



TBI TODAY

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

VCU TBI MS SCHEDULES EDUCATIONAL WORKSHOPS: GETTING BETTER AND BETTER AFTER TBI

Sign Up NOW!

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TBI Today is published by Virginia Commonwealth University's Department of Physical Medicine and Rehabilitation's Neuropsychology Service. This newsletter, is a project of the Virginia Model System, which is funded by the US Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The views, opinions, and information presented herein are those of the publisher and are not necessarily endorsed by the US Dept of Education.

Survivors and family members often face long-term difficulties after traumatic brain injury. Many people are disappointed with the pace of recovery. Some are disappointed by the lack of resources in their home communities. Many survivors and family members have questions about getting better and the types of help that can best meet their needs.

The VCU Traumatic Brain Injury Model System of Care (TBIMS) has been in place for more than 15 years. The system has excellent resources to meet the needs of survivors in the hospital. The system also has a variety of resources to help survivors get better after they leave the hospital.

To better help meet the needs of survivors and family members, the VCU TBIMS is pleased and proud to announce the scheduling of two informative workshops in 2005 for survivors, family members, and friends. The "Getting Better and Better after TBI" workshops will focus on common challenges and concerns expressed by survivors and family members. Practical information, ideas, and suggestions will be discussed by experienced rehabilitation professionals from the VCU Medical Center. Workshop participants will be encouraged to ask questions and discuss their concerns about physical and emotional recovery.

How much does registration cost and how can I register?

Registration is **FREE!** thanks to our co-sponsors. To register, or for more information, simply call 804 828-9055 and ask to speak with Mary Beth King or Jenny Marwitz. You can also email your questions to jhmarwit@vcu.edu. Please register early; seating is limited.

When and where are the workshops scheduled?

The workshops will be held in Richmond, VA on Saturdays, March 5th and May 14th at the VCU Medical Center, in the Learning Center on the first floor of the Main Hospital. Each workshop will start at 10:00AM and finish at 3:30PM.

What topics will be covered on March 5th?

- ◆ Improving Memory after Brain Injury
Dr. Jan Niemeier
- ◆ Building Relationships and Overcoming Loneliness
Dr. Jeff Kreutzer
- ◆ Riding Out the Roller Coaster: Managing Stress and Intense Emotions
Dr. Laura Taylor and Dr. Lee Livingston

What topics will be covered on May 14th?

- ◆ Strengthening Families
Dr. Jeff Kreutzer
- ◆ The Use of Prescription Medications in Recovery
Dr. Richard Kennedy
- ◆ How to Build and Keep a Positive Self-Image
Dr. Jan Niemeier

Who is sponsoring the workshops?



A partnership including Virginia Commonwealth University Medical Center, the Brain Injury Association of Virginia, and the National Resource Center for TBI.



PART I: AVOIDING GUILT AND BLAME

After injury, survivors and their families often spend time thinking about their lives and choices they have made. People think about how the injury occurred and what they can do to bring things back to where they were. Many people ask themselves difficult questions like -

- ▶ How have things turned out?
- ▶ Did I make the best choices?
- ▶ What should I have done differently?
- ▶ What mistakes did I make?
- ▶ How did things get so bad?
- ▶ What should I be doing now to make things better?

Often, people blame themselves for past mistakes. Many survivors blame themselves for getting hurt and bringing new problems on their family. Family members may feel guilty or blame themselves for not preventing the injury or doing more to bring about recovery.

Think about how you've been feeling and what you've been thinking about the injury. Check off the items in the "Guilt and Blame Checklist" that describe thoughts you may have had.

Review the items you've checked and the ones you haven't to better understand your feelings. The more items you've checked, the more likely it is that you are experiencing guilt and blaming yourself. Is there a pattern to the items you've checked? Talk with trusted family and close friends about your answers and see if others feel the same way you do.

