

**EDITOR** Margie Martinez, B.A.

**PRINCIPAL INVESTIGATOR** Jeffrey Kreutzer, Ph.D.

**CO-PRINCIPAL INVESTIGATOR** David Cifu, M.D.

**PROJECT COORDINATOR** Jenny Marwitz, M.A.

MEDICAL DIRECTOR William Walker, M.D.

**BIOSTATISTICIAN** Adam Sima, Ph.D.

**DISSEMINATION COORDINATOR** Kelli Gary, Ph.D.

**PROGRAM EVAULATION** Jeong Han Kim, Ph.D.

#### **RESEARCH ASSOCIATES**

Amma Agyemang, PhD. Kristin Graham, PhD. Nancy Hsu, Psy.D. Herman Lukow, Ph.D. Melody Moadab, M.S. Margie Martinez, B.A. Abby Welch, B.S.

#### DIRECT CORRESPONDENCE TO:

Margie Martinez P.O. Box 980542 Richmond, VA 23298-0542 (804) 828-5781 Email: mariegrace.martinez@vcuhealth.org

The contents of TBI Today were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0033). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of TBI Today do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

#### Stop Arguing About It. Take Safe First Steps To Independence After a TBI by Michael Cerreto

After a brain injury, you strive to do many of the things you used to enjoy and that provided you independence. You may want to return to work, drive, cook, or date again. As you voice your interest and desires to a family member or friend, you may hear them say "you can't do that" or "I will do that for you." This can make you frustrated because your desire for independence is strong but the activities may be limited to you by your brain injury.

People with a brain injury are often unaware of some limitations, but they still have their desire independence. Caregivers are not trying to cause frustration by saying "no" but are looking out for your wellbeing. There is nothing they want more than to have you return to an independent life.

The conversations you have with your caregiver about doing things they believe you cannot manage can sound very black and white. You voice your desire and they say no and try to talk you out of it. These black and white conversations can make you feel like a child, misunderstood, and stuck.



The solution is for you and your caregiver to have a different type of conversation called Safe First Step. Instead of having "no you can't" conversations, you can take any desire for independence you have and identify a small, safe, first step to take in that direction. For instance, if you want to cook meals again, you can start by cooking with someone who is managing the entire process. You can read each step of the recipe, make the salad, and wash the dishes. Then, over time, you can practice cooking an entire meal by yourself.

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 TBI 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-</u> <u>talented-mind.mightybell.com</u>. If you have any ideas for a future article about cognitive rehabilitation, please contact Michael at cerreto@atalentedmind.com.



#### **Richmond Supportive Survivors**

- When: Tuesdays 6-8pm
- Location: Regency Mall Food Court, 1420 Parham Road, Richmond, VA 23229
- Contact: Ted Taylor at (804) 852-6644 or taylorted58@yahoo.com

#### **Richmond Aphasia Support Group**

- When: 2nd Thursday of every month from 6-7pm
- Location: First Unitarian Universalist Church, 1000 Blanton Ave, Richmond, VA 23221
- Contact: Lynn Burris at (804) 439-2657 or Jan
  Thomas at rva.aphasia@gmail.com

## Richmond Support Group for Adults with TBI, Family, Friends

- When: 3rd Monday every month at 6:15pm
- Location: Children's Hospital Auditorium, 2924 Brook Road, Richmond, VA 23220
- Contact: Christine Baggini, (804) 355-5748

#### Brain Injury Association of Virginia Annual Conference: Making Headway

- When: March 10-11, 2017
- Location: Hilton Richmond Hotel: Short Pump
- Contact: Please visit www.biav.net/biavconference.htm for more info or call (804)355-5748

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 (804) 828-3704 or email jennifer.marwitz@vcuhealth.org.

#### **BIAV Annual Conference: Making Headway**

The Brain Injury Association of Virginia (BIAV) is holding their annual conference. The conference provides an educational opportunity to learn more about issues relevant to the brain injury community, such as navigating social security benefits, ethics and brain injury rehabilitation, neuropsychology, effective cognitive remediation programs after brain

injury, post-concussion syndrome, and more.

Those with brain injury, caregivers, family members, and professionals working in the field are all welcome and encouraged to attend.



There will be a preconference work-

shop (for professionals only) highlighting the topic of Enhancing Clinical Practice on March 10th, a day before the annual conference on the 11th. These will take place at the Hilton Richmond Hotel and Spa in Short Pump.

#### The 2017 Brain Injury Rehabilitation Conference: Practical Solutions to Real World Problems

In May 2017, the Williamsburg Brain Injury Rehabilitation Conference will celebrate its 41st consecutive year.

