

TBI TODAY

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

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MODEL SYSTEM OF CARE GRANT AWARDED

In 1987, the U.S. Department of Education, National Institute on Disability and Rehabilitation Research (NIDRR) provided funding to establish the Traumatic Brain Injury (TBI) Model Systems of Care. These new research and demonstration projects focused on developing comprehensive systems of care for persons with TBI. The model system programs (TBIMS) stressed continuity and comprehensiveness of care. Each center provided a coordinated system of emergency care, acute neurotrauma management, comprehensive inpatient rehabilitation, and long-term interdisciplinary follow-up services.

For research purposes, the TBIMS programs also collected and analyzed information on the types of injury and outcomes. Many patients have volunteered for annual follow-up evaluations. They have helped us learn a good deal about the long-term course of recovery and the benefits of rehabilitation therapies.

Between 1987 and 1997, there were five federally funded centers, including Virginia Commonwealth University. With encouragement from the Brain Injury Association of America, the TBIMS program was dramatically expanded. There are now 16 centers funded through 2007. We are pleased to announce that VCU is among the centers recently awarded five more

years of funding.

In addition to providing comprehensive clinical services, the VCU program is committed to carrying out scientific research. Our newest research programs focus on improving care and quality of life for people with brain injury and their families. The benefits of family support and education, identification and treatment of depression, and the effectiveness of early rehabilitation are new areas of study. More detailed information about the first two research projects is provided in this newsletter.

With our new grant award, we are also pleased to present this, our first issue of *TBI Today*. The newsletter will be published quarterly and feature information about brain injury, rehabilitation, and research. The newsletter will also feature information about upcoming events, an advice column, answers to frequently asked questions, and information on regional resources.

The faculty and staff of the Department of Physical Medicine and Rehabilitation along with VCU Health System staff of the Rehabilitation Research Center (RRC) are committed to working together and improving the lives of persons with TBI. We welcome your questions and suggestions and look forward to hearing from you.



Richard Kennedy, M.D.

is the project director for the TBIMS research on depression. Dr. Kennedy has been involved in the neuropsychiatry of TBI for the past 8 years, and is an Assistant Professor

in the Departments of Psychiatry and Physical Medicine and Rehabilitation at VCU. His previous work includes serving as an Investigator for the TBIMS of Mississippi subproject on delirium. Dr. Kennedy is author of 11 journal articles and has lectured extensively on the interface of TBI and psychiatric disorders. He is also recipient of a National Alliance for Research on Schizophrenia and Depression (NARSAD) foundation grant

investigating the use of depression scales in acute brain injury. In addition to TBI, Dr. Kennedy has expertise in geriatric psychiatry and Parkinson's disease. Dr. Kennedy graduated from the University of Mississippi Medical Center, finished residency training at the University of Arkansas for Medical Sciences, and completed fellowship training in the Department of Psychiatry at VCU.

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RESOURCES TO THE RESCUE



The Brain Injury Association of Virginia (BIAV) is a non-profit agency that serves the needs of people with brain injury, their family and friends and professionals statewide. Founded in 1982, by a group of parents struggling with the consequences of their children's injuries and recovery, it has grown significantly, especially in the last year.

Two grants, awarded in 2001 and 2002, have made it possible to open four Regional Resource Centers (with one more on its way). These Centers serve the Roanoke area, Hampton Roads, Shenandoah Valley and the far southwest region of Virginia; the office serving the Fredericksburg/Northern Neck area will open soon. The goals of these Centers are to:

- improve awareness of brain injury
- work with local resources to develop, expand and enhance local services and supports
- conduct outreach and educational activities

Information and referral remains one of BIAV's primary services. With a large clearinghouse of information, anyone having a question about the consequences of brain injury can get information about the many issues that survivors and their families face. Referrals to professionals, treatment providers, entitlement programs and attorneys are also available by calling the toll-free Family Help-Line (800-334-8443 or, in Richmond, 804-355-5748). BIAV also has a network of support groups around the state and is willing to work with people who would like to start one in their own community.

