

TBI TODAY

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

Asking for Help in Brain Injury Recovery: One of the Keys to Whole-Family Success

By Emilie Godwin

THE VIRGINIA TBIMS TEAM

EDITOR

Matthew Wetsel, B.S.

PRINCIPAL INVESTIGATOR AND PROJECT DIRECTOR—FAMILY RESEARCH

Jeffrey Kreutzer, Ph.D.

CO-PRINCIPAL INVESTIGATOR

David Cifu, M.D.

PROJECT COORDINATOR

Jenny Marwitz, M.A.

PROJECT DIRECTOR — ACUTE CARE RESEARCH

Janet Niemeier, Ph.D.

PROJECT COORDINATOR—FAMILY RESEARCH

Emilie Godwin, Ph.D.

PROJECT COORDINATOR—CULTURAL COMPETENCY

Juan Carlos Arango, Ph.D.

MEDICAL DIRECTOR

William Walker, M.D.

BIostatistician

Jessica Ketchum, Ph.D.

RESEARCH ASSOCIATES

Christine Trotta, B.A.

Matthew Wetsel, B.S.

Nancy Hsu, Psy.D.

Lindsay Farrar, B.S.

DIRECT CORRESPONDENCE TO:

Matthew Wetsel

P.O. Box 980542

Richmond, VA 23298-0542

(804) 828-3703

Email: wetselme@vcu.edu

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Recently, a popular magazine talked to some of the most successful people in our society and published an article on what they said. Well-known individuals, such as Donald Trump, were asked to state which parts of their personality they believed had helped them to be so successful. While some people said things like never giving up or being creative, there was one thing that every person in the article mentioned: they were willing to ask for help. Over and over, millionaires, Nobel Prize winners, and long-time politicians summed up their success in this way: 'I am doing so well because I know I can't do it all by myself. I ask for help from others so that instead of having one brain to count on, I have many!' What does this mean for you as a caregiver or survivor in TBI recovery? These successful people can help you understand the importance of your rehab team's instruction to ask for help when you need it.

Most people work hard to follow instructions from professionals when building a new life after brain injury. Patients and their families pay close attention to

medications and prescriptions, follow-up with doctors, and seek resources and support in their daily lives. However, even though most people have heard a professional say, "It is important that you ask for help when you need it," they may not understand that this too is part of the prescription for healing. Survivors might say, "I'm just not the kind of person who asks for help. I've never done it before and I don't like to do it now." Family members often say, "I'm a very independent person, I always have been. I'd rather try to handle it on my own than bother other people." But ignoring this part of the rehabilitation plan will keep your family from doing your best.

Everyone asks for help in some ways. Unless you are a mechanic or very familiar with cars, you probably take your car to the shop when it needs to be serviced. We rely on others who have both knowledge and experience when we aren't sure what we should do. We also ask for help when we have the skills and knowledge, but don't have enough time to do everything. (contd on p.2)

The Rehabilitation of the Adult and Child with Brain Injury Williamsburg Conference

We are excited to announce the 35th annual conference, **Rehabilitation of the Adult and Child with Brain Injury**, which will be held in Williamsburg, Virginia May 5-6, 2011. The conference committee is very excited to welcome family members and caregivers to participate in the two day professional conference. There will be networking opportunities available to caregivers with some of the leaders in brain injury rehabilitation and research.

Presentations will be given over the two days from almost 20 guest speakers. They will address a wide variety of topics, such as the best ways to help families navigate resources after brain injury, strategies to support children with TBI, crisis management, ethical issues in TBI rehabilitation, and methods of coping, among others.

Special rates for families are available. For more information visit the website, www.tbiconferences.org. You can also contact Lisa Garver 703-451-8881 ext 224 or by email (lgarver@braininjurysvcs.com) with your questions.

(contd from p1) Although you could take your own trash to the dump every week, many people hire a trash collection company to do this for them so that they may save that time to do other things.

If you are a TBI survivor, you are in the process of learning to do things in some very new ways. You might try a new approach or two and find that they are not working. You also may have trouble coming up with new ideas for solving problems. To get some different ideas, approach a family member, friend or professional who you trust. If you find yourself scared or embarrassed to ask for help, imagine yourself in a garage talking to your mechanic and saying, "I rotated the tires and filled them with air, but the car is still wobbling. I'm going to need some help from you guys with this one!"

