# Spring 2005 VOLUME 3 NUMBER 2

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

#### THE VIRGINIA TBIMS TEAM

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# BUILDING RELATIONSHIPS AND OVERCOMING LONELINESS

Many survivors and family members describe changes in their relationships after the injury. They may not hear much from friends, co-workers, and extended family members. Others notice that their phone calls, emails, and letters are left unanswered. Some survivors find themselves feeling alone even when they spend much of their time with family members or friends.

# ARE YOU CONCERNED ABOUT YOUR RELATIONSHIPS WITH OTHER PEOPLE?

You may be wondering how other people feel about you and what they think about you. To help you better understand how you feel about your relationships, read the list of words in the "Relationships Concern Checklist." Check off the words describing how you feel now.

Think about the items you checked and the ones you did not. The more items you checked off, the more unhappy you may be with your relationships.

Keep in mind that relationships are a two-way street. You may be thinking a lot about how other people treat you. Just as important is thinking about how you treat other people. The way you act toward other people affects the way they treat you.

(Continued on page 2 - Relationships...)

Relationship Concerns Checklist	
Disrespected	Lonely
Disliked	Neglected
Unworthy	Abandoned
Different	Ignored
Unsupported	Isolated
🔲 Misunderstood	Rejected

#### (Continued from page 1, Relationships)

COULD YOU BE PUSHING OTHER PEOPLE AWAY WITHOUT MEANING TO? People sometimes do things that hurt their relationships without realizing it. Review the items below to help you recognize if you are doing things that might hurt your relationships. Check off the items that describe you.

- I often talk about my brain injury and how my life has changed for the worst.
- □ I have a hard time listening when other people speak.
- I interrupt people more than I should.
- □ I often argue with other people or disagree with them.
- I have a hard time thinking about other people's needs and feelings.
- □ I talk about myself a lot.
- I ask people very personal questions.
- I usually don't listen to other people's advice or suggestions.
- □ I have trouble accepting people's offers of help.
- □ I touch or hug people without asking them if it's okay.
- □ When talking, I stand very close to other people.
- □ I talk more than I should.
- □ I usually say the first thing that comes to my mind.

Look at the items you checked off. Talk to trusted family members, friends, and professionals about the ones you checked. Then, ask yourself these important questions: "Am I making it harder for other people to like me?" "Am I being a good friend to other people?"

Building healthy relationships

is important to many people. Most people want to feel understood, liked, loved, and accepted. We've talked to lots of survivors and their families to learn how they cope with feelings of loneliness and how they build relationships. Following are a number of strategies that have worked for them. Look over this list with trusted family or friends and try out the strategies you think will work for you.

- WORK ON BEING A LIKEABLE PERSON. Remember, in order to have friends, you must be a good friend too. Be the kind of person people like to be around.
- BE A KIND AND CONSIDERATE PERSON. Be polite. Try to do things that will help other people feel good about you and about themselves.
- BE A GOOD LISTENER AND OTHER PEOPLE WILL WANT TO SHARE MORE WITH YOU. Ask and talk to others about their lives, interests, and wellbeing – and listen carefully to what they say.
- LEARN TO COMMUNICATE IN POSITIVE AND HELPFUL WAYS. Avoid being too quick to share negative thoughts and feelings with others. Talk about good things in your life and the world around you.



BE CAREFUL NOT TO BE OVER-COME BY YOUR PROBLEMS AND THE CHALLENGES YOU FACE. Look for the good in other people as well as in yourself. Remember, most VOLUME 3 NUMBER 2

people have a good heart and enjoy helping others.

► BEFORE YOU SPEAK, THINK CAREFULLY ABOUT WHAT YOU WANT TO SAY AND HOW OTHERS MIGHT REACT. Try to say things in a way that brings a positive reaction. Avoid confrontation and try to be agreeable.

- TAKE CARE OF YOUR APPEAR-ANCE. After injury, many people become discouraged about themselves and their lives. Feelings of helplessness and discouragement can lead some people to stop taking care of themselves. No matter how you feel, don't let the basics go undone - wear clean clothes, brush your teeth, and comb your hair. People will have a better view of you, and you'll feel better about yourself.
- AFTER BRAIN INJURY, YOU MAY FEEL OVERWHELMED BY CHANGES IN YOURSELF AND YOUR LIFE. You may have trouble <u>not</u> thinking about your injury and the challenges you face. Try to think about others at least as much as you think about yourself. Thinking about others is a skill. The more you practice, the better you get.
- KEEP AN OPEN MIND ABOUT WHAT YOU CAN DO AND WHAT YOU WANT TO DO. It is often easier to talk to someone and start a relationship when you have something in common. Look for new activities or hobbies. Join a support group, club, fitness center, or sports team.
- DO VOLUNTEER WORK. By helping others, you are likely to meet people with a kind and giving heart.

