

TBI Updates

TRAUMATIC BRAIN INJURY MODEL SYSTEM
UNIVERSITY OF WASHINGTON
DEPARTMENT OF REHABILITATION MEDICINE



Volume 3

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Notes from a Survivor: Recovery at Home, Part III

By Stacy Rosevear

After 72 days in hospitals, I returned to our little apartment with a wheelchair, walker, a couple of tubes still in my body, a relieved spouse and some difficult days ahead.

Months of several Physical, Occupational, Speech Therapy, and doctor appointments each week finally turned into bi-weekly, monthly, and finally, occasional visits. But here's the funny part: at first I looked forward to going because it was a safe place, I had encouragement and people knew my history and how far I'd come. Transitioning home proved more difficult than my spouse or I thought. Eventually, traveling to these appointments by bus on my own with the help of a cane was a huge step forward. But I'm getting ahead of myself.

I'm convinced that daily decisions to keep fighting, struggling and working toward more movement stayed next to impossible. Depression overwhelmed me early on. I sought help, finally, after my stubbornness wore down and my loved ones begged me to get assistance. I

regret I waited so long. Medication and weekly counseling continue to this day.

While recovery for those first six months was quick, recovery continues. The work continues, the improvements still tangible. Absolutely everything is therapy: getting out of bed, dressing myself, cooking meals, showering, taking my medicine, getting enough sleep, figuring out transportation, leaving energy for relationships and getting fulfillment out of something of my choosing, folding laundry and practicing my penmanship. Daily life is recovery. Many times I think about how easy it would have been to sit in a corner of my apartment and not venture out in public or take some physical and vocational risks.
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Who's Who



Leslie Kempthorne

Leslie Kempthorne has a B.S. in Biology and a B.A. in Psychology. She has worked with the TBI Model System since 2000, and spent the first two of those years doing enrollment and consenting at Harborview Medical Center. She currently handles the telephone follow-up calls for the study and hopes you enjoy talking with her!

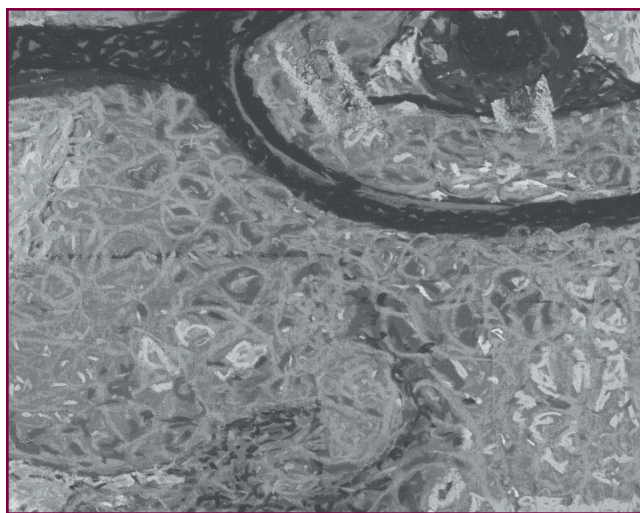
Previous to working with the TBI Model System Study, Leslie worked in a microbiology lab at the University of Washington doing research on white blood cells. She also has many years experience as a coordinator for a homeless youth shelter, as well as working with people with AIDS, and the needle exchange program. Her interests include traveling to foreign lands, politics and her son Max, now 3 years old.

Beyond the Injury continued...

Truly, though, if I had chosen that, I would not be where I am today.

There are still things I have to do differently. I have to prepare for the occasional incontinence incident. I have to take anti-depressants or I'm hard to live with, hard to reason with. I have to keep my doctor appointments. I have to switch hands or take a rest when my hand starts shaking. I have to be careful not to fall when I am walking. I have to let people help me while balancing my sense of independence. I absolutely must get enough sleep, with the assistance of medication. I set routines that felt silly at first but keeping them makes me feel responsible. I have to write articles like this. And I must remember this journey.

Please stayed tuned for the last installment of this 4-part series...



Please look carefully at artwork
"Eye (Self-Portrait III)
Soft pastel on Wallis Archival
15x15
Stacy Rosevear, Summer 2005
stacy@yo-yodyne.com

Want to Work But Worried About Losing Your Medical Benefits?

If you have been afraid of pursuing your career goals for fear of losing your health coverage, this program may be perfect for you. The Healthcare for Workers with Disabilities (HWD) program recognizes the employment potential of people with disabilities, and represents Washington State's response to the "Ticket to Work" legislation passed by Congress in 1999.

Under HWD, people with disabilities can earn more money and purchase healthcare coverage for an amount based on a sliding income scale.