For caregivers, you are most likely overwhelmed by the amount of new responsibilities you have. Also, you may have some jobs, like balancing the checkbook or cooking dinner, that are new to you. Asking friends or family members for advice or for help can significantly reduce your stress. This will also create more time for important tasks at work or home.

Think of following rehabilitation instructions like making a cake. If you do just what the recipe says, adding each ingredient and taking each step with care, but then decide to ignore the instructions, "Add 2 cups of flour," the food that you pull from the oven will not look or taste like the cake that you wanted. Your careful attention to all of the other instructions will suffer because of the one step you overlooked. Asking for help when you need it is the flour in your family's recovery! By asking for help, you are in the company of people like Mr. Trump who have found that having a supportive team of helpers is the key to success.

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!

March 12, 2011

- ◆ **Event:** 10th Annual Brain Injury Association of Virginia Conference "Opening Doors"
- ◆ **Location:** Holiday Inn Richmond Airport
- ◆ **Contact:** www.biav.net to register, call 1-800-444-6443 for more info
- ◆ 804-355-5748 or visit www.biav.net

May 5-6, 2011

- ◆ **Event:** Williamsburg Brain Injury Rehabilitation Conference
- ◆ **Location:** Williamsburg Hospitality House
- ◆ **Contact:** Call 703-451-8881, ext 224 or visit www.tbiconferences.org
- ◆ **See our ad on the front page of this issue!**

Just For Fun!

Try to unscramble these words!
HINT: They were all taken from articles in this issue!

Answers on Page 7.
No Peeking!

- | | |
|--------------------|---------------------|
| 1. CEGOLLE _____ | 7. ACEIRGERV _____ |
| 2. ANAMEG _____ | 8. EMNDICEI _____ |
| 3. RSIRESSUP _____ | 9. SYGCPOYLHO _____ |
| 4. LAYEHHT _____ | 10. ENSWESARA _____ |
| 5. OTRFCOM _____ | 11. EHOCCSI _____ |
| 6. ESAERCHR _____ | 12. CAETPIRC _____ |



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: Since the brain injury, my co-workers have asked me a lot of questions about what happened. I'm not sure how much information to share. I don't feel comfortable telling them everything. Any suggestions?

A: It is important to be cautious when talking about your brain injury. Here are some of the reasons. First of all, most people don't know a great deal about disabilities including brain injury, and they may have negative stereotypes as a result. Another reason to be cautious about communicating information to others is that you may worry that other people will not keep your personal information private. These are valid concerns; therefore, it is important to ask yourself the following questions:



- Is this the right time or place to talk about my injury?
- How well do I know this person and what's my relationship to them?
- What do I feel comfortable with them knowing?
- How much information should I share?
- Do I trust this person with this personal information?
- Will this person use the information in a way that could hurt me?
- How would I feel if this person told other people I'm not very close to?
- What is this person really trying to find out about me?
- Will I look bad if I share details about my recovery?
- Could the information I share affect my job?

Questions can also bring back painful memories for you about the time you spent in the hospital and remind you of those difficult initial days, weeks, and months of recovery. You may think that you "owe" others an explanation as to why you have been out of work or why you can't go back full-time.

People are very curious beings and there probably isn't any way to prevent people from initially asking these questions. However, you can have control over the type and amount of information you communicate and how you communicate it.

1. Keep in mind that you can make choices about what you tell others about your injury. You should only tell people what they need to know and what you feel comfortable telling others. Keeping answers short, simple, and to the point is another good rule of thumb. It is also important to know how to answer questions without becoming upset or making the person asking the question uncomfortable.

2. Politely decline answering questions if you feel uncomfortable. For example, you could say, "I appreciate your concern, but I'd rather not talk about it right now." Talking to other survivors about how they deal with difficult questions is another recommendation. It is important to disclose only the most personal information to people you really trust such as family members, close friends, doctors, and therapists.

3. Practice answering these questions (role playing) with trusted family members and friends. This can give you additional confidence in how to address the situation with your colleagues.



