

TBI TODAY

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

THE VIRGINIA TBIMS TEAM

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TBI Today is published by Virginia Commonwealth University's Dept. of Physical Medicine and Rehabilitation's Neuropsychology Service. This newsletter is a project of the Virginia Model System, funded by the US Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The views, opinions, and information presented herein are those of the publisher and are not necessarily endorsed by the US Dept of Education.

Timing Is Everything

By Jeffrey Kreutzer, Ph.D.

After brain injury, people want their lives to return to normal as soon as possible. People who are working full time strongly desire to start working full-time again. People who are in college strongly want to resume their normal studies.

Know that most people, especially college students, try to go back too soon. Consider the following two scenarios...

David S., a 37 year old construction worker, had a severe brain injury four months ago. He was in the hospital for less than two weeks. Despite a very serious injury, he made rapid progress and was discharged to home weeks before originally expected. Before his injury, he often worked overtime. After his injury, he found himself bored at home, and missing his work buddies and his sizeable income. David went through a series of tests to help his doctors decide if and when he was ready for work. Afterward, the doctors expressed concern

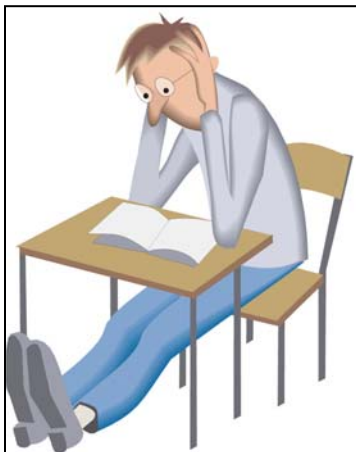
about his safety. They recommended he wait at least another three months before trying to return to work part-time. The evaluations had shown problems with slowness, coordination, vision, and very serious memory problems.



David insisted that the doctors were wrong and that he was recovered, so he returned to work full time as a backhoe operator. During his first morning back his employer discharged him and told him never to come back. While operating the backhoe, David had injured another worker who was rushed to the hospital by ambulance.

Roger J., a 21 year old college student, received a moderate brain injury in a local bike race when he crashed into another rider. He was briefly admitted to (contd on page 2)

(Timing, page 1) the hospital and returned to live with his parents. At a follow-up appointment with his doctor, his parents spoke of problems with memory, word finding and reading. His doctor referred him for neuropsychological testing. The tests showed that Roger did well in several areas. On the other hand, the doctors were concerned about low scores on tests of memory, reading comprehension, and math. They recommended he hold off on school and return part-time in the fall. Concerned about missing any school, Roger returned to school full-time.



Two weeks after returning to school, Roger withdrew from two of his spring semester classes. At the end of the semester he learned that he had failed the remaining classes. Roger decided he might best give up on plans to get a college education.

Appreciate that most people try to return to work or school before they are truly able. Understand that recovery takes time and try to be patient. Know that your doctors and therapists do not want to hold you back. From survivors who have failed and those who have succeeded, they have learned that **timing is everything**. People who take on too much too soon are likely to experience frustration and failure.

Your doctors and therapists will work to understand your goals and your abilities. They will do their best to develop a treatment plan that doesn't hold you back and offers you every chance to succeed in reaching your most important goals.

This article is adapted from the upcoming 2nd edition of "Getting Better After Brain Injury: A Guide for Survivors," a publication of the National Resource Center for Traumatic Brain Injury.

Mark Your Calendar!



T.G.I.F.

- ◆ **Location:** 1st Friday of each month, Belmont Recreation Center, 1600 Hilliard Rd.
- ◆ **Description:** the local departments of recreation & parks host this monthly social event for survivors of brain injury, ages 18+
- ◆ **Contact:** Call Kariayn Smith, 804-501-5135, for more information and/or to be placed on the mailing list for monthly reminders.