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*(Continued from page 2)* DON'T LOSE TRACK OF YOUR FAITH. You may meet under-

standing and kindhearted people with similar interests and values at your house of worship.

- EVERYONE DOES BETTER WITH UNDERSTANDING AND SUP-PORT FROM OTHERS. Offer to help and do things for others without expecting anything in return. Try to do at least one nice thing for someone else every day. You'll feel better, and so will the people you help.
- SHOW A COMMITMENT TO HELPING YOURSELF. People will be more supportive and respectful if you do.

- TALK TO AND SPEND TIME WITH PEOPLE WHO CARE ABOUT YOU. Write, call, or email family and friends even if you're just saying "hello."
- ADOPT A PET. Pets are wonderful companions and can help you deal with loneliness. There are many

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take care of them. By offering them a loving home, you can find yourself a grateful companion.

This column was written by Jeff Kreutzer and Laura Taylor from the VCU TBI Model System Program. For more information about outpatient rehabilitation services and VCU research programs, please contact Dr. Taylor by phone at 804-828-3703, toll free at 1-866-296-6904, or by email at taylorla@vcu.edu.

If you'd like more information about building relationships and overcoming loneliness, be on the lookout for a new book entitled,

pets out

there without

anyone to

Recovering Relationships after Brain Injury: The Essential Guide for Survivors & Family Members,

to be published by the National Resource Center for TBI. Visit **www.neuro.pmr.vcu.edu** for information on ordering this book.

# WOMEN, DISABILITY, & THE JUSTICE SYSTEM: TRAINING FOR LAW ENFORCEMENT & THE COURTS



R esearch suggests individuals with disabilities face a 4 to 10 times greater risk of being victims of crime. Women with disabilities, especially victims of domestic violence and sexual assault, often encounter justice system personnel lacking knowledge and understanding about the individual's disability. Lack of knowledge creates frustrating barriers and discourages open access to the resources of a justice system that is willing and able to protect them.

The Partnership for People with Disabilities at Virginia Commonwealth University, in collaboration with the groups Virginians Against Domestic Violence and Virginians Aligned Against Sexual Assault, seek to minimize barriers by training police and court personnel (e.g., judges, magistrates, prosecutors) to improve access to women with disabilities who are victims of violent crimes. The goals of this project include:

- Assembling an advisory board with board members, representing a variety of organizations.
- Developing a statewide action agenda.
- Keeping the project going by preparing and distributing products and certified training, which awards continuing education credit.
- Improve the ability of law enforcement and court personnel to recognize victimization of individuals, especially women, with disabilities.

- Help victims overcome barriers as they access the justice system.
- Providing 2-day regional training sessions to teach law enforcement and court personnel approaches and resources for accommodating an individual's disability followed by 60 hours of technical assistance training.

Project Staff include Linda Harris, Betty Harrell, and Connie Kvarfordt. For more information contact Linda Harris:

PHONE: 804-828-6926

E-MAIL: lwharris2@vcu.edu

website: www.vcu.edu/ partnership/ access\_to\_justice

# JUST THE F requently A sked Q lestion S

• What can I do to improve my memory? Is it possible to fully recover this function?

 One of the most frequent • complaints from survivors of brain injury is reduced memory capacity. Research shows that 70% of TBI survivors continue to experience memory problems 1 year post-injury. Although survivors experience different types and degrees of memory problems, there are common patterns. Early in recovery many, if not most, survivors have difficulty remembering events that took place immediately after their injury (e.g., ambulance ride, going to the hospital). This type of memory problem is called post-traumatic amnesia. During recovery, some survivors notice that they start to remember more events that took place just before and right after the injury.

Short-term memory problems are very common after a brain injury. Often, survivors describe having difficulty remembering what they are supposed to do next, where they put things, what they read, and what happened the day or week before. Short-term memory problems typically continue for a long time following injury. Some survivors with moderate or severe brain injuries continue having memory problems for the rest of their lives.

Memory rehabilitation programs have been developed around the country and are a part of many inpatient and outpatient cognitive rehabilitation programs. These programs focus on teaching compensatory skills, retraining attention ability, and retraining memory processing. There are many compensatory strategies that may be helpful for individuals with memory problems. Here are several ideas:

- Repeating information and instructions several times is often a helpful way to store the information in your brain.
- Write down important information or have others write the information down for you. Use "to do" lists, Post-It notes, calendars, and schedules.
- Research has shown that "memory notebooks or logbooks" are effective ways of enhancing recall. These books act as data banks for all important dates, personal information, and anything else you want to remember. Refer to your notebook often.
- Leave important items, like your keys or wallet, in the same place every time. Then, you'll know where to find them.
- Setting alarms may help you remember important information like when to take food out of the oven or when to take your medicine. Try using a watch with alarm function (e.g., Timex Turn and Pull<sup>™</sup> Alarm Watch, Mitaki Japan® Talking 4 Alarm Watch) so you can have it with you at all times.