*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: My son was hit by a car while riding a bicycle in 2009. Ben spent 3 weeks in the inpatient rehabilitation unit while in the hospital and then 2 more weeks at an outpatient rehab center. He doesn't remember what happened to him or his stay in the hospital. I knew it would take him awhile to recover since his doctors told me that Ben is lucky to be alive, but suffered a severe brain injury.

Ben was 23 when he was hurt and lived by himself in an apartment. His doctors told me and my husband that Ben will need help for at least the first year during his recovery. So, we moved him home with us for safety reasons. Ben still lives with us though I know he wants to be on his own again. The thing is that he is not ready to be independent.

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

I am worried about Ben because he doesn't think he has any problems. He thinks he is doing just fine and

can live by himself. I'm afraid he'll burn down the house or get seriously hurt. What can I do or say to him that will help him improve his awareness? Would I be making things worse by bringing up my concerns?



PAT'S RESPONSE: Lack of awareness is a common problem after brain injury. People with 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 TBI. 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 Ben to work on together. First, you can help him to write down all the events related to the accident and his hospital stay. This exercise will increase his understanding about how the accident has impacted his life and your family. Keep the list of events related to the accident nearby. He may come to realize the seriousness of his injury and how

far he has come in the last year.

When the fact that he has had a brain injury has sunk in, Ben may be able to handle some gentle feedback from you. You could talk to him about things he may wish to work on in the future for getting better and staying safe. Asking questions is a good way to get people thinking about things. When you notice Ben having trouble with conversations, you may say something like, "You seem to have gotten lost. What was the last thing you remember us talking about?" Don't lose sight of the positive things he can do. Praise him often!

In the meantime, make sure you continue to carefully monitor Ben's activities and try to keep him safe from danger. Encourage him to try out different ways of doing things that may be less risky. You could help him learn new recipes for cooking with the microwave or buy him a book on making sandwiches. With your enthusiasm and support, you can help improve his awareness of post-injury problems without ruining his self confidence.

Support groups are a great way to get feedback from others, if you wish to recruit more people in helping Ben become more aware. Your local Brain Injury Association of American likely has a list of support groups your son may attend. To contact BIAA, you may call their family helpline (1-800-444-6443) or send them an e-mail at family-helpline@biausa.org. The website for BIAA (www.biausa.org) 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.



**HAVE YOU
MET STEPHEN
SMITH, PH.D.?**

Stephen Smith, Ph.D., is a postdoctoral fellow in the Department of Physical Medicine and Rehabilitation at VCU. He provides neuropsychological and psychological assessments to child, adolescent, and adult patients with traumatic brain injury and other health concerns. Dr. Smith also sees patients for individual psychotherapy to address difficulties coping with post-injury changes and emotional problems. Outside of work, he enjoys playing music, honing his barbecuing skills, and spending time with his friends, family, and dogs.

Dr. Smith was born and raised in Moline, Illinois and graduated from Illinois Wesleyan University in May of 2003, with a Bachelor of Arts degree in Psychology and research honors. In the fall of 2003, he entered the Doctoral Training Program in School Psychology at the University of Texas in Austin. Dr. Smith earned his Master of Arts degree in Educational Psychology from the University of Texas in Austin in 2007 and completed his doctoral requirements in 2010. His clinical experiences include training at Austin State Hospital, Austin Neuropsychology, and several Texas school districts. His professional experiences include serving as a research assistant and a teaching assistant at the University of Texas, a psychometrician at Round Rock Psychological Services and San Gabriel Psychological Services, and a clinical researcher at the University of Texas Health Science Center in San Antonio. Dr. Smith completed his clinical internship at Virginia Beach City Public Schools with a focus on neuropsychology.



INDIVIDUALS WITH TRAUMATIC BRAIN INJURY NEEDED FOR REHABILITATION STUDY

The purpose of this research is to compare motor coordination, balance abilities, thinking abilities and emotional well-being between individuals with traumatic brain injury (TBI) and those without TBI. We will also study how these are related to connections within the brain. Finally, we will study if exercise or bright light sessions can improve coordination, balance, mood and how the brain works.

