Winter 2019 VOLUME 17 NUMBER 1

# TBB TODAY NEWS, IDEAS, AND RESOURCES FROM THE VIRGINIA TBI MODEL SYSTEM



#### THE VIRGINIA TBIMS TEAM

#### **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.

#### **RESEARCH ASSOCIATES**

Grace Denio, B.S. Kristin Graham, Ph.D. Nancy Hsu, Psy.D. Daniel Klyce, Ph.D. Margie Martinez, B.A. Ana Mills, Psy.D.

#### **DIRECT CORRESPONDENCE TO:**

Margie Martinez P.O. Box 980542 Richmond, VA 23298-0542 (804) 828-3703 Email: mariegrace.martinez@vcuhealth.org

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# Brain Exercise To Improve Communication After a TBI by Michael Cerreto

The start of a new year can bring new possibilities and relationships into your life after a brain injury. This article is about using an effective brain exercise to improve your conversations with people. It will hopefully help you have more effective conversations, meet new people, and deepen relationships in the new year.

#### DIFFICULTY COMMUNICATING AFTER A TBI

After a brain injury, do you have difficulty communicating what's on your mind or following what people say? Do you avoid talking with people because you don't know what to say in conversations?

These are common concerns for brain injury survivors. If you have these concerns, they can shrink your world because you may limit interactions with people.

One of my clients recently said that she avoids people outside the family because she worries that her communication struggles will "make me look stupid." That is a strong, negative concern she places on herself. She is not stupid or any other negative label she uses, and neither are you.

Most communication challenges after a brain injury can be the result of your mind's struggle to:

- Follow and remember what you hear in one-on-one or group conversations
- Avoid feeling overwhelmed by background noise or sensory overload
- Interpret non-verbal information
- Identify the thoughts or feelings that are appropriate to communicate in the moment
- Use the right words and concept organization to clearly say what you think and feel
- Pronounce words so others understand



#### KNOWING WHAT TO SAY

Many brain injury survivors say that they can follow most of a conversation but can't think of anything to say in response. During a conversation, your mind needs to generate a quantity of ideas to communicate, then pick the best ones to mention in the moment. The more ideas or thoughts you can generate, the more flexible you will be to use the appropriate one to communicate. If you have only one idea to express, it may not fit the conversation. However, if you have more than one potential idea, your mind has more ideas to choose from in conversations. This mental process is called Idea Productivity. (cont'd on page 4)



#### **Aphasia Support Group**

- When: 2nd Thursday of the month, 6-7pm
- Location: Wells Coleman office building in Monument Corporate Centre office park, 5004 Monument Avenue. Richmond. 23230
- Contact: Susan Hapala at (804) 908-3261 or Jan Thomas at rva.aphasia@gmail.com

## Stroke/Brain Injury Survivor & Caregiver Support Group

- When: 2nd Wednesday of the month, 2-3pm
- Location: Sheltering Arms Rehab Hospital, 8254
   Atlee Rd, Mechanicsville, 23116 Conference Rm C
   OR 13700 St. Francis Blvd, Midlothian, 23114 4th
   Floor Conference Rm
- Contact: Kate Lim at (804) 764-5290 or klim@shelteringarms.com

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

- When: 3rd Monday of the month, 6:15pm-7:45pm
- Location: Disability Law Center of Virginia, 1512
   Willow Lawn Drive, Suite 100, Richmond, 23230
- Contact: Christine Baggini at (804) 355-5748 or christine@biav.net

#### **Supportive Survivors**

- When: 2nd, 4th, and 5th Tuesdays, 6-8pm,
   Outings planned for the 1st and 3rd Tuesdays
- Location: Regency Mall Food Court, 1420 Parham Road, Richmond, 23229
- Contact: Ted Taylor at (804) 781-2144 or taylorted58@yahoo.com

#### Women's Luncheon Group

- When: 2nd Tuesday of the month for lunch, 11:30am
- Location: The Mill House, 7812 Shrader Road, Henrico, 23294
- Contact: Jen Candela at (804) 386-0926 x 104 or jenniferc@communitybraininjury.org

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.

