens an increasingly important factor when families must decide what can be done for their loved ones (Friedman, 2007). Hownsell (2007) outlines common financial stresses of caregivers, which include the loss of salary or wages and related benefits due to quitting or reducing the number of hours they work, the loss of promotions that require more hours of dedication, and the loss of opportunities to train for a better position or one that may require travel. Other

(Continued on pg. 11)



*The welcome reception was the perfect time to make new friends.*



*Attendees had lots of time to interact with exhibitors.*

(Continued from pg. 2)

On Sunday morning, William Ditto described programs and services available from state government agencies and Tina Trudel, PhD, discussed aging issues for both survivors and caregivers. Susan Connors closed the conference on Sunday, June 8, with a plea for caregivers to stay connected to one another and to their state and national associations.

The Brain Injury Association of America sincerely thanks all of the conference speakers for volunteering their time and sharing their vast knowledge. BIAA commends the members of the conference planning committee, which was lead by Carolyn Rocchio and included Mike Davis, Julie Peterson-Shea, Peggy Keener, Lisa Silver, and BIAA staff Mary Reitter, Greg Ayotte and Jenny Toth.

The Association is grateful to the following exhibitors for sponsoring the opening reception, meals and networking breaks:

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- Coastline Community College
- CORE Healthcare
- HOMELINK
- Learning Services Corporation
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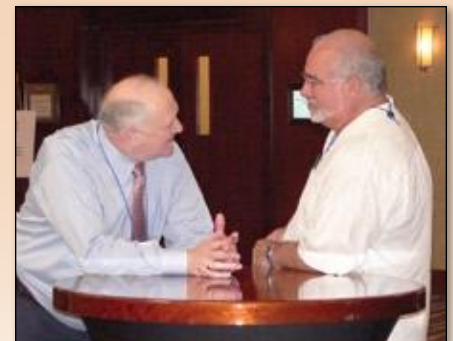
The Brain Injury Association of America will host its caregivers' conference again next year. Please watch [www.biausa.org](http://www.biausa.org) for date and location announcements.



*After delivering the morning plenary, Mike Howard continued his lecture in the hall.*



*Janet Tyler visited with Linda Wilkerson before their presentation.*



*Mike Davis caught up with Hector Gutierrez during the break.*



*Committee members Peggy Keener and Carolyn Rocchio enjoyed a laugh together.*



*Old friends like Susan Connors and Geoff Lauer were re-united.*



*At the end of the conference, Mary Reitter, Charley Bowen and Greg Ayotte share a hug and a smile.*

## KEY LESSONS FROM THE 2008 CAREGIVERS' CONFERENCE

**YOU ARE NOT ALONE.** Through BIAA's network of state affiliates and local support groups, there are others sharing similar experiences every day. They can help with information and support.

**THERE IS MUCH TO LEARN ABOUT RECOVERY AFTER BRAIN INJURY.** Caregivers can stay informed about what's new in brain injury research and services by attending local, state and national conferences, by reading books and pamphlets, and browsing the Internet.

**STAND OUT FROM THE PACK.** Being a vocal, determined and persistent advocate for your loved one can make all the difference in your ability to access the services that are available, whether in the military and veterans systems or in the civilian sector.

**PEOPLE WANT TO HELP.** In the days and weeks that follow the injury, caregivers may be too overwhelmed to ask for help or to accept it. At such times, caregivers can ask for a rain check – a promise of future help with laundry, errands or yard work. Once life settles down a bit, caregivers can keep a running list of challenges, problems and areas where help is needed. The list can be shared with health professionals, family members, friends and neighbors. The more specific caregivers are about the needs of their loved ones, the better able others are to help. Remember to include on the list the needs of the caregiver as well.



*The conference was a great place to share and learn from each other.*

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# ADVOCACY UPDATE

By Laura Schiebelhut, Brain Injury Association of America

After achieving a major legislative goal, reauthorization of the Traumatic Brain Injury Act, in the first part of this year, BIAA has focused its efforts for the remainder of the year on other key policy priorities, including preserving and increasing funding for federal TBI programs and research; monitoring the implementation of Wounded Warrior legislation to improve TBI care for returning servicemembers; and promoting official coverage of cognitive rehabilitation by the military's health care program, TRICARE.

Congress adjourned on October 3, 2009, but plans to return after the November election for a short "lame duck" legislative session. In either case, most legislation will fall into the "to be continued" category, for potential carry over into the new 111th Congress, which is scheduled to convene on January 3, 2009. The ultimate fate of Fiscal Year 2009 federal funding for all civilian health programs, including key TBI programs and research, will remain undecided until early next year.