There are many other compensatory strategies and technological devices to help with memory problems. Neuropsychologists, rehabilitation psychologists, speech and occupational therapists, and case managers often help survivors develop strategies that work for them. Consider talking to a professional to gather ideas that might work for you. 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: ddwest@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 substitute for consultation with a doctor or rehabilitation specialist. The identity of authors submitting questions to "Chat with Pat" will be kept strictly confidential.

**DEAR PAT:** I was injured in an automobile accident almost 20 years ago. Way back then, little attention was paid to my head injury and the orthopedic surgeon was mostly interested in fixing my broken bones. About 10 years ago, I began noticing head-injury related symptoms as they became more annoying and painful with age. I've been to an ENT [Ear, Nose and Throat doctor] for tinnitus [ringing in ears] (she gave me sinus medication), a neurosurgeon for advice about tingling and crawling sensations in my left side (he said that removing cervical spine bone spurs would not solve the problem), an orthopedic surgeon for arthroscopy on my left knee (this helped a little, but my leg still hurts), a neuropsychologist (she has identified logical and reasoning issues that seem related to frontal lobe injury), and a psychologist (he thinks I have a personality disorder). In the last several months, I've seen a neurologist who thought I had MS [multiple sclerosis], but now that (Continued on page 5)

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#### (Continued from page 4)

he has decided that I don't have MS, he doesn't know what's wrong with me.

Taking matters into my own hands, I've gone back to the hospital that treated me after my accident to retrieve old records. After much back and forth. I was able to sweet-talk someone into finding the microfilm. I read through the records and discovered that I had an open wound in the frontal area and that xrays showed a soft tissue injury in the parietal region. Could the parietal region injury be to blame for the pain in my left side, which includes inability to discriminate temperature and pressure, surface tingling and burning, zapping sensations that feel like weak electrical shocks especially in my foot and hand, maddening tinnitus and increasing weakness in my left arm and leg?

**PAT'S RESPONSE:** I doubt that 007 could have done much better retrieving the microfilm from your medical records! All joking aside, active participation in your medical care is vital for survivors of brain injury. Brain injuries generally result in complex problems requiring help from a number of professionals such as physiatrists (doctors of physical medicine and rehabilitation) and other "neuro" specialists (neurosurgeons, neuropsychiatrists, and neuropsychologists). As you have experienced first-hand, even medical professionals may have difficulty knowing exactly what is going wrong with an individual coming to them for help.

An important first-step is seeking out advice about symptoms and recovery from a treatment professional with expertise in helping people with brain injury. Your local chapter of the Brain Injury Association of America (Phone: 800-444-6443 or Email: familyhelpline@biausa.org) can provide you with a list of rehabilitation specialists in your area. Offering education, support, and referral services for individuals with brain injury and their family members are primary functions of Brain Injury Associations around the country.

People with brain injury sometimes feel strange sensations on their skin or notice other physical changes. *Paresthesia* is a term describing abnormal skin

# VIRGINIA CAREGIVERS GRANT PROGRAM IS BACK!

The Virginia Caregivers Grant Program provides annual grants of up to \$500 to caregivers who provide unpaid care to a needy relative. Grants are awarded for care provided for at least six months of the previous calendar year. The caregiver and person receiving care must be related by blood, marriage, or adoption and reside in Virginia. The caregiver's annual income cannot be more than \$50,000. The Virginia Department of Social Services will only accept applications between February 1 and May 1 of each year. Applications postmarked after May 1 will be disqualified. To receive a copy of an application or for more information, please contact the Fairfax Area Agency on Aging at 703-324-5485. Applications can also be downloaded from this Web site: www.dss.state. va.us/family/as/caregivegrant.html sensations such as burning, prickling, itching, or tingling usually felt in the hands, arms, legs, or feet with no apparent physical cause. Injury to the brain's parietal lobe or sensory pathways may result in paresthesia. Other medical conditions such as MS. stroke, diabetes, and rheumatoid arthritis have also been known to cause paresthesia according to the National Institute of Neurological Disorders and Stroke (NINDS). For more information about neurological and medical conditions associated with paresthesia, vou may contact NINDS directly (301-496-5924) or visit their web site (www. ninds.nih.gov).

