SPRING 2003

VOLUME 1 NUMBER 2

# TBI TODAY

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

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## HOW I GOT BACK TO "REAL LIFE" AFTER MY TBI

After I was hit by a car and spent five days in a coma in 1988, I had a "crash course" in learning how to survive a TBI. I thought that getting back to "Real Life" meant getting back to the way I was before my accident. It took me some time to realize that getting back to "Real Life" actually meant getting back to enjoying myself and being a happy, healthy and productive person.

I had to learn to be "normal" again, and after six months in the hospital and rehab, I had sort of forgotten what that was like. It took me a long time to get my brain and body working at a speed where I could have a regular job. I started out doing some volunteer work so that I could gain some experience with a lot less pressure. Everybody wants volunteers – museums, hospitals, nursing homes, the YMCA, animal care groups – there are thousands of opportunities. Just pick a field you like and get involved.

Besides getting you ready to work again, volunteer work gets you to spend some time around people who aren't in a hospital – something I'd forgotten all about. I ended up going to company parties and picnics, and going out for social activities with my co-workers. They introduced me to even more new people, and soon my social circle got even bigger than it had been before I was hurt.

Taking a class was another way I met a lot of people, improved my self esteem, and became more involved in the community. Classes at local community colleges are generally inexpensive, not extremely difficult, and a great way to get out of the house and around new people. There are a wide variety of courses to choose from, and it's easy to find something that interests you. I've taken courses in plant care, Spanish, and computers.

I wear a big brace on my leg and limp pretty badly sometimes, so people naturally asked questions about what had happened to me. It's tempting to talk a lot about what's happened, because in my case it was the biggest and most difficult thing that I had ever experienced. I'm sure recovering from a TBI is more difficult than law school, medical school, or anything like that. At first I wanted to open every conversation with "what happened to me." I wanted tell everyone every single detail, but I gradually learned that people only want the "Reader's Digest Condensed Version." Think about how boring it would be if people just started walking up to you and telling you the story of their lives. It's a lot easier to make good conversation by asking people about what's going on in *their* lives! Remember, you're a lot more interesting than just "some person

*(Continued on page 3 - Life Back)*

## HAVE YOU MET LAURA TAYLOR?

Laura Taylor, M.A. is the project coordinator of family and cognitive research projects for the TBIMS. She started a fellowship in the Department of Physical Medicine and Rehabilitation at VCU in September of 2001. In addition to her research on family treatment and cognitive interventions, she also helped to write the TBIMS grant.

Before coming to Richmond, Ms. Taylor completed a pre-doctoral internship in psychology at the University of North Carolina. Areas of interest other than TBI include domestic violence, family therapy, and therapy with adolescents. She has co-authored five journal articles as well as seven publications for the National Resource Center for Traumatic Brain Injury.

Ms. Taylor graduated with honors from the University of Richmond with a BA in Psychology and a minor in Art History. She is a doctoral candidate in psychology at the University of Montana and is currently completing her doctoral dissertation on domestic violence, for which she received an American Psychological Association dissertation award.

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# RESOURCES TO THE RESCUE

## THE MILL HOUSE: A CLUBHOUSE MODEL PROGRAM FOR ADULTS WITH BRAIN INJURIES

The Mill House is an innovative vocational rehabilitation program for people with brain injuries who live in the Richmond metro area and surrounding counties. The program helps survivors of brain injuries to achieve greater levels of independence and productivity. By design, the program's primary goal is to help members achieve greater community integration through participation in the workforce.

Since opening in late 1999, The Mill House has developed from a small part-time program with a few members to its current state of being a full-time vocational program with a wide array of services for survivors of brain injuries. During that time, The Mill House has served nearly 125 survivors of brain injuries and currently has over 40 active members.

### WHAT IS A CLUBHOUSE?

The Mill House is a "Clubhouse Model" program. The Clubhouse model has been in existence for more than 50 years and has consistently been one of the most effective models in helping its members achieve greater levels of independence and return to work. A clubhouse is a place where people with similar experiences come together to work, learn, socialize, and support one another.

The Mill House is one of a small handful of Clubhouse programs nationwide that has been designed specifically for individuals with brain injuries. It was the first clubhouse program in Virginia for people with brain injuries. Since opening, two additional brain injury clubhouses have opened in the state.

