

TBI TODAY

News, Ideas, and Resources from the Virginia TBI Model System

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WORKSHOPS PROVIDE FREE TRAINING FOR TBI SURVIVORS & THEIR FAMILIES

"Overall, really good workshop."

"I enjoyed doing this."

"Very informative."

"Great speakers."

These are just some of the positive comments from attendees at the 2006 Spring "Getting Better and Better after Brain Injury" community education workshops. The workshops featured topics such as: dating, romance and intimacy (presented by Dr. Jan Niemeier); persistent post-injury medical problems (presented by Dr. Nathan Zasler); and long-term recovery issues (presented by Dr. Jeff Kreutzer). A survey of workshop participants indicated that the workshops were well received, with the majority (more than 50%) rating the workshops as well organized and relevant. The instructors were rated as highly qualified, as well.

The "Getting Better and Better after Brain Injury" community education workshops were developed to help meet the needs of survivors and family members as they struggle with post-injury challenges. Presented by experienced rehabilitation professionals from the VCU Medical Center, these workshops offer practical information, ideas, and suggestions. Attendees are encouraged to participate by asking questions and discussing physical or emotional recovery concerns.



Offered free of charge, the workshops are sponsored by a partnership among Virginia Commonwealth University Medical Center, the Brain Injury Association of Virginia, and the National Resource Center for TBI. The workshops are held at Richmond VA's VCU Medical Center Learning Center during the Spring and Fall of each year.

Another workshop is planned for April 29, 2006. Topics will include: building and keeping a positive self image (presented by Dr. Jan Niemeier); getting back to work (presented by Dr. Jeff Kreutzer); and taking

care of yourself (presented by Dr. Lee Livingston). For more information, including a downloadable brochure and registration form, visit the NRC for TBI Website at: www.nrc.pmr.vcu.edu/announce/consumer_workshops.htm#.

We value the input of survivors, their families, and others who work with them. If you would like to suggest a topic for a community education workshop, please contact Debbie West at ddwest@vcu.edu or call her at 804-828-8797.

**To register or for more
information contact:**

Jenny Marwitz

PHONE: (804) 828-3704

E-MAIL: jhmarwit@vcu.edu

***A few seats remain for the
April 29, 2006 workshops. Call
NOW to reserve YOUR seats!***

SUCCESSFULLY SURVIVING A BRAIN INJURY: AN APPEAL TO SURVIVORS AND CAREGIVERS (1ST IN A SERIES)

We are eight-year survivors of a traumatic brain injury. Jessica is the survivor; Garry is the caregiver.

We believe we are surviving Jessica's TBI successfully. But what is a "successful" recovery from a brain injury? How do survivors and caregivers survive successfully? We are examining these questions for a forthcoming book, *We Changed Our Minds: Successfully Surviving a Brain Injury*.

Of course, by "successful" we do not mean a complete recovery—a return to the person you were before the injury. The most important element to a successful recovery is acknowledging and learning to live with the permanent impairments caused by the brain injury. Without this understanding by *both* survivor and caregiver, the recovery is doomed to failure!

For instance, Jessica has slowly developed a full, satisfying, and productive new life despite considerable cognitive, physical, emotional, and behavioral impairments. She exercises regularly at the gym. She volunteers at a hospice and a pediatric intensive care unit. She is an active volunteer and member of the board of directors of a monkey sanctuary. She has turned our house into a foster home for rescued cats. She participates in a monthly book discussion group. Moreover, she has developed a wide circle of warm and caring, bright and energetic, friends, who through their joint activities, challenge Jessica to continue her recovery every day.

However, in the early stages of Jessica's recovery, we felt that we were barely hanging in there, certainly not "succeeding." As we look back over what we've learned during the past eight

years, all too often we say to each other:

- ▶ Why didn't we think of that?
- ▶ If only we had done that.
- ▶ Why didn't the experts tell us that?

For example, Garry wishes someone had *forcefully* encouraged him to take better care of himself and to accept more of the many offers from others to help care for Jessica. He often was far too tired and frazzled to be a good caregiver. If he had relaxed more, outside the physically and emotionally draining world of brain injury, his time with Jessica would have been more productive and satisfying for both of them.

Jessica regrets not being more assertive in challenging the therapists and doctors in her outpatient rehabilitation when they emphasized one area of her rehabilitation (recreational therapy) at the expense of an area that she felt was far more important (speech therapy).