## FISCAL YEAR 2009 (FY09) APPROPRIATIONS UPDATE

Following last year's disappointing \$156,000 cut in funding for the Health Resources and Services Administration's Federal TBI Program, BIAA once again galvanized its efforts to preserve and increase appropriations. Unfortunately, partisan vitriol during a hotly contested election year resulted in the passage of only a few FY09 appropriations spending bills.

The majority of FY09 appropriations measures, including the Labor-HHS-Education funding bill which contains major TBI programs, did not receive floor consideration in either chamber. Instead, Congress passed an omnibus continuing appropriations bill to fund most government programs, including TBI and trauma-related programs, at last year's levels until enactment of their respective appropriations measures, or March 6, 2009, whichever comes first. The Fiscal 2008 levels, and thus continuing funding levels through the beginning of next year, are as follows:

- CDC TBI Programs: \$5.709 million
- HRSA TBI State Grant and Protection & Advocacy System Programs: \$8.754 million
- TBI Model Systems of Care: \$8.155 million

Thus, despite BIAA's best efforts in visiting numerous appropriations staff on Capitol Hill during the first few months

of the year, providing written testimony to both House and Senate Appropriations Subcommittees, and helping to draft numerous letters to key appropriators, federal funding for civilian TBI programs remains stagnant at this time. BIAA remains dedicated to continuing to work with leaders in Congress next year to increase ultimate federal funding levels for TBI programs in both Fiscal Years 2009 and 2010.

## TBI & THE MILITARY

Reflecting one of BIAA's biggest public policy accomplishments this year, a group of Senators issued a letter on August 4, 2008 to Defense Secretary Robert M. Gates urging official TRICARE coverage of cognitive rehabilitation. The group of 10 United States Senators, led by Evan Bayh (D-IN) and Barack Obama (D-IL), sent a letter to Defense Secretary Robert M. Gates calling on him to enact official coverage of cognitive rehabilitation within the military's TRICARE health insurance program. Several major media outlets covered this story, quoting Democratic Presidential Candidate Barack Obama in describing cognitive rehabilitation therapy as "one of the most accepted treatments for TBI."

BIAA worked closely with Senator Bayh's office on this important effort to increase access to timely, state-of-the-art care for returning servicemembers with traumatic brain injury. A copy of the letter, along with talking points in support of TRICARE coverage of cognitive rehabilitation, and a summary of evidence attesting the efficacy of cognitive rehabilitation, is available on BIAA's website at <http://www.biausa.org/policyissues.htm>.

In a similar effort, the Co-Chairs of the Congressional Brain Injury Task Force, Rep. Bill Pascrell (D-NJ) and Rep. Todd Platts (R-PA) sent a letter in September, signed by over 60 House members from both parties, to Defense Secretary Robert M. Gates urging TRICARE coverage of cognitive rehabilitation. BIAA is closely monitoring the situation and will share news of Secretary Gates' response as soon as it is publicly issued.

In its omnibus appropriations bill passed in September, Congress included Fiscal Year 2009 appropriations for Defense, Homeland Security and Military Construction/Veterans Affairs. The Defense appropriations measure included contains \$300 million in funding for Traumatic Brain Injury

and Psychological Health initiatives within the Department of Defense.

The Military Construction-VA appropriations measure includes \$41 billion for the Veterans Health Administration (veterans medical care), representing \$1.8 billion above the President's budget request earlier this year and \$4.1 billion above 2008 levels. The funding bill also provides \$510 million in funding for research on PTSD, TBI, suicide prevention, and polytrauma. This funding is \$30 million above 2008 levels and rejects a \$38 million cut proposed by President Bush. The Military Construction-VA appropriations bill also included important report language (strongly supported by BIAA) urging the Department of Veterans Affairs to increase returning servicemembers' access to TBI care and expertise in the civilian sector.

In addition, shortly before adjourning Congress passed provisions of The Epilepsy Centers of Excellence Act (H.R. 2818/S. 2004), which BIAA has strongly endorsed, as part of an omnibus veterans health care package (S. 2612). The legislation, championed by the American Academy of Neurology and endorsed by BIAA, anticipates an expected increase in the number of TBI-related epilepsy cases among veterans returning from service in Iraq and Afghanistan. The bill will create up to six Epilepsy Centers of Excellence (ECoE) at the Department of Veterans' Affairs (VA), and is aimed at restoring the VA as a national leader in epilepsy care and research.

