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# Getting to Know the Brain Injury Association of Virginia

Christine Baggini, MSW, CBIS, Information & Referral Services Manager

The Brain Injury Association of Virginia was founded in 1983 and is the only state-wide, non-governmental organization serving people with brain injury, their families and the professionals who work with them.

Information and Referral (I&R) has always been one of the central services BIAV provides and it's available to anyone living in Virginia. When someone calls our toll-free number (800-444-6443), our I&R staff determine that individual's particular needs. We may send information about various aspects of brain injury and/or a referral to a service provider in their area. Service providers include medical or community based services, medical or psychological professionals and/or attorneys with an understanding of and experience with brain injury. Sometimes a referral can be to a community resource that is not specific to

brain injury but useful to meet the caller's need.

Anyone who has been living with brain injury knows there are gaps in available services and many unmet needs. BIAV gathers data on the unmet needs identified during our I&R calls and uses this information in our advocacy efforts. These advocacy efforts include educating elected and appointed policymakers about needs and solutions; serving on the Virginia Brain Injury Council, actively participating in various state agency work groups, and providing training to help individuals become stronger advocates.

BIAV's Regional Resource Coordinators (RRCs) bring BIAV's work into their local communities and are available in a few areas around the state. (contd on page 2)

## Important Conference Announcement! Rehabilitation of the Adult and Child with Brain Injury Williamsburg, VA June 3-4, 2010

The conference committee is very excited to welcome <u>family members and</u> <u>caregivers</u> to this two day conference. Participants will have an opportunity to hear from leaders in the field of rehabilitation and network. We are excited to announce a special discounted rate for family members and caregivers. For more information please visit the conference website, www.tbiconferences.org. You can also contact Lisa Garver 703-451-8881 ext 224 or by email (Igarver@braininjurysvcs.com) with your questions.

Sponsored by Virginia Commonwealth University, Brain Injury Services, and the National Resource Center for Traumatic Brain Injury

#### (Contd from Page 1)

They educate local human service providers about brain injury, collaborate with them to improve available services, and reach out to the general community through multiple awareness, education and outreach activities. RRCs provide I&R and assist local support groups either by facilitating the groups or helping the support group leaders in their areas. There are RRCs in Tidewater and Upper Shenandoah Valley, the Petersburg area and the Fredericksburg/Northern Neck/ Middle Peninsula area.

There are 23 support groups around Virginia helping survivors and their families. Last year BIAV offered a Support Group Leader Training and we're planning another one this Spring. If there is not a group near you, we'll help you start one in your area.

Our ninth annual conference, "Opening Doors" is scheduled for Saturday, March 27<sup>th</sup>. It is open to survivors, families and professionals, and features topics of interest for all audiences. Additionally, for those who work in the brain injury field, BIAV offers the opportunity to become a Certified Brain Injury Specialist.

For over 25 years, BIAV has hosted Camp Bruce McCoy, a 2-week camp for adults who have sustained brain injury. It provides fun, typical camp activities (such as horseback riding, canoeing, team sports) for the camper and valuable respite for family caregivers.

These are just some of the activities of the Brain Injury Association of Virginia. If you want more information about any of these services, please call us at 804-355-5748, e-mail us at <u>info@biav.net</u> or visit our website: <u>www.biav.net</u>

# Mark Your Calendary

- 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 10-14, 2010

- Event: International Brain Injury Association's Eighth World Conference on Brain Injury
- Location: Washington, DC
- Contact: www.internationalbrain.org

#### May 22-June 5, 2010

- Event: Camp Bruce McCoy
- Location: Triple-R Ranch, Chesapeake, VA
- Contact: Call 804-355-5748 or visit www.biav.net

#### June 3-4, 2010

- 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!