Our accomplishments and failures over the past eight years have taught us much that can be useful to others. We want to share this information through our book, so that others facing brain injury will have the resources we lacked.

We also recognize that there is a wealth of information on recovering successfully from a brain injury that we still have to learn. Therefore,

We are asking for your help.

How do you define a "successful" recovery? What worked especially well in your rehabilitation and when you returned home and reentered society? Are there things you wish you had done differently? What advice do you have for survivors

and their families who are just beginning their recovery?

This is your opportunity to help our readers become successful survivors. Correspondents who provide material used in the book will be recognized, but only with their permission. Also, we will donate any profits from the book to brain injury associations.

We would be most grateful to hear from you. Please tell us your story. Write to us at Info@BrainInjurySuccess.org or to Brain Injury Success, c/o Prowe and Whitmore, 7025 NW 52 Drive, Gainesville, FL 32653. Or, visit our website at www.BrainInjurySuccess.org

Together, we can make life easier for future survivors of brain injury and their caregivers.

Garry Prowe & Jessica Whitmore

Garry Prowe and Jessica Whitmore are writing a book titled We Changed Our Minds: Successfully Surviving a Brain Injury. This article is the first in a series that will cover many aspects of the recovery and rehabilitation from a brain injury. The purpose of the series is to examine the elements that contribute to a "successful" recovery from the perspective of both the survivors and caregivers. Garry and Jessica welcome your comments at Info@BrainInjurySuccess.org. Or, visit their website at www.BrainInjurySuccess.org.

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Contact Debbie West at

ddwest@vcu.edu or 804-828-8797

to sign up for our TBI Today mailing list.



BIAA CHOOSES VCU TBI MODEL SYSTEM FACULTY TO WRITE PUBLICATION FOR BRAIN INJURY AWARENESS MONTH PROMOTION

Overcoming
Loneliness and
Building Lasting
Relationships
after Brain Injury

Living with Brain Injury



Brain Injury
Association
of America

VCU TBI Model System faculty were asked to develop a publication for the Brain Injury Association of America (BIAA) for its Brain Injury Awareness month packet of materials. The booklet, *Overcoming Loneliness and Building Lasting Relationships after Brain Injury*, was written by Dr.'s Jeffrey Kreutzer, Laura Taylor, and Lee Livingston of the VCU Medical Center. This booklet is based on the *Help You Need Guide* of the same name available from the National Resource Center for Traumatic Brain Injury (www.neuro.pmr.vcu.edu).

The *Overcoming Loneliness and Building Lasting Relationships after Brain Injury*, along with several other titles, is available for download from the BIAA website (www.biausa.org): www.biausa.org/BIAUSA.ORG/word.files.to.pdf/biam2006/loneliness9.pdf

Specifically written for individuals with brain injury,

the *Overcoming Loneliness and Building Lasting Relationships after Brain Injury* booklet suggests effective ways to understand and cope with the social and behavioral problems often faced by people living with a BI. Frequently after a brain injury, relationships change. The booklet provides ideas and suggestions to interact with others and tips to maintain relationships. Other booklets and brochures available to promote Brain Injury Awareness include:

- ▶ *A Basic Glossary : Legal Terms for People with Brain Injury* booklet
- ▶ *Preparing for Life after High School: Next Steps* booklet
- ▶ Centers for Disease Control and Prevention's *Facts about Traumatic Brain Injury* fact sheet
- ▶ Directory of the Association's Chartered State Affiliates
- ▶ *Traumatic Brain Injury Model Systems* sheet
- ▶ *Brain Injury Awareness Activity Guide*

Research Volunteers Needed

VCU Acquired Brain Injury Outpatient Rehabilitation Services Program

VCU Researchers are seeking adults with acquired brain injuries (such as stroke, aneurysm, traumatic brain injury, anoxic brain injury) and their families to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program. During the course of 5 sessions, participants will be given information on brain injury, local resources, skills development, and positive coping strategies. Qualified volunteers will also be asked to complete several questionnaires. All participants must be at least 18 years old.

Rehabilitation services will be provided at no charge at the Medical College of Virginia Campus. Volunteers will be reimbursed for their time and effort in completing questionnaires.

FOR MORE INFORMATION ABOUT THE PROGRAM, PLEASE CALL:

JENNY MARWITZ

PHONE: (804) 828-3704 OR (866) 296-6904 (TOLL FREE)

E-MAIL: JHMARWIT@VCU.EDU

JUST THE

FREQUENTLY ASKED QUESTIONS

Q: My doctor strictly advised me not to consume alcohol (or any other non-prescription drugs) since my brain injury. He said the *negative effects of alcohol and drugs* would be magnified several times in my case, since my brain sustained permanent damage. What exactly does this mean? Would a few beers cause further brain damage?