**OTHER BIAA GOVERNMENT AFFAIRS ACTIVITY**

BIAA continues to be active on Medicaid and Medicare issues. Most recently, BIAA signed on to a coalition letter urging Congress to enact a moratorium on a regulation proposed by the Centers for Medicare and Medicaid Services (CMS) to restrict Medicaid reimbursement for outpatient services. This regulation is termed the "Medicaid Outpatient Clinic and Hospital Services Rule," and it would reduce federal Medicaid funding to states for freestanding health clinics and hospital outpatient departments.

Throughout the year, BIAA has also been strongly supportive of efforts to pass legislation to restore protections established by the Americans with Disabilities Act (ADA). BIAA signed on to numerous coalition letters as part of an effort which eventually culminated in legislative success on September 25, 2008, when President Bush signed legislation to restore vital civil rights protections of the Americans with Disabilities Act (ADA). The ADA Amendments Act, which was widely supported by business and disability advocacy organizations, has now become law.



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(Continued from pg. 4)

financial stresses are a decrease in savings and investments, the loss of opportunities pertaining to compound returns or a 401(k) company matching contributions, and, due to a decrease in money, the inability to make home improvements which could help increase the value of the home if resold.

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## **WOMEN CAREGIVERS’ FINANCIAL BURDEN**

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Women are especially impacted by financial burden as they make up the majority of caregivers. Women who assume a caregiving position are 2.5 times more likely to become impoverished than non-caregivers (Hownsell, 2007). Likewise, single women who are caregivers are four times as likely to become impoverished later in life. Hownsell describes some of the mistakes women caregivers frequently make in an effort to put the needs of others before their own. These mistakes include not making their own financial status a priority, using their own assets to pay for the care recipients’ needs, trying to pay for more than they can afford, not considering whether or not they may have to live on their own someday, and, not saving for their own retirements because they allocate their resources to the needs of the care recipient and others, such as children and grandchildren (Hownsell, 2007).

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## **DIFFERENCES IN MALE AND FEMALE CAREGIVERS**

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Although the majority of caregivers are women, men are increasingly assuming caregiver positions. In a webcast, Dr. Carreno spoke of the need to focus on this growing minority. Since the caregiving role has been taken by mainly women in the past, the results of many studies focus on women. However, with more men taking on the responsibility, research has to be geared toward understanding and helping alleviate their stress as well. Our culture, for all its auspices of equality, does not treat or perceive its citizens equally. Professions, positions, and jobs can sometimes be associated with a gender. Caregiving is no exception, and despite loving the person in need, men are more likely to perceive caregiving as a “woman’s role.” In addition, men are less likely to ask for help because they perceive asking for help as a sign of weakness, thus making it an “unmanly” maneuver.

Chronister & Chan (2006) identified gender and age as determinants of higher levels of caregiver stress. Studies show that younger caregivers are more prone to psychological distress, experience more burden, and have

fewer of their own needs met (Fitting & Rabins, 1985; Nabors et al., 2002; cited in Chronister & Chan, 2006). Significantly, Chronister and Chan’s (2006) research supported the theory that women report more subjective burden than men and that wives of care recipients experienced more depression. It is estimated that a woman will spend 50% more time caregiving than a man and will handle the most difficult tasks such as toileting, bathing, and dressing (Carreno, 2008).

Chronister & Chan (2006) found that men may experience lower burden and a higher quality of life than women. The reason the authors suggested for this outcome is that the men in their study reported using fewer problem-focused coping efforts. However, this study used self-report data so the reported differences between men and women may be a product of socialization. Socialization accounts for our society’s tendency to consider men “unmanly” or to be more judgmental of men for reporting depression, anxiety, and an inability to handle something, including a caregiving burden. For these reasons, men are less likely than women to report emotional, psychological, or financial distress.

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## **CARING FOR CHILDREN**

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Individuals with a brain injury experience different difficulties, abilities, and limitations that are dependent upon several factors including the severity of the injury, the time since the injury, their age, and their level of functioning prior to the injury. Discrepancies exist in the way one cares for a child with a brain injury as opposed to an adult with a brain injury.

It has long been established that in clinical studies, in terms of care, recovery, and development, pediatric cases should be set apart from those of adults. Children and adolescents still have significant periods of growth ahead of them at the time of a brain injury. Spontaneous recovery may be a determinate of age suggesting children and adolescents may recover at faster rates due to their age. However, Kultz-Buschbeck, Hoppe, Golge, Dreesmann, Damm-Stunitz, and Ritz (2003) found that a young age at injury was not associated with better recovery.