This **TBI Exercise Protocol** (10-CC-0150) requires 4 outpatient visits to the National Institutes of Health (NIH) in Bethesda, MD over a 7 month period. Each visit has 2 parts. The first part is testing motor coordination, balance, thinking abilities and emotional well-being. Tests involve walking, running, jumping, balancing on moving and non-moving surfaces, and answering questions that require quick thinking and remembering, as well as reporting on how you are feeling or have felt in a variety of situations. These tests will take 3-4 hours. The second part is a brain scan. This part will take no more than 2 hours.

This study also involves an exercise program that lasts 3 months and involves using an elliptical trainer with a focus on arm and leg speed of arm and 3 months of bright light exposure. All equipment for these will be loaned to you for use in your home.

We are currently seeking young adults for this study. **You may qualify if you are:** between 18-44 years of age, have a diagnosis of TBI and are at least 6 months from your initial injury, are able to stand and walk independently without assistance or without a high risk of falling, and are able to follow fairly complex (multipart) instructions. **You do not qualify if you** have an injury to any extremity or medical condition that affects your ability to exercise, diagnosis of a manic or bipolar disorder, history of or at risk for retinal disease or damage, or extreme sensitivity of your eyes or skin to light. For the brain scan you cannot be pregnant, be claustrophobic, or have any metal fragments, wires, electrodes, etc in your brain or on any part of your body.

There is no cost to participate and a small amount of compensation is offered to those who participate. If you are interested in learning more about this study, please contact us at (301) 451-7529 or damianod@cc.nih.gov. The federal relay TTY number is 1-866-411-1010. You may also find more information at www.clinicaltrials.gov.



Managing Life as a College Student and Traumatic Brain Injury Survivor

By Jannelle Charlemagne

My name is Jannelle Charlemagne, and I am a college student and traumatic brain injury survivor. Eight years ago, I suffered a severe traumatic brain injury secondary to a blunt trauma and assault against me and my eight month old daughter, who was in my arms during the attack. The attack left me in a vegetative state and unresponsive. In a coma for some time, I awoke only to find out my daughter had not survived. I've sustained physical, mental, and emotional pain inside and out. The ongoing years have been difficult for me along with frequent doctors' appointments and out-patient rehab at Sheltering Arms.

Life is too short for me to feel like a victim!

I may be wounded now, but I won't stay that way and I don't let the sad part of my life stand in my way to live my life. I also won't let my disability stop or limit me from my education or limit myself from achieving an education. After rehab ended, I went back to school with the help from the Department of Rehabilitation Services (DRS). I had a great rehabilitation counselor who took the time to help me in whatever way I needed help with getting an education at J. Sargeant Reynolds Community College (JSRCC) in Richmond, VA. I'm very grateful to my counselor and DRS for their help making my education at JSRCC possible. I continued to balance more doctors' appointments, classes along with walk-in help from my professors, and even meeting with a tutor twice a week every semester I attended JSRCC.

Recovery from TBI left me facing so many challenges, learning how to live life in new ways, yet at times feeling very frustrated about how slow my mental recovery process can be. Every time I used to feel that way, I would go to my daughter's gravesite for comfort and to clear my mind. Her gravesite was my therapy; my mood would get better every time I left. I still have trouble in school with concentration problems, depending on the subject, such as calculus, pre-calculus with trigonometry and certain parts of chemistry problems where there are four to five steps needed to solve a problem.

While my loss is painful, my journey isn't over. I've learned that no matter how tough things may get, not to give up on myself and most of all not to dwell on misfortunes; keeping a positive outlook is also important. I set reasonable expectations for myself. My life's a journey and only I can help myself get better. I truly focus on my accomplishments and actions, and my self esteem determines my outcome. I'm still trying my best to turn my worries into a goal and to work around those stumbling blocks. I need to continue to stay focused on what lies ahead. Attending JSRCC has taught me preparation, hard work, dedication and gave me the opportunity to remain confident in my ability to succeed.

Life is full of surprises, but also opens new doors!

As years go by, things are becoming more attainable for me. Also, I've learned to appreciate the value of patience and persistence in achieving my goals. With patience and persistence, I was able to successfully transfer to the University of Louisville in Louisville, Kentucky, where I'm now living. I'll be attending Fall 2011 as a Junior working towards my Bachelor of Science in Biology with a concentration in Genetics/Subcellular Biology. In the meantime, I'm working towards a book on surviving TBI and hope to get it published before the end of 2011.

