Brain Injury Association of Texas
enewsletter

Regional Seminars Boast Strong Line-up of Speakers

The BIATX Regional Seminar Series is offering some of the best speakers in the state on subject of TBI Rehabilitation. These one day sessions will include information for brain injury survivors and their families as well as CEU credits for professsionals. Some of the confirmed speakers include:

- Cindy Ivanhoe, MD
- Mary Carlile, MD
- Jim Misko, Psy D
- Tim Atchison, Phd
- William Loving, MD
- David Starnes, OD
- John Bertelson, MD
- Lauren Brandt, RN

The dates for the seminars will be:

Austin - Friday, Sept 8
Amarillo – Saturday, Oct 7
Houston – Saturday, Oct 28

Visit www.biatx.org for all the details. Excellent sponsor and exhibitor opportunities are still available!

For information, contact
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"I feel with my heart, I speak without words… I am in here."

Jason Ferguson, Severe Traumatic Brain Injury Survivor

After a Traumatic Brain Injury (TBI) a lot of changes happen to the survivor. Physical, cognitive, emotional and awareness are common changes that occur. Every TBI is unique and what may work better for one person may not have as significant results for another. There are three things for loved ones, caregivers and healthcare workers to keep in mind that I feel will be helpful for all TBI survivors. First, no matter the situation they have to have hope. Second, just because the survivor can't respond, it does not mean he can't hear you. Third, do not give up just because you hear a diagnosis that is undesirable.

Having hope eases the caregiver's heart and gives the survivor something to look forward to. A survivor may be less inclined to try hard or at all, if the environment is negative or he or she thinks the situation is hopeless. Try to refrain from saying, "Well, all of the other patients I have read about have never recovered from the state your in." Your survivor is not everyone else. I remember when I was at the inpatient rehabilitation hospital and Susannah had pushed me in my wheelchair outside to get some fresh air. I was sad about my situation and was a little emotional. I did not think it was fair for her to have to take care of me. When we got to her car Susannah bent down eye to eye with me, grasped my hands, told me that she loved me and if I ever never got out of the wheelchair that she would always be by my side. Those were the perfect words for me to inspire me to try harder. Remember, every brain injury is unique no matter how severe or mild it is. If the caregiver is not going to have hope, then how is the survivor going to feel. A supportive, hopeful environment is essential for the survivor's recovery to go farther. For the sake of your loved ones have hope, show respect, be positive and listen. Having this attitude will make a remarkable difference in their recovery. After I was released from the hospital, I had to be on twenty-four hour supervision. I stayed at my mothers and fathers house out in the country. On the weekend Susannah would come and pick me up to go to her house. For the next hour and a half ride home she would let me vent or get what ever off my chest.

If the survivor is unable to talk or does not respond in any way it does not mean they cannot hear you. As hard as they might try, the words won't come out. When they do, they may come across as speaking gibberish at first. It may sound like gibberish to others, but to the survivor it sounds right in their head. The survivor can feel that he or she is trapped with no way out. Treat the survivor with dignity, respect and compassion. Positive remarks and mannerisms will show them that things will be ok. Remember, they are still alive and they did not ask for this to happen.

We want for our loved ones to do the best they can, especially when it comes to our loved ones well-being. Brain injury is something that is not an easy task to deal with. The recovery process isn't fun either, but worth giving it all you can. Recovery is not something that happens and the person is "recovered", with a brain injury they will be recovering the rest of his or her life. As in life in general expect the unexpected, hope for the best and keep in mind miracles happen everyday. Hang in there and don't give up!

Think
by Jason Ferguson

There are no cures for a Traumatic Brain or Spinal cord injury,
But most cases can be prevented by what we do daily,
The little things can take us far,
Like wearing our seatbelts when we get in a car,
It doesn't matter whether we are in the front seat or the back,
Tell your friends to buckle up and do not cut them any slack,
It is not cool to be dead,
Use your brain to think first instead,
Your friend thinks that wearing helmets and seat belts is uncool,
You do not give into the pressure of being a fool,
We all know that it is against the law to drink and drive,
It is also the difference between being dead and alive,
" I do it all of the time, what's it going to hurt?"
It only takes one quick time before you're six feet under the dirt,
So you don't die aren't you so lucky?
To be lying there motionless looked at with pity,
People with whom you were so close are no longer there,
You start to think that no one cares,
Maybe you will be fortunate enough to only have a brain injury and maybe one day you'll be able to walk,
Somebody else will have to take care of you and you can't talk,
You were warned about what would happen if you did not wear your seatbelt or if you drink and drive,
But what does it matter now you're still alive.