# Congratulations, Dr. Arango!

In December 2009, Dr. Juan Carlos Arango received a letter from the president of Colombia, Dr. Alvaro Uribe Velez, congratulating him for the two awards that he received from the American Psychological Association in August 2009 in Toronto, Canada, and for his professional accomplishments in the area of traumatic brain injury research. The first award was the American Psychological Association, Mitch Rosen-

thal Division 22 Early Career Award. This award is presented to the individual that the committee judges as having made the most significant contributions to the science of rehabilitation psychology in the 10 years since they earned their doctoral degree. The second award was the American Psychological Association Division 45 Emerging Professional Award. This award is given to an individual who has made outstanding contributions in the promotion of ethnic minority issues within 10 years of graduation. Candidates for this award may have made contributions within the areas of education, research, or practice.



Page 3

	-	JUST FOR FUN		
Unscramble the words and fill in the boxes. When you're	REVMOECO	4	DIKN	5
done, copy the letter in the numbered boxes into the final	CCONSISOUN	2	SELOACTB	
box to solve the last word! Need a clue?	TURNEOVEL	6	PIALTCY	
Each word comes from an article in this issue! Answers on	SORTFUTRIAN		RERERFAL	8
the back page if you get stumped.	TOERGF	3	FERLIE	
	1			

## **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

# JUST THE

 $F_{\text{requently}} A_{\text{sked}} Q_{\text{uestion}} S$ 

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 MEDI-CAL OR MENTAL HEALTH PROFESSIONAL.

**Q:** What are the signs of a concussion? My mother fell down the stairs recently and I think she may have suffered one.

A: It is important that your mother be seen by a physician to determine if she does have a concussion. The doctor may refer her for a comprehensive neuropsychological evaluation to further assess areas of impairment. Here is a list of symptoms that patients commonly have weeks or months after a concussion. Have you noticed your mother having any of them?

- Headaches
- Dizziness
- Feeling tired
- Moving slowly
- Trouble falling asleep
- Nightmares
- Feeling frustrated
- Impatience
- □ Irritability or short temper
- Feeling sad or blue

- Misplacing things
- Losing train of thought
- Thinking slowly
- Poor concentration
- D Forgetting if you have done things
- Generating what you read
- General Forgetting names or phone numbers
- □ Trouble following instructions
- □ Trouble following conversations
- **Trouble coming up with the right word**



*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* 





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 am a 41-year-old wife and mother of two young girls. I was in a car accident almost two years ago. I was on my way to work when a pickup truck rear-ended me at a red light. I was listening to the radio, just thinking about the day ahead of me, and didn't see the truck coming behind me. Anyway, my car was hit so hard that my head hit the steering wheel and I blacked out for a while. Next thing I know, I was being taken to the hospital. The rest was just a blur until a few days later. The whole experience was so terrifying that I still get nervous when I drive.

So, I couldn't go back to work after the accident because my brain wasn't working right. I was easily distracted and had a hard time focusing for a long time. I was also very forgetful. But, the most frustrating thing that I'm no longer able to do is multi-task, which was something I was proud of before the injury. Because of all these problems, I had resigned to stay at home and be a full-time mother, which I enjoy tremendously.

My husband has been very supportive and helpful; yet, he has a job and can't be home with me all the time. Pat, I get overwhelmed just trying to get through the day. Fatigue is a big factor. I get tired so easily and am pretty useless in the afternoon. Taking care of the house and my daughters is exhausting. And recently, the holidays took everything out of me. Having family members come in and out of the house constantly was stressful. I think I was still recoverPage 4

ing a week later.

It's been almost two years now since my accident, but I still feel tired all the time and am not sleeping well. Anything I do seems to be more difficult, and it takes all of my energy to do something. What can I do to not feel like I'm ready to break down and cry? I need to be strong for my daughters.

Desperate Mother



Dear Desperate Mother,

It is obvious that your family is very important to you and you want to care for your husband and daughters despite the challenges. Oftentimes, people forget about themselves when they are in a caretaking position. You're so used to taking care of others' needs that you forget about your own. With the brain injury, it is even more important for you to take care of yourself. You will not be able to care for your family if you are ill. Here are some ideas to manage the fatigue. First of all, schedule frequent breaks to rest and rejuvenate throughout the day. Secondly, schedule challenging activities at times (e.g., mornings) when you feel most energetic. In addition, here are ten important ways to take care of yourself:

1. Remember no person is an island. Ask for help when you need it! Everyone needs help at times in their lives, especially when facing new challenges. Let trusted family and friends help carry the load.