While some people blame themselves, others blame family, friends, professionals, the health care system, other agen-

cies, or the person at fault if there was an accident. They may say things like -

- ▶ If only she had gotten better care while she was in the hospital.
- ▶ They should've kept him in that rehabilitation program longer. He could be doing much better.
- ▶ The insurance company is to blame. If they'd kept paying for physical therapy, I know he'd be walking now.
- ▶ If only the doctor would try a different medication. I know she could be doing better.
- ▶ Why don't my wife's parents help us out more? Most of this mess is their fault.

- ▶ I can't believe his boss fired him. His boss just doesn't understand how badly he needed this job.
- ▶ I can't believe the guy who caused the accident hasn't called and offered to help. It's his fault my wife got hurt. He owes us an apology and some help.

Do any of these statements sound like things you've said or heard others in your family say? Are there people or agencies you blame for your situation? You know you are in trouble when you spend much of your time thinking about what other people should have done, what they could have done, what they said, and how they've treated you. Maybe they'll apologize, but probably not.

Blaming others or yourself may seem justified, but doing so won't make things better. Know that blaming yourself or others is harmful for a number of reasons -

- ▶ Others may see you as bitter and negative.
- ▶ Focusing on blame will hurt your relationships with other people. They will be uncomfortable around you and choose to avoid you.
- ▶ Other people may not want to help you if they fear they'll be blamed later on.
- ▶ A negative attitude makes it harder to give 100% effort toward getting better

We've talked to lots of survivors and their families to find out ways they cope with feelings of guilt and the temptation to blame themselves or others. In the Spring 2005 issue of *TBI Today* we will discuss strategies for coping with feelings of guilt and blame.

GUILT AND BLAME CHECKLIST

- I have made so many mistakes.
- I have let myself and my family down.
- I should have been able to keep the injury from happening.
- Everyone else blames me for what happened.
- I can't let this happen again.
- What happened is my fault.
- Sometimes I wish I was the one who was hurt instead.
- I get blamed for everything that goes wrong.
- I should be doing more to get better.
- I should be doing more to help.

INSPIRATION POINT

A collection of leather art work created by Paul Beverly and Sandy Dyche was displayed at Resources for Independent Living in Richmond, Virginia in late November 2004. The team has been working together for over 5 years creating art out of leather.

What began as a therapy to recover from brain injury, evolved into life's work for the pair.

At the age of 12, Paul was in an automobile accident and suffered a severe brain injury. He crafted his first piece of work from leather as a teenager, a 6-inch wristband as Hercules would have worn. The wristband represented strength at a time of personal struggle. He continued to hone his craft as a young adult, creating costumes, accessories, and 3-dimensional figures. Paul's fascination with folklore and cultural icons is demonstrated in his creation of leather Vikings, pirates, and the pioneer, Daniel Boone. To quote the artist, "I make the things I love and admire, things I

remember from childhood."

Sandy was injured in a car accident in the early 1990's while a student at J. Sergeant Reynolds Community College. She described a desire to complete her studies despite the many challenges of recovering from a brain injury. The college allowed for accommodations which helped Sandy finish her courses. She listened to books on tape and was provided with class notes from other students. After completing her degree in occupational therapy, Sandy began looking for appropriate work. She was disappointed by the home health jobs she found.

When Sandy met Paul at a brain injury support group for survivors, she did not realize the course her career would take. Her interest in painting was revived and she began working with Paul making leather crafts. In 2001, the couple was commis-

sioned by the Leukemia Society to create 31 Richmond landmarks. Among their art collection, one finds a variety of work ranging from historical buildings (e.g., Byrd Theater, the Egyptian building, John Marshall House) and intricate structures to ornamental gift boxes and piggy banks. Wall sculpture, hats, bracelets, and miniature swimming pools and golf sets are examples of hundreds of pieces one will delight in viewing. "I take something (leather) and make it more pleasing to myself and to others," Paul stated. He described how his mind, and therefore his values,

had been changed by brain injury. For example, Paul noticed an increased need to be surrounded by and create things of beauty after the injury. Things of beauty are certainly their specialty. *Lee Livingston*

Do you have or know another survivor who has an inspiring story to share with our audience? We'd love to hear from you. Contact Debbie West at (804) 828-8797 or ddwest@vcu.edu.