Richmond Chapter and Support Group

- ◆ **Location:** 3rd Monday every month at 6 pm, Children's Hospital Auditorium, 2924 Brook Rd.
- ◆ **Contact:** Call the Richmond BIAV at 804-355-5748 for more info!

Hopewell Tri-Cities Support Group

- ◆ **Location:** 2nd Tuesday of every month at 6:30pm, Nelson Library, 209 East Cawson St, Hopewell, VA 23860
- ◆ **Contact:** Call the Richmond BIAV at 804-355-5748 for more info!

May 20-26 (Week 1) May 27-June 2 (Week 2) 2012

- ◆ **Event:** Camp Bruce McCoy
- ◆ **Location:** Triple-R Ranch in Chesapeake, VA
- ◆ **Description:** The Brain Injury Association of VA hosts a week-long recreational program with activities adapted to everyone's ability. Weekend mini-camps at reduced rates available.
- ◆ **Contact:** <http://www.biaav.net/camp-brucemccoy.htm> or call 1-800-444-6443.

If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please contact Matthew Wetsel at 804-828-3703 or wetselme@vcu.edu

JUST THE FREQUENTLY ASKED QUESTIONS

THE INFORMATION PROVIDED IN THE FAQ IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

Q: I'm worried about my daughter who plays college lacrosse. She just hasn't seemed herself since she got a blow to the head during the last game.

A: It is important that she seeks medical attention right away as your daughter might have sustained a concussion. You can't see a concussion, and the signs and symptoms might not have shown up right after the injury.

Have you observed the following?

- Appears dazed or stunned
- Is confused about events
- Answers questions slowly
- Repeats questions
- Can't recall events prior to the bump
- Can't recall events after the bump
- Shows behavior or personality changes
- Forgets class schedule or assignments

Has she complained about the following?

- Difficulty thinking clearly
- Difficulty concentrating or remembering
- Feeling more slowed down
- Feeling sluggish, hazy, foggy, or groggy
- Headache or "pressure" in head
- Nausea or vomiting
- Balance problems or dizziness
- Fatigue or feeling tired
- Blurry or double vision
- Sensitivity to light or noise
- Numbness or tingling
- Does not "feel right"
- Irritable
- Sad
- More emotional than usual
- Nervous
- Drowsy
- Sleeps less/more than usual
- Has trouble falling asleep

JUST FOR FUN!

See if you can unscramble these words. Hint: they all have to do with the Springtime. Answers on page 7!

- 01. RGINSP _____
- 02. HRCMA _____
- 03. ARLIP _____
- 04. YMA _____
- 05. ORWSFEL _____
- 06. LSLABBEA _____
- 07. NREGE _____
- 08. ASSRG _____

- 09. SSNIUHNE _____
- 10. HTAW _____
- 11. TLME _____
- 12. OEHSWRS _____
- 13. ANRI _____
- 14. LMRBLUAE _____
- 15. TEESRA _____
- 16. DBRIS _____



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: jhmarwit@vcu.edu





CHAT WITH PAT

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

DEAR PAT: I have a brain stem injury from a motorcycle accident back when I was 24. I was young and reckless, and thought I was invincible. Looking back, I'm just thankful that I survived the accident. It wasn't an easy road to get to where I'm at now, but I know I'm better off than many people I know who were in motorcycle crashes. I have my own place, a car, and even a girlfriend. I would say I have a "normal" life like other people in their 30's, except...

Work. I have not been able to keep a job. I was working as an architect when I got hurt. I had a hard time keeping up with the deadlines due to my slow thinking process. Over time, my employers saw my limitations and let me go. They gave the reason that my performance was sub-par as the excuse for firing me.

The trouble is that nobody understands brain injury and the difficulties I experience daily. Most of the time, I'm hesitant to tell my employers about my accident, hoping it won't be a factor. Since I look pretty good on the outside, I'm able to get hired based on my resume and experiences. Then problems come up after about a month or so when I can't keep up or make mistakes. It's hard to build trust and be given room for errors when you're a new employee.

