

Mind Matters Summer 2006

Survivor optimistic despite challenges

By Karla Oman

Anne Adams' story is one of you and me — where injury, despair, hope and inspiration meet.

Anne was a doctoral candidate who taught at the University of Utah, in addition to teaching middle-school level English as a Second Language in Park City, Utah. On a sunny day in July 2001, she was driving I-80 to Park City and rear-ended a semi that was traveling at 17 miles per hour.

When she woke up several days later, she had — and has — no memory of the accident that required Jaws of Life to extract her from her vehicle or the flight to the University of Utah Hospital.

There were several surgeries to reattach her right foot, and getting her eyebrows and eyes stitched back into a semblance of order. These were the highest priorities and concerns of the hospital staff, but Anne knew that something was wrong with her brain and her thinking process. When she questioned the medical staff, she was told time and again, "You had a concussion, and things will resolve."

As Anne progressed through physical therapy for her foot and ankle, she kept reiterating that something was wrong with her brain. The medical staff repeated that it was only a concussion and that everything would be fine. Two months later, she saw a doctor in physical medicine. "Well, no wonder," he said. "You have brain injury." He showed her the CT scan that had been taken when she was first brought in after her accident. This most significant injury had been overlooked, and she didn't get the appropriate treatment when she needed it the most.

Now that she had an official diagnosis, Anne was a candidate for cognitive rehabilitation therapy. At the end of three months, the therapist told Anne that she had taken her as far as she could. Upon reflection, Anne now realizes that the therapist's statement was indicative of the limitations of the care she was able to give Anne — the limitation was not Anne's.

She took a year's leave of absence and was told that she would have to

find another way to make a living. She was depressed and suicidal, but determined to go back to work, only to discover that she was not able to do so.

Anne's situation went from bad to worse, as she relocated to a quieter area of northern Utah, only to have well-meaning people misunderstand her. Her brain injuries (she now had three) made it difficult for her to understand others, and for others to understand her, with the added difficulty of balance impacted by a compromised right foot and ankle.

Several unfriendly visits with the police and lack of social filters put Anne in risky situations. She was jailed at one point, and she was raped. She suspects that this may be a common occurrence for those who have experienced brain injury, especially with those who have no friends or family members to help. She believes it is very important for medical professionals to listen carefully and ask good questions when taking medical histories from those who are brain injured, as it may take prompting to get complete information. If this had been done, Anne would not have been jailed. She eventually ended up living in her car.

Unbeknownst to Anne, there were advocates in her corner. While on vacation in Port Townsend, Wash., a few years earlier, she had made the chance acquaintance of a gentleman — and they had one of those profound and life-changing conversations that you remember forever. Anne was in dire straits, but remembered his name, and called him. The gentleman happened to be a psychologist who talked through the events from the previous two years, and helped her recognize resources that she didn't realize she had. She took his advice, and contacted three friends who got busy researching on the Internet. They connected her with the Brain Injury Association of Washington.

Anne says the BIAWA staff "are the most kind, caring and encouraging; they are just wonderful." The staff was able to arrange for volunteers to pick up Anne's belongings and transport them back to Seattle. She started with the Virginia Mason cognitive rehabilitation therapy program, attending twice a week during spring, summer and fall of 2005.

Anne is now able to live on her own, although she requires household help. She has had additional surgeries on her foot and ankle. She has to take medication for migraines and has recently experienced some other manifestations of her brain injury. But she remains optimistic.

While significant challenges remain, Anne is reaching out to help others. She says, "I've never lost my ability to talk," and her sense of humor remains intact.

Disability insurance: What people with TBI need to know

By Fred Langer, Nelson & Langer, PLLC

Traumatic brain injuries (TBI) change many aspects of people's lives. It is well documented that individuals who suffer from TBI are more likely to become disabled than the general population. If someone with a traumatic brain injury attempts to obtain disability insurance, it can be an extremely difficult process given the invisible nature of TBI.

There are three main sources of income for disabled individuals: Social Security Disability Income (SSDI), employer-sponsored group plans and private individual policies.

Many employers offer workers disability insurance as part of the "employee welfare package" (EWP). While the purpose of this insurance is to replace income if an individual becomes disabled, this insurance is difficult to qualify for, provides less income than anticipated and offers little in the way of legal redress. One way to avoid these problems is by purchasing a private policy early in life.

Typically, EWP insurance has several definitions of disability. One of the key components to proving that someone meets the definition of disability is with "objective medical evidence." People with mild TBI cannot always do that. Sometimes, lacking radiology, the best objective medical evidence may be neuropsychological testing and a vocational assessment. Even then, insurance companies often try to limit benefits by characterizing the TBI victim's disability as psychological, rather than organic.

