# Updates

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

#### Volume 3



Number 2

## Notes from a Survivor: Beyond the Injury By Stacey Rosevear

My name is Stacy. I'm an artist, spouse, daughter, friend, an activist and an advocate. I'm a brain injury survivor: a stroke survivor. I'm 32 years old. On September 16, 2000 my life changed suddenly as did my family's.

I was 27 years old. Active, newly married, living in Seattle, working full time, paying off student loans. One of the questions asked in the ER the day I had a stroke was, "have you had any injuries lately?" Three weeks earlier I had been playing tennis, made an aggressive jump at the net, and felt immediate pain in my neck when I landed. At 27, one thinks it's muscular. I bought a heating pad and wore it at work for a week. The pain subsided eventually. I didn't pay attention to the frequent headaches in the following weeks and mark them as "unusual."

After playing a soccer game on the morning of September 16, exhausted and thirsty, we drove home to relax and prepare for dinner at a friend's house. I couldn't shake a funny feeling and took a nap. When my husband returned from an errand, he found me sobbing uncontrollably on the side of the bed.

Odd behavior, but chalking it up to

exhaustion, we continued with our plans. The brief slightly slurred speech and stumble down the front steps on the way to the car were ignored. On the way to dinner I experienced continued waves of crying.

My attentive husband decided we'd detour to the ER despite my protests. I was momentarily feeling better. This is silly, I thought. They will pat me on the head and send me home. In the ER, I began to feel a hot sensation grow from my feet to my head. I tried saying I felt hot but couldn't speak the word. I began seizing at that point. I remember waking briefly, white clad figures around me, nurse at my head, comforting me while compressing the intubation bag on the side of my face. I remember feeling scared. That's all I remember.

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## Who's Who



## **Aaron Scrol**

Aaron is primarily responsible for coordinating the daily activities of the TBI Model Systems Study and the Exercise and Depression Study. Aaron identifies, enrolls and performs baseline assessments for new subjects in the TBIMS Study and assists in subject tracking, retention and follow-up.

Aaron has a M.A. in Applied Anthropology from Northern Arizona University and over five years of experience in both environmental and public health research and community organizing/advocacy. He has worked on several projects examining the risk behaviors of gay, ethnic minority, and drug using populations as they relate to the spread of infectious disease. He has also been involved in a number of clinical trials for medications targeting various substance abuse disorders.

#### Beyond the Injury continued...

I'm told it took the hospital staff a while to figure out what was wrong. Once they did, a team worked on me for over eight hours. Experimental procedures for me, life or death decisions, and papers to sign for my husband. Goodbye's for my family to an unconscious me on an operating table. Lots of uncertainty. Scary stuff. My husband suffers from that trauma to this day. I suffer in a different way. But we take each day at a time. It's been a long road, one I wouldn't wish on anyone. But we've survived...and thrived. I look forward to sharing details of my experience in rehabilitation, recovery at home, and how I came to where I am now in the next three issues of this newsletter. We are survivors, all of us.

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



"Lyn Nude" Charcoal Drawing by Stacey Rosevear 2004, sold

## **Medicare Savings Programs**

If you receive Social Security Disability (SSDI) and Medicare, you may qualify for one of the Washington state programs that pay for the cost of your monthly Medicare premiums and related out-ofpocket expenses. The Qualified Medicare Beneficiary (QMB) program pays for all Medicare premiums, deductibles and copayments and is for individuals whose monthly income is at or below \$798.00. The Special Low Income Medicare Beneficiary (SLMB) and the Qualified Individual (QI-1) programs pay for Medicare Part B premiums only and are provided to those whose monthly income is at below \$1077. For each of these programs a person's countable resources must be valued below \$4000. For households with two or more people, the state uses higher income and resource guidelines.

For more information contact your local DSHS Community Service Office (CSO) and ask to apply for the "Medicare Savings Programs". You can find the location of your local office and even apply on-line by going to www.onlinecso. dshs.wa.gov or call 1-800-737-0617

## Brain Injury Association Launch Party

Date: Wednesday June 22nd, 2005

- Location: BIAWA's Office, 800 Jefferson Terrace, #600 Seattle Washington 98104 (206) 388-0900
- Time: 6:00-7:00pm: Tour of the new location Refreshments will be served

7:00-7:30pm Silent Auction & Networking Harborview Hall Auditorium

7:30-8:00pm Introduction of New Board

8:00-8:30pm Socializing & networking More Refreshments

Everyone involved in the prevention, education, treatment, and advocacy of brain injury, survivors, their family members, friends, care givers and providers.

#### Subjects Needed For Brain Injury Studies at UW!!!

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 Aaron at 206-731-5196. Researchers in the Department of Rehabilitation Medicine at Harborview Medical Center are seeking people with traumatic brain injury (TBI) to participate in a federally funded research study about depression. Major depression may occur more frequently in people with TBI because the injury changes the delicate balance of chemicals in the brain. We hope that early identification and treatment of depression after TBI might improve recovery from and adaptation to this type of injury. If you are interested in this study, please call 206-341-4730 or 1-800-407-8124.

## Fall 04/Spring 05 Videoconference Series Tapes

Thank you for your interest in obtaining recordings of the TBI Education Series #1. The UW is no longer selling this series. However, both DVD and VHS copies of the series are available for purchase from the National Clearinghouse of Rehabilitation Training Materials (NCRTM). You will be notified via email when the TBI Education Series #2 DVD/VHS copies are available.

Contact the NCRTM at www.nchrtm. okstate.edu (search on key words Brain Injury) or you can contact Carolyn Cail at:

Carolyn Cail Information Coordinator, NCRTM 206 W. 6th Street Stillwater, OK 74078-4080 800-223-5219 Fax 405-744-2001

## New Multi-Site Telephone Intervention Study

The University of Washington is the lead center in an innovative, three-site TBI telephone intervention funded by the National Institute on Disability and Rehabilitation Research. The study is being carried out here as well as at two other Model Systems Centers across the country: Moss Rehabilitation Research Institute in Philadelphia, Pennsylvania and Methodist Rehabilitation, in Jackson, Mississippi

The aim of the study is to evaluate the effect of a low-cost phone intervention for persons with moderate to severe TBI in such areas as community integration and employment at one and two years after injury. Participation in the study will be offered to individuals with TBIs who are receiving inpatient rehabilitation services at Harborview and the UW Medical Centers. The hope is to refine a model of service delivery that would be costeffective, simple to replicate in a variety of settings, and effective in meeting the needs of those with less access to traditional community rehabilitation services. The study was modeled after a successful pilot project carried out at the UW between 1998-2002. The pilot found that those who received the phone intervention had better outcomes of overall function and quality of life. The current project expands the number of subjects and the length of the intervention. Involving three separate sites that differ widely in regional location will also allow the investigators to evaluate whether the effects of the interventions are similar in different geographical areas and demographic subgroups.

Persons in the treatment group, along with a significant other, will receive phone calls from a Research Care Manager (RCM) periodically for 21 months. The RCM will provide supportive counseling, educational information about TBI, problem-solving assistance and referral to community resources. The intervention focuses on helping individuals increase their success at dealing with the multiple, complex challenges experienced after a TBI.

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/