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

THE VIRGINIA TBIMS TEAM

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Breaking Free From Loneliness After Brain Injury by Michael Cerreto

Over the years, you wake up each morning with the certainty that your life would remain relatively stable. Then one day, you have a bad car accident. When you wake up after the accident, you are surrounded by nurses, tubes, beeping monitors, and the shock that something serious occurred but you cannot remember what. You find it hard to speak, remember, move. You are staring down a future of doctors, rehabilitation, and uncertainty.

But time and resilience march on. After being diagnosed with a traumatic brain injury, you receive wonderful support and treatment and get a little better each month. You are encouraged by your progress but still think about the job you can no longer do and the friends who stopped calling. You feel guilty about how your family has been affected, and powerless to care for them as before.

You Want More Out Of Life

With each small success, you begin to want more out of life but feel constrained by your inability to follow conversations, remember, and do physical activities that once were so easy. You feel lonely but reluctant to journey out of the house. So you withdraw into your own world of TV, reading, eating, and doctor's appointments. Greater isolation and loneliness set in.

As humans, we try hard to avoid isolation and loneliness by creating expansive lives through school, friendships, sports, arts, religion, and family. After a brain injury, your world shrinks and you can quickly withdraw into isolation and loneliness, which are shackles that constrain recovery.

You Can Break Free From Loneliness

You can break free from loneliness and expand your world again. Having a life of meaning and achievement can help you feel worthwhile and productive after a brain injury. You can have a renewed sense of mastery and control over your life, which are important to recovery.

The first step is to work with a friend or family member to answer the Breaking Free From Loneliness questions on page six to determine how you want to expand your world. I discuss these questions with my patients and the discussion helps them determine how to escape from loneliness. So, find someone you trust and answer these questions for yourself. (contd on page 6)

Back to Nature!

After injury, it's not uncommon for people to struggle with finding things to do outside of the house, not to mention having limited income. A reader shared some information with us on national and state-level park services (thanks, Bill!) and we thought we would share it with our readers.

First, there is a lifetime pass for access to National Parks and Federal Recreational Lands that is free to U.S. citizens and permanent residents with permanent disabilities. This pass also includes some discounts on amenities for things such as swimming or camping. Passes require documentation of disability. For more information, visit:

https://www.nps.gov/planyourvisit/passes.htm and look under 'Access Pass.'

Second, for Virginia residents, similar passes are available for people with disabilities which are free of charge. Applications must include a Social Security disability benefit verification letter. These passes include parking fees as well! Veterans with disabilities can obtain free passes, too, which include a few additional discounts and benefits. For more information, visit:

http://www.dcr.virginia.gov/state-parks/passes



Mark Your Calendar,

Supportive Survivors

- When: Tuesdays 6-8pm
- Location: Usually at the Regency Mall Food Court (Richmond)
- Contact: Contact Ted Taylor at (804) 852-6644 or taylorted58@yahoo.com

Richmond Aphasia Support Group

- Location: 1st Thursday of every month from 6-7pm at First Unitarian Universalist Church, 1000 Blanton Ave, Richmond, VA 23221
- Contact: (804) 439-2657 or email at ricaphasia@vahoo.com

Richmond Support Group for Adults with TBI, Family, Friends

- Location: 3rd Monday every month at 6:15pm, Children's Hospital Auditorium, 2924 Brook Road, Richmond, VA 23220
- Contact: Liz Perry-Varner at 804-276-5761

Therapeutic Recreation—Chesterfield County

- Location: Various locations
- When: All summer
- What: A variety of activities and events for individuals with intellectual, physical, emotional, and/or developmental disabilities to enhance health, independence and well-being. Visit http://www.chesterfield.gov/content2.aspx?id=3134 for more info or see contact information below!
- Contact: Call 804-751-4134 or email mcclellana@chesterfield.gov

Looking for a support group in your area? Check out www.biav.net/virginia-support-groups.htm for more support groups organized by region!