A real pitfall for disabled TBI victims occurs once a claim is denied. EWP insurance has an administrative review process of 180 days. During this time, it is the disabled person's responsibility to provide the insurance company with all the information necessary to prove the disability — at his or her own cost — and the company has no obligation to tell the disabled person what information is acceptable. The insurance company will not accept information received after the 180-day appeal. Therefore, if a TBI victim is denied disability benefits, it is imperative to get sound legal advice immediately.

One other issue is economic. EWP insurance usually provides for 60 percent of an employee's wages. This 60 percent is offset by Social Security benefits. So, if an individual earned \$5,000 a month, the total

benefit (60 percent) is \$3,000. After Social Security pays at \$1,800, the carrier's obligation is reduced to \$1,200 — taxable.

Additional unpleasant surprises occur when a disabled person receives both SSDI and EWP benefits. SSDI can start one to two years after the disability occurs and is retroactive. Once SSDI is granted, the disabled person receives a payment from Social Security for retroactive/back benefits. Here is the rub: The company is entitled to reimbursement of these benefits (the SSDI retroactive benefits). If the disabled person does not reimburse the carrier, the carrier will lawfully cease payment of disability benefits.

The above highlights just a few of the problems associated with TBI victims' experience with disability insurance. If one becomes disabled, a quick consult with competent counsel early on can save thousands of dollars and endless headaches.

Chairman's Message

First half of 2006: a time of growth

The first half of 2006 has been a very busy, energizing and positive year for the Brain Injury Association of Washington. If 2005 was a year of fertilizing new ground and planting seeds, then this year has been one of nurturing along the seeds into a healthy and sustainable crop. In other words, projects that we talked about in 2005 are now underway and moving forward. New people are stepping forward and joining BIAWA as members and "doers."

I am very pleased to report that good work is getting done by good people and the organization is growing. The positive energy that fills a board meeting is an indication of an even brighter future for the implementation of our mission of prevention, education, support and advocacy. If you have not attended an Executive Board Meeting, I encourage you to come, sit in and watch the work of the association take shape.

Here are examples of seeds that have been planted and fruits that have been or will be harvested in the near term:

1. Legal Advocacy Seminar: The Brain Injury Association sponsored a legal seminar for attorneys on May 12, 2006. More than 60 attorneys and legal staff personnel attended a day-long seminar at the Washington

State Convention Center to hear top-rated doctors and attorneys present the latest information on how to better understand TBI and advocate for the rights of TBI survivors.

2. Executive Director Search: A search committee has been formed for the hiring of a new Executive Director for the Brain Injury Association of Washington. Resumes are starting to arrive. We hope to have the Executive Director position filled by early fall 2006. This will be a significant milestone in the growth and revitalization of the association.

3. BIAWA Database: Our association's database software upgrade has been completed. It is now current, better organized and simpler to use. This will make for more cost-efficient use of time and resources in our direct mailing to members, volunteers and other interested folks.

4. DSHS Contract: The Brain Injury Association of Washington was awarded a contract by the Department of Social and Health Services (DSHS) to distribute two very important documents throughout the state of Washington. These two documents are called the "TBI Toolkit" and the "TBI Resource Guide for Western Washington." It is our commitment to distribute 1,400 copies of these comprehensive books and then reapply with DSHS for an additional grant for further distribution.

5. Social Activities for Survivors: Thanks to the work of our Social Activities Coordinator on the Executive Board, we now have social activities and events for survivors to come together and play together. Events organized so far include a movie and dinner out. Many more events are planned. If you are interested in additional information, please visit our Web site: www.biawa.org.

6. Support Group Training: We intend to address a long overdue need of our members and their families by providing facilitation training for BIAWA's support group leaders. Planning is underway to bring all support group leader into Seattle for a comprehensive, multi-day training on how to become better facilitators and how to more effectively run support groups in the community.

7. Educational Video: Another important project that is getting our attention involves a request that we co-sponsor the production of a video/DVD that explains the "stories" of three different TBI survivors. When completed, this video/DVD will be viewed on UWTV and BIAWA's Web site. Once the video/DVD is completed we will begin working with the public television station to run a special on TBI.

8. Dinner/Auction: BIAWA's Executive Board has unanimously agreed to move forward with a public event, a dinner/auction. Planning is underway

for this project and more information will be available in the next newsletter, on our Web site and by direct announcement to you in the mail. This will be an exciting evening that will focus on generating awareness of TBI as a "silent epidemic" and raising dollars to help support projects that are noted above and those that are in the early planning stages.