### UPCOMING CONFER-



# Saturday, March 9, 2019 The Renaissance Portsmouth-Norfolk Hotel Portsmouth, Virginia

Brain Injury Association of Virginia's 18th Annual Conference is designed for individuals with a brain injury, caregivers, and professionals who want to learn more about serving persons with brain injury.

Keynote speaker: Abby Maslin Information and registration: www.biav.net/conferences



### Brain Injury Conference for Professionals Monday, May 6 - Tuesday, May 7, 2019

The Westin Richmond Richmond, Virginia

Brain Injury Association of Virginia and Virginia Commonwealth University present a VCU TBI Model Systems event: a two-day brain injury rehabilitation conference (formerly known as "the Williamsburg Conference"). This conference is designed for advanced continuing education professionals to hear extensive discussion from international researchers and practitioners in the field of brain injury rehabilitation.

#### Information and registration:

www.forwardtogether512947513.wordpress.com

#### **My Survivor Story: 30 Years Later**

by Charles Rose

I suffered a TBI when I was 18 years old, just under 30 years ago; I am now 48-years-old. I got a similar diagnosis to what a lot of TBI survivors get. I was told I would not be able to run, not go to college, and I would be lucky to live on my own independently. Although it was almost 30 years ago, it still seems like yesterday. My parents worked with my insurance case worker, who recommended I attend a facility in Ann Arbor, Michigan called New Medico. There, I could continue to recover with hard work in order to go to college and graduate, learn to run, and just get a better life. I was there for an additional four months after my initial accident. I accomplished completing a college class, I began running, and I became better socially, physically and emotionally.

I married when I was 25 years old in June of 1996 and thought it would be forever. I am now divorced and have two daughters, but the marriage was definitely a victim of TBI. My ex-wife started out as my biggest supporter, fighting for me to get jobs and maintaining her own jobs, along with being a mother to two awesome daughters, all while still trying to be my wife. With that being said, repeated rejections, failures, and life consequences of living with a person with a TBI takes its toll on folks no matter how much love is there. I got fired from jobs, could not always support the family financially, and was often isolated due to embarrassment of failures and let downs in life. My ex-wife and I are very close today, and we understand what living with a TBI is like and how it affected us.

I never stopped working on bettering myself physically, emotionally and cognitively. I have always worked, but some of the jobs I had could not financially support my promise to support a family and live everyday happy, healthy, and hopeful. Today, some of my accomplishments are that I graduated with a Bachelor's Degree from Michigan State University in 1996 and earned a Master of Science, MSA, in Health Services Administration in 2000 from Central Michigan University. My real jewel, aside from my two daughters, is my Master of Arts from Michigan State University in Vocational Rehabilitation Counseling, received in 2007. I passed my CRCC, and I have my LPC. I continue to work out daily and even taught spin (inside cycling) classes at a local fitness center.

I currently work at Michigan Protection and Advocacy Service (MPAS) as an advocate. I will be starting a different job at MPAS as Representative Payee monitor for beneficiaries of social security. I also counsel individuals on a part-time basis. I have had many life experiences in all different life situations, but as successful as this story seems, TBI has taught me one thing over and over: accomplishments are slow and very rarely take a straight line to the finish.

I read story after story about TBI survivors and feel so bad because of the pain survivors are dealing with cognitively, physically, emotionally, and socially. TBI is what it says it is, traumatic, and no progress happens overnight; it is a very slow and tedious recovery that a TBI survivor deals with every day whether it be one day, one week, one month, one year, or 30 years.



#### 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 be featured in a future issue of TBI Today!

Submit to: jennifer.marwitz@vcuhealth.org or TBI Today, VCU P.O. Box 980542 Richmond, VA 23298-0542

(Communication, cont'd) Idea productivity is the total number of ideas someone can naturally generate in their minds for any topic. It is the first step in the creative process (conversation is a creative process, like art) before people choose the best idea to use. People who have high idea productivity are good at thinking on their feet because they can generate many potential options to respond to conversations.

#### BRAIN EXERCISE TO GENERATE IDEAS TO COMMUNICATE

If you have low idea productivity after a brain injury, you may need more time and prompts to think of ideas to communicate. A brain exercise called the "Idea Generator" can train your mind to generate a larger quantity of ideas to choose from for conversations.