After many job failures, I decided to become an independent contractor

and do free lance work, which works pretty well but the money isn't steady. I get too stressed out because I don't know if I'll make enough money to pay my rent. So now, I'm considering going back into the work force. I need some advice on how I can keep a job.

When starting a new job, what are your recommendations with sharing or not sharing about your disability? What rights do I have as an employee with a disability? What about using a job coach, where could I find one?

Thank you,
Frustrated Job Seeker



PAT'S RESPONSE:

Thank you for sharing your story with me. I commend you for your persistence and fighting to make a living for yourself. Working and feeling like a productive member of society is important to all of us.

First of all, I would recommend that you become familiar with the resources from the Americans with Disabilities Act (ADA) about your rights as an employee. Information about the ADA may be found at most public libraries or you can visit their website at: <http://www.ada.gov>.

On the right side of the home page, there is a section called General Publications. There you will find a link to *A Guide to Disability Rights Laws*. This is a 21-page booklet that provides a brief overview of ten Federal laws that protect the rights of people with disabilities and provides information about the federal agencies to contact for more information. You'll also find *A Guide for*

People with Disabilities Seeking Employment, a 2-page pamphlet for people with disabilities provides a general explanation of the employment provisions of the ADA and how to file a complaint with the Equal Employment Opportunity Commission.

For those who are self-employed with a small company, you may also find this information useful. Below the General Publications section is a section for businesses with a link to *ADA Guide for Small Businesses*. This 15-page guide presents an overview of some basic ADA requirements for small businesses that provide goods and services to the public. It provides guidance on how to make their services accessible and how tax credits and deductions may be used to offset specific costs.

Toll-Free ADA Information Line: Call to obtain answers to general and technical questions about the ADA and to order technical assistance materials: 800-514-0301 (voice); 800-514-0383 (TDD)

To find out about job coaching and other employment services for persons with disabilities in your state, you may wish to contact the state's Department of Human Services, Division of Rehabilitation Services.

After understanding your rights as an employee, you can decide on how and what to share about your injury with your employer. You may wish to consult and discuss with your treating healthcare professionals, including psychologist, neuropsychologist, therapist, rehabilitation counselor, regarding your decision to share or not share about your injury. If you decide to share, you may wish to share documentations of your disabilities or limitations, such as a neuropsychological report, with your employer or trusted colleagues to prevent problems from arising in the future. Creating a collaborative relationship with the Human Resources department and your supervisor is important to establishing a positive working environment.

Stephanie Lichiello, B.S., is a psychometrist and research specialist in the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University. Stephanie was born and raised in Forest, VA and graduated from The University of Mary Washington in 2011 with a double major in Psychology and Biology. She currently conducts research and provides neuropsychological assessments to adults with TBI and other health concerns. She is also the Project Coordinator for the Commonwealth Neurotrauma Initiative Trust Fund Grant, "Best Practices Model for Incarcerated Youth with Brain Injury."



She was very involved in student clubs and organizations during her college career including Psi Chi – The International Honor Society in Psychology, in which she held an officer position. She was a member of Students Helping Honduras which allowed her to volunteer at an orphanage and help construct houses for a growing community in El Progreso. She has studied abroad in Spain and spent the summer of 2009 living in Bermuda and working with Atlantic bottlenose dolphins. She has been involved with several research projects in collaboration with Virginia Tech, Georgetown University, and Lynchburg College and remains interested in a wide variety of research topics.

**HAVE YOU
MET STEPHANIE
LICHIELLO, B.S.?**

Outside of work, Stephanie enjoys spending time with friends and family, attending sporting events and concerts, watching movies (comedies are her favorite), scuba diving, snorkeling, any activity involving water and the beach, and traveling for both leisure and to attend psychology conferences. She will present a poster for her undergraduate senior honors thesis at the 120th Annual Convention of the American Psychological Association later this year.