TROLLEY



LIGHTHOUSES

HAVE YOU MET RACHEL EVERLEY?

Rachel Everley, B.S., has been a research specialist in the Department of Physical Medicine and Rehabilitation at VCU Health System since March 2004. In this position Ms. Everley primarily conducts neuropsychological assessments. She also works with the Project Coordinator for Family and Cognitive Research on two ongoing studies supported by the TBIMS. Ms. Everley is also the research assistant for the Selegiline as a Treatment for Post-Traumatic Cognitive Dysfunction Project, which is

supported by the Commonwealth Neurotrauma Initiative. She conducts neuropsychological assessments of patients enrolled in the study and meets with trauma coordinators and nurses at VCUHS to determine patient eligibility. Prior to joining the staff in this department, Rachel worked as an administrative research assistant for VCU's Family Support and Research Center.

Ms. Everley is a recent transplant from Kentucky, having moved to Richmond after receiving her bachelor's in psychology from Eastern Kentucky Univer-

sity in 2003. Ms. Everley's husband is enrolled in the Ph.D. Chemistry program at VCU, which led to their move from rural western Kentucky to the "big" city of Richmond. Rachel has applied for the Master's program in Sociology at VCU, and is currently taking a graduate course in the program. Her future plans are to pursue her doctorate in Social Psychology, assume the role of a world traveler, and learn Chinese. In her free time, Ms. Everley enjoys reading, shopping, and trying foods from different countries in preparation for her prospective travels.

JUST THE

FREQUENTLY ASKED QUESTIONS

Q: I have heard that an injury to the frontal lobe of the brain can result in major personality changes. Why does this happen? Does the injured person ever return to normal? Is there anything we can do to help?

A: Personality changes often occur after brain injury because the frontal lobe of the brain has been damaged. The frontal lobe is very involved with how we behave. Think of the frontal lobe as the conductor of an orchestra. The orchestra depends on the conductor to lead them, telling them when to start playing and when to end. Without the conductor leading all of the orchestra members, the music probably will not sound too great, even though all of the instruments are well-tuned and the musicians are skilled. The frontal lobe functions like a conductor for the brain. So, when the frontal lobe is injured, we may exhibit changes in our ability to start activities (i.e., initiation), stop activities (i.e., perseveration), switch from one activity to another, withhold overly angry responses, etc.

Personality changes may also reflect difficulty adjusting to life changes after injury. Often, people become frustrated when they have difficulty doing things they used to do with ease. They may also get frustrated if they cannot do things they used to do before the injury (e.g., drive, work, live alone). Temper problems may emerge as frustrations build.

Sometimes, people have per-

sonality issues which were there before they got hurt. These personality "traits" may get worse after the injury. It's always important to separate issues of personality "traits", adjustment issues, and "organic" personality changes that occur because of the injury. This is not an easy task and often requires help from a professional trained in identifying and diagnosing these problems (i.e., a neuropsychologist and/or neuropsychiatrist).

You asked if the injured person is likely to return to "normal." If by "normal" you mean exactly the way things were before the injury, then the answer is "usually not," although some mild and very specific or focal injuries may decrease in terms of their behavioral effects. Most survivors continue to notice changes long-term after an injury.

In terms of treatment options, sometimes medication can be helpful in reducing problematic behaviors. Many times behavioral therapies can also promote changes. Consultation with a neuropsychiatrist and/or a neuropsychologist to explore treatment options would likely be beneficial. Neuropsychological evaluation may also prove helpful as a means of identifying problems and their sources.

Questions for Pat or the FAQ column are welcomed.

**Send them to:
"ASK PAT" OR
"FAQ"**

**P.O. BOX 980542
RICHMOND, VA
23298-0542**

or e-mail:

ddwest@vcu.edu



CHAT WITH PAT

Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not substitute for consultation with a doctor or rehabilitation specialist. The identity of authors submitting questions to "Chat with Pat" will be kept strictly confidential.