The conference is designed primarily for multidisciplinary rehabilitation professionals and others who serve individuals with brain injuries and their families, including: case managers, vocational rehabilitation specialists, neuro/psychologists, counselors, physicians, social workers, special education teachers, and more. Continuing Education Units (CEUs) will be available for a variety of disciplines.

The conference will take place May 4-5. There will also be a pre-conference day of workshops on Wednesday, May 3. For more information on guest speakers, schedules, cost, and registration, please visit www.williamsburgtbiconference.com.

### DEAR PAT,

I am a 37-year-old wife and mother who was in a horrible car accident almost three years ago now. I don't know what happened. The only thing I remember from that day was leaving work to go home and the next thing I know I was in the hospital hooked up to tubes. People told me that an SUV crashed into me. It's hard to believe that I survived that crash when I look at pictures taken of my car. Anyway, my hospital stay was a big blur to me, though I know I was in the hospital for a long time between the ICU and rehab. I had to learn how to walk and talk again.

It took a total of two years after the accident for me to get my life in order or at least some kind of order in my world. I was not able to go back to work as a bank teller and became a full-time mother to my two young children. Through trials of failures, I figured out how to make it through the day without collapsing. It is still exhausting but at least it's manageable now. I still take a lot of breaks and am pretty mentally drained by 7pm.

The reason I'm writing is because of my relationship with my husband, Eric. He was there for me the first 6 months. He was at my bedside the whole time I was in the hospital. He took care of our kids even when I



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.

came home from the hospital. He helped out around the house, without waiting for me to ask. I wouldn't have been able to get through those months without him. Well, the picture is different now. Three years later, Eric thinks I should be better by now. He doesn't think I have any problems. I don't know if he's in denial or just doesn't care.



So, I have been angry at him for the last few months, even feeling resentful. I hate to admit to feeling this way, and I feel guilty about having these thoughts. I know this has been a lot for him to handle, too. He didn't ask for this, especially the pressure of being the sole income earner of the house. Yet, I just wish he would understand that I still have a lot of problems with finding the right words, remembering things, and processing information quickly. And, this fatigue thing is still an issue. Eric has never been a patient person so he gets frustrated easily. Instead of waiting for me to get my words out, he just walks away. I think he can be inconsiderate at times. I wish he could be more understanding.

What can I do to make him understand and do things without me asking? How can I get him to initiate more to help out? I need advice on how to communicate better with him.

**Frustrated Wife** 

#### **PAT'S RESPONSE:**

First of all, I want to congratulate you on all the improvements you have made since your brain injury. It sounds like you have come a long way. Way to go! Secondly, it is understandable to feel angry and resentful when you feel like you have not been treated fairly. It is also frustrating to feel like you are doing your best and are not being appreciated for what you do. (*Cont'd on page 5*)



#### <u>Across</u>

- 4. worn around the neck on a cold day
- 6. Valentine month
- 8. frozen water
- 10. January 1st
- 12. keep your hands warm
- 14. popular winter sport
- 15. frosty fellow with a carrot nose

#### <u>Down</u>

- 1. warm drink made of apples
- 2. sport played on ice
- 3. bears do this all winter
- 5. roasted on a fire during the winter
- 7. bird that lives in Antarctica
- 9. soft material that makes shirts and blankets
- 11. no two are alike
- 13. covers the ground

#### (Chat, cont'd)

With that said, it is common to experience changes in marital relationships following a brain injury because of changes in roles between spouses. The roles that used to be carried out by you and Eric are different now. Household responsibilities are divided between you two instead of being done by just you. In addition, Eric is likely coping with changes that he has seen in you. He might be having a difficult time adjusting to the "new" you. He might have expected you to go back to the person you were before the injury and would like things the way they were. Eric is not used to this person who has trouble coming up with words, forgetting things, and not understanding what he is saying. It is difficult to adjust to change. Change can cause anxiety and distress.

It will be important for you and Eric to develop some skills to cope with the changes. Following are some ideas to consider:

- Realize that your feelings are a common, normal response to a difficult situation.
- Be hopeful and say positive things.
- Avoid thinking about making comparisons to how things were.
- Try to do fun things together and get to know each other again.
- Talk about the future you both want and the best ways to get there.
- Talk to and spend time with people who care about you.
- Give yourself breaks and learn when and how to ask for help.



You might also want to consider couples counseling with a family marital therapist who specializes in working with families after brain injury. It will be important for you and Eric to talk about your respective experiences since the injury. Finally, seek out support from others by joining a local support group.