The contract that BIAV has with the VA Central Brain Injury Registry helps to facilitate outreach to those who incur traumatic injuries. Hospitals are required to report to the state anyone who sustains a traumatic brain injury (whether it is mild or severe). BIAV then sends out material to these survivors alerting them that help is available and encouraging them to call the helpline and get connected.

This spring marks the 20th season for BIAV's Camp Bruce McCoy. Camp is an opportunity for recreation and fun for survivors and respite for families. It takes place at the Triple R Ranch in Chesapeake, VA during the last 2 weeks of May. Camp applications become available in February.

In the last two years, BIAV has increased its educational activities and has sponsored conferences in Richmond and Roanoke. This is in addition to the efforts of the Northern Virginia Chapter that has hosted the *Journey Toward Independence* Conference for the last seventeen years. BIAV has also been presenting to a variety of school systems about working more effectively with children with brain injury. A "Best Practices" Manual for school re-entry has been written and may be distributed by the Virginia Department of Education to schools by the start of the 2003 school year.

The Brain Injury Association of Virginia remains committed to advocating for survivors and continues to keep their needs known to lawmakers. If you want more information about BIAV, feel free to visit the office, someone there would be glad to speak with you.

BIAV-AFFILIATED CHAPTERS AND SUPPORT GROUPS

Central Va. Chapter & Support Group

Meet 1st Thurs. of each month at 7:00 pm, Heritage United Methodist Church 582 Leesville Rd. Room 206. Lynchburg. Call Betty Zaring (804) 947-4646.

Danville – Southside Support Group

Meet 2nd Thurs. of each month at 7:00 pm Mount Hermon Baptist Church. Call Sue Jones at (434) 724-7070.

Eastern Shore Survivors' Group

Meets each Wed. at 3:30 for Tai Chi, Body Fit Gym. Call Margaret Young (757) 787-3131. Quarterly support group meetings with facilitators held on the 2nd Tuesday every 3 months. Call Kim Diaz at (757) 665-5133.

Fredericksburg Chapter & Support Group

Meet 3rd Thurs. of each month at 7:00 pm, Disability Resource Center, 409 Progress Street. Call Dave & Danica Cramer at (540) 785-8717 or Jerry Craft at (540) 899-2925.

Northern Virginia Chapter & Support Group

Falls Church: Meet 1st & 3rd Thurs. of each month at 7:30 p.m., Falls Church High School. Call (703) 569-1855.

Richmond Chapter & Support Groups

Meets on the 1st and 3rd Mon. nights at 6:00 pm. in the Auditorium of Children's Hospital at 2924 Brook Rd. On the 1st Mon., there are two facilitated support groups, one for survivors and one for family and friends. On the 3rd Mon., area professionals and service providers speak on different topics. Call John Hughes (804-320-7711, ext. 257) or BIAV (804-355-5748).

Roanoke Chapter & Support Group

Meet 1st and 3rd Thurs. of each month at 7:00 pm in Roanoke. Call Barbara Iddings (540) 992-1650 for details.

Shenandoah Chapter & Charlottesville Support Group

Meet 3rd Thurs. of each month at 6:00 pm, John Jane Center, 401 E. High Street, Charlottesville. Call Joan Herrion at (434) 589-4884.

Southside Support Group

(Farmville and Crewe areas)
Call Rev. Clyde Shelton (434) 767-2259.

Southeast Chapter & Newport News Support Group

Education- advocacy- support group meets each Wed. at 6:00 pm, 1st floor classroom of Riverside Rehabilitation Institute (RRI), Newport News. Call Shelley Brown at RRI, (757) 928-8152 or Denyse Harris at (757) 928-8335.

Tidewater Chapter & Support Group

Meets on the 2nd Mon. of each month at SEEK in Virginia Beach. Contact Joann Mancuso at (757) 493-0300.