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## **CARING FOR ADULTS**

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Differences in perspective of burden vary depending on whether the caregiver is the parent or the spouse of the care recipient (Blais & Boisvert, 2005). Parents tend to better handle the burden of their adult child returning to them as a care recipient because it is a familiar role, because they



have each other and generally a better social support system than spouses, and because parents and children do not have an option to divorce one another (Blais & Boisvert, 2005). Parents also report lower levels of burden and a better quality of life via social support (Chronister & Chan, 2006). However, parents may experience greater disappointment in terms of their child's improvement.

It is well documented that spouses feel depressed, socially isolated, and overwhelmed by the role reversal from equal partners to the care recipient being dependent. Spouses have difficulty coping with the person they take care of being different than the person they married in terms of cognition, personality, and physical ability. As a result, they may not want to interact sexually with the individual. The brain injury can also impact a couple's sex life in that it can cause sexually inappropriate behavior such as public masturbation, exhibition, one-sided sexual demands, and an increase in unreasonable sexual demands (Blais & Boisvert, 2005). Unfortunately, there is a scarcity of research indicating differences in challenges experienced when the caregiver is the parent, spouse, or child.

## OTHER FAMILY MEMBERS

While a primary caregiver can be expected to feel the most burdened, other family members are affected by the changes that accompany taking care of a person with brain injury. However, research centers on primary caregivers or fails to differentiate between differing roles and levels

of responsibility when measures are applied to the whole family. Children may share a small responsibility for caregiving and may be uneasy about seeing their injured parent in a role that is no longer dominant, supportive, or in control (Florian & Katz, 1991). Some common ways children react to a parent's brain injury involve acting out, drug use, increase in sexual promiscuity, and a seeming lack of interest, anger, or aggression toward the parent who sustained a brain injury. Kreutzer et al. (1994b) found that higher levels of family dysfunction were reported by caregivers of people with brain injury as compared to non-patient control groups.

## TECHNOLOGICAL SAVIORS

Technological advances in the field of long-term care have allowed some people to regain parts of their lives that would otherwise be consumed by caregiving. One such advancement is the Comprehensive Health Assessment Support System (CHESS), a computer-based system that incorporates information, health measurement, that advice and is designed to help both the patient and the caregiver. CHESS also helps the caregiver with coping styles, social support, problem-solving skills, and is individualized to inform and help users change harmful behaviors.

(Continued on pg. 17)

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## HELP FOR FAMILY CAREGIVERS: SELECTING HOME CARE

*By Sheila McMackin, LCSW, National Private Duty Association*

When loved ones who have sustained a brain injury return home, finding and choosing a home care provider is among the most important decision family caregivers face. When selecting an agency to provide in-home care, there are some very important questions that you should ask of your prospective service providers:

The first and most important question is whether or not the care provider is a home care agency, an employment agency, a registry/broker, or an independent contractor. Your choice is critical because you could accidentally become an employer, with all of the tax and regulatory burdens assigned to an employer. By choosing a full service home care agency rather than an independent contractor (someone privately hired or hired through a registry or employment agency), you are free of these employer responsibilities and can focus on the care your loved one needs. Moreover, full service home care agencies accept responsibility for screening, training, insuring, monitoring the care and supervising their staff. The other models do not.

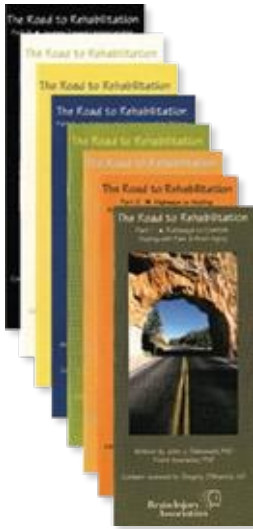
When selecting among different home care agencies, you'll want to ask how long the agency has been

providing private duty home care and whether or not the agency and/or the caregiver is experienced in working with individuals with brain injury. For example, you will want to know how the agency screens, selects and trains care providers prior to an assignment. Be sure to ask how references are checked and whether or not criminal background checks and drug screens are conducted on all employees.

To make sure the care will be as expected, an individualized plan of care should be developed in advance. Ask how often the plan will be re-evaluated. Try to meet with the prospective staff before they are assigned to provide care, if possible, and check whether or not the agency makes regular and/or unscheduled visits to their client's home. Be sure to ask how emergencies are handled both during and after normal business hours.