Here are five steps to exercise a brain injury survivor's idea productivity.\* The exercise is explained as if it is being administered by a family member or friend to a brain injury survivor.

**Step 1:** Get five sheets of blank paper and draw one of the following shapes on each individual sheet: straight line, circle, square, triangle, or spiral. Each shape should fill up an entire sheet.

**Step 2:** Show the person doing the exercise one of the shapes and ask him or her to verbally tell you what else the shape can be other than a geometric image. Have the person think of as many options as possible. For instance, the square can be a wrapped present, window pane, computer screen, wallet, table, chair, platform shoes, or photograph. Don't worry about the number of ideas generated initially. Getting them to start thinking differently is the key.

**Step 3:** After the person runs out of ideas, you can provide clues as prompts. Give them time to think but don't cause any frustration.

**Step 4:** Do this exercise with as many of the shapes as the person can tolerate without getting fatigued or frustrated.

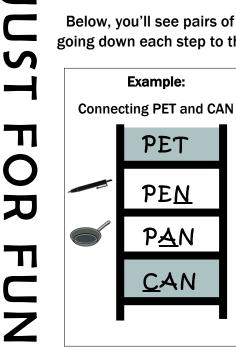
**Step 5:** Repeat this exercise 3-4 times a week. It's okay if the person repeats the same ideas. The ultimate goal is to increase the list of ideas over time as he or she gets better at generating ideas. You can also add more shapes (or rotate the line and triangle) to make the exercise more fun.

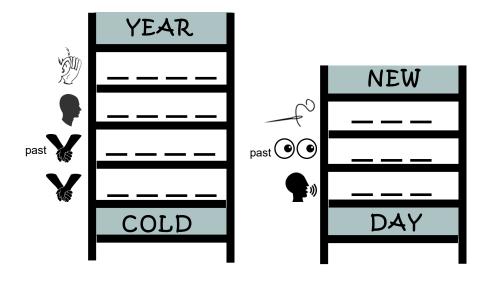
\*This five-step exercise is based on the work of the Highlands Company. To learn more, visit www.highlandsco.com.

Michael Cerreto, MS, CPCRT, CSC, LDR is a Certified Cognitive Rehabilitation Therapist with A Talented Mind Clinic in Richmond, Virginia. Learn more about Michael at <a href="https://www.atalentedmind.com">www.atalentedmind.com</a>.

#### **WINTER WORD LADDERS**

Below, you'll see pairs of words. Using the clues, change one letter, starting from the top word, going down each step to the bottom word. If you get stuck, the answers can be found on page 7!





# **DEAR PAT,**



Since my brain injury, I often feel sad and cry for no reason. I have no energy or desire to do anything, even things that used to bring me joy. The depression has gotten worse since the weather got cold. My husband has tried to get me to do things with him and our friends, but I don't even want to be around them. What can I do to help myself feel better? I don't want my family and friends to worry about me.

**PAT'S RESPONSE:** I commend you for taking this first step. Seeking help is not a sign of weakness. Depression is a common problem after TBI. Many people complain about feeling down, sad, blue, or hopeless; loss of interest or pleasure in usual activities; feeling worthless, guilty, or that you are a failure; changes in sleep or appetite; difficulty concentrating; withdrawing from others; tiredness or lack of energy; moving or speaking more slowly, or feeling restless or fidgety. Some people even have thoughts of death or suicide.



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.

It is important to see a healthcare professional in order to receive a proper diagnosis and receive appropriate treatment. Studies have shown that antidepressants or counseling, or a combination of both, can help most people who have depression. If you are not currently under any physician's care, I would recommend seeing your primary care physician, who could either prescribe the antidepressant or refer you to a specialist (e.g., psychiatrist, physiatrist, psychologist). Survivors have benefitted from seeing a mental health counselor who specializes in working with persons with a TBI. You could contact your local Brain Injury Association chapter for a referral. In the meantime, you might want to consider exercising, increasing social and leisure activities, or developing a new hobby to help improve your mood.