2. Take time out to do things you enjoy. Read a book, go dancing, watch a movie, etc. You'll be happier and better able to cope with life's stresses if you take time to do things you enjoy!

3. Set aside alone time. We all need time alone to re-charge our batteries. Take a little time out of each day to do something alone – take a bath, go for a walk, write in a journal, meditate.

4. **Protect your health**. Eat a balanced diet. Get enough sleep. Exercise regularly. Avoid alcohol and drugs. Follow up with your doctors regularly and take medications as prescribed.

5. Give yourself credit for things you accomplish. Everyone likes to be recognized for their successes. Don't wait for others to praise you. Reward yourself when you take positive steps or reach a goal.

6. **Don't overload yourself**. When you take on new responsibilities, drop some of your old ones. Ask others to step up to the plate and help.

7. Keep track of your stress level and emotions. Monitor them regularly, so you can get help and support as needed.

8. Remember that no one can do everything. Recognize your limitations. Try to take on activities which play to your strengths. Ask for help with tasks that are difficult for you.

9. Ask others how they've coped with similar problems. You can learn a lot from people who have had similar experiences. Find out how others deal with problems. They may be able to save you time and pain.

10. **Be kind to yourself**. You have been through a number of difficult situations. Give yourself credit for doing your best.

Lastly, getting involved with a local support group would help you to feel less alone and overwhelmed. You will have the opportunity to meet others who may be struggling with the same challenges. If you wish to get involve with your local support group to share your experience, Brain Injury Association of America (BIAA) 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 familyhelpline@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 8201 Greensboro Drive, Suite 611, McLean, VA 22102.

If you are located in Virginia, call 804-355-5748 or email info@biav.net.

# Notes From a Survivor

Bv Sara E. Lewis

Mrs. Lewis appears to have sustained a

moderate traumatic brain injury in 1977...

Despite the severity of her injury, Mrs.

Lewis' long-term recovery of cognitive func-

tions appears to be quite good ... with the

exception of low average/borderline im-

paired performance on the measure of rea-

soning and problem solving... Of more con-

cern is Mrs. Lewis' poor emotional adjust-

ment... Personality problems of this nature

are frequently seen in individuals with trau-

matic brain injuries which affect the frontal

lobe, with problems including disinhibition, reduced ability to modulate affect, poor

frustration tolerance, impatience, and great

susceptibility to being stressed by multiple

stimulation...

Neuropsychological evaluation

September 13, 2004

April 28, 1977 was the last day of classes at William and Mary. On that without thinking, and regretted my decisions later. When put on the evening, I decided to take a study break before exams. I would meet my mother in Newport News for some shopping. I had been accepted in George Washington University's Master of Arts in Teaching - Museum Education program that would start in July and we wanted to pick up some summer clothes. After a quick trip around the mall and

dinner, my mom went back to Gloucester and I headed for Williamsburg.

At about 9 p.m. that evening on a rainslicked Route 143 at its intersection with the Route 199 overpass in James City County, I drove my baby blue 1970 Volkswagen Beetle into the side of an older model sedan. My bug was totaled and his car sustained minor damage. I will never know what happened that night. It is a blessing of nature that we block pain and trauma. There were no witnesses.

When I broke through the fog weeks later, I found my left leg in traction. I had broken the femur about one inch from the hip. My right leg had sustained a compound fracture. The doctors did their best, but my right leg is forever shorter than the left. Everyone feared that I would never walk again. They

said I was lucky they could save my right leg. Everyone was amazed by the technology that had saved it-and my life.

Only passing attention was paid to my head injury. Yes, I limp a little. But this visible reminder of the accident is nothing compared to the invisible injuries I sustained when my head broke through the windshield. I have certain invisible physical problems like ear ringing and parasthesis, for which there is no cure. These chronic conditions make me irritable and moody, but it is the thinking-related problems that are even more invisible and, if left unappreciated, could have been fatal.