Couples Needed for New Study

Doctors at VCU are studying how brain injury effects relationships between couples. Both the survivor of the brain injury and their partner will complete a set of questionnaires, be part of a series of focus groups, and do an exercise with photos.

To qualify for the study, couples must be in a committed relationship and have met prior to the injury. The nature of the injury must be non-progressive, such as a traumatic brain injury or a stroke. Both the survivor and partner must be willing to participate.

You will be compensated for your time, and may also qualify for travel reimbursement if certain conditions are met.

To participate or get more information, please contact Brittney Chappell at (804) 828-2377 or bschappell@vcu.edu.



Just the Way I Am

By Mary Ellen Schattman

My husband, Mike, had a heart attack and quadruple bypass at 52. He had four cardiac arrests during surgery, spending a week in ICU and a month in the hospital. He was never the same, although he continued to practice law for another ten years. During this time he had four more heart surgeries. It took a year for doctors to admit he had lost his hearing in one ear and three years before they agreed he needed neuropsych testing.

Unfortunately, during those three years I was brain damaged at 53 by malpractice. I have asthma and was prescribed cortisone. I developed undiagnosed Cushings and then severe hyponatremia. My salt was replaced too fast, causing Central Pontine Mylenolysis. I could tell something was wrong - it felt like I was dying. I'd talk to Mike, but he had suffered brain damage himself as a complication of his multiple surgeries. Trying to resume work and be 'normal' caused him so much cognitive fatigue that it was difficult for him to help me.

Thankfully, friends intervened and saved my life. Later, we had a successful malpractice suit. Though we looked normal, I went from making \$90,000 a year as a hospital executive to being unable to walk or even read. My once-great memory seemed to have vanished. Neuropsych testing showed the extent of the damage and I was told not to handle money without supervision – a central aspect of my work at the hospital. This was even more devastating knowing that it could have been prevented. Instead, due to carelessness, failure to read a lab test (twice, a week apart) and a failure to properly treat my condition when diagnosed all added up to my current condition.

I have been through rehab several times. While I noticed the enormity of my loss rather early, my husband was less aware of his new deficiencies. He has severe neuropathy along with a defibrillator. He is also pacemaker dependent. He can still drive locally, but can no longer read maps, much to the horror of our adult children. I myself don't drive. He is now 65, and I am 64. Finding a neurologist who understands the dynamics of our individual impairments has proved difficult. He is my working memory, and if his fails I will be lost.

We moved from Texas to Pennsylvania to assist our daughter, Rita. She and her husband have two girls. Their younger daughter, Amy, is six and has global developmental delay. She attends Overbrook School for the Blind and speaks with a computer device. We assist with her therapies. Unlike Mike and myself, we don't know what caused Amy's condition.

Because I had been so smart, I was keenly aware of my new cognitive deficits. My daughter Rita is a social worker. She determined that my happiness would lie in doing something I had never done before, so that the little voice in my head wouldn't tell me how badly I was doing. She suggested art lessons, and got me an art teacher for children who understood that I wouldn't learn in the normal sense but could learn to enjoy the hour I was painting. (cont on p7)

Survivor Stories Wanted!

Recovering from a brain injury can be very difficult. Sometimes, one of the most helpful and inspiring things is simply hearing from other survivors who have gone through recovery and faced the same challenges. Are you a survivor with a story you'd like to share? If so, then we'd like to hear it, and it might get into a future issue of TBI Today!