If you wish to get involved with your local support group to share your experience, Brain Injury Association of American has a list of support groups you and your husband may attend. To contact BIAA, you may call their National Brain Injury Information Center (1-800-444-6443) or send them an e-mail at <u>info@biausa.org</u>. The website for BIAA (<u>www.biausa.org</u>) provides links to state chapters and additional brain injury resources.



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.

#### **QUESTION:** Since my brain injury, I have a hard

time falling asleep, even though I'm exhausted. I end up tossing and turning most of the night, and sleeping only a few hours each night. Is there anything I can do without taking medication?

**ANSWER:** Sleep problems are common following a brain injury. Here are some things you can try out.

Good luck!

- Set a regular sleep schedule: go to bed at the same time every night and set an alarm to wake up at the same time every morning.
- Avoid watching television, eating, or reading in bed.
- Create a pre-sleep routine that relaxes your body and prepares it to go to sleep. For example, take a bath, brush your teeth, and then listen to soft music or practice relaxation skills for 10 minutes.
- Create a restful atmosphere in the bedroom that is free of distraction, noise and bright light.
- If you don't fall asleep in 30 minutes, do not stay in bed. Get up and do something until you feel drowsy.
   Return to bed only when you are ready to sleep, so you associate bed with sleeping.
- Try to exercise regularly, but avoid strenuous exercise 3 5 hours before bedtime
- Avoid consuming caffeine and alcohol, particularly in the late afternoon.



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



Kristin Graham, PhD, CRC, is a new Postdoctoral Fellow in the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University (VCU). She is involved in many ongoing clinical research projects, including the TBI Model Systems Project at VCU.

Kristin grew up in Ohio and West Virginia, but spent the last 7 years in Pittsburgh, Pennsylvania. While in Pittsburgh, she pursued graduate degrees in rehabilitation counseling (MS) and rehabilitation science (PhD), with special

concentrations in TBI, telerehabilitation, and assistive technology. Kristin's

research interests include the use of new assessment approaches to understand important outcomes such as community participation after TBI. In her dissertation, she developed and examined the utility of a measure of participation that was delivered daily using a smartphone application.

Outside of work, Kristin enjoys exploring her new home of Richmond and watching the reigning Stanley Cup Champion Pittsburgh Penguins take the ice. Kristin likes to spend time with friends and family, attend concerts, travel to new places, and her favorite person is her 2 year old niece, Paige.



#### **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

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

# TGIF

Adult survivors of brain injury and their family are invited to attend T.G.I.F, a social group that meets on the first Friday of every month. Chesterfield County and Henrico County's Parks and Recreation departments offer an evening full of music, dining, activities, and fun times. If you are interested in joining, contact Aleana McClellan at mcclellana@chesterfield.gov or call (804)751-4134 to get on the mailing list!

#### Join a Supportive Online Community for TBI Survivors and Families

The Comeback Project is a free, private online community for survivors of brain injury and their families to help you get your life back after a brain injury. You can join the community to share and get the support you need at: a-talented-mind.mightybell.com.

The community is provided by A Talented Mind Clinic in Richmond, Virginia, that provides cognitive rehabilitation therapy to brain injury survivors and families. For more information, you may also email Mike Cerreto at cerreto@atalentedmind.com.

## Has Your Balance Been Affected by a Concussion, Head or Brain Injury?

If so, You May Qualify for This Clinical Research Trial.

- Are you 18-65 years of age?
- Have experienced a concussion, head or brain injury, over 1 year ago?
- Have difficulty with balance?
- Did not lose consciousness for more than 24 hours when you were injured?

Compensation is available for qualified participants.

To learn more about this trial:

#### visit: BrainInjuryTrial.com call: 1-877-844-4960

MONS .21	
11. SNOWFLAKES	15. SNOWMAN
9. FLANNEL	14. SKIING
7. PENGUIN	T2. MITTENS
5. CHESTNUT	10. NEWYERRARY
3. НІВЕЯИАТЕ	8' ICE
2. HOCKEY	6. FEBRUARY
ד. כוסבא	4. SCARF
Imod	Across
Here are the answers to the crossword on page 4. How did you do?	

#### SKILL-BUILDING, SUPPORTIVE AND EDUCA-TIONAL 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.

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

**Did you Know?** You can subscribe to *TBI Today* by email and get every issue sent directly to your computer, tablet, phone, or any other device that supports PDF. Best of all, it's free! Go to http://model.tbinrc.com and look for 'Join Our Mailing List' on the lower right. We also have back issues available. VCU, PM&R

TRAUMATIC BRAIN INJURY MODEL SYSTEM

P.O. BOX 980542

**RICHMOND, VA 23298-0542** 

**RETURN SERVICE REQUESTED** 

Go to http://model.tbinrc.com to subscribe by email and to access back issues!