I remain humbled by the extraordinary work and efforts by the Executive Board members and volunteers of the Brain Injury Association of Washington. Their commitment and work serves as an inspiration to me and many others. If you want to see what the buzz is all about, come to a Board meeting. If you want to get involved, come to a Board meeting. If you want to help others, come to a Board meeting. We meet the third Wednesday of every month (except July and August). Meetings start at 7 p.m. and end at approximately 8:30 p.m. I'll look forward to seeing you shortly.

Sincerely,
Richard H. Adler
Chairman of the Executive Board
Brain Injury Association of Washington

"Paid Advertisement" Development Movement Center

On a February day in 2005, Nick was doing what many boys do after school — heading home, crossing a busy street at an accustomed intersection, hanging out with a friend and having good 12-year-old boy fun — when the mirror of a van driving through that same intersection took away everything that Nick identified as himself. In that moment of mutual inattention, Nick lost his athletic ability, his straight-A academic skills, his joy at singing in the Northwest Boys Choir, and his ability to speak, see and move purposefully or to be conscious of the world around him. At Harborview Hospital, where Nick's life lay in the balance for days, the diagnosis was clear: severe traumatic brain injury — the ultimate insult to the wholeness of any human being.

At the Developmental Movement Center in Seattle, we recognize that Nick is not alone. Our organization is committed to helping those with brain injuries recover at all levels of proper

functioning to their full potential. The story of Nick's recovery is one of hope, and it is our purpose to extend this hope to others by reintroducing

concepts in the treatment of brain injury that have been understood for decades, but not often considered as an option.

The Developmental Movement Center, founded as a non-profit and employing practitioners who have been treating clients in Seattle since 1988, is committed to treating clients with non-progressive injuries to the central nervous system and to restoring lost functions by repeating processes seen in normal brain development. DMC practitioners know how resilient and durable the human brain can be and that many brain injuries can be conquered.

Our approach recognizes that the tearing apart of neurons — the shearing off of axons and dendrites that connect neurons to one another when the brain is injured — is the source of functional losses. In the case of a minor brain injury, intact brain cells, which still remember how to do the job they were doing, can grow new dendrites and axons and reconnect with other cells in the system. At the source of the shearing on the neuron, a process called sprouting occurs, in which a brain cell that is stimulated will begin to grow new connections and rewire itself.

But what about severe injuries such as Nick's, in which whole regions of the brain are left incapacitated? The brain begins to swell, much like a bruised area on your body that has suffered a blow. If the swelling diminishes in a short period of time, blood will start to flow again and functions will return to normal. However, if the swelling continues, the brain will not get enough oxygen and brain cell death ensues. Can such a severely damaged system be rewired?

Please recall that brain cells that are stimulated will begin a process of growing new connections. A brain that has suffered severe injuries has the ability to reassign tasks to other areas of the brain if stimulated intensively, consistently and appropriately. Our approach to reacquiring brain function is the model of infancy. The newborn infant cannot walk, talk, control its body or be conscious of the world around it in a way that makes sense. But that infant will acquire those skills because of specific stimuli that are written into the genetic code and experienced by any unimpeded, unimpaired child. That infant will crawl, creep, roll and do specific patterns of movement, all of which are designed to stimulate the brain.

Although Nick was still in a coma in May of 2005, we put him tummy down on the floor, as one would an infant. At other times, a team of volunteers moved his head and limbs through patterns typical of the early infant. A program was designed to get more oxygen to his brain, and intensive sensory stimulation was used to reeducate him about sensation and the location of his body in space. Within the month, Nick

was out of his coma and relating to his family. His personality and sense of humor began to return. Nick gained control over one arm, then a leg. We began to literally push him across the floor in the tummy crawl position and his brain found ways to move both legs so that he could begin to push himself.

At the one-year anniversary of Nick's accident, he had acquired speech in short sentences and even a few words in French. He returned to school where he can do simple math in his head. Nick now reads, writes his name and uses a cell phone. Nick will walk again someday, but we are rebuilding his skills stage by stage, using the brain's resilience and amazing durability even in the face of life threatening injury.

We want to ensure that more patients are aware of this option for recovery that has been used since 1955 throughout the U.S., Japan and Australia and is being introduced by the Developmental Movement Center to England. Our contact information is below. We welcome the chance to educate you about recovery from TBI.

Developmental Movement Center
12351 Lake City Way N.E., Suite 102
Seattle, WA 98125
Phone: 206-525-8038, Fax: 206-417-3265
E-mail: dmc@developmentalmovement.org