Submit to: jhmarwit@vcu.edu

or

TBI Today, VCU P.O. Box 980542
Richmond, VA 23298-0542

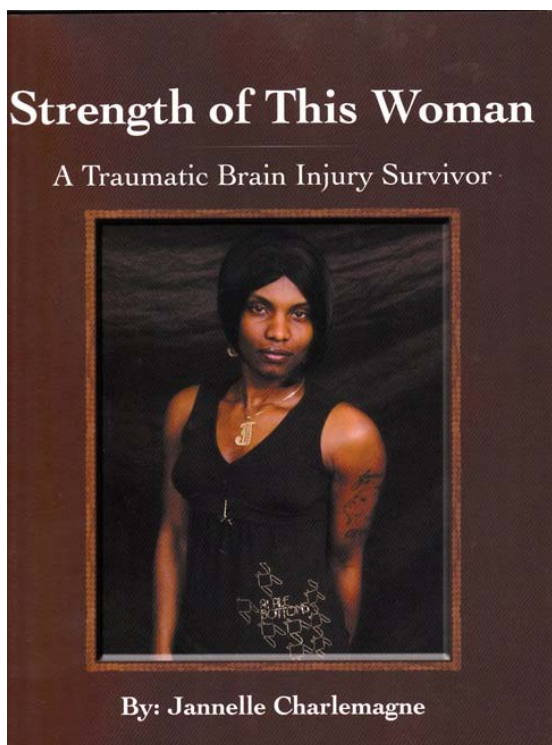


(Way I Am contd)

I could identify as a "painter" to myself and to others. I had never taken music lessons, so Rita arranged for me to take primal drumming lessons. I had a new identity. I was a drummer. Oddly I can only keep to the rhythm if I talk about something else at the same time. But I was no longer the sum of my brain damage.

I don't like the term survivor. Amy was born with her unusual brain. She didn't "survive" anything, she was born that way. She owes her progress to thousand of hours of therapy. Mike survived aborted sudden death and kidney cancer, but his brain was significantly changed. Like "Z" in "The Man with the Shattered World" by Luria, I did not survive at all. My memories, my talents, my personality, my ability to recognize life long friends all died in April 2001. A new person rose from the ashes, like a phoenix.

All four of my grandchildren were born after the new me arrived. They love me just the way I am.



Book Announcement

TBI survivor Jannelle Charlemagne, who contributed a survivor story to Volume 9, issue 1 of *TBI Today*, has completed her self-published account of her injury.

The survivor of a tragic assault, Jannelle has put her life back together and is working on completing her Bachelors at the University of Louisville in Kentucky.

Jannelle has a unique writing style that is brutally honest, recounting the tragedy that befell her in a very direct way. Be advised, some of her story is quite heart-wrenching, but through it all she finds a positive outlook.

She writes: *"Despite my setbacks, pain, loss, hurt and struggles, I'm still making the best of a bad situation. Also, I hope that even one person, and hopefully many more, can gain strength from my story."*

You can purchase *Strength of This Woman* at www.authorhouse.com or via Amazon.com.

JUST FOR FUN!

ANSWER KEY

Here are the answers to the Word Scramble from page 3. How did you do?



- | | |
|--------------|--------------|
| 16. BIRDS | 08. GRASS |
| 15. EASTER | 07. GREEN |
| 14. UMBRELLA | 06. BASEBALL |
| 13. RAIN | 05. FLOWERS |
| 12. SHOWERS | 04. MAY |
| 11. MELT | 03. APRIL |
| 10. THAW | 02. MARCH |
| 09. SUNSHINE | 01. SPRING |

VCU, PM&R

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P.O. BOX 980542

RICHMOND, VA 23298-0542

RETURN SERVICE REQUESTED



Founded in 1983 by families and concerned professionals, the Brain Injury Association of Virginia is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them. Over 10,000 people find help from BIAV each year.

BIAV is a chartered state affiliate of the Brain Injury Association of America and exists to be the voice of brain injury through help, hope and healing for Virginians with brain injury and their families. We educate human service professionals and the community on the risks and impact of brain injury and advocate for improved medical and community-based services. Many of our staff members are Certified Brain Injury Specialists (CBIS Certified).

To find out more information about BIAV, contact us at 1-800-444-6443 or 804-355-5748. Or visit our website at www.biav.net.



The Voice of Brain Injury: *Help, Hope & Healing*