Greetings from the High Plains of West Texas

By Tim Atchison, Ph D
West Texas Regional Conference Chair

Amarillo, Texas is a misunderstood place by many Texans. I have lived in many areas of the state and when we would tell them we were going to Amarillo we often got strange looks and statements like isn't that close to the North Pole. Well we are a long way from there but we are also a long way over 600 miles for Houston. The climate is different we have 4 seasons and we do know what snow looks like. However, people here often do feel they are forgotten by much of the rest of the state. When I moved up here, to work at West Texas A&M University after graduating from the University of Houston, I knew what I was getting into as my wife grew up here. One thing that was important to me was to help bring services to this part of the state.

When I was asked to be a board member of BIATX I felt this was a real opportunity to do this. Since my coming on the board with the help of several volunteers we have also helped start a support group that meets twice a month. I am especially excited that we are now holding regional seminars and that one will be in Amarillo. It is set for October 7th and we have a great lineup of speakers. The most exciting thing though is the reaction of people here. I have been meeting with the medical rehabilitation people and they are thrilled to have this opportunity as distance kept them from going to the state gathering. I also got to meet with out Mayor to tell here about the conference and she asked if she could give a greeting to those attending. The camber of commerce has offered assistance and gift bags for the conference. This conference is a great chance to raise awareness state wide for BIATX.

I invite you to visit us here on the high plains. We are a part of Texas and we look forward to more involvement in BIATX. I think becoming involved throughout this large state of Texas will be very important in increasing the effectiveness of BIATX.

Unidentified Traumatic Brain Injury – An Article from TBI Central

The aim of TBI Research Review is to summarize current research on traumatic brain injury (TBI), offer suggestions for future research planning and suggest application of research findings to clinical practice and policy. The focus in this second issue is on Unidentified TBI

Millions of people have experienced a traumatic brain injury (TBI), but they are unaware that TBI is the underlying cause of problems they subsequently experience, such as poor memory, difficulties in learning and behavioral changes. These individuals had a blow to the head, were dazed and confused, perhaps even lost consciousness, perhaps got medical attention and then went on with their lives. They thought once the headaches or dizziness went away all would be fine, but they didn't notice that all was not right.

Or, they did notice but didn't identify the source of their problems as the brain injury. The result is that they have substantial, persisting cognitive, behavioral and social difficulties – seemingly out of the blue – with no explanation and nowhere to turn. And, as we discuss below, because of the lingering challenges they face, individuals who have sustained brain injuries are at very high risk of social failure. The need to identify people with "hidden TBI" and address their challenges, to prevent social failure, is the subject of this newsletter.

Personal Stories

We illustrate the problem of unidentified TBI with the experiences of two people:

* Tim experienced a brain injury while diving, after which he sought medical care in an emergency department. There, the doctor explained very little about brain injury, suggesting that "all would be fine". Based on this, Tim expected no continuing symptoms – whether physical or cognitive. So, like millions of others with brain injuries, he did not associate the problems he later experienced with the TBI. Instead, Tim said to himself, "I'm just a guy getting older, forgetting more often." He probably will not seek help, and, if he does, neither he nor his doctor is likely to define the prior brain injury as a possible root cause of Tim's problems. Tim is a person with "hidden TBI", in the sense that he has daily challenges associated with a brain injury but is unaware of their cause.
* In contrast, because John was hospitalized with a TBI two years ago, he was educated about the probable consequences of brain injury. Because of this awareness, when he visits his psychologist for treatment of clinical depression, she knows to carefully adapt her methods to accommodate John's substantial post-TBI memory problems. For example, she repeats certain exercises several times so that he is able to learn the ideas and apply them in daily life. Also, because of her knowledge of TBI, she realizes that a referral to a job coach may be needed for John to keep his employment and reduce some of his concerns, which are contributing to his mood disorder and diminishing his quality of life. In this simple scenario, we see that John's having an identified TBI has raised the therapist's awareness of John's brain injury, how it affects his functioning and how accommodating her practices to his memory problems; this provides the basis for taking actions that can aid him in achieving his goals.

