New York TBI

Model System News

Issue Two : May 2004

Getting the Word Out

A major component of the New York TBI Model System is sharing information and new knowledge with people who need it and can use it. That includes people with TBI, their families, professionals and policy makers. The NYTBIMS will use its website (www.mssm.edu/nytbims) as a mechanism for getting ideas out. The Resources section of the website links visitors to information that may be helpful. The website also provides links to frequently asked questions about TBI and to a variety of other websites providing information, chat rooms, support and linkages to resources across the U.S.

As our Model System research bears fruit, we will share our results in summaries known as TBI Consumer Reports (see examples of Reports based on prior research, on the web site), in publications for professionals and through presentations on research at meetings around the country. Also, we are collaborating with the Brain Injury Association of America to produce several issues of a policy newsletter that translates research done by all of the TBI model systems and other researchers into policy recommendations, as well as implications for consumers and clinicians. The first issue on Post-TBI Depression is available through contacting us or by visiting the website.

Research Volunteers are Needed

The New York TBI Model System at Mount Sinai School of Medicine is conducting a research study that focuses on fatigue and the effects it has on the lives of people with brain injuries. To do this we need volunteers who have had a traumatic brain injury – whether fatigue is an issue or not – and also (for comparison) volunteers who have never had a brain injury. In this study you will be asked to answer questions about how much fatigue you experience, your health, and your quality of life. You will also be asked to complete tests of thinking abilities, such as memory and attention, to see how fatigue affects your thinking. You will be paid for your time. If interested, please call 866-528-7490.

GCO #02-0677, IRB approved through 09/04.

In a second study, the Model System is seeking people who have had a traumatic brain injury and are experiencing depression. The study is evaluating the effectiveness of the drug Zoloft, an anti-depressant, in helping individuals who are depressed after brain injury. To be in this study you must be suffering from depression and be willing to try this medication for a period of 12 weeks. Participants will be randomly assigned, to receive either Zoloft or a sugar pill that contains no medicine. You will be asked to visit Mount Sinai every two weeks to monitor whether changes occur in your level of depression. You will be paid for your time. If interested, please call 866-528-7490.

GCO #02-0677, IRB approved through 09/04.

In a third study, researchers in the Department of Rehabilitation Medicine at Mount Sinai are conducting research on the benefits of an Internet web page with information and tools for helping

www.mssm.edu/nytbims

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people with brain injuries to better monitor their health and interact with their doctors and other health care providers. If you meet the following criteria, you are a candidate for the research:

■ You have been diagnosed with a traumatic brain injury or multiple sclerosis, which causes you problems with memory, initiation, organization and the like;
■ You use the Internet from your home to collect information, chat with other people or for other purposes, and consider yourself an experienced user;
■ You write, speak and understand English;
■ You are at least 18 years of age; and
■ You live in the New York City area and are willing to travel to Mount Sinai to take part in this study.

As part of the research, you will get together with investigators and other people with brain injuries and discuss what you think are the best methods to organize the content and format of the website the investigators want to create. The duration of the meeting will be about 3 hours. You will be reimbursed for your time and effort. For more information, contact Joshua Cantor at 212-241-8850, or e-mail Joshua.Cantor@mountsinai.org.

GCO #03-0513-01, IRB approved through 09/04.

Write Your Way to Freedom

Courage is a fiery tower that sways my mind towards hope

–Tad C., TBI Survivor

A lesson on metaphor taught Tad C. how to write a poem. He had been a visual artist and actor prior to sustaining two TBIs in the 1990s. Tad now struggles in his writing and his speech, sometimes wandering off the point he is trying to make. It is for people like him that I developed “Write Your Way to Freedom” creative writing workshops. My intention was to use my skills as a workshop leader, my training in creative arts therapies as well as the skills I gained in cognitive, speech and language rehabilitation, and psycho/social group dynamics. My desire is to share my love of language as a healing art with the community of people with brain injuries.

Prior to my brain injury in 1994, I had been an award winning writer and poet. I taught workshops on writing and creative movement to special needs populations for over a decade. After my injury, I slowly rebuilt my language and verbal skills, although aphasia still presents some problems. Now, from several directions, my abilities as a writer and a teacher have been reconfirmed. In 2000, I won First Prize in the National Pain Association’s Pain Awareness Week essay contest. Several of my poems have been published, and I am accepting invitations to read at poetry events around New York City. Also, I joined the roster at Teacher & Writers Collaborative. With this evidence of my skills in hand, in 2002 I proposed “Write Your Way to Freedom” to the Mount Sinai Rehabilitation Center.