If at any time you are not satisfied with the care, it is important to let the agency know right away. To find a full service home care agency, visit the website of the National Private Duty Association, found at <http://www.privatedutyhomecare.org>.

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## SPOTLIGHT: CALBIA HOSTS CAREGIVER CONFERENCES IN FIVE LOCATIONS

*By Paula Daoutis, California Brain Injury Association*

At the beginning of 2007, the California Brain Injury Association (CALBIA) set out to host identical caregiver conferences at multiple sites throughout the state. As a newly organized association, it was imperative to solicit a funding source to make this goal a reality. It came to CALBIA's attention that a major Energy Company, **Aera Energy** in Bakersfield, California, had a special interest in brain injury and the work of CALBIA. A grant request was submitted and subsequently funded in the amount of \$25,000 from the **Aera Energy Fund Kern Community Foundation**. With the funding in place, letters were sent to support groups and organizations throughout the state seeking donated meeting space and assistance with the onsite coordination of the conferences. Each of the onsite coordinators also assisted CALBIA with securing local speakers to present the following topics that were viewed as the most beneficial for caregivers:

- Advocacy: Taking Charge & Influencing Change
- Family Dynamics After Brain Injury
- Communication Issues: Tips & Tricks
- The ABC's of Behavioral Management
- Managing Medications With Your Personal Physician
- Stress: How to Combat Caregiver Burnout
- Preparing for the Future: Medical & Financial Issues

Five locations were selected from the positive responses received from the communities. The first was held at Casa Colina Centers for Rehabilitation in Pomona. Casa Colina was very generous in providing us with the meeting space as well as breakfast and lunch for the conference attendees. Many of their staff also served as speakers.

Within a few days, we were off to the Santa Clara Valley Medical Center in San Jose. Once again, attendees were treated to light snacks and lunch provided by SCVMC. Like Casa Colina, several staff members donated their time to present the topics developed by CALBIA.

Next was the conference in Red Bluff. Thanks to the staff at the Brain Injury Coalition and the Mountain Caregiver Resource Center, they were able to secure a Community Center to host the conference and solicited local speakers and additional sponsors to pay for the facility and meals.

In early October, we traveled to the Community Regional Medical Center in Fresno. Thanks to the staff and support group in Fresno who helped to advertise the conference.

Last but not least, we were in San Diego on October 22, the day after the massive fires broke out. The San Diego site had the highest number of pre-registered attendees, but due to the fires and closure of many of the surrounding freeways, about half of the attendees could not make it. Thanks to the members of the San Diego Brain Injury Foundation who assisted with the planning and onsite coordination.



*Dr. Mark Ashley, Chairman of the CALBIA Board, welcomes registrants.*

Based on the evaluations we received from each site, the majority of the attendees felt that the information presented was useful and can be applied in their homes. Each attendee was also provided with a Caregiver Resource Guide that contained each of the topics presented, as well as helpful resources in the state. Most recently, CALBIA had the above topics professionally video taped and the DVDs will be available soon from the CALBIA website at [www.calbia.org](http://www.calbia.org) for \$20 for each presentation.

For more information about CALBIA, or the Caregiver Conference DVDs, please contact Paula Daoutis at (661) 872-4903 or by e-mail at [calbiainfo@yahoo.com](mailto:calbiainfo@yahoo.com)



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(Continued from pg. 12)

The Link2Care system helps to ease the stress of caregivers by providing an online database, support from experts, information, a personal journal, discussion boards, and links to other helpful sites. Link2Care is currently designed for California residents who are caregivers of individuals with Alzheimer's, stroke, and multiple sclerosis and offers tips on caregiver coping skills, seeking respite, and expert opinions on cognitive deficits (Smith, 2007).

Telehealth is another technological device that is being used to help caregivers, especially those in rural settings. Telehealth involves the use of a picture phone where a nurse can see the patient and caregiver. In this system, a nurse can show the caregiver how to perform a procedure. Some more sophisticated telehealth technology can even allow the nurse to monitor heartbeat, listen to the patient's lungs, and even take oxygen measurements and other health screens. Telehealth technology has been shown to reduce the number of doctor's visits by 33% (Smith, 2007).

Other devices and approaches as simple as an automated pill dispenser, a wristwatch with an alarm, or even a 10-minute nap CD can ease the burden on caregivers. Although cost is an issue for some technologies, advancements happen frequently and with new technology, costs may be driven down. Telephone and Internet-based help centers, such as the Brain Injury Association of America's National Brain Injury Information Center, 1-800-444-6443 provide information, advice, forums, chat rooms, articles and self-help tips for caregivers.