DEAR PAT: My older brother, Ted, was involved in 2 car accidents several years ago. In the first accident, he was driving home from work when a truck hit his car head-on. Luckily, he was only in the hospital for one night with minor cuts and scrapes. I was worried about him because he complained of headaches, dizziness, and blurred vision for days afterwards. The following year, Ted's car was rear-ended while he was stopped at a traffic light. Again, he was discharged from the hospital rather quickly despite problems with neck pain, headaches, and nausea. Ted tried to continue working, but he lost his job several months ago. He said he feels tired all the time and had trouble concentrating on the job. His doctor told the family Ted had a "concussion injury" both times. What exactly is a concussion?

PAT'S RESPONSE: A concussion is sometimes called a mild brain injury. Mild brain injury is the most frequent kind of injury, occurring 8 out of 10 times someone has a head injury. When there is no loss of consciousness, most people return to pre-injury levels of functioning within weeks or months. Many people, however,

(Continued on page 5)

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8797** TO ADD YOUR NAME TO OUR E-MAIL LIST.

(Continued from page 4)

experience longer lasting effects of up to a year or more. In some cases, the effects of concussion may last for years. People with multiple injuries are even more vulnerable to long-lasting effects of concussion.

With more serious cases of brain injury involving lengthy periods of unconsciousness, the effects are more likely to be long-lasting and require intensive medical care. Problems with attention, memory, stress tolerance, and fatigue may last for as long as 20 years after injury for some people.

Your brother's history of re-

peated injury and lingering trouble with fatigue and distractibility are cause for concern. Ted may need additional help to get better. You should encourage him to contact his local chapter of the Brain Injury Association of America (1-800-444-6443) for a list of qualified doctors and specialists in brain injury rehabilitation. He may also wish to consider discussing concussive symptoms with his physician or get a referral for appropriate treatment. Professionals specializing in neuropsychology, neuropsychiatry, physiatry, and vocational rehabilitation are experts in helping people recover

from brain injury. Ted and your family may also wish to get information about brain injury and options for treatment from the Brain Injury Association of Virginia (804-355-5748 or 1-800-334-8443, toll-free).

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.

— BECOMING A BETTER AND BETTER TBI SURVIVOR —

Sometimes people have a hard time knowing what to work on following a brain injury. They may get lots of advice from family and friends. Success in continuing to get better depends on knowing the steps to take. Take the "What You Don't Know Can Hurt You" quiz to see if you know about the challenges you may face.

It may still be very early in your recovery. Even if it has been quite a while since your injury, it is normal for you to still have problems doing things. Survivors who have been surviving successfully in the community for many years told us some of their secrets for overcoming problems. Following are a few of their ideas for being a better and better survivor:

- ▶ *Count your blessings.*
- ▶ *Know what you can and can't do.* Ask people you trust to tell you what you are having trouble with if you are not sure. Ask your family members, doctors, friends, and therapists about which brain injury symptoms you have and what you can do to cope with these.

- ▶ *Accept your problems:* Stay open to listening to what friends, doctors, therapists, and relatives are telling you. It may be hard to accept what they are saying but it helps to

understand your problems when you are trying to get better after a brain injury.

- ▶ *Don't try to be someone else.* Everyone has a different injury and everyone heals at different rates. Just do better than you did the day before. Don't compete with someone else.

- ▶ *Have goals for improvement.* Pick things that you can really do, that are realistic. Example: If you want to improve your memory, your goal could be to remember one new name a week using a new memory strategy. A goal of recalling every new person's name in one day without any help may be unrealistic.

- ▶ *Keep on using all the strategies you have learned.* You may find some work better for you than others. Don't keep doing what doesn't work. Example: Use a memory log or day planner to help you keep track of your past and future activities and appointments.

- ▶ *Build yourself up and praise*

(Continued on page 6)

"WHAT YOU DON'T KNOW CAN HURT YOU"

Check any items below that are true about you now:

- People tell me I move or talk too fast.
- People always tell me to be more careful.
- Sometimes I snap at people I love or my friends before thinking about it.
- I forget where I am supposed to be and what I am supposed to be doing.
- I have trouble getting it together to dress, organize an activity or explain things to other people.
- I have trouble understanding what others are saying to me.
- People have trouble understanding me.
- I do things too slowly.
- I get tired all the time.
- People are just trying to make things hard for me.