Presently co-sponsored by the NY TBI Model System and the Mount Sinai Rehabilitation Center, the workshop meets once a week for two hours. The workshop is structured, to provide a sense of consistency for the members, while remaining flexible, to acknowledge the ups and downs of living with a brain injury and also each individual’s special needs. Guest lecturers have included writers I know, who have taught classes on poetry and the personal essay. Meeting for two years now, two of the original members still attend. Others have joined, a few have left, and, with each new session, one or two more join.

For more information, e-mail me at tbiwritersgroup@msn.com, or call 718 463-3403.

by Margie Ann Stanko
Women’s Support Group

In 1991, Mount Sinai issued an open invitation to women with brain injuries to a meeting, to assess whether they had issues distinct from men with brain injury and to gauge their interest in forming a support group for women. Over 100 women attended and gave voice to issues they had held in silence. They discussed the loss of personal and professional identity, disruption to the family structure, lack of knowledge and understanding about brain injury and common problems after a brain injury, such as fatigue, depression, isolation and changes in sexuality. This seminal meeting identified a set of TBI survivors with common needs that had not been addressed. This was the genesis of the Women with TBI Support Group.

This group continues 13 years later as the only one of its kind in New York City. It provides a monthly gathering place for women to discuss their cognitive and emotional needs, grapple with challenges common to female survivors of brain injury and to learn from the experiences of their peers. Group members remark that when they come to group, they feel understood, at ease and accepted, something often lacking in their everyday relationships.

Over the years, many women have found support in the group as they adapted their lives to accommodate new goals, given the changes thrust upon them by brain injury. For example, 9 years ago Janet was taking courses to allow her to pursue a position in veterinary care when she slipped on icy pavement and hit her head. Since then, she has built a business caring for people’s pets while they are at work or out of town. This provides her financial security and a job she loves. Dr. Kathleen Watson was relocating her medical practice to her native country of Jamaica when she was hit by a car, sustaining substantial injuries to her brain and body. She has since left her practice and is now the chairperson for the Medical Committee of the International Field Hockey Federation. Additionally, she has written a book, The Road Back, about her recovery experience. Dr. Watson recently completed a Ph.D. thesis about osteoporosis and is “celebrating my eighth year since my accident”. Margarita, a schoolteacher, suffered a brain injury several years ago and all but withdrew from involvement in activities outside of her apartment. A year ago, she began to volunteer at a nearby school one day per week. She increased her commitment there and several months later was asked to become a paid substitute teacher. When a position became available for the 2004 school year, the NYC school system offered her a full-time position.

I joined Mount Sinai as a research assistant in 1996 and later became co-leader of the Women’s Support Group (a postdoctoral fellow in neuropsychology, Dr. Doris Chun, is the second co-leader). I had been a financial executive when I suffered an aneurysm in 1990. I now feel that brain injury survivors – me included – derive great hope from seeing others with brain injury functioning well and enjoying their jobs everyday. My TBI was a shock, then a challenge, which turned into a new beginning. During the recovery process, I discovered that while one door had closed behind me, a window had been opened.

By Seton Melvin

Women interested in attending a meeting of the group can contact Dr. Wayne Gordon (see back page for contact information) for schedule and location.
Many of the people with TBI that I see in my practice complain of problems with sleep. For them, sleep no longer plays its important role of revitalizing a person after a tiring day. Because sleep is a complex process that involves many parts of the brain, a variety of sleep disturbances are seen after brain injury, depending on the site and extent of injury. Sleep disturbances have been found in people with all severities of injury – from mild to severe.

The term “insomnia” covers a variety of problems: difficulties in getting to sleep or staying asleep or failing to feel restored or refreshed after sleeping. Surveys of the population suggest that insomnia is more often found in people who have experienced a TBI (27% to 56%, depending on the poll) than in the general population (4% to 33%). Generally the insomnia rate is higher directly after injury and decreases as time passes.

Insomnia is known to compound problems resulting from brain injury, including behavioral and cognitive difficulties, and it adds to difficulty with new learning. Thus, ensuring a full restful night’s sleep is an important part of any brain injury rehabilitation program.

WHAT CAN PEOPLE WITH TBI DO TO REDUCE OR ELIMINATE INSOMNIA?

I’ve provided a checklist below of steps to take – whether you have a TBI or not:

- Consider the non-prescription drugs that you take, including over-the-counter sleep aids, caffeine, diet pills, herbal remedies and nicotine.

- Because the most common over-the-counter sleep aid medications contain an antihistamine (commonly diphenhydramine), which for people with TBI can lead to disturbances in memory and new learning, these sleep aids are not recommended. Retention of urine, dry mouth, nighttime falls and constipation are also possible side effects of this class of medications.

- Nicotine from tobacco is under-recognized as a cause of sleep impairment. One more good reason to stop smoking!

- Some people think of alcohol as a handy remedy to promote sleep, but it may actually cause sleep disruption. Because it decreases deep sleep (REM stage), it leads to less refreshing sleep.