Behind a seemingly happy and ordinary life, a series of personal disappointments almost sent me over the edge. For years I tried to live a normal life but it was frequently and increasingly interrupted by spells of frustration with my low-level physical pain and that "something else" that I didn't know how to name as a cognitive dysfunction. One psychiatrist thought I had a personality disorder and another told me I was a hypochondriac. I frequently acted hastily and hurriedly, seemingly

spot, my social skills dissolved and I was prone to emotional outbursts. Ultimately, lack of self-awareness led to embarrassment, marriage problems, inability to function as an employee and plans to commit suicide.

> In 2004, on the verge of collapse, I was referred to a neuropsychologist whose evaluation finally set me on the road to recovery.

Once I was made aware of my reasoning and problem-solving deficit and how I reacted behaviorally to manifestations of the deficit, I was able to understand at last that I wasn't crazy-I was brain injured. Only since accepting that these are brain injury issues-not thoughtlessness or lack of social skills, things that I can will myself to correct-have I been able to stop acting mad at others and myself.

Although I can't go back and repair the relationships or reclaim the jobs I've lost, I can at the very least stop blaming others and myself. I can acknowledge my difficulty by asking for more time to make thoughtful decisions on the job, by educating my family and friends and

asking for their tolerance, and by being less hard on myself for occasionally fumbling through problem-solving tasks or jumping to conclusions. I have a cognitive deficit—but I also have an IQ in the 94<sup>th</sup> percentile. I can perform, but I need space and time to cope, to be more focused. Will you have patience with me?

After neuropsychological testing, I volunteered to participate in a study conducted by the Traumatic Brain Injury (TBI) Model System Project, a research and service program at Virginia Commonwealth University. I was so happy to find this organization and practically flew home after participating in my first study. To see that there was an entire wing of doctors' offices dedicated to TBI research and rehabilitation validated all that I had read and heard and gave me hope that I could be rehabilitated-even 27 years later.

What a relief. Now I can finally start to get well.

Sara Lewis is a marketing consultant, freelance writer and member of the Brain Injury Association of Virginia's Middle Peninsula Support Group.

Emilie Godwin, Ph.D. is a Marriage and Family Counselor in the Department of Physical Medicine and Rehabilitation at VCU. Currently, she manages the Brain Injury Family Intervention, a five-session program designed to assist families and survivors in developing tools to address challenges following TBI. Her goals for this program include increasing awareness in the TBI community that these services are available at no-cost to many families recovering from TBI. Additionally, Dr. Godwin is involved in research related to families and TBI. She has co-authored two recent manuscripts for medical journals in addition to articles for patients and

their families regarding family change after brain injury and tools for success.

A Virginia native, Dr. Godwin moved after high school to attend the University of New Orleans and later earned her Master's Degree in Marriage and Family Counseling from Our Lady of Holy Cross College. In 2005, Dr. Godwin returned to Virginia to pursue a Ph.D. at the College of William and Mary. She focused her studies on helping families recover from trauma and wrote her dissertation on family changes following Hurricane Katrina.

Outside of work, Dr. Godwin is a wife and a mother to three young children. She enjoys spending her free time with her family and friends. Favorite family activities include visiting grandparents, attending her two older children's sports games, and trying out different Richmond festivals. Additionally, Santa Claus brought a brand new miniature dachshund to her family this year and they are enjoying playing with and training the newest Godwin: "Pepper the Puppy."



# Overcoming Obstacles to Returning to Work After Brain Injury

Page 6

If you have a desire to be more productive or go back to work, then you have a lot in common with many persons who are recovering from a brain injury. The statements below are from real people and show some of the obstacles they face in getting back to work after injury:

"I have memory and balance problems, but I still have to support my family."

#### OR

"I used to make \$28 per hour. Now, the only job I can get pays \$6.50."

OR

"I'm not sure what I can do, but I have to do something."

After a brain injury it may take a long time to get back to work or being active. There are several reasons for this.