A: Permanent brain injury typically results in fewer resources to deal with the additional impairing effects of alcohol. Alcohol can impair judgment which may already be clouded by the brain impairment (in other words, the poor judgment which may be a result of brain injury may be magnified by the dulling effects of alcohol). If alcohol impairs judgment, cognitive abilities and sensory-motor functions, which already may be negatively affected by the brain injury, it can increase the probability of a later traumatic brain injury. In such a case, the brain is more vulnerable to additional impairment.

Alcohol has a direct impairing effect on brain tissue in the following ways:

- ☠ It decreases the flow of oxygenated blood to the brain.
- ☠ It destroys important vitamin B complexes.
- ☠ It disrupts electrolyte balances.

Alcohol has a direct toxic effect on brain tissue (as well as other physiological impacts).

Use of alcohol, typically over long periods of time, can actually destroy brain cells (neurons). It also

can directly affect the potency and effectiveness of medications and lower seizure thresholds. For all of these reasons, it is not advisable for anyone with a brain injury to drink alcohol or use other non-prescribed drugs.



CHAT WITH PAT

Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not substitute for consultation with a doctor or rehabilitation specialist. The identity of authors submitting questions to "Chat with Pat" will be kept strictly confidential.

DEAR PAT: I'm writing because my daughter had a brain injury several years ago and I need some advice about how to help her. She was hit by a car while jogging along a road in 2003. She spent 3 weeks in the hospital trying to recover then she spent 2 more weeks at a rehabilitation center. She didn't remember what happened or why she was in the hospital. The doctors told me it would take a while for her to seem more like herself again. Right before she was discharged from the hospital, I was so frightened because I was sure she couldn't live by herself anymore. I tricked her into coming to live with me so she could "take care of dear old mom." Really, I was worried about her safety if she was to go back to living on her own. She came home from the hospital with me and has been living with me ever since.

There are a number of things about my daughter that have been worrying me. For example,

she loses her train of thought all the time. We can't seem to make it through a simple conversation without her forgetting what we're talking about. Or she'll be in the middle of cooking some food and she'll wander outside, forgetting that she left the stove on.

I am truly concerned about my daughter's lack of awareness about her forgetfulness and trouble paying attention. I'm afraid she's going to burn down the house or get seriously hurt. What can I do or say to her that will help her improve her awareness? She appears quite content with how she is doing and thinks she is doing just fine. Would I be making things worse by bringing my concerns to her attention?

PAT'S RESPONSE: Lack of awareness is a common problem after brain injury. People with recent head trauma often have trouble concentrating, remembering what they are doing, or following along in conversations. Awareness of difficulties after brain injury typically improves with time as the person heals.

A number of people, however, seem to take longer getting their awareness back after having a brain injury. They may not be aware that problems with memory, motor skills, judgment, or slowed thinking are causing them difficulty. It is not unusual for such individuals to wonder what's wrong with *you* or others in their social circle. They could feel like there's nothing wrong with them and that nobody understands how badly they want to live on their own, drive a car, or return to work.

Helping to improve awareness is an important goal for you and your daughter to work on together. First, you can help her to write down all the events related to the accident and her hospital stay. This exercise will increase her understanding about how the accident has impacted her life and your family. Keep the list of events related to the accident nearby. She may



Questions for Pat or the FAQ column are welcomed.

Send them to: "ASK PAT" OR "FAQ"

P.O. BOX 980542. RICHMOND, VA 23298-0542

or e-mail: ddwest@vcu.edu



IMPAIRED SELF-AWARENESS AFTER TRAUMATIC BRAIN INJURY

Franklin

You almost needed brain surgery. Luckily, the swelling in your brain from a serious sports injury went away with treatment. They're telling you that you had a severe brain injury and you have weakness in your left arm and leg. After a month in the hospital, you are discharged home to continue with outpatient rehabilitation. You're young and strong. You estimate that, with hard work and exercise, you'll soon be back on the field as quarterback.