- Melatonin and valerian are commonly used herbs to aid with sleep. However, both have multiple drug interactions, and your doctor should be made aware of your using either of these herbs.

- Avoid caffeine, nicotine and alcohol in the afternoon and evening.

- Prescription drugs also can be a cause of insomnia. Common offenders are some medications used to treat asthma and depression. Also, stimulants that are meant to treat daytime sleepiness, if taken too close to bedtime can cause insomnia. These problems can often be stopped by adjusting the timing of the medication or by substituting a different drug – of course, in consultation with your physician.

- Healthy habits to promote sleep (or, “sleep hygiene”) should be tried, to see if some relatively simple steps work for you:

  - Exercise regularly, but time your workout to end no later than three hours before bedtime.
  - Avoid napping during the day.
  - Make sure your bedroom is protected from noise and light.
  - If you don’t fall asleep in 30 minutes, get out of bed and do something relaxing or boring until you feel sleepy.

- Contact your physician to have a sleep evaluation. Before recommending any action, he or she will explore with you a variety of possible causes for your insomnia, including pain or depression, which often bring with them sleep disturbances. A comprehensive medical evaluation for insomnia also needs to consider other psychiatric, pulmonary, cardiac, gastric and endocrine disorders. To treat insomnia, prescription medications may be considered by your doctor. Special caution needs to be given when choosing a medication for an...
Timothy Pruce, a survivor of TBI, is a NY TBI Model System staff member who is responsible for coordinating advocacy and peer support. He meets with newly injured individuals at Mount Sinai and at Elmhurst Hospital and with their family members. He provides them with a packet of information about TBI resources in the metropolitan area, including materials from the State VR agency, the local independent living centers and from the Brain Injury Association. Speaking as a survivor, he discusses the road to recovery and “puts a face on” the potential for recovery. He answers questions and makes himself available for further contact via telephone. His phone number, for many families, has become an additional resource aiding them in the first months after injury. Mr. Pruce also facilitates weekly sessions in the Phase II outpatient program. His focus is on reintegration into the community. He provides peer mentoring, resource literature, and information on resources (e.g., the NYS TBI Waiver). He also is a member of the inpatient TBI support group, both as a survivor of TBI and an advocate and peer mentor. Below, in his own words, he describes his road to recovery.

Sustaining and surviving a TBI has changed my life in many ways. One of the biggest and most difficult changes had to do with my job and career. Prior to my injury, I had been a regional public relations manager in Southern California. After I experienced an injury in a car crash in 1994, my immediate concerns were rehabilitation and therapy. This was a long, tedious process, and at a certain point it became painfully clear to me that I could no longer work in the same capacity I had for the previous eight years. Fatigue, memory and focus problems, among other things, made it nearly impossible for me to work full time, let alone function at the high level I had before my accident. At one point, I was told by a vocational counselor that I shouldn’t really get my hopes up in terms of finding meaningful employment. As I neared completion of my outpatient day program, I realized that I would have to find something to do, establish a new career path, if for no other reason than to keep me busy, and give me structure and routine. It seemed to me that the obvious choice would be doing something that I knew a lot about firsthand – something that I had a deep personal interest in. I wanted something I could utilize the skills I had left, which in my case is talking ably to people. I also wanted to do something that would affect other people’s lives. I decided that I wanted to become an advocate for people with TBI.

I had no idea how I could do this. But, at the time I had just moved to New York City and was looking for volunteer work. Through personal contacts, I had heard that there was a research group at Mount Sinai that gave opportunities to people with TBI. The volunteer position they gave me provided an opening – I just answered phones and Xeroxed. As time went on, I was given more responsibilities and access to different people and organizations within the community of people with TBI – including advocacy organizations and groups. I even got paid. In a strange way, my education in becoming an advocate has been similar to my rehabilitation experience. It took place slowly, one day at a time, over a long period and required help and support of people who showed a willingness to help and nurture. Now, almost five years after arriving in NYC and Mount Sinai, not only do I refer to myself as an advocate, but so do health care professionals who I work with regularly. My story and my current role in the Model System gives me the opportunity to tell people that life goes on after TBI, and also I can be an example and show them in person.

by Timothy Pruce
individual with TBI, to avoid daytime sedation or worsening of cognitive and behavior problems. Anticonvulsants, antidepressants and antipsychotics may all be useful in treating insomnia.

☐ Check out other resources. You can obtain a lot of information on sleep problems at www.sleepnet.com. Also, the following journal articles, primarily aimed at professionals, provide specific data on disturbances and sleep management relevant to people with brain injuries:


by Brian D. Greenwald, MD
Associate Director of Brain Injury Rehabilitation
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IF YOU HAVE A QUESTION YOU WOULD LIKE ANSWERED IN THIS NEWSLETTER, e-mail your question to wayne.gordon@mssm.edu.