ALL ATTEMPTS ARE MADE TO ENSURE INFORMATION ACCURACY, HOWEVER BE SURE TO CALL CONTACT PERSONS BEFORE GOING TO A MEETING TO MAKE SURE THERE HAVE NOT BEEN ANY CHANGES.



DON'T FORGET TO HAVE FUN!

Henrico, Hanover, and Chesterfield County Departments of Parks and Recreation host monthly social events called T.G.I.F. for adult survivors of brain injury.

The events are scheduled for the 1st Friday of each month from 6:00 to 9:00PM. Upcoming events will be held on February 7th, March 7th, and April 4th. Events are typically held at Belmont Recreation Center, 1600 Hilliard Road in the Lakeside area of Henrico County. Please call **501-7489** for more information.

NON-BIAV-AFFILIATED SUPPORT GROUPS

Bluefield & Princeton, West Virginia Support Group

For information, call HealthSouth Southern Hills Rehabilitation Hospital (304) 487-8000. Hospital is located at 120 12th Street, Princeton, WV 24740.

New River Valley Support Group

Meets the 4th Tues. of the month at 7 pm at Radford University, Waldron College Room 227. Call Brain Injury Services of SWVA at (540) 344-1200.

Richmond Supportive Survivors (This has the same name as the Richmond Chapter, but is a different group). Meets every Tues. at 7:00 pm at the Food Court at the Shops at Willow Lawn. Call Ted Taylor at (804) 837-3300.

Riverside Rehabilitation Institute Brain Injury Support Group

Meets every Wed. at 3:30 pm in 4th floor chapel of Riverside Rehabilitation Institute in Newport News. Contact Woody Rea (757) 928-8327.

Southwestern Area – The Survivor Group Meets 2nd Tues. of each month at 7:00 pm at the Bristol Regional Medical Center. For more information, contact Mary Hayes at (540) 475-3441.

Staunton-Augusta County Area Support Group

Meets 2nd Tues. of each month at the Mary E. Switzer Building at Woodrow Wilson Rehab Center campus, Fishersville. Contact Helen Cloud (540) 886-5420 or e-mail hcloud35@msn.com.

Tri-Cities (Tennessee) Support Group Meets the 2nd Thurs. of the month (except Dec. & Jan.) at 7 pm at the Quillen Rehabilitation Hospital, 2511 Wesley Street Johnson City, TN. Call Bette Lucas at (423) 952-1751.

Winchester Support Group

(includes Flint Hill, Front Royal, Winchester, and surrounding areas). Meets on the 3rd Thurs. of each month at 3 pm on the 2nd floor of the Winchester Rehab Center. Call Mary Mattingly, Rehabilitation Social Worker at Winchester Rehabilitation Center (540) 536-5182 or (800)382-0772.

ALL ATTEMPTS ARE MADE TO ENSURE THE ACCURACY OF INFORMATION, HOWEVER BE SURE TO CALL CONTACT PERSONS BEFORE GOING TO A MEETING TO MAKE SURE THERE HAVE NOT BEEN ANY CHANGES.

CHAT WITH PAT

Pat answers your personal questions about brain injury with compassion and practical advice. The identity of authors submitting questions to Pat's column will be kept strictly confidential.

DEAR PAT: My sister (she's in her mid-20's) had a traumatic brain injury during a car accident almost one year ago. She's been home from the hospital for several months and is doing a lot better. She continues to have weakness on the right side of her body and some memory problems, though. Also, her confidence seems to be low. I wonder if she'll ever get back to being like she was before the accident. How long does it take to get better after a severe brain injury? What can I do to help her? Thanks, Pat!

PAT'S RESPONSE: Bravo and keep up the good work! It sounds like you care a lot about your sister and want the very best for her. Now that she has been home for a while, you have a chance to look toward the future. Help her anticipate new challenges that may surface. Provide support and encouragement when they do. A little "sisterly love" goes a long way.