## CONCLUSIONS

Caregiving can be a negative influence on physical, psychological, and emotional well-being. For this reason, researchers, psychologists, and physicians focus on alleviating distress among caregivers who are putting themselves at risk in order to care for their loved one. More research is needed in terms of what can be done to help caregivers manage their tasks efficiently and satisfactorily and at the same time maintain their own health, finances, and have time away from the care recipient. It is only through this knowledge that we can truly lessen the impact of caregiving and help bring about an understanding of the intricate ways brain injury affects individuals, families and others. ■

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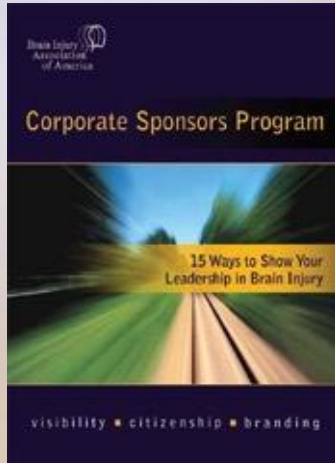
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| Brain Injury Association of Arkansas                       | 501-374-3585 ~ 800-235-2443 | Brain Injury Association of New Hampshire  | 603-225-8400 ~ 800-773-8400 |
| Brain Injury Association of California                     | 661-872-4903                | Brain Injury Association of New Jersey     | 732-745-0200 ~ 800-669-4323 |
| Brain Injury Association of Colorado                       | 303-355-9969 ~ 800-955-2443 | Brain Injury Association of New Mexico     | 505-292-7414 ~ 888-292-7415 |
| Brain Injury Association of Connecticut                    | 860-721-8111 ~ 800-278-8242 | Brain Injury Association of New York       | 518-459-7911 ~ 800-228-8201 |
| Brain Injury Association of Delaware                       | 800-411-0505                | Brain Injury Association of North Carolina | 919-833-9634 ~ 800-377-1464 |
| Brain Injury Association of Florida                        | 850-410-0103 ~ 800-992-3442 | Brain Injury Association of Ohio           | 614-481-7100 ~ 866-644-6242 |
| Brain Injury association of Georgia                        | 404-712-5504                | Brain Injury Association of Oklahoma       | 703-761-0750 ~ 800-444-6443 |
| Brain Injury Association of Hawaii                         | 808-454-0699                | Brain Injury Association of Oregon         | 503-413-7707 ~ 800-544-5243 |
| Brain Injury Association of Idaho                          | 208-342-0999 ~ 888-374-3447 | Brain Injury Association of Pennsylvania   | 717-657-3601 ~ 866-635-7097 |
| Brain Injury Association of Illinois                       | 312-726-5699 ~ 800-699-6443 | Brain Injury Association of Rhode Island   | 401-461-6599                |
| Brain Injury Association of Indiana                        | 317-356-7722 ~ 866-854-4246 | Brain Injury Association of South Carolina | 803-731-9823 ~ 800-290-6461 |
| Brain Injury Association of Iowa                           | 511-244-5606 ~ 800-444-6443 | Brain Injury Association of Tennessee      | 615-248-5878 ~ 877-757-2428 |
| Brain Injury Association of Kansas and Greater Kansas City | 913-754-8883 ~ 800-783-1356 | Brain Injury Association of Texas          | 512-326-1212 ~ 800-392-0040 |
| Brain Injury Association of Maine                          | 207-861-9900 ~ 800-275-1233 | Brain Injury Association of Utah           | 801-484-2240 ~ 800-281-8442 |
| Brain Injury Association of Maryland                       | 410-448-2924 ~ 800-221-6443 | Brain Injury Association of Vermont        | 802-985-8440 ~ 877-856-1772 |
| Brain Injury Association of Massachusetts                  | 508-475-0032 ~ 800-242-0030 | Brain Injury Association of Virginia       | 804-355-5748 ~ 800-334-8443 |
| Brain Injury Association of Michigan                       | 810-229-5880 ~ 800-772-4323 | Brain Injury Association of Washington     | 253-238-6085 ~ 800-523-5438 |
| Brain Injury Association of Minnesota                      | 612-378-2742 ~ 800-669-6442 | Brain Injury Association of West Virginia  | 304-766-4892 ~ 800-356-6443 |
| Brain Injury Association of Mississippi                    | 601-981-1021 ~ 800-641-6442 | Brain Injury Association of Wisconsin      | 262-790-9660 ~ 800-882-9282 |
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