

# TBI TODAY

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

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## Parenting as a TBI Survivor: Developing a New Set of Skills

By Emilie Godwin

Laura walked into my office. She was a 40 year old mother of three young boys who was looking for information on how to make some changes in her life. One year before her visit, Laura had been involved in a very serious car accident that left her with a severe TBI. The last year had been quite difficult for her. She had worked as hard as she could to do everything the doctors had told her to do to help her recovery. But now, as she sat on my couch, tears formed in her eyes:

"It's not that I'm not trying to be a good mom. I used to be a great mom and I still give it everything I can. Somehow, though, I can't even manage to get through one day without feeling like I have let my kids down. The TBI has stolen their mommy. I don't even know who is raising who anymore."

During recovery from TBI, survivors and their families face the challenge of learning to live life in very new ways. Often, the skills and strategies that worked before the injury just don't work anymore. Families have to change as well. These changes can include learning what new post-injury relationships will be like – sons must get to know their new fathers, daughters must get to know their new mothers, and spouses must find out how they will now share the responsibility of parenting. While no family is expected to be excited about these changes, researchers have found that families who can take time out to look for and think about the good things that have happened because of the injury are the families who do the best in the long-term.

Often, before an injury parents may not have had any formal training or education in how to be the best parent possible. Most people just tried different approaches

with their children and kept the ones that worked. However, after brain injury, parents must take the time to develop an organized set of skills they can rely on. Families looking for the positives might take this opportunity to learn more about what works in parenting than they knew before.

To get started developing a post-injury set of parenting skills, survivors and caregiving partners can review these tips. Still, the most important part of change is creating a plan to use these strategies over and over again until they begin to work.

□ **Try to relax.** When you are feeling angry or frustrated with yourself or your child, remember that all parents have times when they become upset. Make a plan for these times: First, make sure your child is safe. Then, take a break, go outside, or call a friend or family member who will understand. Return to your child when you have had time to let off some steam.

□ **Develop a new attitude.** Parents, with or without brain injury, who think they have all the right answers are cheating their kids. Children who have parents who can borrow ideas from others get the best from many different minds. Write down the people you trust to help you with parenting choices and call and check in with them before making any major decisions about your kids.

□ **Create a system that will help both you and your children recognize what you are doing well.** Make a chart and hang it in the living room. EVERY time you see your child doing something well, write it on the chart. Ask them to do the same for you – when they notice you succeeding, have them write what you have done under your name. (contd on Page 2)

*Parenting...* (contd from page 1) At the end of each week, decide on something special you can do together with your children and read the list aloud to each other while you do it. This type of activity can create a house where people are on the lookout for good behavior and are encouraged by their own successes.

□ **Set aside your pride.** Look for help anywhere you can find it... parenting class at a community center, the guidance counselor at your child's school, social service agencies that provide education and information. When you show your children that you are putting a lot of effort into being a good parent, it sends a message that even though you may make new mistakes now, you love them and are trying your hardest.

The best way to feel better about yourself as a parent is to work hard at doing a good job. Do not get discouraged when you make a poor decision or have a bad day.... everyone is allowed to make mistakes. Success in life comes from looking for help and practicing new skills. Survivors who work every day to improve their parenting skills will be the ones who have the most success.

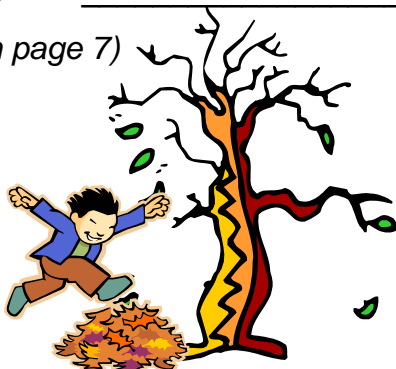
## Just For Fun!

Seasonal Word Scramble

Try to unscramble the words below. Hint: They all have to do with the Fall season!

1. WLAEHNOLE \_\_\_\_\_
2. PPUIKNM \_\_\_\_\_
3. AERNOG \_\_\_\_\_
4. YLOLEW \_\_\_\_\_
5. UMTSCOE \_\_\_\_\_
6. TOCRBOE \_\_\_\_\_
7. NUAUMT \_\_\_\_\_
8. ADYNC \_\_\_\_\_
9. ENVBOMER \_\_\_\_\_
10. EVHRAST \_\_\_\_\_
11. VLSAEE \_\_\_\_\_

(Answers on page 7)



## Mark Your Calendar!



- ◆ **Event:** Chester Christmas Parade
- ◆ **Location:** December 12, 1-5pm at the Chester YMCA, 3011 West Hundred Road, Chester, VA 23831
- ◆ **Description:** Persons with disabilities are invited to join the Therapeutic Recreation staff on a themed float in the Chester Christmas parade.
- ◆ **Contact:** Space is limited, participants must apply to be with the float. Call 751-4134 for more information!
  