The appropriate treatment for paresthesia depends on accurate diagnosis of the underlying medical cause. Doctors base their diagnosis on a number of factors like a patient's complete medical history, physical examination, and laboratory tests. A comprehensive evaluation by a physician with experience treating persons with head injury may be beneficial. You may also benefit from speaking with other survivors of brain injury and their families about ways they have found relief from brain injuryrelated symptoms. The Brain Injury Association of American is an excellent source of information about support groups in your area. If you have internet access, their web site is www. biausa.org. You will also find links to local Brain Injury Association chapters through the site.

THE INFORMATION PROVIDED IN THE FAQ AND CHAT WITH PAT IS INTENDED TO FA-MILIARIZE THE PUBLIC WITH ISSUES RE-LATED TO TRAUMATIC BRAIN INJURY. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

# RESOURCES TO THE RESCUE

Richmond recently gained an innovative resource for persons with disabilities, the Positive Vibe Café. Started by Garth and Max Larcen, the Positive Vibe Café is a training restaurant. The facility offers persons with disabilities a place to learn basic kitchen and restaurant skills. thus enhancing their ability to secure employment. The training program was developed with the assistance of area chefs, food service consultants, and physical and occupational therapists. The restaurant is staffed primarily by volunteers, and training is provided by area chefs. The program relies on community support and Positive Vibe Café profits for its funding, rather than state or federal sources. Community support includes donations from major corporations and small businesses. Proceeds from the Positive Vibe Café, a non-profit corporation, are dedicated to enhancing the training program, with surplus funds being donated to the Muscular Dystrophy Association.

Since starting in 2004, the Positive Vibe Café has trained and found employment for four



Founder Garth Larcen (I.) and employees of the Positive Vibe.

individuals with disabilities. Individuals are referred for training by the Department of Rehabilitative Services, the Muscular Dystrophy Association, the Association of Retarded Citizens. the Central Virginia Center for Independent Living, and other local and state programs. The training program provides individuals the opportunity to work in a real restaurant environment, with the bulk of training taking place during non-peak hours. Trainees learn about waiting tables, clearing and setting tables, food preparation, and food presentation, as well as a variety of other food service jobs. Initially, the training class size will be small (3 to 5 students), but there are hopes to increase the size as the training program progresses. The goal is to train approximately 100 individuals per year in basic restaurant skills and place them in jobs.

The Positive Vibe Café is open for lunch and dinner Tuesday through Sunday, and has live music several times per week. The menu offers a variety delicious and reasonably of priced meals. from salads, and burgers to sandwiches. seafood and buffalo sirloin. The Positive Vibe Café is located on the South Side of Richmond at 2825 Hathaway Road in Stratford Hills Shopping Center. For more information, visit the Positive Vibe Café website at www.getlostmd.org. Please call (804)560-9622 if you'd like to volunteer, make a donation, lend support, or make your а reservation for a fantastic meal.

Contributed by Laura Taylor

#### VOLUME 3 NUMBER 2 HAVE YOU HAD A BRAIN INJURY? HAVE YOU BEEN FEELING DOWN OR SAD?

If yes, then you might qualify to be in a study of depression medications for people with traumatic brain injury (TBI). TBI includes brain injuries from car accidents, falls, assaults, or sports injuries.

We are comparing Effexor (a medication to help with depression) to a placebo (sugar pill). If you qualify to be in this study, you will be seen by a doctor regularly for 12 weeks. There are no charges for the doctor's visits or the study medications, and you will receive up to \$55 for your time and effort. You must be 18 years or older to participate.

This study is conducted by the VCU Department of Physical Medicine & Rehabilitation.

CONTACT JENNY MARWITZ: PHONE: (804) 828-3704 or (866) 296-6904 (TOLL FREE) E-MAIL: jhmarwit@vcu.edu USPS: VCU Department of Physical Medicine & Rehabilitation Box 980542

Richmond, Virginia 23298-0542



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Contact Debbie West: ddwest@vcu.edu 804-828-8797 to join our *TBI Today* mailing list.

- Deep in thought
- Broken promise
- 4. Back to square one
  - 3. Too little too late
- 2. For once in my life (4 ones in "my life")

1. For instance (4 in "stance")

Answers to pictograms on page 8:

TBI TODAY

# COLLEGE SCHOLARSHIPS FOR STUDENTS WITH PARENTS WITH DISABILITIES

In recognition of the more than nine million parents with disabilities in the U.S. and their families, Through the Looking Glass (TLG), a non-profit organization, is pleased to announce the 2005 College Scholarship Fund specifically for graduating high school seniors who have parents with disabilities.