Lastly, getting involved with a local support group could help you feel less alone. You will have the opportunity to meet others who may be struggling with the same challenges. 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 family may attend. To contact BIAA, you may call their family helpline (1-800-444-6443) or send them an e-mail at <a href="mailyhelpline@biausa.org">familyhelpline@biausa.org</a>. The website for BIAA (<a href="www.biausa.org">www.biausa.org</a>) provides links to state chapters and additional brain injury resources. You may also write BIAA for more information at 1608 Spring Hill Road, Suite 110, Vienna, VA 22182.



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



# ADJUSTMENT AND RESILIENCE BRAIN INJURY STUDY

# Have you had a traumatic brain injury (TBI)? You May Qualify for a New Research Study!

Virginia Commonwealth University researchers are seeking adults with traumatic brain injuries to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program to help people adjust to having a brain injury. Qualified volunteers will participate in seven rehabilitation and education sessions and possibly three additional 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. All participants must be at least 18 years old.

During the sessions, the following topics will be discussed:

- Understanding the changes that normally follow brain injury
- How to improve recovery
- Goal setting for success
- Problem solving effectively
- Understanding and managing stress and intense emotions
- Communicating effectively and rebuilding relationships
- Maintaining a positive outlook

There will be no charge for services.

Volunteers will be 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.

#### 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.

The Journal of Head Trauma Rehabilitation has developed the following press release to accompany the article, "Thirty Years of National Institute on Disability, Independent Living, and Rehabilitation Research Traumatic Brain Injury Model Systems Center Research—An Update."

#### Traumatic Brain Injury Model Systems Centers Mark 30 Years of Research

by Wolters Kluwer Health

The Traumatic Brain Injury Model Systems Centers were established by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in 1987, with the goal of improving healthcare –especially rehabilitation care – and outcomes for patients with moderate-to-severe TBI. The original objective of the TBIMSC program was to demonstrate the value of coordinated medical, social, and vocational services for this group of patients, a group that had previously been placed in psychiatric hospitals or other long-term care facilities.

Currently, there are 16 funded TBIMSCs across the United States. All of these institutions carry out research activities connected to clinical care for patients with TBI, including emergency, acute, neurosurgical, and inpatient and outpatient rehabilitation services. The TBIMSCs perform site-specific and collaborative research to build the evidence base for advancing care and outcomes for patients with TBI. For the past decade, the TBIMSC program has collaborated with the Department of Veterans Affairs Polytrauma Research Centers, focusing on TBI as the "signature injury" of the Middle-East wars.

A central component of the program's mission is the creation and maintenance of the TBI National Database. The database includes information on all eligible adult patients with moderate-to-severe TBI at each TBIMSC institution. Standardized data are collected at the time of initial injury, at one, two, and five years post-injury, and every five years thereafter. The first group of patients recently completed their 25th year of follow-up.

Since 1989, TBIMSC institutions have contributed about 16,500 patients to the TBI National Database, building a uniquely rich source of data to answer clinical questions and evaluate long-term outcomes after TBI. Ongoing efforts continue to assess and expand the quality and value of the data collected.

Over the years, the TBIMSCs have produced hundreds of research papers advancing the field of TBI care. The scope of research is broad, with outcomes including not only long-term health and functioning, but also social participation, employment, and quality of life. Research has also focused on new approaches for problems such as sleep and fatigue, emotional dysregulation, and memory and cognitive impairments.

Emerging initiatives include efforts to identify genetic or other factors to help in understanding why some patients with moderate-to-severe TBI have better outcomes than others. The TBIMSCs also collaborate with another NIDILRR initiative, the Model Systems Knowledge Translation Center, following a variety of strategies to ensure that research is "relevant and accessible" to people with disabilities and their families, as well as to researchers, clinicians, policy makers, and advocacy groups.

The TBIMSC program includes the largest research database for TBI in the world. Researchers continue to learn from the data collected in their efforts to advance the field. With a focus on relevance to stakeholders, the TBIMSCs' have and continue to improve outcomes for individuals with TBI.

Dijkers, M.P., Marwitz, J.H., Harrison-Felix, C. (2018). Thirty Years of National Institute on Disability, Independent Living, and Rehabilitation Research Traumatic Brain Injury Model Systems Center Research – An Update. *J Head Trauma Rehabil*, 33(6), 363-374.

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**RICHMOND, VA 23298-0542** 

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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 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