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 call 828-3703 or email melissa.jackson@vcuhealth.org.

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: jennifer.marwitz@vcuhealth.org

SKILL-BUILDING, SUPPORTIVE AND EDUCATIONAL PROGRAM FOR COUPLES AFTER BRAIN INJURY PARTICIPANTS INVITED!

Are you in a relationship? Have you or your partner had an acquired brain injury? You May Qualify for an Ongoing Research Study!

Virginia Commonwealth University researchers in the Department of Physical Medicine and Rehabilitation are seeking adults with brain injuries to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program to help couples adjust to brain injury. Qualified volunteers will participate in five to six support and education sessions. Study volunteers will be given information on brain injury, local resources, skills development, and positive coping strategies. Volunteers will also be asked to complete several questionnaires. Participants must be at least 18 years old. There is no charge for services and volunteers are compensated for their time.

During the sessions, the following topics will be discussed:

- Effects of brain injury on the survivor, partner, and couple
- Healthy communication and managing stress
- Setting goals and solving problems
- Rebuilding intimacy
- New challenges and strategies to parenting (optional)
- Strategies for optimal recovery



If you are interested in participating, please call Jenny Marwitz at 804-828-3704 or toll free at 866-296-6904 or email jennifer.marwitz@vcuhealth.org

Survivor Story: My Testimony by TeQuila Kelly Connors

In 2003, the Lord saw it fit to deliver me from a near fatal accident. While traveling on 295 North, one of my tires blew out and my little Acura was pulled into the path of a tour bus. Not only was my car knocked across three lanes of traffic but it was crushed liked a paper bag. The only remaining parts of my first and favorite car were the driver seat and the steering wheel. Part of my skull was knocked out (replaced by a titanium screen), I suffered a bruised brain, and I woke up in the hospital not knowing where I was or why I was there. I could not speak, and could not move any part of my body. I just looked up into my mother's eyes as tears came down her face and thought this was it for me. But GOD!

The information that I told you in the beginning of this testimony was told to me, I actually have no memory of that day or many days in my life. The doctors told us that it would take about a year before I would regain mobility and even my speech will take some time to come back. I had to learn the most basic things (speaking, walking, writing, sitting up, etc.) all over again. And as I was learning, my brain and body did not always work together. I would be thinking sit up but my body would have a whole other action in mind. Sometimes the spasms would be so great that all I could do was cry. But GOD! (contd on page 7)



DEAR PAT:

I am a working mother of three young children. This past winter, I took them sledding at our neighborhood park on a snow day from school. I decided to join the fun for a ride down the hill that ended in me colliding with a young woman at the bottom. I bounced out of the sled and landed on my head. And that's how I got my concussion! My head hurt for days and I had a hard time focusing because of the pain. I tried to rest as much as I could but it's hard with three kids. Some days, I had to force myself out of the bed to get them on the bus to school. Then I would go back to bed and sleep in darkness. Bright lights really bothered me so I was in the house with all the blinds shut. My neighbors probably thought I was crazy, doing weird things like wearing sunglasses indoors. I took some time off from work because I couldn't even function at home. Doing something, anything, took a lot of energy out of me. Thank goodness, most of the problems got better for me over time. I don't struggle with

the light issue and constant headaches now. The headaches still happen when I'm stressed, but they're not as frequent or as intense. So why am I writing you?

The problem that drives me crazy is my short-term memory. I feel like a flaky and disorganized woman who can't seem to get herself together. I forget stuff all the time and can't keep track of my kids' activities. It's been really hard juggling work and being a mom. My boss was nice enough to let me work part-time, even though I'm still exhausted by the end of the week. And, of course, you don't get a break on weekends with the kids. I need help organizing my life and figuring out what to do about the memory issue. I used to be such an organized person and didn't miss a beat with taking care of my kids. Now, my husband has to step up and help out. I don't know what I would do without him looking over my shoulder. How can I get some order back in my life? What do I need to do so I'm not always a step behind everyone else?