(BETTER — Continued from page 5)

yourself for meeting challenges and working hard, don't get mad at yourself for not doing better. Learn from your mistakes. Don't beat yourself down when you make them.

- ▶ *Help yourself as much as you can* but don't be afraid to ask for help when you do need it.
- ▶ *Know that recovery from brain injury is a long-term process.* Progress can be slow at times.
- ▶ *Make plans and stick to them.*
- ▶ *Exercise your body and mind.*
- ▶ *Stay on top of stress.* Figure out what is causing it and do something about it. Stress

can be from outside—and we often can't control it. Tornadoes, for example, are stressful and we can do little to control them. When our stress comes from worry, or silly thoughts, we can control it. Thinking that you are worthless, for example, because you take longer to get dressed, is a silly thought that could cause stress.

- ▶ If using too much alcohol or drugs had something to do with your injury, *get help in your community to control these addictions.* Alcoholics and Narcotics Anonymous are in the local phone book. Look them up, go to meetings and recover more successfully.

- ▶ *Use the Brain Injury Association support services* in your community. The number for the Brain Injury Association of Virginia is 804-355-5748. The National Brain Injury Association number is toll free 1-800-444-6443. Find out from your doctors, social worker and therapists what other agencies and activities you might be able to go to for help.

The road to being a survivor is a life-long road. You will find supports and supporters along the way. Hopefully, these ideas for living better and better will help smooth out the road ahead.

Adapted from First Steps Towards Recovery From Brain Injury. (Niemeier & Kreutzer, 2002, 2003)

NEW STUDY BEGUN AT VCU TBI MODEL SYSTEM



Richard Kennedy, Jeff Kreutzer, and Jenny Marwitz have begun research comparing Effexor (an antidepressant also known as venlafaxine) to a placebo (sugar pill). Effexor has had good results in treating depressed people without TBI. We want to learn if Effexor works for people with TBI and if it helps them think better.

People who volunteer for this study will be asked about their depression symptoms. If the person has depression, they will be asked to take learning and memory tests and have a physical examination. Dr. Kennedy will then give the person the study pills. Every two weeks, Dr. Kennedy or one of the other doctors sees participants in the clinic. Physical health and medications are checked and some tests about depression are given. The study lasts for 12 weeks. There is no cost for being in this study, and participants receive \$55 for their time and effort.

If you are interested in the study, call Jenny Marwitz at (804) 828-3704 or toll free at (866) 296-6904, or email her at jhmarwit@vcu.edu.

ART THERAPY



Steve R. had a severe brain injury over a year ago. In an instant, the life he once knew was shattered. Steve praised his wife and family for keeping him strong. In the months following his injury, he worked hard to learn how to do things many people may take for granted. According to Steve, "It's hardest to learn something you *should* know." He had a lot of pain and trouble remembering his past.

Depressed and worried, he felt he had to "fight" not to lose himself. Steve started making copies of pictures for mental exercise. He would cut pictures out of books and magazines and work on them using his home computer. Over and over again, he practiced working with the images. In great humor, he described his art as a "tribute to OCD (obsessive-compulsive disorder)." Steve further stated, "It helps me get joy and happiness through art because I turn what cripples me into something good."

Steve believes creating art can help all people with trauma, not just people with TBI. Wanting to encourage others, he submitted his artistic creations to a local art show in Richmond, Virginia and won 2 first place awards. The work of Steve and other artists with disabilities will be featured at a number of exhibitions at Art Works, Inc. in the upcoming months.

Contributed by Lee Livingston

JUST FOR FUN!

Just how much do you know about that brain of yours? Just for fun, take this little "quiz" and guess which of these facts are true (T) and which are false (F). The answers (page 8) might surprise you!

