

MINDMATTERS

A Newsletter from the Brain Injury Association of Washington
Winter 2004

Prevention Support Education Advocacy

Support groups provide
'tough love', survivor says



Eleven years ago, Lou Nash of Edmonds was a 55-year-old successful businessman with "an excellent job, great benefits and a new car." Then Nash, a smoker and an admitted "Type A personality," suffered the first of several strokes that changed his life.

Left him with weakness on his left side, Lou Nash Nash couldn't tie his shoes - "I had to get shoes with Velcro straps" - and couldn't button his shirt - the buttons were too small.

"There were lots of things I used to do that I couldn't do," he notes. One day I'm the breadwinner. The next day, it's all gone. I couldn't accept it." Nash says he has made progress with years of therapy. "I have great caregivers," he says. But emotional support is also important to brain injury and stroke survivors, which is why Nash leads a monthly support group for South Snohomish County brain injury and stroke survivors.

"Having a support group has given me self-esteem," Nash says. "The support group teaches survivors how to cope and get the information they need. It's a chance to talk to someone who has been there, done that. It's kind of tough love - life goes on.

Nash, who works closely with the American Stroke Association, notes that the group consists of both stroke and brain injury survivors. "This is a good match because basically we have the same problems but sometimes deal with them in different ways," he says. "A support group brings all of this information together."

Nash recently restarted the group after a couple of months off, and is joined by a facilitator, Ed Culpepper. The idea is to "mentally, physically and spiritually support and assist brain-injured people," Nash says.

The South Snohomish County support group meets the third Thursday of each month between 6:30-8:30 p.m. at Edmonds Community College, 20000 68th Ave. W., Lynnwood. The meetings, accessible to people with disabilities, are held in the Meadowdale Building, Room 124.

Caregivers are also invited to attend the support group. Some areas offer support groups for caregivers only, which Nash feels is important. "Caregivers have their own set of problems," he adds. "A lot of times they can't talk around survivors because the survivors might get upset."

What advice would Nash give to those who have suffered a brain injury? Be receptive to various therapies, like acupuncture. You have to be open and flexible. Progress really depends on the mindset of the individual," he says.

For a full listing of support groups statewide, see the back page of this newsletter

BIAWA's mission: Support for all brain-related problems

The Brain Injury Association of Washington has long provided support for the brain-injured community in the form of literature, support groups, medical information and a Web site.

The BIAWA provides the same degree of support for other survivors with brain-related problems including those with brain aneurisms, brain tumors, strokes, anoxia (oxygen deprivation to the brain) and brain concussions.

For more information, contact the BIAWA at 425-895-0047

Chair's Message: Growing our Board of Directors

We have liftoff! BIAWA is alive and well as seen from the great turnout at the Brain and Nutrition Seminar on Sept. 29 at the Meydenbauer Conference Center.



More than 150 survivors, family members, caregivers and health care providers came to hear David Musnick, MD and Daniel Murphy, DC, DABCO talk about the use of nutrition, diet and exercise in the treatment and rehabilitation of brain injury.

Another reason to feel good about the direction of BIAWA is the excellent and positive response to our "Calling all Volunteers" initiative. Many folks stepped forward and indicated a willingness to help on projects. We are now in the process of integrating our new volunteers into BIAWA's mission of prevention, education, support and advocacy for survivors of traumatic brain injury survivors, their family members and caregivers.

Moreover, we continue to make great progress on our model-helmet

initiative with the Issaquah Rotary.

In this project, we have proposed fitting a helmet on every child's head in the K-12 grades in Issaquah. To continue to spread our services and reach more survivors, we need to grow our Board of Directors.

If you (or someone you know) has some time and are interested in making a difference in our community, let us know. We need your skills and energy to make a difference in BIAWA's mission of prevention, education, support and advocacy for survivors of traumatic brain injury, their family members and caregivers. A future board member will be overseeing and coordinating an area of activity for the association in areas such as:

Support Group Coordinator: Help develop skills for BIAWA's local support group leaders; help coordinate speakers and content for support group presentations.

Educational Program Coordinator: Organize educational programs for BIAWA's members.

Seattle-to-Portland Bike Run Affiliation Coordinator: Work with STP on helmet awareness and getting BIAWA named as a sponsor and recipient of donations.

Legislative Advocacy Coordinator: Develop and implement a plan to get laws enacted allowing BIAWA to receive funds from criminal and civil fines assessed against negligent motorists.