In response to your question about recovery time, the short answer is, "It depends." Recovery from brain injury—as you are learning first hand—is usually a long-term process. People may recover quite rapidly in the first six

months to a year after their injuries. Then, people tend to find the rate of recovery slows down. The good news is that most individuals continue to recover for some time, just at a more gradual pace than before. Others find their physical or cognitive problems seem to linger on indefinitely. Your sister is far from the "indefinite" phase of recovery. Her problems with weakness and forgetfulness may continue to improve. It depends on a number of factors including her own individual strengths (supportive family, motivation, young age) or challenges (severity of brain damage, access to rehabilitation resources), whether this will be the case.

Never stop working toward improvement! Recovery depends on what you do to help it along. To make the most of her progress, your sister should keep regular visits with doctors and specialists trained in rehabilitation (physical and occupational therapists, neuropsychologists, and physiatrists). Talking to other people about her condition may help renew confidence lost after the accident. Rehabilitation counselors and support groups offer a caring environment of guidance and education about surviving brain injury. Strategies to overcome and/or adjust to memory problems can be developed with the help of a rehabilitation psychologist. Many people find talking with others that have survived brain injuries helps them better manage their own adjustment. Go to a support group for family members of

survivors, kind sister, and take advantage of the companionship and understanding you too deserve.

DEAR PAT: My life is in a rut. I do the same thing every day and see the same old people. Life is dull. Plus, it's been three years since I had a head injury and I haven't been out on a date since. At first, I was too busy getting well to worry about dating. I didn't know what the future had in store for me. But now, I really want something or *someone* special in my life. Help!

PAT'S RESPONSE: Could this be a case of the "winter blahs" or something more terminal like "love sickness?" Either way, you are not alone. We all experience times in our lives that seem a little too familiar and routine. Are you ready to make some changes, shake off the snow, crawl out of hibernation, etc.? If so, read on...

First, give yourself some credit for taking the time to get better after your injury. Reliable schedules and familiar people make the recovery time easier for most people. *Second*, Pat suggests you take stock in your life. What other areas may need a makeover (besides your love life)? When was the last time you picked up a new hobby, tried a different sport, took a class, or went to the library and browsed the aisles? These types of activities not only improve the "inner"

(Continued on page 4)

you, but also increase your exposure to new ideas *and* people. When you broaden your range of interests, you increase the chances others will be interested in you! *Third*, you may want to consider ways to accentuate your outward appearance as well. Ask yourself (and answer) these types of questions to see where you could improve your "people skills."

- * *Would others consider you a warm and friendly person?*
- * *Are you a good listener and show interest in the other person during conversations?*
- * *Do you make the most of your appearance (neat haircut, clean clothes, big smile)?*

If you're kind to yourself, find new interests, and appear approachable, you are well on your way to being a good friend to yourself and someone else. Good Luck!

THE INFORMATION PROVIDED IN THESE COLUMNS IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED 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.

JUST THE FREQUENTLY ASKED QUESTIONS

QUESTION: Why does it seem that survivors of brain injury are easily upset?

ANSWER: For many survivors and family members, brain injury brings on a period of intense and prolonged stress. Decreased ability to cope with stress is a common problem for survivors of brain injury. Increased anxiety, sudden mood changes, and irritability can result from being overwhelmed by stress. There are several things you can do to limit the effect of stress in your life.

First, think about what you find stressful. For example, if you are trying to work and finding work stressful, try to decide whether you are really ready to return to work. Are you able to handle the pressures of your job? Are memory problems, attention problems, or other symptoms leading to job-related problems and stress? If so, figure out whether working is really

the best thing for you right now. If you find certain people stressful to be around, find ways of politely avoiding those situations. Try to avoid arguments or fights that become too emotional.

Second, try to avoid pushing yourself too hard and be patient with yourself. Remember that taking on too much too soon may cause problems and lead to failure. Instead, try to set reasonable goals and expectations for yourself. It can often help to make a "to do" list, order the items by priority, start with #1, and work down the list. Be sure that you work on only one or two problems at a time, so you don't get overwhelmed.