### WHAT MAKES THE MILL HOUSE SPECIAL?

The clubhouse provides an opportunity for individuals who have an acquired brain injury to come together as "members", not "clients", or "patients". Members are involved in all aspects of the program's daily operations, from managing the upkeep and cleanliness of the facility to helping plan and coordinate fundraising activities. As members work side by side with staff to run the program, they improve work skills/behaviors, develop confidence, establish supportive relationships, improve endurance and begin to realize that they can return to work.

### CORE SERVICES OF THE MILL HOUSE

Members of The Mill House have access to all of the following services:

☑ Day Clubhouse / Vocational Program (participation in a structured work-ordered day)

☑ Case Management Services (service coordination, linking, and referral)

☑ Employee Development / Work Adjustment Training (formal 30-90 day work evaluation program)

☑ Community Volunteer Program (e.g. Meals on Wheels, Lewis Ginter Botanical Gardens, Henrico Humane Society)

☑ Evening and Weekend Social Program (member directed social / recreational activities)

☑ Job Club (weekly club that addresses a variety of issues necessary to achieve and sustain employment in the community)

☑ Access to Supported Employment (competitive employment with intensive, on-site, and ongoing supports)

### HOW CAN I FIND OUT MORE?

If you would like more information on the program, would like to set up a time to visit the program, or are interested in becoming a member, please contact **Jason Young**, Program Manager, at (804) 261-7050.

Contributed by ***Jason Young***

## 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.**

## 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.***

*(Life Back – continued from page 1)*

who hurt their head." Treating people the way you'd like them to treat you is a sure fire recipe for having a lot of good friends around all the time.

As I recovered, I didn't get better every single day, and it took me a long time to get used to that. Sometimes things would be going along great for several days, and I'd think I was headed in the right direction. Then I'd have a setback – a seizure, or I'd lock my keys in my car while it was running, lose my wallet, all kinds of stuff. But I've found one quality I have in common with a lot of other successful survivors of TBI's – I'm stubborn or, as I like to put it "Hard Headed"! I'm amazed at the amount of successful TBI survivors who are "hard headed." I guess that's how we survived in the first place! Being hard headed and stubborn and successful means moving on after you have those setbacks, especially when it seems like the setbacks happen more often than the progress.

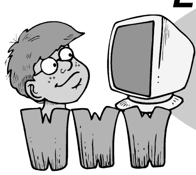
Don't forget – if you sound and appear happy, people will treat you like you're happy, and you'll just get happier. Keep smiling, keep working hard, and keep treating people the way you'd like them to treat you – and you'll be back to "real life" before you know it.

Contributed by
***Jay McLaughlin***

## DEPRESSION DIAGNOSIS PROJECT

VCU's TBI Model System includes a research project to better understand how to measure depression after brain injury. Depression can be a big problem for people after brain injury and understanding how to diagnose depression for persons with brain injury can be hard to do. Participants for this study do **not** need to feel depressed to be included. Participants do need to have had a brain injury within the last 4 months and be at least 18 years old.

If you have questions about the project or would like to be involved, please call Jenny Marwitz at: (804) 828-3704 or toll free (866) 296-6904, or email her at 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.

## JUST FOR FUN!

Can you find the words below hidden in the puzzle? The word list was inspired by the content in this TBI Today issue. Words may lie across a row, down a column or diagonal. There are no backwards words.

**BIAV**
**BRUCE**
**CHAT**
**FAQ**
**LIFE**
**MCCOY**
**MILLHOUSE**
**MODEL**
**PAT**
**REAL**
**RESOURCES**
**SYSTEM**
**TBI**
**TODAY**
**VIRGINIA**

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| E | H | L | K | G | B | W | L | I | M |
| Y | B | H | X | V | I | X | Q | H | D |
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Need a hand? Answers are shown on the back page.

# JUST THE FREQUENTLY ASKED QUESTIONS

**Question**: How long do the effects of brain injury last?

**Answer**: This depends on a number of factors. In cases of a concussion injury, most people will return to their pre-injury levels of functioning within a period of weeks to months. However, some people experience longer lasting effects of up to a year or more. In some cases, concussion injuries have effects that last years or can even be permanent. With more serious cases of brain injury involving loss of consciousness, the effects are more likely to be long lasting and require rehabilitation. Some studies of brain injury have found a substantial number of people with ongoing problems related to attention, memory, diminished stress tolerance and fatigue up to 15 to 20 years after their injury.