- ◆ **Event:** Craft Closet
- ◆ **Location:** Once a month at Chester Library at 11800 Centre St, Chester, VA 23831.
- ◆ **Description:** Individuals 18 years and older with disabilities are invited for seasonal crafting. All supplies provided, must register at least one week prior to date. Remaining 2010 dates: Oct. 26th, Nov. 23rd, Dec. 21st. All dates from 10:15am-11:15am.
- ◆ **Contact:** Call 751-4134 for more info.

## 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 Emilie Godwin at (804) 828-3701 or toll free at (866) 296-6904.



**HAVE YOU  
MET KATY WILDER  
SCHAAF?**

Katy Wilder Schaaf, PhD is a postdoctoral fellow with the Department of Physical Medicine and Rehabilitation at Virginia Commonwealth University. She received her B.A. in Psychology and Sociology from the University of North Carolina-Chapel Hill and her M.S. in Marital and Family Therapy from the University of Maryland-College Park. In addition, she received her PhD in Counseling Psychology from Virginia Commonwealth University. She recently completed clinical internship with the Minneapolis Veterans Affairs Medical Center working with veterans in mental health and rehabilitation settings. Dr. Wilder Schaaf's research interests include the use of family systems based intervention to both improve patient outcomes and improve family/caretaker experiences within medical systems of care.

At the VCU Medical Center, Dr. Wilder Schaaf is involved in both clinical and research activities. Currently she is helping to implement interventions targeted to survivors of brain injury and their families in both outpatient and inpatient settings. She helps facilitate the Brain Injury Family Intervention (BIFI) and Brain Injury Inpatient Guide for Families and Caregivers (BIIG-FACS). In addition, she provides individual, couple, and family therapy.

Dr. Wilder Schaaf was born in Little Rock, AR, and has lived in CA, NC, MD, VA and MN. When not working, she enjoys spending time with friends and family. Her favorite activities include group exercise classes, cooking, yoga, swimming, squash, and walking her rescued hound-mix, Roy Williams, with her husband. She also enjoys travel, and has visited every state in the USA except Alaska and Vermont (which is on her list of things to do). After spending the past year in Minneapolis, Dr. Wilder Schaaf is excited to be back in Richmond with family and friends (and excited that the temperature in Richmond does not typically go below 0).



## JUST THE FREQUENTLY ASKED QUESTIONS

THE INFORMATION PROVIDED IN THE FAQ IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

**Q:** My doctor keeps telling me to stop drinking after my brain injury. What is the big deal about having a few drinks on the weekend?

**A:** There are a number of reasons why your doctor may recommend avoiding alcohol after a brain injury. Alcohol and drug use can:

- Slow the recovery process
- Increase the risk of another head injury
- Make balance, walking, and talking problems worse
- Worsen disorientation, reasoning, memory, temper, and concentration problems
- Impair judgment and decision-making abilities
- Increase the risk of family and relationship problems
- Lead to more problems, including saying and doing things without thinking that worsen your situation
- Make depression worse and cause negative personality changes
- Cause health problems
- Lead to problems at work or school
- Result in legal problems



*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](mailto:jhmarwit@vcu.edu)*





## CHAT WITH PAT

***Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not substitute 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 need your opinion! My youngest daughter, Beth, was in a car accident over the summer. She was on her way to pick up her son from daycare when an SUV struck her on the passenger side of the car. The other driver wasn't paying attention to the road and didn't see Beth making the turn. Beth smacked her head on the side of her car and felt dazed while sitting there in the car waiting for the ambulance. The ambulance took her to the hospital so the doctors could check her out. She was having a lot of pain when she got to the hospital. The doctor examined her thoroughly and told her that tests done did not show anything broken. So, he gave her some pain medications and sent her home. Beth was to take it easy for a few days.