Alicia

It was "touch & go" for a while. The doctors weren't sure you were going to make it after the devastating fall requiring neurosurgery to save your life. Although you suffered a very severe brain injury, you're recovering pretty rapidly. After various stages of rehabilitation, the doctors are predicting you'll be able to return home. You have a young child, who could make recovery stressful, though you have a very loving husband who's willing to take on responsibility for your care. You believe once you return to a loving and familiar environment you'll be better prepared to handle life situations. You'll still be able to help around the house and have a lot more time to baby sit.

Zeth

You were discharged from the hospital after a short stay in rehabilitation. Although the doctors diagnosed a moderate TBI, you only had minor physical injuries from the accident, so you think that returning to work won't be a huge problem. Maybe your boss will let you take it easy and not ask you to run all his errands. After all, you did have a major car accident. Now that you've returned to work, you're motivated to do to all the work it'll take to make up for the time you were gone.

Can you identify with any one of these scenarios? After your injury, did some of these thoughts come to mind? Maybe you felt this way early in recovery, but later realized that many of the work, school, and household chores you once did with ease are now very difficult to perform? Maybe before your injury, you logged on to your computer everyday and used several user IDs and passwords? Now you're constantly forgetting your passwords and your boss is complaining about how much time it takes you to get things done. Perhaps, you're physically ready to play ball, but your thought processing is so slow, you can't remember the plays. You used to be the star athlete, but now your teammates feel your performance is not good enough to win the game. Maybe, before your injury, you could handle taking care of a five-year old while working a full-time job and being a loving and attentive wife? Now you're no longer able to keep up with the demands of rearing a young child and even doing simple household chores.

The scenarios described above are examples of impaired self-awareness after TBI. The medical term for this type of disturbance is "anosognosia." The person is less often aware of the impact those changes have on their ability to carry out tasks. This lack of self-awareness can have a very negative effect on rehabilitation and reentry into the community. For example, rehabilitation may be slowed by frequent clashes with therapy personnel related to different perceptions of what the patient is really ready to start doing.

Persons with limited self-awareness may be quite determined to resume pre-injury activities or roles that are clearly unsafe for them to carry out. Yet, when confronted with the reality of such failures as job loss, lower school

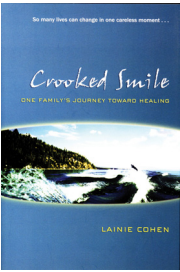
grades, or further injury, the survivor often becomes distressed and feels less sure of themselves, leading to lowered self-esteem and feelings of depression.

Impaired self-awareness can make recovery after TBI difficult. With the help of rehabilitation staff, family, and other caregivers, improvement is possible. First, it is important to understand that impaired self-awareness is not necessarily denial, though the two can be interrelated. Limited self-awareness has more to do with physical changes in the brain than with a psychological or psychiatric disorder. So, when dealing with an individual with impaired self-awareness, a helpful attitude, rather than criticism, is important. Secondly, persons with limited self-awareness should be encour-

aged to listen carefully to their healthcare providers and trust their advice about activities to avoid. Rehabilitation professionals are not "being mean;" they are basing their cautions on their own clinical experience. Thirdly, the best way for caregivers to help is to be very honest and truthful. Objective feedback may not be what your relative wants to hear, but *is* what they need to grow and improve. Lastly, try to give honest feedback instantly, using different methods. Sometimes waiting until later is not the best solution, particularly when your relative has poor memory. Using a camera for snapshots or videotaping to record their behavior can provide instant visual and audio feedback.

Kelli D. Williams

BOOK REVIEW



Title: Crooked Smile: One Family's Journey Toward Healing, by Lainie Cohen, 2003

Publisher: Toronto, ECW Press, 2003

ISBN: 1-55022-573-1

Price: paper \$19.95 CA

Description: 337 pp.

When I was asked to review *Crooked Smile: One Family's Journey Toward Healing* by Lainie Cohen, I was reminded by the Editor-in-Chief that a review need not be a critique. After reading this easy-to-read, yet gripping personal story of a family's life-transforming experience with traumatic brain injury, the Editor's words seem to have been unnecessary. For how can anyone possibly "critique" another's life and experiences?

Lainie Cohen's story is of her son's recovery from a brain injury sustained as the result of a motor vehicle rollover, and concurrently her own and her family's journey of discovery and healing. This book joins a growing list of books describing the consequences and, invariably unique, pattern of hope, adjustment, joy, anger, elation, sadness, struggle, triumph and determination.

While the author's stated purpose for writing the book is to "try to recapture events to help (her son) understand that period of time for which he has no memory", it has significance well beyond this single objective.