**Question**: Is there a "typical" course of recovery for people with traumatic brain injuries?

**Answer**: There is no typical course of recovery from traumatic brain injury since brain injury affects each person in a unique way. After all, we start out as individuals, and even after the injury, we are *still* individuals. In general, a person achieves the most dramatic recovery during the first year after the brain injury, but improvement can continue to occur over the next several years. Recovery is not necessarily a smooth process. Sometimes people stop getting better for a time (plateau) and then make progress again.

There are two types of recovery that need to occur after brain injury, physical recovery and emotional recovery. Physical recovery means getting the body to work right, and emotional recovery means feeling good about yourself and your life again. The physical healing of brain tissue usually occurs faster than emotional recovery, but eventually tapers off. After that, the door remains wide open for personal growth.

**Question**: Is there anything a person can do to extend the recovery process?

**Answer**: Intensive rehabilitation services can greatly enhance one's improvement, but these services don't last forever. After intensive rehabilitation services end, there are many other things survivors and their families can do to extend the recovery process. Here are a few ideas to consider –

- Participate in appropriate therapeutic activities and follow doctors' recommendations.
- Embrace a healthy, active lifestyle – give up smoking, drinking, and using drugs; exercise; eat right; and try to get enough rest.
- Keep working to learn and develop more effective ways of doing things.
- Set goals, monitor progress, and stick with plans that work.
- See what works for other people and what doesn't.
- Learn how and when to ask for help.
- Listen to other people's ideas.
- Consider constructive feedback from family and friends.
- Stop doing things that don't work.

Remember, the key to recovery is for the survivor to strive for continuous improvement and to learn from their mistakes.

***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.***

# CHATWITH 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 husband suffered a serious brain injury at work 5 years ago. He was hit in the head by a piece of large equipment. It was almost a year before he was able to walk on his own, again. He now uses a cane and walks slowly. In fact, everything he does seems slowed down. He doesn't think as fast as he used to. It takes him a long time to say what's on his mind. I can tell it makes him frustrated and sad. In short, he's a lot different than he was before the accident. We've lost many friends because of all this. Family doesn't come to visit as often. Strangers even stare at him when we go out together. People can be so insensitive. It makes me mad that people treat him differently. I think they must assume he's stupid. I wish people would understand that he's had a brain injury. Is there anything I can do to make this better?

*Socially Stigmatized*

**PAT'S RESPONSE:** The situation you are describing is all too common for those who survive a serious brain injury. People can often be inconsiderate of others' needs, even when they are dealing with family members or close friends. To reduce the impact of false assumptions and negative judgments, it might be helpful to consider some reasons *why* stereotypes are formed in the first place.

1) Stereotypes, social stigma, and labeling others are caused by a *lack* of accurate information about individuals.
2) Stigma develops out of others' faulty thinking and biases.
3) Labeling people based on group traits is a short-cut to getting to know someone as an individual.

Pat suggests that you start with your immediate social group when it comes to improving their tolerance and understanding. Knowing someone on a personal level can reduce others' faulty

*(Continued on page 5)*

*(Continued from page 4)*

thinking and biases about that person. To help others feel more comfortable, you could try encouraging friends and family to ask questions about your husband's injury. Anxiety about upsetting you or your husband may have kept them from asking questions about his injury and recovery in the past. Inviting open discussion lets others know you are comfortable talking with them about their concerns and worries. Helping people feel at ease around someone considered as "different" tends to decrease others' fear and future avoidance.

If all else fails, try to see the ignorance of other people for what it really is –- ***Their problem***. Surround yourself with knowledgeable, understanding people that not only tolerate, but also appreciate differences (and similarities) among all of us. For example, you may want to check out a local support group for survivors of brain injury and their families. The Brain Injury Association of Virginia (BIAV) sponsors groups for people to meet other folks with similar experiences and needs. In the Richmond area, the BIAV group meets on the 1st and 3rd Monday of every month in the Auditorium at Children's Hospital (2924 Brook Road) at 6:00 p.m. The first monthly meeting has two separate groups, one for survivors and one for family members. BIAV may be contacted at (804) 355-5748 to learn about other support groups in your area. You can also find a list of support groups for survivors of brain injury and their families in this newsletter. [*Note: see pages 2 and 3*]

THE INFORMATION PROVIDED IN THE FAQ AND CHAT WITH PAT 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.