A few days later, Beth called me for help with the kids. I knew something was wrong because she has never needed help with her children. Sure enough, when I got to her house, Beth complained that her head, neck, and shoulder hurt so bad that she decided to go see a doctor. She has not been sleeping well with all the pain. Beth has always been a healthy person. She exercises and tries to eat well. I don't even remember the last

time she went to see a doctor. Anyway, the doctor didn't really tell her anything was wrong, but gave her more medications for the pain, which she didn't like taking because of work and taking care of her children. So, she decided to go see her chiropractor. The pain got better over time with the treatments but it's still a problem for her. Beth said she has learned to deal and live with the pain.

But, the pain is not why I'm writing, Pat. I'm worried about her because she's a different person. It's been three months and Beth still has many problems that concern me. Initially, I just thought that her body needed to recover from the accident and once the pain stopped, she'd be better. Now, I'm wondering if there's something else going on. I'm helping her out more these days, so I see the changes. It takes her much longer to do things. Beth is very smart, graduated at the top of her high school class. She was very organized and took care of everything around the house. Now, she can't seem to get it together. She gets confused easily. Beth also has trouble finding the right words to use, which really frustrates her. It hurts me to see her struggle like this!

While waiting at my doctor's office the other day, I ran across an article about concussion. I couldn't believe it. The person in the article sounds like Beth! I think Beth has a concussion, what do you think? If that is the case, will she get better? How can I help her?

Sincerely,  
Concerned Mother

### Dear Concerned Mother,

It is a helpless feeling to watch your daughter struggle, not knowing what is wrong or how to help her. I am sure Beth really appreciates the support you have given her in the last few months. She could be feeling scared, too, not knowing what is going on with her.

The symptoms you have described sound like Beth did sustain a concussion in the accident. Word-finding problems, thinking slowly, disorganization due to inability to multi-task,

and feelings of frustration are common problems people with a concussion often have. Many people also struggle with memory difficulty, poor concentration, losing their train of thought, fatigue, and sleep disturbance. Many of the problems typically resolve over time on their own, while some problems persist as time goes on. Developing compensatory strategies will be important to help with the lingering problems. The recovery period varies individually, depending on severity of injury, type of injury, age, and other factors. Therefore, it is difficult to predict the course of Beth's recovery. Beth would likely benefit from seeing a physiatrist, a doctor who specializes in rehabilitation medicine, specifically one familiar with post concussive symptoms. She might also consider attending rehabilitation therapies to improve functioning and get plenty of rest to combat fatigue. Finally, I would suggest that Beth ask her treating physician about a referral for a comprehensive neuropsychological evaluation. The evaluation could give her a better overall picture of her cognitive difficulties and offer recommendations to help her get better.

Beth might want to consider finding a counselor who specializes in treating persons with brain injury and has experience working with cognitive problems following a brain injury. Changes in mood, particularly depression, is very common following a traumatic event. It is important to discuss losses and changes following the accident. (contd on Page 5)





(*Chat...* Contd from Page 4) You have described some changes in your daughter which likely have affected her mood and self-perception. Ways for you to help her include: to focus on what Beth can do instead of what she can't; be hopeful and say positive things; learn about treatments, resources, and recovery; and avoid thinking about and making comparisons to how things were.

If you wish to get involve with your local support group to share your experience, Brain Injury Association of American has a list of support groups you and your daughter 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](mailto:familyhelpline@biausa.org). The website for BIAA ([www.biausa.org](http://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 live in VA, please contact the Brain Injury Association of VA (contact info is on page 8 of this newsletter).



## Predicting Recovery Rates from Traumatic Brain Injury

By Matt Wetsel

**Welcome to the next in a series of articles summarizing research findings based on the TBI Model Systems project. Here is a brief summary of a research paper which came directly out of the Model Systems. The paper is titled, “A Multicentre Study on the Clinical Utility of Post-Traumatic Amnesia Duration in Predicting Global Outcome After Moderate-Severe Traumatic Brain Injury” (what a mouthful!). This article was published in the *Journal of Neurology, Neurosurgery, & Psychiatry* in January 2010.**

Doctors use a variety of measures to track recovery after brain injury. The Galveston Orientation and Amnesia Test (GOAT) is a test that can be used to find out the length of post-traumatic amnesia, or PTA. Someone who is experiencing PTA is not forming “new” memories on a day-to-day basis, or might just be remembering bits and pieces. They may not be oriented to things which seem obvious to others, such as the fact that they were injured, their name, or even what month it is. Doctors say a patient has “exited” PTA when they begin remembering on a continuous basis again and are oriented to their surroundings (know things like their name, date of birth, the date, and the day of the week).