- The healing process itself can take as long as two years or more.
- Feeling tired a good deal of the time is a frequent complaint. This common challenge following brain injury can make it difficult to get back on track. If you are tired, it can feel like an effort to just get up and get dressed, let alone go to a job site.
- It also may take you longer to accomplish such things as dressing, grooming, and organizing yourself to get out the door.
- A negative outlook and self-talk can also prevent you from trying out work or other activities.

To see if you have some things standing between you and more fulfilling activities or jobs, try taking the following questionnaire:

## What's Holding You Back?

Read each statement and check each one that you feel applies to you.

I don't think I can get along with other people in a work setting.	
I don't have any energy!	
I feel like I can't reach my goals for going back to work.	
I just can't seem to get organized.	
I worry that my memory problems will make it hard for me to get work.	
Pain keeps me up at night so I feel sleepy all day.	
I don't know what I should tell people about my injury.	
I am waiting to get the same kind of job I did before my brain injury!	
I am worried that my volunteer work won't count.	
I usually need a helper to get up, dressed, and out in the morning.	



If you checked many, about half, or even a few boxes, you may have some challenges and obstacles that the following ideas could help you overcome.

### Top 8 Tips for Overcoming Obstacles to Going to Work or Becoming More Active

- Aim for regular sleeping and waking times
- Choose waking and sleeping times during the week days that are similar to those that regular employees keep. For example: Getting up at 7 a.m. may allow enough time to get ready, eat breakfast, and get to work if your work day is 8:30 to 4:30.
- Notice what time of day you get the most tired. Build in a short rest break at that time. Drink a not-too-sugary sports drink and eat an energy bar or peanut butter crackers.
- Stay away from the television unless it is a weekend and you have finished your daily tasks.
- Keep set habits and routines: lay out clothes at night for the next day, make your lunch the night before, stick to a regular schedule, do all grooming each day early at a set time.
- Dece yourself, don't race yourself!
- □ Use a list of steps when you do complicated tasks to help you fight fatigue.
- □ Keep a Positive Outlook! Avoid negative self talk and have realistic goals.



So whether your goal is to get a paying part- or full-time job or to just become more active and productive, setting a clock to keep regular working hours, using a task list and schedule, and working on your confidence and positivity will be steps in the best direction.

The worksheet "My Typical Day" is another tool that can help you learn about your personal obstacles to returning to work or activity. Fill the form out honestly to learn if you do too much or too little, get too tired, don't eat right, or stay up too late and don't get enough rest. When you have finished, see if you can work on changing some habits and building in routines that will move you toward your goals.

My Week	My Activities	When do I get tired?	Meal Times	When I go to bed
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Now you know more about your personal obstacles and challenges to returning to work or a more productive daily life. Some of these, like fatigue, a negative outlook, disorganization, and difficulty with maintaining a routine, can be overcome. You have learned some things about your own obstacles to getting off the couch and out the door to accomplish your work and activity goals! Keep working on your weekly schedule and habits until you find your energy and self-talk improving.

(Synopsis of material from Choosing, Finding, and Keeping a Job After Brain Injury, Janet Niemeier, Jeffrey Kreutzer, and Shy Degrace, 2009)

## VCU's Brain Injury Family Intervention Project

Virginia Commonwealth University has developed the Brain Injury Family Intervention (BIFI) program directed toward both TBI survivors and their family members. This program is available to families regardless of how long it has been since the TBI. The purpose of the program is to strengthen families and promote long-term recovery after TBI.

Many families have described the program as very helpful. A decrease in depression symptoms and an increase in independence of the TBI survivor are just a couple of the positive outcomes some participants in the BIFI program have experienced.

Families are welcome to participate in the BIFI program, and the program is free. If you would like to participate in the BIFI program or learn more, please contact Jenny Marwitz at (804) 828-3704 or toll free at (866) 296-6904.

4. FRUSTRATION	10. RELIEF
3. VOLUNTEER	9. КЕГЕRRAL
2. CONCUSSION	8. TYPICAL
1. OVERCOME	7. OBSTACLE
	9 <sup>.</sup> KIND
SAEWSNA	5. FORGET

**JUST FOR FUN!** 

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