# UPCOMING EVENTS

## FIRST FRIDAY OF EACH MONTH (6:00 — 9:00 p.m.)

**Event:** T.G.I.F

**Location:** Typically at Belmont Recreation Center, 1600 Hilliard Rd. in the Lakeside area of Henrico Co.

**Description:** Henrico, Hanover, and Chesterfield County Departments of Parks and Recreation host monthly social events for adult survivors of brain injury

**Contact:** Call 501-7489 for more information.

## APRIL 21, 2003 (Monday, 6:00 p.m.)

**Event:** Speaker Meeting of the Richmond Chapter of the BIAV

**Location:** Children's Hospital, 2924 Brook Rd.

**Description:** Dr. Mark Bender, Ph.D., speak on "Dealing with Substance Use After Brain Injury"

**Contact:** BIAV at 355-5748 for more information

## APRIL 25-26, 2003

**Event:** *The 2nd Annual Brain Injury Conference for Southwestern VA*

**Location:** Heth Center at Radford University in Radford, Virginia

**Description:** 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

**Contact:** call 540-343-5339 or email sandywillis50@hotmail.com.

## MAY 19, 2003 (Monday, 6:00 p.m.)

**Event:** Speaker Meeting of the Richmond Chapter of the BIAV

**Location:** Children's Hospital, 2924 Brook Rd.

**Description:** A representative from VCU's Rehabilitation Research and Training Center (RRTC) will present on the topic: "Supported Employment and Back-To-Work Issues."

**Contact:** BIAV at 355-5748 for more information

## JUNE 6-8, 2003

**Event:** *27th Annual Williamsburg Conference on Traumatic Brain Injury Rehabilitation*

**Location:** Williamsburg Marriott Hotel

**Description:** Nationally recognized experts will provide information on clinical and research innovations in the field of TBI

**Contact:** Carole Hettema at 804-828-5416 or VCU Office of Continuing Medical Education, Box 980048, Richmond, VA 23298.

## JUNE 16, 2003 (Monday, 6:00 p.m.)

**Event:** Speaker Meeting of the Richmond Chapter of the BIAV

**Location:** Children's Hospital, 2924 Brook Rd.

**Description:** Dr. Michael Martelli, Ph.D., speaks on "Controlling Yourself in a Chaotic World"

**Contact:** BIAV at 355-5748 for more information

## JULY 21, 2003 (Monday, 6:00 p.m.)

**Event:** Speaker Meeting of the Richmond Chapter of the BIAV

**Location:** Children's Hospital, 2924 Brook Rd.

**Description:** Joanne Marcus speaks on "Community Trust Funds"

**Contact:** BIAV at 355-5748 for more information

## SEPTEMBER 20, 2003

**Event:** Brain Injury Association of Virginia's 3rd Annual Conference: "Opening Doors: New Answers for a New Era"

**Location:** Holiday Inn Select, Koger South Conference Center

**Description:** For survivors, family, friends, and professionals to learn more about brain injury, its consequences and coping strategies

**Contact:** BIAV at 355-5748 for more information

# A FAMILY PERSPECTIVE ON LIVING WITH TRAUMATIC BRAIN INJURY:

# An Interview with Rosemary Rawlins

**Interviewer:** Thank you for agreeing to talk with us about brain injury, changes, and family life for the TBI Today newsletter. Tell us please, how much did your lives change after your husband's injury?

**Mrs. Rawlins:** The influence of TBI on a family is enormous. We are a close family with a fairly non-descript life - good marriage, twin teenage girls and two working parents. Hugh's traumatic brain injury literally redefined our entire existence in one second flat. The landscape of our lives, our roles in the family, and even the way we structure our day, has all been altered. In fact, the only thing that is for certain seems to be uncertainty itself.

> **In fact, the only thing that is for certain seems to be uncertainty itself.**

**Interviewer:** Tell us a little about your husband's injury, especially the first few days and weeks afterward.

**Mrs. Rawlins:** On April 13th last year, my husband of 25 years was hit by a car while riding his bicycle. A seasoned athlete, he had worn a helmet. He was rushed to MCV via rescue squad where he had the finest medical care he could receive. From a physical standpoint, his recovery has been remarkable. He has endured and overcome the loss of his left side as well as multiple cognitive problems. The first three months were very challenging due to his bone flap operation, removal of part of his skull to allow brain swelling to recede. He had a soft spot on his head and had to wear a helmet and gait belt – a strap we had to hold on to so he would not lose his balance and hit his head. During this time his memory was seriously impaired. He spent just over a month in the hospital and on his last day there, when a doctor asked him, "Mr. Rawlins, do you know where you are?" he answered with a quizzical look, "In a government building?"