The amount of time that a patient experiences PTA has proven to be a good measure of the severity of the injury. But, it's very difficult to predict how well someone will recover after an injury. Researchers from the TBI Model Systems wondered if there was an effective way to use PTA to better know how well a patient would recover.

To do this, they paired length of PTA with another measure called the Glasgow Outcome Scale (GOS). The GOS places patients into one of five categories:

- \*Deceased: patient did not survive
- \*Vegetative: patient is unresponsive; coma
- \*Severely Disabled: unable to live independently
- \*Moderately Disabled: able to live alone, but cannot work
- \*Good Recovery: able to live alone, able to work again

Rehabilitation professionals determine which category a patient belongs in based on how much help they need with caring for themselves, if they are able to return to work, and other things relating to the injury which can affect daily life.

So, VCU researchers compared the number of days a patient was in PTA to the GOS rating at one and two years post-injury. They found that the longer someone had PTA, the less likely they would be to have a “Good Recovery” and the more likely they would be to have “Moderate” or “Severe Disability.” The most important findings were that when PTA lasted *less than* four weeks, Severe Disability was unlikely and Good Recovery was the most likely by two years after injury. Similarly, when PTA lasted *more than* eight weeks, Good Recovery was highly unlikely, and Moderate to Severe Disability was very likely.

One of the most significant things that we can learn from this study is that outcomes generally did improve from one to two years after the TBI. Patients who are eager to move on with their lives and put their injury behind them are often frustrated by how slow the recovery process can be. After six months or even a year, it's easy to feel like everything should be “back to normal.” Previous studies using GOS focused only on recovery at one year post-injury and tended to be more absolute in their conclusions for overall recovery. We can see now, though, that improvements are still being made at two years post-injury for many patients.



## A Brief Guide to Brain Injury Internet Resources

By Katy Wilder Schaaf

The internet is a rich resource for anyone hoping to better understand the world of brain injury. There are many sites dedicated to providing up-to-date information about brain injury, current resources for those affected by brain injury, or creating a space for those affected by brain injury to share their story. Although information about brain injury is abundant on the internet, sometimes it is difficult to wade through these vast resources and find what you need. Below you will find a description of some of our favorite sites. Included are: 1) websites with helpful information, tools, and links, 2) blogs that help to provide understanding and hope to people affected by brain injury, and 3) social media sites dedicated to providing a forum for exchange of information and interaction.

As you explore all the internet has to offer, please remember that much of what is posted in the context of blogs and other survivor stories reflects an individual's personal experiences. These may be different from your own, but can be appreciated as they offer an idea about the variety of experiences that individual, families, and friends face when encountering brain injury.

### Websites and Blogs

[www.brainline.org](http://www.brainline.org)

BrainLine.org is a multimedia project that seeks to provide a sense of community around the issue of TBI. The site is intended for anyone who feels their life has been affected by brain injury and provides tabs that provide guidance for the user: "TBI Basics", "For People with TBI", "For Family and Friends", and "For Professionals." BrainLine.org offers information and resources about preventing, treating, and living with TBI. In addition, the site provides webcasts, an electronic newsletter, and an extensive outreach campaign in partnership with national organizations concerned about TBI.

<http://www.biausa.org>

The Brain Injury Association of America (BIAA) is a national organization dedicated to providing information and support to individuals, families, and professionals who are affected by brain injury. The BIAA website brings you helpful information regarding brain injury, but also has some unique features. Users may click on the "Policy and Legislation" tab for a weekly update on federal policy action or to join the Legislation Actions Center, an online tool for communicating with your local or national government. This website also provides a list of ongoing brain injury studies needing participants under the "Research" tab, and reports on the perspectives of survivors, family, and friends affected by brain injury with the "Living with Brain Injury" tab.

<http://tbisurvivorsnetwork.ning.com/>

The TBI survivors network is a collection of blog groups all connected by brain injury. Groups include "Parents with TBI", "TBI Book Club", "Veteran Caregivers", and various regional support groups. All are welcome to browse the blogs, but you must join in order to post your own story or comment on others' stories.

<http://www.braininjuryfamily.net/>

This website was created by a family affected by brain injury, and is intended to provide information, support, and resources to other families dealing with the same hardship. A unique feature of this website is the "Ask Marilyn" tab that allows family members (adults and children) to write to Marilyn for her advice. Marilyn will answer the questions based on her own experiences or refer to an expert if needed.