Frazzled Mom



Pat's Response:

Dear Frazzled Mom,

Getting better from a concussion

takes time and I commend you for taking an active role in the process. It sure sounds like you have a full plate, being a full-time mom and working part-time. Dealing with memory challenges on top of that can be frustrating. The good news is that you can develop compensatory strategies to optimize your functioning.

You are right, becoming more organized and developing ways of compensating for your memory problems can bring order to your home life. You can consider a professional organizer or a tablet; whichever you feel more comfortable using. Some people prefer paper formats while others prefer electronic tools. If you decide on a paper version, I would recommend that you purchase a memory log book that contains a yearly calendar and a notepad section. In the log book, write down your appointment times, create to-do lists, track your medications, and events that happen throughout the day. Similarly, in the tablet, enter your appointment times into the calendar, create to-do lists, use an app to track your medications, and write down events in the note section. Carry the log book/tablet with you everywhere. For example, it would be helpful to take your book/tablet with you to your doctor's appointment. You can write down notes from the visits to share with your family and schedule future appointments. You can also write down guestions you may have for your doctor during your next visit.

It is important to designate an area to keep your note-book/tablet so that it is in the same place every time you

put it down. Initially, you might need to post sticky notes as a reminder to use the log book/tablet or set a timer to go off every 1 or 2 hours. You can also ask your husband to remind you to check your log book or tablet. Once you utilize the tool consistently, it will become part of your routine and you won't have to think about it.

Working with a mental health counselor who specializes in working with persons with a TBI to help implement these strategies might be beneficial. You could contact your local chapter of Brain Injury Association for a referral. In the meantime, try these strategies to see if they work for you. You might have to modify them to fit your lifestyle and preference. I hope these tips will be a good start to organizing your life and putting the pieces back together. Good luck!

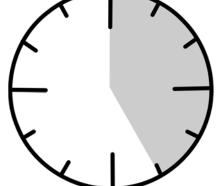
JUST THE FREQUENTLY ASKED QUESTIONS



Q: My doctor keeps telling me to be patient; recovery takes time. I was never a patient person. How do I work on being patient?

A: Luckily, patience is a skill that you can learn over time. Here are some tips for you to practice:

- ☐ You can <u>choose</u> to be patient or impatient.
- □ Remind yourself that you are trying your best to get better and give yourself a break.
- □ Don't stay angry. Find ways to get and stay calm. Practice slow breathing when you feel overloaded. Breathe slowly and deeply ten times.
- □ Define success by all the things you have accomplished *since* your injury. Think about progress you have made since the injury instead of comparing yourself to how you were before injury.
- □ Focus on accomplishments, not failures. Keep a list of gains you notice from day-to-day, focusing on progress.
- ☐ Give yourself credit and reward yourself for taking small steps toward reaching your goals.
- ☐ Avoid becoming overloaded. Focus on one or two tasks/goals at a time.
- Ask for help from family and friends. Taking a break from solving the problem will allow you the time to slow down and find a better solution.





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: jennifer.marwitz@vcuhealth.org



(Loneliness, contd)

Make Everything a Routine: Whatever you choose to do outside the home to rebuild your life, make sure the activities are scheduled routines each week. For instance, every Monday you are at the gym exercising from 12:00pm to 1:00pm; Tuesday you are taking a painting class from 4:00pm to 5:00pm, and so on. By making your activities set routines each week, you are more likely to follow through and be consistent.

Breaking Free From Loneliness Discussion Questions

Step 1: Before your brain injury, what did you enjoy doing in the following areas?

Step 2: What other activities or interests do you have now that you did not have before your brain injury?

Step 3: Based on the lists above, select the top three activities that you want to consistently do with others outside the home at this time.

Step 4: How can you get involved with those activities outside the home each week on a regular, consistent basis?