**Interviewer:** What were things like when your husband first came home from the hospital?

## CAMP BRUCE MCCOY

This spring marks the 20th anniversary for BIAV's Camp Bruce McCoy. This residential camp, held in Chesapeake, offers adult survivors an opportunity to participate in a variety of typical "camp" activities. There are two one week sessions (May 18 - 24 and May 25 - 31). This is also a wonderful opportunity for students in a wide range of educational programs (O.T., T.R., Nursing, pre-med, P. T. etc.) to get invaluable experience working with survivors and learn about brain injury. To get an application for camp or to find out more about staff positions, please call (804) 355-5748.

**Mrs. Rawlins:** Hugh required the care of a night sitter so my daughters and I could sleep a few hours without worrying that he would wander, fall or leave the house. This expense was not covered by our insurance. He slowly improved through extensive full day rehabilitation at HealthSouth in all therapies: occupational, physical, psychological, speech and group therapies. As he recovered and improved, we celebrated. We constantly looked for signs of the man we used to live with. He was elusive. He would appear, then slide back into a staring zombie state. He would smile his old smile, then quickly fade and fall asleep frighteningly fast. We knew he was in there and slowly coaxed him out with lots of affection and loving care. Each familiar encounter was precious to us.

> **We knew he was in there and slowly coaxed him out with lots of affection and loving care. Each familiar encounter was precious to us.**

**Interviewer:** A lot of people say that brain injury affects family life especially in terms of relationships between parents and children. Do you think that's true?

**Mrs. Rawlins:** We have gone from a family of two fit parents to one disabled parent and one weakened parent (due to exhaustion and stress). Our children have had to grow up fast. Their needs, once the central issue in our family, have been put aside or on the back burner at times. Their father's needs took over. His appointments, treatments, and progress became the focus of everyday life for many months.

**Interviewer:** Have your children changed?

**Mrs. Rawlins:** My teenage girls have vacillated between being children and adults; they have learned to take charge and make decisions. They have looked outside themselves and into the lives of their parents, seeing them as people rather than just parental figures. Their foundation has been rocked but not cracked.

**Interviewer:** As a wife, how has the injury affected you?

**Mrs. Rawlins:** I have changed. At times I feel a thousand times stronger and other times twenty years older than my 46 years. I have learned the life lessons that come with the near finality of death. I have experienced the frustration of bureaucracy at it's worst (dealing with insurance companies). I have spent entire days pressing "1" for English and "0" to speak to a representative, just to get the services my husband needs. I have lost untold hours of sleep worrying about the future and how we will pay for it all. But, I have also experienced the wonder of a life returning from the brink, the newness of an old love, the kindness of strangers, and the incredible goodness in most people.

> **...I have also experienced the wonder of a life returning from the brink, the newness of an old love, the kindness of strangers, and the incredible goodness in most people.**

*(Continued on page 7)*

*(Continued from page 6)*

**Interviewer:** A good amount of time has passed since your husband was in the hospital. What's life like for him now?

**Mrs. Rawlins:** My husband has lost his job and is on long-term disability. He cannot participate in the sports he once loved, cycling or skiing, they pose too high a risk for him. His stamina is much less than it used to be. He is on several medications and requires lots of rest. He has lost his right to drive a car due to TBI complications. Most of the things that once defined him are not options for him anymore. He has had to virtually retrain himself and remake his life over. He fights depression and tries not to become obsessed with these losses. We both struggle with how to arrange our lives to make them work.

**Interviewer:** You mentioned concerns about the future during one of our earlier conversations. Could you please explain?

**Mrs. Rawlins:** We have a diminished sense of security. We have found first hand that serious accidents can and do happen, and that brings with it an element of worry and apprehension in many situations that did not exist in our imaginations before. Brain injury is a rolling tumbleweed of trouble. First you think it's a physical injury that will just heal. Slowly you realize it's so much larger and more complicated than that. Changed personality, speech, balance, vision, thinking, memory, comprehension, can all become problems that persist. Just last week, ten months after his injury, my husband suffered his first seizure while working out at the gym. It totally took us by surprise and forced us to confront the fact that new challenges would arise from this one injury, possibly for years to come.