In its 39 brief chapters and epilogue spread over 337 pages, the families of other individuals affected by brain injury will find much in common with their own

experiences-- both exhilarating and desperate. So, too, will professionals who do not have an inflated assessment of their own self-worth and expertise in the yet imperfect field of applied neuroscience and rehabilitation.

In a candid reading of this book, professionals will hopefully acknowledge, as Lainie Cohen's story of her son's recovery makes clear, that we do not yet know with any certainty the trajectory that any person's recovery will take, even though some will undoubtedly continue to offer predictions that serve to confuse and distress rather than encourage and support. Yet precise predictions about expected outcomes are typically what families new to this human tragedy of brain injury so desperately seek in the early days and months following injury.

But as Cohen's own discoveries reveal to the reader as the story of recovery gradually unfolds over the first one and a half years following injury, the path must be paved with the bricks of self-discovered hope and determination-- two elements that medicine and neuroscience cannot quantify or administer, or that they may even find as uncomfortable allies. Cohen also reveals that the path of recovery for the families and loved ones of someone who has sustained a brain injury must become one that focuses on looking forward to and pursuing a new "reality," rather than struggling with an evaporating effort to recapture the past.

Perhaps Cohen's most important revelation is the power that family, friends and cultural and religious ritual provide to the process of "re-creation." For someone like me who may take weeks or even months to finish a book, to be able to say that this

book was read cover-to-cover in less than 24 hours is a testament to its interest, relevance and sheer humanity. Anyone who has been touched by brain injury, or who works in a professional capacity with those who have, would do well to read this story. Perhaps other readers, like this reviewer, will wish that one day they too may have the opportunity to meet this family if for no other reason than to fill in the gaps between where the main part of the story leaves off at 18-months post-injury and the epilogue that tantalizes the reader with images from years later of smiling family faces and brief anecdotes of successes and accomplishments.

If the experience of others serves as a valid reference point, it is likely that this interim period was as filled with agonies and elations as were the first 16 to 18 months. We can hope that Lainie Cohen will enrich us with a second book that will take us further along the journey and help describe what, like the 90% of the iceberg resting below the surface, comes to be the life lived by someone who has sustained a brain injury and the loved ones around him. This part of the story of brain injury survivorship and recovery needs to be told.

Reprinted with permission from the International Journal of Disability, Community & Rehabilitation (IJDCR), Vol. 3, No. 4 by Gerrit Groeneweg, Ph.D., C. Psych, Executive Director, Brain Injury Rehabilitation Centre, Calgary, Alberta, Adjunct Assistant Professor, Department of Psychology, University of Calgary. Readers are encouraged to visit www.crookedsmile.org to read chapter one of the Crooked Smile.

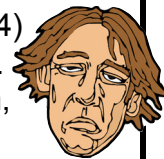


HAD A BRAIN INJURY? FEELING DOWN OR SAD?

If so, then you might qualify to participate in a study of depression medications for people with traumatic brain injury (TBI) from a car accident, fall, assault, or sports injury.

Researchers are comparing Effexor (a medication to help with depression) to a placebo (sugar pill). If you qualify to be in this study, you will be seen by a doctor regularly for 12 weeks. There are no charges for the doctor's visits or the study medications, and you will receive up to \$55 for your time and effort. You must be 18 years or older to participate.

This study is conducted by the VCU Department of Physical Medicine & Rehabilitation. Contact Jenny Marwitz for more information. Phone: (804) 828-3704 or (866) 296-6904 (TOLL FREE); **E-MAIL:** jhmarwit@vcu.edu; **USPS:** VCU Department of Physical Medicine & Rehabilitation, Box 980542, Richmond, Virginia 23298-0542



- Just for Fun Answers to Word Puzzle (Pg 8)
- 1. CROOKED
 - 2. SMILE
 - 3. SELF
 - 4. AWARENESS
 - 5. PIANO
 - 6. BETTER
 - 7. WORKSHOP

JUST FOR FUN! What a Mix-up! *By Debbie West*

Oops! These words seem to be all mixed up. Can you figure out what these words are supposed to spell? You can find each of these words somewhere in this issue, so you might want to read the issue, first. First letter cues, if you get really "stuck" are on page 5. Answers are on page 7. Good luck!

1. KODCREO _____
2. MSIEL _____
3. LFES _____
4. WARNSEASE _____
5. AOIPN _____
6. EETTBR _____
7. PRSWKHOO _____
8. CHARESER _____

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