The Many Reasons for Hidden TBI

How can it be that brain injury can remain hidden to the person? Hidden TBI occurs when the link between an injury to the brain and associated problems is unclear. Like in the case of Tim, who sought medical help, health professionals may fail to provide adequate guidance on the possible consequences of injury. Or, TBI may remain hidden if the blow to the head does not send the person to the hospital but is a repeated part of life, as in people who are physically abused or get into repeated fights. In these cases, the effects of the brain injuries may accumulate gradually and never are viewed as a consequence of recurring trauma. Or, hidden TBI may occur when the period between a blow to the head and the emergence of problems is lengthy – such as in many childhood brain injuries. Or, the injured person may be positively reinforced for not seeing cause-and-effect, for example, professional athletes whose continued livelihood depends on not noticing the effects of repeated concussions. There are many other reasons that TBI may remain hidden. Thus, there are many people like Tim, who, as a result of their unawareness, fail to seek and get the services and help that they need. Without such help, they remain at increased risk for social failure – which we discuss below.
How Big a Problem Is This?

How many people are likely to have a hidden TBI? The numbers are huge. But, the numbers are imprecise, for two reasons. First, with a few exceptions, incidence surveys of TBI only count people hospitalized or seeking care in an emergency department. But hidden TBI is to a large degree not a phenomenon of people who have sought care. Second, most people who experience a “mild” brain injury – whether they get care or not – recover fully 1 , so they go on with their lives quite nicely – and these lucky ones are not part of our concern. So, estimates of "hidden TBI" that places people at risk for social failure must take these two facts into account.

We can begin estimating the numbers of people with hidden TBI in the U.S. by starting with the population of those with known TBI. The 1998 NIH Consensus Statement on TBI 2 estimates this number as 2.5 - 6.5 million people, while the Centers for Disease Control places the number at 5.3 million (2 percent of the U.S. population) 3. These large numbers of people with known (not hidden) TBI need to be multiplied, because research suggests 4,5 that, for every person hospitalized with a brain injury, 3-5 others who are injured do not receive any care at all (these are the children on the playground, the battered women, much of the hidden TBI population). Thus, given the number of those with known TBI and those who go untreated 4,5, the full population of those injured could exceed 30 million people, with the number of those with TBI-related problems that don't "heal themselves" somewhat smaller. In a population-based survey, Silver and colleagues 6 found 7 percent of those surveyed (in a typical U.S. community) reported a brain injury with continuing challenges.

Social Failure and Unidentified TBI

TBI is strongly associated with multiple, often overwhelming, challenges that can undermine the person's efforts to live a healthy, productive life. Combined, these challenges often result in the person with TBI becoming a "social failure". At the extreme, Lewis and colleagues 7 found that all of the inmates they interviewed on death row had experienced one or more TBIs. Among prisoners in general, estimates of TBI range from 42 percent to 87 percent 8-10 , with most of these brain injuries preceding the start of criminal activity. TBI is also common in inpatient psychiatric populations, and, similarly, the TBI usually precedes onset of psychiatric symptoms 11-12. TBI is associated with high levels of depression and anxiety 13 and those with TBI attempt suicide four times more often than those with no brain injury 6. Additionally, those who are severe substance abusers often have a history of early TBI 14,15. Simpson and Tate 16 found suicide 21 times more likely in those with combined TBI, substance abuse and major depression. Finally, children with TBI are at increased risk for social failure as they mature into adulthood. TBI in children is associated with poor academic performance 17 as well as problem behaviors 18. Glang and colleagues 19 estimate that 130,000 U.S. children need special education classes because of TBI, but that, in fact, only 11 percent are currently enrolled. These children truly remain "hidden" to their schools.

Implications: Step One

Large numbers. Large problems. Why haven't we done better in finding children with TBI and educating them appropriately or in identifying and assisting adults with TBI before they become residents of psychiatric and penal institutions? A primary explanation is that our understanding of both the risk for social failure that TBI may trigger and the estimated size of the population of people with hidden TBI is relatively recent 6,20. Now that we recognize that a sizable, life-wrenching problem exists, we need to begin screening to find people with hidden TBI. Once identified we can bring to bear appropriate interventions to assist them in avoiding the major risks described above and in achieving the kinds of goals that often are out of reach because of TBI's cognitive, emotional and behavioral consequences.

How does one screen for TBI? We developed the Brain Injury Screening Questionnaire (BISQ) to address this need, the only such instrument of which we are aware 21. The BISQ is structured to first review the kinds of situations in which a brain injury can occur, with the idea that memory of perhaps long-ago events is aided by reviewing specific examples (e.g., "on the playground", "falling down stairs") 22. If a blow to the head has been experienced, respondents are asked to recall whether they experienced being dazed and confused or a loss of consciousness. If the answer is yes, they self-report on 100 symptoms commonly found after TBI, which were adapted from existing lists 23-24.