- | | | |
|--|---|---|
| 1. Three pounds is the average weight of the human brain. | T | F |
| 2. Information travels in the nerves at speeds up to 26 miles per hour. | T | F |
| 3. The average human brain has 100 billion neurons. | T | F |
| 4. The heaviest human brain weight ever recorded was 5 pounds, 1.1 ounces. | T | F |
| 5. People who average 8 hours of sleep daily, sleep 122 days per year. | T | F |
| 6. The brain weighs about 5% of the body's total weight but uses more than 20% of the body's blood to survive. | T | F |
| 7. There are nearly 3 hundred miles of axons in the human brain. | T | F |
| 8. There are over 1,000 disorders of the brain and nervous system. | T | F |
| 9. Six muscles are involved in moving each of our eyeballs. | T | F |
| 10. The pons is the outermost covering of the brain. | T | F |
| 11. The word "cerebellum" is taken from a Latin word meaning "little thought." | T | F |
| 12. During the first year of life, the brain triples in weight from 300 grams to 900 grams. | T | F |
| 13. More than 50,000 auto accidents each year are blamed on sleepiness. | T | F |
| 14. Centuries ago people thought that the heart, not the brain, was important for memory. | T | F |
| 15. The right side of the brain controls movement in the left side of the body, and the left side of the body brain controls movement on the right side of the body. | T | F |
| 16. Seven out of ten people are right handed. | T | F |
| 17. Each year about 600,000 people have a stroke, and 25% die from it. | T | F |
| 18. About 4 million people living in the US have Alzheimer's, a disease of the brain. | T | F |
| 19. The first lobotomy in the United states was performed in 1836 by Walter Freeman. | T | F |
| 20. The adult human brain in about 12% of total body weight. | T | F |

MARK YOUR CALENDARS

FIRST FRIDAY OF EACH MONTH

(6:00 — 9:00 PM)

Event: T.G.I.F

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

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

Contact: Call (804) 501-7489 for more information.

MARCH 5, 2005

Event: Getting Better and Better After TBI

Location: VCU MC, Richmond, VA

Description: Workshops for TBI survivors and their families addressing important information for enhancing recovery. Topics include improving memory, relationship building, and stress management.

Contact: Call (804) 828-9055 or email jhmarwit@vcu.edu to register or for more information.

MARCH 29-30, 2005

Event: Fourth Annual Transcending Brain Injury Conference for Southwest Virginia

Location: Holiday Inn/Tanglewood, Roanoke, VA

Description: Topics, geared to help TBI survivors & offer useful information to caregivers & health professionals, include: coping with brain injury, access to services, & treatment strategies.

Speakers include Dr. Jeff Barth, Dr. Don Kees, Dr. Paul Aravich & author Cathy Crimmins (keynote speaker). CEUs available.

Contact: To register or learn more visit www.radford.edu/~conf-serv or call (540) 831-5800.

MAY 14, 2005

Event: Getting Better and Better After TBI

Location: VCU MC, Richmond, VA

Description: Workshops for TBI survivors and their families addressing important information for enhancing recovery. Topics include strengthening families, use of prescription medications in recovery, and building a positive self image.

Contact: Call (804) 828-9055 or email jhmarwit@vcu.edu to register or for more information.

JUNE 9—10, 2005

Event: 2005 Williamsburg Conference— Rehabilitation of the Adult and Child with Brain Injury

Location: Williamsburg, VA

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

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

Research Volunteers Needed

VCU Traumatic Brain Injury Outpatient Rehabilitation Services Program

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

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

**For more information about the program, please
call Laura Taylor at 804-828-3703 or toll free
866-296-6904 or by email at taylorla@vcu.edu.**

JUST FOR FUN

1. True
2. False. Information travels in the nerves at speeds up to 260 miles per hour.
3. True
4. True
5. True
6. True
7. False. There are nearly 3 million miles of axons in the human brain.
8. True
9. True
10. False. The *dura mater* is the outermost covering of the brain.
11. False. The word "cerebellum" is taken from a Latin word meaning "little brain."
12. True
13. True
14. True
15. True
16. False. **Nine** out of ten people are right handed.
17. True
18. True
19. False. The first lobotomy in the United states was performed in 1936 by Walter Freeman.
20. False. The adult human brain is about 2% of total body weight.

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