Third, remember that life can be hard for anyone - injury or not. Some people have health problems or money problems that can't be easily solved. Remember to balance the stress and the bad times with things you enjoy. Take a walk in the park, visit a museum, go to church, take a long bath, read a book, or watch television. Make a list of things that make you feel good. When you're stressed out, pick an item off the list and go do it! You will probably feel better.

Fourth, when we are under stress, it often helps to talk to your friends and family or other people you trust. Join a brain injury support group, so you can learn from others who have coped with similar stress. Contact BIAV (804-355-5748 or 1-800-334-8443) to learn about support groups in your area.

Fifth, it is important to take care of yourself when you are under stress. Try to eat well, get enough rest, and exercise. Alcohol and drugs can often provide quick fixes, but lead to more problems in the long run.

Sixth, relaxation techniques can be helpful when people feel stress. Imagine yourself in a pleasant situation or place that you enjoy. It is also helpful to take long, slow, deep breaths.

Finally, if none of these suggestions seem to help, consider counseling. A good therapist can help you find solutions that can fit your specific situation. Maybe there are some new ways to cope with stress

you haven't tried. It's possible that brain injury or stress has triggered an anxiety disorder or clinical depression. If that's the case, medication may be an option to help you feel better and deal with the stresses of life.

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@hsc.vcu.edu.

UPCOMING EVENTS

The 27th Annual Williamsburg Conference on Traumatic Brain Injury Rehabilitation will be held June 6-8, 2003 at the Williamsburg Marriott Hotel. Nationally recognized experts will provide information on clinical and research innovations in the field of TBI. For more information, contact Carole Hetteema at 804-828-5416 or VCU Office of Continuing Medical Education, Box 980048, Richmond, VA 23298.

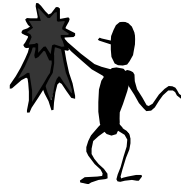
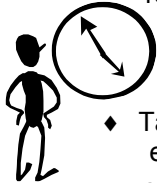
The 2nd Annual Brain Injury Conference for Southwestern Virginia will be held April 25-26, 2003 at the Heth Center at Radford University in Radford, Virginia. Nationally recognized experts, including Al Condeluci, will provide information on clinical and research innovations in the field of TBI. Topics include: adjustment to brain injury for parents, siblings, and extended family; return to work; getting educational services for your child; neuropsychological assessment and educational planning for children and adolescents; Internet resources; sexuality and brain injury; sports-related injuries; pharmacology; technology; and quantitative EEG. For more information, call 540-343-5339 or email sandywillis50@hotmail.com.

SURVIVAL TIPS: COPING WITH LOSS AND CHANGE

Brain injury often brings about drastic life changes for survivors as well as their families and friends. As a result, many people have a mixture of feelings including sadness, fear, hopelessness, and frustration. Most people want to feel better and learn to cope with life changes, but don't know how.

Here are some ideas for how you can help yourself adjust to changes and losses:

- ◆ Realize that your feelings are a common, normal response to your situation.
- ◆ Be kind to yourself. Give yourself and others time to adjust.
- ◆ Take one step at a time, set goals for each day.
- ◆ Appreciate the value of patience and persistence in reaching your goals.
- ◆ Think about the future you want and the best ways to get there.
- ◆ Learn to focus on your successes, strengths, and resources.
- ◆ Avoid thinking about and making comparisons to how things were.
- ◆ Recognize there is a natural human tendency to



worry and focus on the negative.

- ◆ Focus on what you can do instead of what you can't.
- ◆ Be hopeful and say positive things (e.g., "We will make it through this," "We've come so far.")
- ◆ Talk to and spend time with people who care about you.
- ◆ Join a support group. Talk to others for support and ideas for coping.
- ◆ Allow yourself to ask others for help and support.
- ◆ Remain active, try to do things you enjoy.
- ◆ Distract yourself with music, a book, a movie, or television.
- ◆ Give yourself breaks and try to be patient with yourself.
- ◆ Learn about treatments, resources, and recovery.