Scholarships funds are available to graduating high school students who demonstrate academic and personal achievement; have grown up with at least one parent with a disability; and will be a high school graduate or graduating senior by Summer 2005.

Up to four separate \$1,000 awards will be given out in Summer 2005. (A new round of awards will be given out in 2006.) These awards are one of several projects of Through the Looking Glass' National Resource Center for Parents with Disabilities. This National Center is funded by the National Institute on Disability Research and Rehabilitation (NIDRR), U.S. Department of Education.

More information and application forms are available on Through the Looking Glass' website: <u>www.lookingglass.org</u> Forms may also be requested by calling 1-800-644-2666.

Founded in 1982, Through the Looking Glass (TLG) is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability. Since 1998, TLG has been funded by NIDRR as the National Resource Center for Parents with Disabilities. The overall goal of this national center is: To increase knowledge regarding parenting with a disability and support more accessible and disability-appropriate resources for diverse parents with disabilities and their children. The Center's services and activities include: national toll-free information and referral: technical assistance and consultations: professional trainings, workshops and presentations; national library and resources clearinghouse; publications and training modules; a national parent-to-parent network of parents with disabilities; international newsletter; website and bulletin boards; and regional and statewide systems development.

> Darlene Bubis, MFT Family Clinician; Website & Outreach Specialist Through the Looking Glass 2198 Sixth Street, Suite 100 Berkeley, CA 94710 (510) 848-1112 ext. 172 (800) 644-2666 ext. 172

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## MARK YOUR CALENDARS

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# FIRST FRIDAY OF EACH MONTH

(6:00 — 9:00 PM) Event: T.G.I.F

Location: Typically at Belmont Recreation Center, 1600 Hilliard Rd. (Lakeside area of Henrico Co.)

**Description:** Henrico, Hanover, and Chesterfield County Departments of Parks and Recreation host monthly social events for adult TBI survivors **Contact:** Call (804) 501-7489 for more information.

### MON. MAY 2. 2005, 6 PM

Event: BIAV Support Group Speaker Meeting Location: Children's Hospital, 2924 Brook Road, Richmond, VA

Description: Jan Niemeier, Ph.D. presents "Dating and Sexuality After Brain Injury."

Contact: Call (804) 355-5748 or e-mail: info@biav.net

#### MAY 14, 2005

Event: Getting Better and Better After TBI Location: VCU MC, Richmond, VA

- **Description:** Workshops for TBI survivors and their families addressing important information for enhancing recovery. Topics include strengthening families, use of prescription medications in recovery, and building a positive self image.
- Contact: Sorry, but these workshops are filled. Please call (804) 828-9055 or e-mail jhmarwit@vcu.edu for information about upcoming workshops.

#### MON. JUNE 6. 2005, 6 PM

Event: BIAV Support Group Speaker Meeting Location: Children's Hospital, 2924 Brook Road, Richmond, VA

Description: Barbara Mann, LSCW, presents "Humor and Healing after Brain Injury." Contact: Call (804) 355-5748 or e-mail: info@biav.net

#### JUNE 9—10, 2005

Event: 2005 Williamsburg Conference– Rehabilitation of the Adult and Child with Brain Injury Location: Williamsburg, VA

**Description:** Lecture, break-out sessions, and panel discussions addressing 1) community integration 2) cognitive rehabilitation and pediatric brain injury and school reentry.

Contact: Call BIS (703) 451-8881 or email llee@braininjurysvcs.org for more information.

JUST FOR FUN

# Research Volunteers Needed VCU Traumatic Brain Injury Outpatient Rehabilitation Services Program

VCU Researchers are seeking adults with traumatic brain injuries (TBI) and their families to be part of a research study. We are evaluating the helpfulness of an outpatient rehabilitation program. During the course of 5 sessions, participants will be given information on TBI, local resources, skills development, and positive coping strategies. Qualified volunteers will also be asked to complete several questionnaires. All participants must be at least 18 years old.

Rehabilitation services will be provided at no charge at the Medical College of Virginia Campus. Volunteers will be reimbursed for their time and effort in completing questionnaires.

For more information about the program, please call Laura Taylor at 804-828-3703 or toll free 866-296-6904 or by email at taylorla@vcu.edu. Can you solve the following pictogram (rebus) puzzles? Each picture represents a saying (see example, below). You may have to look in between the lines, literally! Answers are on page 6, but try not to peek unless you have to! For more fun word games, visit www.fun-with-words.com.



VCU, PM&R TRAUMATIC BRAIN INJURY MODEL SYSTEM P.O. BOX 980542 RICHMOND, VA 23298-0542