Steph 5: List the steps you need to take to get started (such as calling, emailing, or signup).

Michael Cerreto, MS, CPCRT, CSC, LDR is a Certified Cognitive Rehabilitation Therapist with **A Talented Mind Clinic** in Richmond, Virginia. He helps children, adolescents, and adults with a traumatic brain injury improve the quality of their daily lives. He also facilitates **The Comeback Project** that is a free, private online community for brain injury survivors and their families. You can join the community to get the support you need at: <u>a-talented-mind.mightybell.com</u>. If you have any ideas for a future article about cognitive rehabilitation, please contact Michael at cerreto@atalentedmind.com.

Abby Welch, B.S., B.A., is a new Research Specialist in the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University. She is responsible for recruiting patients and collecting data for the TBI Model Systems Project at VCU, including the couples program.

Abby was born and raised in Alexandria, Virginia, and graduated early from VCU with degrees in Psychology and Gender, Sexuality, and Women's Studies. She has worked on several studies outside of the TBI Model Systems project, including research on discrimination within the medical field and racism in the food service industry. During her time in undergrad, Abby played rugby for the Women's Rugby Club of VCU, where she learned how to "scrum down," lead a team, and tackle women twice her size. Outside of work, Abby likes to spend time with friends, go to museums, play

video games, watch movies, and hang out with her pets Chive and Nebula.

She also loves anything green and leafy, and has been known to spend an excessive amount of time wandering around the garden center at Lowe's.



(*My Testimony*, contd) My family took care of me in ways that an independent woman such as I would be ashamed. But GOD! I am here today not because of the report of the doctors but because of the report of the LORD! That I will live and not die. So I can on this day and every day, declare the works of the Lord. It took only three months for me to regain mobility and I was back at work doing twelve hour shifts as if nothing ever happened. Residual effects are minor compared to where I came from. I am even rocking a fly haircut as a result, that I ain't mad at!

Since the accident; I have obtained my MBA in Professional Studies, written and self-published 3 books, started Prov31 Dance & Development Center for girls ages 5 to 21 and Prov31 Publishing. I have been invited on many of occasions to minister in dance and teach dance. I also married a wonderful man of God that loves me as Christ loves the church! Praises to the Most High for today and every day! I serve a God of a second chance!

[Editor's Note: Many people find great resources in communities of faith. While TBI Today does not endorse any one particular belief system, we readily acknowledge and appreciate the important role that religion plays in the lives of many survivors of TBI.]

Survivor Story Update!

Jannelle Charlemagne is a traumatic brain injury survivor who was published in the 2011 Winter issue of *TBI Today*. We recently caught up with her and she shared about her progress over the past few years.

She has recently completed her Bachelor of Arts degree in Political Science with a minor in Communication at the University of Louisville in Kentucky. She is currently living in Jeffersonville, Indiana, where she is working at the Amazon Fulfillment Center as a Warehouse Associate.

In order to get through her undergraduate studies, Jannelle told us that instead of looking at where she had been, she started looking at where she could be. While at college, she learned new ways to study and adapt post-injury. Her commitment to education helped her face many challenges at the University of Louisville. While her brain injury made it difficult to retain some information taught in class, she sought out resources that aided her with her studies, and even made the Dean's List one semester. [Editor's note: many schools have disability offices to assist students who are differently abled, whether cognitively or physically. A complete list of



potential needs for returning to school post-injury can be found at http://model.tbinrc.com/facts].

Jannelle wanted to share this update in the hopes that her progress and accomplishments will inspire other brain injury survivors. Janelle emphasized to us that while she cannot change the past, she can still look forward to the future. For her, there is value in learning, and recovering from a TBI has been about learning to overcome obstacles and challenges.

To read more about Jannelle's experiences and recovery, you can find her book, *Strength of This Woman: A Traumatic Brain Injury Survivor*, on Amazon.



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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 edu-

cate 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