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If you have questions or concerns, talk with your doctor or a professional at a local hospital, mental health center, or church about ways to get help.

EVALUATION OF DEPRESSION DIAGNOSIS & MEASUREMENT TECHNIQUES

Depression can be a big problem for people after brain injury. Researchers have found that depression can make recovery from illness or injury more difficult. Understanding how to diagnose depression for persons with brain injury can be hard to do. First, sadness is a normal reaction to illness or injury, and telling the difference between sadness, grief, and depression is not always easy.

Just feeling sad is not enough to know whether or not there is depression. Depression is a syndrome with a mixture of emotional symptoms (sadness, crying spells, feeling worthless or hopeless) and physical symptoms (disturbed sleep, low energy, weight or appetite change, difficulty concentrating or making decisions). But problems with sleep, energy, appetite, and concentration are often a result of brain injury. Doctors often have difficulty deciding whether symptoms are due to the brain injury, depression, adjustment to losses and changes, or a mixture of these things.

The NIDRR Virginia TBIMS Depression research study aims to evaluate the usefulness of different tests of depression for people with brain injury. We hope to understand better what problems after brain injury may make people more likely to have depression. We also want to learn about differences between people with brain injury who are depressed and those who aren't. Through this research we plan to develop a process for better identifying depression in people with brain injury.

People might be interested in learning more about this study if they:

- had a TBI within the last 3 months
- are at least 18 years old

There are also some other conditions and requirements for the study, but people do **not** have to feel depressed to be in the study. If you recently had a TBI, we may need your help with this project. We'll need people to answer questions about how they are feeling, fill out some questionnaires, and take some short tests of memory and concentration. People would come in for visits at about 3 months after their injury and then again about 6 months after their injury. For more information, contact:

Jenny Marwitz
In Richmond: 804-828-3704
Toll free: 866-296-6904
E-mail: jmarwitz@hsc.vcu.edu.



Looking for more TBI information?

On the Web visit the National Resource Center for Traumatic Brain Injury at:

<http://www.neuro.pmr.vcu.edu>

This is a great site for TBI-related resource materials.

NIDRR TBI MODEL SYSTEM FAMILY SUPPORT PROGRAM

Family members play an important role in recovery and rehabilitation after TBI. The recovery process can take months or even years. After hospital discharge, many family members have questions or concerns, but are unsure where to turn for help.

The VCU TBIMS Family Support Program was developed to learn about the benefits of education, support, and referral for family members and survivors living in the community. The Family Support

Program was designed to teach family members and survivors about the effects of brain injury. The program will also help people locate resources in their home communities and better adjust to life after brain injury.

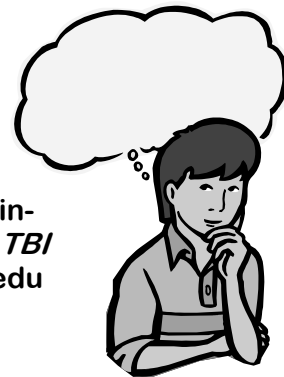
People with brain injury and one or more adult family members (or friends) can enroll in the family support program. Participants will meet regularly with rehabilitation professionals, and receive educational material and referral information. To

help us learn about the most effective ways to help families, participants will also be asked to complete surveys and questionnaires before and after they complete the program. Participants will be paid up to \$25 for being in this study. If you have questions or would like to enroll in the program, please contact:

**Laura Taylor, M.A., Coordinator
In Richmond:** 804-828-3703
Toll free: 866-296-6904
E-mail: taylorla@vcu.edu

IMAGINE...TBI TODAY UPDATES E-MAILED TO YOUR COMPUTER!

Sign up for our List Serve and receive the latest information and findings from the TBIMS. Contact *TBI Today* editor, Debbie West at ddwest@hsc.vcu.edu (804-828-8797) for information.



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