For those individuals with no blows to the head associated with changed mental status, the BISQ takes about 5 minutes to complete. For those who have been injured, administration time is longer, allowing for review of the 100 symptoms. This final step is critical, as most people who experience brain injuries appear to fully heal, having no negative consequences in their daily lives. However, about 15 percent of people, even those with relatively mild injuries, experience persisting, highly disruptive symptoms that do not "go away" 1. Thus, identifying the functional changes that this 15 percent continues to experience following the blow to the head is critical in making a determination of whether the person screens positive or negative.

To screen positive, current difficulties in functioning reported must be numerous and similar to those of people with a known brain injury. Our research suggests that when individuals who are being screened complain of the same symptoms experienced by individuals with a known TBI, they are likely to have a hidden TBI and that the likelihood of TBI is higher when many complaints fall into the cognitive category 25. If this type of pattern occurs, a recommended next step is to refer the person for neuropsychological testing to confirm the outcome. In the absence of such testing, the report that summarizes BISQ data nevertheless provides a wealth of information to help direct actions and accommodations to assist the person with a possible or probable brain injury.

The BISQ has been used in screening people who do not identify themselves as having a disability. In one study, we found that 7 percent of a group of "non-disabled" college students screened positive for brain injury: they had experienced a blow to the head, loss of consciousness and large numbers of continuing TBI-related problems. In a second study, the BISQ was used with schoolchildren, finding that 9-10 percent of children in New York City schools in neuropsychological testing give evidence of having had brain injuries 26. The BISQ also was used to screen individuals in drug abuse treatment programs in New York State; about 50 percent of those screened were found to have had probable brain injuries 13. Those who screened positive were more likely to have had multiple admissions to substance abuse treatment programs and had more mental health diagnoses, suggesting that they were more difficult to treat. The BISQ is also being used on a pilot basis to screen children being referred for special education in Denver. Preliminary analysis of their data suggests about 40 percent of this group have had a TBI.

The BISQ is currently available in a paper-and-pencil version, which is mailed to Mount Sinai for electronic scanning and computer scoring, with a report generated and mailed back indicating the probability of each person screened having experienced a TBI. A second version – password-protected and web-based, which provides the report directly to the user – is under development. Anyone interested in obtaining more information about the BISQ should contact Dr. Wayne Gordon wayne.gordon @mssm.edu.

Implications: Next Steps

In summary, many studies demonstrate that hidden TBI is a sizable contributor to many forms of social failure. The cognitive problems people experience are often the trigger for social failure. Inexplicably, cognitive rehabilitation treatments are frequently limited or excluded from insurance coverage altogether 27. Hidden TBI is a heavy burden for the individual who is injured, but the costs to society, estimated at $60 billion annually, are also draining 28. If we realize that identification is possible, what steps must be taken to reduce its impact?

1. **Broaden Identification**. Inexpensive, easy-to-use screening tools, like the BISQ, should be administered routinely in school settings, by social service agencies, and among at-risk populations such as military personnel, athletes, prison inmates, victims of domestic violence and individuals seeking mental health or substance abuse services.
2. **Increase Awareness**. One in three Americans are not familiar with the term "brain injury" 29. Public information campaigns describing both the causes and consequences of TBI are needed to prevent the injury and ensure that individuals who are injured seek appropriate medical attention.
3. **Expand Professional Education**. Individuals with known TBI account for 2 percent of the U.S. population and 10 percent of the disability population; yet, few health professionals, educators, rehabilitation therapists, social service workers or others are adequately trained to recognize and treat TBI. Education at the undergraduate or pre-certification level is needed.
4. **Improve Access to Care**. Individuals who sustain TBI may require a variety of services and supports of varying intensities throughout their lifetimes. Expanded coverage for treatment and rehabilitation services paid by third parties, such as insurance companies and health maintenance organizations (HMOs), is needed.
5. **Boost Public Funding**. When personal financial resources are depleted, individuals with TBI and their families turn to government agencies for help 30. Policy makers at the federal, state and local level must allocate more public funds to TBI services. At the state level, this can be achieved through general or special appropriations, Medicaid Home and Community-Based Services Waivers, Trust Funds, and other methods.
6. **Strengthen Coordination**. Better communication and linkage among public agencies and with the private sector is needed so that once a person with hidden TBI is identified, he or she can be referred for appropriate testing, treatment and support.

Now is the time to take action to prevent the secondary disasters that befall many people who have had brain injuries but are unaware that these past traumas may be slowly draining away possibilities for a healthy, productive future. People with hidden TBI can be identified and should be provided with the appropriate care to meet their needs.

New York Traumatic Brain Injury Model System

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