Database Coordinator: Review BIAWA's database software to make sure our data is reliable, accurate and accessible.

Grant Writer: Write grants for BIAWA to receive funds to support its work in prevention, education, support and advocacy.

Helmet Safety Program Coordinator: Coordinate and promote helmet safety awareness at community fairs and schools.

Community Partnership Coordinator: Develop strategic partnerships with other non-profit groups and business. Recruit businesses to join BIAWA as business members.

Fundraising Coordinator: Develop, coordinate and organize events that generate revenue and recognition for BIAWA.

Medical Advisory Board Coordinator: Create an Advisory Board consisting of health care professionals who evaluate and treat TBI survivors

Webmaster: Keep BIAWA's Web site up to date with news, events and announcements.

Speaker's Bureau Coordinator: Develop and coordinate volunteer speakers ready to present at schools, community events and social service groups.

If you are interested in a board position, I invite you to call the BIAWA office at 425-895-0047 or attend a BIAWA board meeting. The BIAWA Board meets the third Wednesday of every month at 7 p.m. (upcoming meetings are Dec. 15,

2004, Jan. 19, 2005 and Feb. 16, 2005). Attending a board meeting is a great way to meet other Directors and see first hand the goings-on of your association.

Your skills and energy will make a difference! Board meetings are held in the conference room of the Adler Giersch, PS law firm at 333 Taylor Ave. N., in Seattle. Call my office at 206-682-0300 for directions.

Warmest Regards, Richard H. Adler, Chair Executive Board

New study to focus on counseling
for brain injury survivors

The Department of Rehabilitation Medicine has received a new grant from the National Institute on Disability and Rehabilitation Research. This five-year grant will allow researchers to study the effectiveness of telephone calls aimed at counseling and education for people with moderate to severe traumatic brain injury and their families in the first two years after injury.

The grant is particularly exciting because it is a multi-center study. The department will be working with investigators at Moss Rehabilitation Center in Philadelphia (Drs. Tessa Hart and John Whyte) and Mississippi Methodist Rehabilitation Center in Jackson, Mississippi (Dr. Mark Sherer). This arrangement will allow investigators to test whether this type of counseling and support improves outcome and quality of life for a diverse population.

The three sites involved are very different from each other. Moss Rehabilitation is located in Philadelphia and serves primarily an urban Northeast U.S. location with a mixed racial-cultural population. Mississippi Methodist in Jackson, Miss., serves primarily a rural population that is approximately 50 percent African American. Seattle, of course, is a mixed urban-rural area with a significant Asian, Pacific Islander and Native American population.

"We will be able to see what other factors make telephone follow-up a success," said Dr. Kathleen Bell, who will be the principal investigator for this study. Other members of the research team are Aaron Scrol, the research coordinator; and Drs. Sureyya Dikmen, Nancy Temkin, JoAnn Brockway and Robert Fraser.

The Department of Rehabilitation Medicine is also delighted with the response to its first ever videoconference series, presented in conjunction with DSHS Aging & Disability Services Administration of Washington (HRSA grant #1-H21-Mc0006801) and the UW TBI Model Systems. Six sessions covered basic information about TBI, behavior, communication and information for self-advocacy and case management, and caregiver support.

"We have stacks of feedback and suggestions from our evaluation forms and

will be using this information to design our next videoconference series for the Spring of 2005," Dr. Bell said. If you have any suggestions on content, structure or presenters, please email uwtbims@u.washington.edu.

Dr. Peter Esselman, one of the investigators on the UW TBI Model Systems, was the guest editorial writer for the Journal of the American Medical Association recently. Dr. Esselman commented on the findings that the decreased length of stay for rehabilitation seems to correlate with increased morbidity and mortality.

UW research project seeks volunteers

Does exercise work to improve the mood and overall quality of life in persons with TBI? You can help the UW answer this question by participating in a research project. All participants are offered a free 10-week guided exercise group at North Seattle Community College's Wellness Center.

To be eligible for this study, you must:

Have had a brain injury in the last six months to five years

Have symptoms of depression

Be able to walk

If you are interested, please call 206-731-5196 for more details.

Donor Honor Roll 2004

The Brain Injury Association of Washington would like to thank the following donors for their generous contributions, which have helped us provide vital services for brain injury survivors and their families. (Donations listed are through Nov. 1, 2004.)

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