**It doesn't matter what I went through. What matters is that I'm still here and what I'll do.
Healthy choices bring healthy results.**

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



Brain Injury and Life Satisfaction in Families

By Matt Wetsel

Welcome to the next entry in a series of articles summarizing research findings based on the TBI Model Systems project. If you have participated in doing follow-ups post-injury with us through Model Systems, you may have asked, “What’s all this research finding out?”

In Volume 8, Issue 3 of *TBI Today*, we discussed research looking at caregivers being at risk for depression, anxiety, or other emotional distress after a loved one sustained a traumatic brain injury. Here is a brief summary of another research paper which came directly out of the Model Systems. The paper is titled “Predictors of Family Caregivers’ Life Satisfaction After Traumatic Brain Injury at One and Two Years Post-Injury: A Longitudinal Multi-Center Investigation,” and was published in *NeuroRehabilitation* in January 2010.

There is increasing interest among doctors and researchers regarding the effects of traumatic brain injury on families. About 1.5 million people suffer a TBI each year. The majority of those patients are discharged back home with their family. As a result, immediate family members, like parents, spouses, or grown children, become caregivers to the survivor as they continue to recover. Family members often assist in meeting a wide variety of short- and long-term needs after discharge. There is concern over how the quality of life is changed for family members caring for survivors of TBI. Researchers at Virginia Commonwealth University and other TBI Model Systems locations analyzed data from interviews with 336 TBI survivors and their families at 1 and 2 year follow-ups post-injury. Both patients and caregivers were given surveys with questions to determine overall life satis-

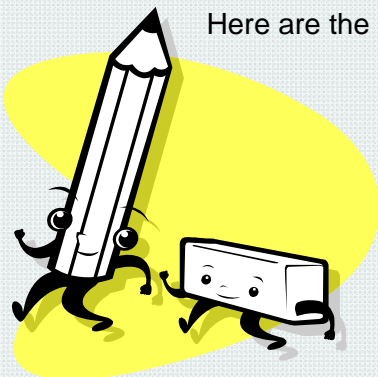
faction, with answers ranging from ‘strongly disagree’ to ‘strongly agree’.

At both 1 and 2 year follow-up interviews, most of the family members were either parents or spouses. On average, at both follow-up years about 40% of family members reported being dissatisfied with their lives. Lower satisfaction with life seemed to correspond with the severity of their family member’s injury, which was indicated by their length of stay in the hospital and overall disability at follow-up. The most important things which had an effect on caregiver life satisfaction were emotional problems such as depression, poor motor skills, and illicit drug use. Also, lower satisfaction with life was reported when patients had problems with some activities of daily functioning, ranging from being able dress and feed themselves to significant memory or socialization problems. These findings were consistent with other research using the same questionnaires, but this study had many more participants. Other research suggests that strong social support to family members helps improve overall satisfaction with life.

So why is all of this important? Once we can see what causes dissatisfaction in caregivers, programs can be developed by rehabilitation professionals to help prevent families from getting “burned out”. When caregiver life satisfaction is low, it is probably safe to assume that the overall quality of care and support they provide to the TBI survivor is lower than it would normally be. So, looking out for the well-being of everyone involved in the patient’s continued recovery benefits everyone, patient and caregiver alike! For this reason, more research must be done to determine other factors which influence life satisfaction so that these problems can be addressed.

Just For Fun Answer Key

Here are the answers in case you’re stumped!



12. PRACTICE	6. RESEARCH
11. CHOICES	5. COMFORT
10. AWARENESS	4. HEALTHY
9. PSYCHOLOGY	3. SURPRISES
8. MEDICINE	2. MANAGE
7. CAREGIVER	1. COLLEGE



The Brain Injury Association of Virginia (BIAV) 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.

BIAV offers help, hope and healing to persons with brain injury and their families, provides education on the impact of brain injury, and advocates for legislation and improved medical and community based services.

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



*Creating a better future for Virginians through brain injury prevention,
research, education, advocacy, and support*

VCU, PM&R

TRAUMATIC BRAIN INJURY MODEL SYSTEM

P.O. BOX 980542

RICHMOND, VA 23298-0542