HWD benefits include:

- Medicaid benefit package
- Greater personal and financial independence
- Members earn and save more without the risk of losing their healthcare coverage

Who qualifies for HWD? Washington residents who

- Are age 16 through 64
- Meet federal disability requirements
- Are employed (including self-employment) full or part time
- Have monthly income at or below 220% the federal poverty level, approximately \$1755 for one person, \$2353 for two

What does it cost? Your monthly premium is based on a sliding scale. It cannot be more than 7.5% of your total income - but it can be less!

To apply for HWD, call toll free the number below, according to where you live in the state:

Region 1: 1-866-865-6150 Counties: Adams, Asotin, Chelan, Douglas, Ferry, Garfield, Grant, Lincoln, Okanogan, Pend Oreille, Spokane, Stevens, and Whitman.

Region 2: 1-877-980-9140 Counties: Benton, Columbia, Franklin, Kittitas, Walla Walla, and Yakima.

Region 3: 1-800-827-1808 or 425-438-4973 Counties: Island, San Juan, Skagit, Snohomish, and Whatcom.

Region 4: 206-272-2169 County: King.

Region 5: 1-866-755-4834 or 253-476-7300 Counties: Kitsap and Pierce.

Region 6: 1-800-960-5456 Counties: Clallam, Clark, Cowlitz, Grays Harbor, Jefferson, Klickitat, Lewis, Mason, Pacific, Skamania, Thurston, and Wahkiakum.

For more detailed information about how working will effect your Social Security income and other government benefits, contact a Benefits Planner who can provide individualized assistance to help you plan to work:

Positive Solutions

- King County (206) 322-8181
- Kitsap County (360) 405-0620

Plan to Work (counties other than King or Kitsap)

- 1-866-497-9443 Voice toll-free

Research Volunteers Needed UW TBIMS Faculty Awarded

The Effect of Community-Based Exercise on Symptoms of Depression in Persons with TBI study is examining the effects of aerobic exercise on depression and anxiety in persons who have had a mild to moderate TBI in the previous 6 months - 5 years. The study offers a supervised 10-week exercise program to participants along with education and motivational components. If you are interested in participating in the study, or for more information, contact Nadya at 206-685-8354.

At the American Society of Neurorehabilitation and the American Congress of Rehabilitation Medicine conference, Dr. Jeanne Hoffman was awarded the Fletcher-McDowell Award for Best Clinical Science Poster. Dr. Hoffman presented on the correlates and predictors of pain one year after TBI. Briefly, she found that almost half of the participants reported some level of pain at one year, with pain reports associated with being female, having lower function, and being more depressed. Additionally, post-injury depression significantly predicted higher level of pain reports.

TBI Web Resources from a Survivor's Perspective

Kelly Gilliam

The last (verbal) advice I received as a Harborview Medical Center patient was to check out Traumatic Brain Injury (TBI) websites after returning home to my somewhat normal routine. This advice, given to me by my speech pathologist, Deanna Britton, stuck in my mind! And like many TBI survivors will agree on, it takes us a bit of time to get readjusted back into our pre-injury lifestyle. So, for starters, I used my discharge instructions as a resource.

One of the recommendations listed on the discharge sheet was to attend a TBI survivor group meeting in my home town. So I did just that. Although, I did not feel the desire nor need to attend a support group, I thought it important to start checking out resources that would meet my needs. The meeting was a worth-while interaction with nine other TBI survivors. However, being that every TBI survivor's brain/personality is unique, support groups work for some people and sometimes not for others. I felt the desire then to put Deanna Britton's advice into practice.

Typing "Traumatic Brain Injury" into the www.google.com "search" box is like opening up a can of worms. There are over 1 million websites affiliated with TBI. Have I checked out every website? Definitely not, but I have found a few that I really enjoy logging onto: www.tbindc.org, which stands for the TBI National Data Center, www.neurologychannel.com/tbi, www.biausa.org, which stands for

Brain Injury Association of United States, and <http://depts.washington.edu/rehab/tbi.index.html>, University of Washington's site.

The internet website resources above have been quite beneficial for me, especially during my first year of recovery. The reason why I have often stated that Deanna's advice was like opening a can of worms was because the above websites educated my mind on what exactly TBI is. I had never heard "TBI" before my mountain bike accident. The websites contain many similarities such as FAQ's (frequently asked questions), symptoms, effects of TBI, history (1.5 million people sustain a TBI each year), etc.

The information found on the websites has had a great effect on my recovery. By acquiring the facts, this allowed me to become aware of what could happen as a result of TBI (fatigue, migraines, mood swings, short-term memory, etc). As a result, I learned how to compensate and avoid those deficits by following some great tips (i.e. cross word puzzles, 8 hours of sleep, and regular exercise).

What I, a TBI survivor, would recommend to other survivors is to search many resources to find what fits your needs (i.e. the web sites listed above in addition to support groups). Every brain and personality is different so what works for one person may not work for another.

If you would like to receive this newsletter by email contact us at:

uwtbi@u.washington.edu

Or visit our website at:

www.depts.washington.edu/rehab/tbi/