[www.nrc.pmr.vcu.edu](http://www.nrc.pmr.vcu.edu)

The TBI National Resource Center (NRC) provides practical information for persons with brain injury, their family members, and professionals. The NRC is housed at Virginia Commonwealth University and offers helpful books for purchase, as well as a large collection of "Chat with Pat" articles and over one hundred FAQ's (frequently asked questions and answers) related to TBI. You can also click on the "TBI Model System" tab to read copies of past TBI Today newsletters, fact sheets about various TBI issues, and to learn more about VCU's research.

### Social Media-Facebook Pages

#### CDC Heads Up Brain Injury Awareness

If you prefer to stay connected to resources via your facebook account, the Center for Disease Control (CDC) has a facebook page that you might want to "like." This page provides links to general information about brain injury, but also has an ongoing conversation on the wall that includes questions about brain injury, personal stories, and feedback from other internet users.



## Survivor Story: Taking a Different Approach

By Annette Danielson



On December 2, 1998 I was a busy stay-at-home mother of six children, ages 3-16. I home-schooled all six as they worked independently with me, their siblings, other home school classmates, and tutors. I was also a serious classical pianist. We had purchased a new home and were packing the house on that December day when my children and I stopped by the farm where we boarded our horse. While loading the young gelding into the horse trailer, he bolted. I was caught in the rope and dragged, causing all 4 lobes of my brain to bleed.

My life changed that day. I could not remember who my children were, how to read or walk, how to play the piano, or how to cook, how to add, subtract or multiply. My world was full of severe headaches, emotional highs and lows, and having to learn how to walk all over again.

After two years of slow recovery, my neurologist informed me that I had peaked out in recovery and not to expect much more improvement. I cried that day and said, "NO! I am not done getting better, and God is not done either!"

That same day I decided to make myself learn to play the piano again. Previously I had performed the Gershwin piano concerto in F Major with the Virginia Commonwealth University Symphony. Slowly I began relearning how to play piano with a different set of hands and brain.

There were times I would feel a "zing" in my brain, but I was not aware enough to understand that I was actually making new connections. This happened numerous times while sitting at the piano. In these moments it was as if things suddenly made sense, whether I was trying to comprehend a paragraph, multi task, or move my legs without "speaking" to them. These new connections happened after my two year peak recovery period. I never gave up and kept trying, and eventually re-learned how to do things.

It has been 12 years now and I am still improving! Singing, dancing, piano and exercise have played a tremendous role in my improvement along with God smiling on me.

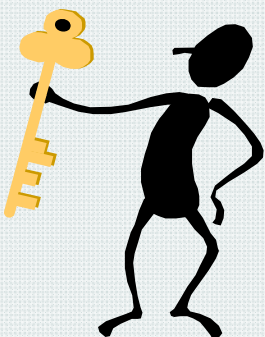
I am now the founder and director of a 501(c)3 community school of performing arts in St. Augustine, Florida. We learn who we are through these difficult seasons of life. I have discovered that I am absolutely a fighter. The very cool thing about it all is how I think completely differently than I did before the brain injury. But it doesn't matter. I can still get things done and so can other survivors, whether from stroke, TBI, or other disability. Sometimes it just takes a new approach to be able to do an old task.

My little school now goes into the community every summer and serves the children free of charge through the department of recreation and parks. We have served 500 youth each summer for the past two years. We are making new connections in their brains, and that is a good thing.

*Annette Danielson is the Founder and Director of the St. Augustine Community School of Performing Arts in St. Augustine, Florida.*

### Just For Fun Answer Key

Here are the answers in case you're stumped!



- |             |              |
|-------------|--------------|
| 11. LEAVES  | 6. OCTOBER   |
| 10. HARVEST | 5. COSTUME   |
| 9. NOVEMBER | 4. YELLOW    |
| 8. CANDY    | 3. ORANGE    |
| 7. AUTUMN   | 2. PUMPKIN   |
|             | 1. HALLOWEEN |

***Want to share your survivor story? If so, please e-mail it to [jhmarwit@vcu.edu](mailto:jhmarwit@vcu.edu) or send by mail:***

***TBI Today  
P.O. Box 980542  
Richmond, Virginia 23298***



The Brain Injury Association of Virginia (BIAV) is the only statewide non-profit organization in Virginia exclusively devoted to serving individuals with brain injury, their families, and those that care for and about them.

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

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



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

**VCU, PM&R**

**TRAUMATIC BRAIN INJURY MODEL SYSTEM**

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