**Brain injury is a rolling tumbleweed of trouble. First you think it's a physical injury that will just heal. Slowly you realize it's so much larger and more complicated than that.**

**Interviewer:** What about your family has helped you adjust?

**Mrs. Rawlins:** We are not a family who hides their feelings and that has helped us. We express ourselves to each other and can help each other as we go along. We seem to take turns picking each other up with a hug or a pep talk. We all try to rally around Hugh so he does not get depressed. We know the better he feels, the better we all feel.

**We know the better he feels, the better we all feel.**

**Interviewer:** Can you summarize for us now and tell us how your lives have been affected?

**Mrs. Rawlins:** How have our lives been affected? In all ways. It affects personal dynamics, friendships, and feelings of self-esteem due to forced dependency. It affects jobs, income levels, and expenses. It introduces possible legal action and the stress related to that. It requires constant treatment, medication and the management of insurance policies. It dumps stress by the truckload on the caretaker and the inflicted. It requires time and patience, and who has that when you have all of the above?

**Interviewer:** You sound like someone who's learned a lot from a difficult experience. Have you thought about what you'd tell other families going through the same thing?

**Mrs. Rawlins:** Our old lives clearly do not work now. Long hours in a demanding job are not an option for my husband anymore. Perhaps the true essence of what we were meant to do will now reveal itself to us. Rather than tying ourselves to past routines, we can explore new possibilities. We are both looking in new directions. We continue to rely on the medical community that embraced us and our family and friends. Without a network of people to help, listen, and pull us out from under the blanket of despair every now and then, we would not have done this well.

**Without a network of people to help, listen, and pull us out from under the blanket of despair every now and then, we would not have done this well.**

**Interviewer:** Have you found it hard at times to have hope?

**Mrs. Rawlins:** We keep facing new problems but we are able to work through them and still have good times. It all boils down to persistence and the determination to keep saying, "I can do anything for one hour, one day, one week, one month, one year…" It is hard, it's very hard, but it's doable. We just have to believe there are better days to come and hope, that maybe, they will be the best days of all.

**We just have to believe there are better days to come and hope, that maybe, they will be the best days of all.**

**Interviewer:** Thank you so much for sharing your experiences. I'm hopeful that what you've said will make it easier for others.

*This interview was conducted by Jeff Kreutzer and Laura Taylor from the VCU TBI Model System Family Support Research Program. For more information about the program, please contact Laura at 804 828-3703,* toll free (866) 296-6904, *or email: taylorla@vcu.edu.*

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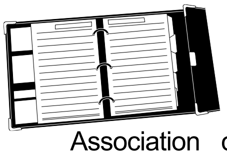

## SAVE THE DATE

The Brain Injury Association of Virginia will be hosting it's third Annual Conference: "Opening Doors: New Answers for a New Era" on Saturday, September 20, 2003. This year it will be held at the Holiday Inn Select, Koger South Conference Center. This is a one day conference for survivors, family, friends and professionals to learn more about brain injury, its consequences and coping strategies.

## DID YOU KNOW?

The Medical College of Virginia organized one of the first international conferences on traumatic brain injury rehabilitation in 1977. The conference, held June 2-4, 1977 was held at the Richmond Hyatt House. Keynote speakers included Mitchell Rosenthal, J. Douglas Miller, W. Bryan Jennett, and Donald Becker. This year, Virginia Commonwealth University's Medical College of Virginia is sponsoring the 27th annual conference in Williamsburg, June 6-8. For more information on this year's conference please contact the Office of Continuing Medical Education (804) 828-3640 or (800) 413-2872.

## BRAIN INJURY ASSOCIATION OF VA OPENS 5TH REGIONAL RESOURCE OFFICE

On February 3, 2003, BIAV expanded its presence into the Fredericksburg/Northern Neck Region. Lorraine Justice will split her time between the Fredericksburg Clubhouse and the Warsaw DRS office. The goals of Regional Resource Coordinators are to improve awareness of brain injury, work with local resources to develop, expand and enhance local services and supports, and conduct outreach and educational activities.

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