The Stroke Network StrokeNet

http://www.strokenetwork.org/ **March 2003**

This month we feature two articles about Dr Shawn Jennings, who is the Medical Director of The Stroke Network. His book "Locked In, Locked Out" is reviewed and his biography is featured. First, Steve Mallory explains changes at the stroke network websites. David Ray reports that his stroke club has held the first meeting of the New Year. Next Michael Roberts reviews Shawn Jennings' book mentioned above.

Rhonda Peterson tells a tale of deciding to shift from sedentary winter and get some exercise. In her monthly review Barbara Layne introduces us to the Virtual Hospital site of the University of Iowa Hospitals and Clinics. This month's bios are of Tony Boxer and Shawn Jennings. A printable version of this newsletter is available on our website.

Lin Wisman, Editor
Lwisman@strokenetwork.org

Organization Highlights

By Steve Mallory

Things are going well for the organization. Several changes are being made. If you have visited the website recently, you have probably noticed some of these changes. The information web site has a new URL and name. You can now reach StrokeNet at several Internet addresses, which will hopefully make the address easier remembered. The new addresses are, either http://www.strokenet.info or http://www.strokenet.biz. I should also note that our support Internet addresses are no longer in use. The URL's http://www.strokesupport.org and http://www.strokecaregiver.org have been retired and are now integrated into the http://www.strokenetwork.org address. They are http://www.strokenetwork.org/survivors/ and http://www.strokenetwork.org/caregivers/, respectfully.

Another big change is coming very soon. The homepage web site is in the process of receiving a facelift. New menus are being added, which will make navigation anywhere on the entire web site a piece of cake. No more ambiguity as to where something is located. We have also purchased new software that will more effectively control the organization membership. The only prerequisite that comes with this is that everyone will be required to register again. This change will allow us to keep records on members from the mailing list and those members from the message board in just one database. The current system causes the staff too much confusion as to who is or is not a registered member. Several members have been asked to register with the organization and many have failed to do so. It will therefore become necessary to register with the organization in order to receive on-line stroke support. Information will remain at http://www.strokenet.info and will not require registration. Newsletter subscriptions will remain in effect although will be available by direct mail, instead of just on-line, to registered members upon request. Hopefully, everyone can appreciate some of the database problems that were the driving force behind this issue.

Life in New Zealand with a Stroke

by David G. Ray

February marks the beginning of the Stroke Club year. At our first meeting we had our meet and greet session in which members exchanged their Christmas and new year experiences and our secretary outlined the programme for the first 6 months. This programme consists of our usual mixture of subjects including medical topics of interest to stroke survivors, practical demonstrations, outings, general interest topics, culmination in our mid-winter lunch in July.

Our second meeting this month was on a subject we all need to know, that we don't like to talk or even think about - funerals. The speaker was an experiences funeral director who explained the procedure and costs in a very easy understood and sensitive manner. We had quite a low attendance of members at this session which made me wonder if this is a subject that we try to avoid. It is inevitable and we should be prepared for it. Making sure that we have covered all the information that will be necessary at the time will

save our family much of the stress associated with a bereavement.

It was surprising to me that at our meetings nothing was said in our general discussions about the happenings in the Middle East. New Zealand is far away from Iraq but the problem still has its affect. All ready there has been an increase in the price of petrol which will have a flow-on effect on other commodity prices. We all hope that the coming events will not escalate into a world conflict where countries employ weapons of mass destruction. My concern is not for myself but for my grandchildren.

The America's Cup saga carries on and on and on. The series of yacht races to find who will challenge Team New Zealand for the "Old Mug" was dogged by fickle weather in the Hauraki Gulf, the venue for the races. This first series of races was for the "Louis Vuitton" Cup and was won by "Alinghi" a yacht sponsored by a Swiss company. "Alinghi" has won the first three races of the America's Cup challenge but bad weather has delayed the balance of the races for over a week. The cup is for the best of nine races. It is interesting to note that both yachts, "New Zealand" and "Alinghi", are skippered by New Zealand yachtsmen.

Summer is coming to an end in New Zealand but now that the children have returned to school, the best of the sunny, hot weather has arrived. Our news tells us that parts of the USA have been snowbound and spring will be welcomed.

Book Review: Locked In, Locked Out

By Michael Roberts

Canadian physician Shawn Jennings has written a remarkable book about his experiences following a brainstem stroke, which struck him on a sunny day in 1999, when he was looking forward to taking an afternoon off for a golf game with a colleague. In his professional capacity, Jennings knew what was happening during both the stroke itself and his long rehabilitation. Luckily for readers, his prose style is accessible to the layman. He has a keen eye for detail. During the journey from one facility to another, he spots an osprey on a tower and shares that with us. He encounters old friends, both patients and doctors and these encounters give us a sense of his membership in a larger community.

Always the physician, Jennings ruminates about the misfortunes that befall some of his patients. An elderly couple dies within hours of one another. An elegant woman who lives alongside a beautiful river succumbs to cancer. The dreariness of the rehabilitation facility and the camaraderie of the patients are visions out of a war zone as are the dark thoughts of hopelessness. These ruminations and the compassion they tap into are part of what sustain Jennings during his own trials.

If I could think of a book that this one brings to mind, It would be paraplegic Vietnam vet Ron Kovic's "Born On The Fourth of July." It has that sort of feel to it. Tom Cruise won't fit in the film version but Anthony Edwards might. I know what happens when Elmer Fudd looks down the barrel of his gun. Early in the book, Jennings suggests that it might not be a kindness to offer this story to a survivor early in their recovery. I'm inclined to agree. The sheer hard work of relearning how to do such simple things as swallow your own saliva might be too daunting to face.

While I was hospitalized, I received two copies of "Angela's Ashes," even an audio edition. Terribly depressing when trapped in a sick bed with no end in sight. "Locked In, Locked Out," Jennings's book is an excellent read for caregivers and survivors who have confronted the initial challenges of recovery.

They will probably have, as I did, many "been there done that" feelings while reading this book. This is a well-told story. Strokes aren't pretty things. I was reminded several times of an occasion when my wife was talking to me in the brain injury rehabilitation unit cafeteria and was taken aback by a litany of my more disgusting personal complaints.

My wife blanched but a fellow patient, an older lady named Isabelle smiled a little bit. I thank her for understanding. I understand Jennings's shock of discovering his catheter. All things considered, I heartily recommend this book to anyone who wants to know what goes through a stroke survivor's mind. Jennings has done an excellent job. Two thumbs up!! The left one's a little slow but it's coming! Read this book.

Available through http://www.amazon.com.ca/or the publisher Dream Catcher.

From the book cover of "Locked In, Locked Out" by Shawn Jennings, MD

Dr. Shawn Jennings' inspiring story is one of determination, strength, love and overcoming adversity that reminds us that anything is possible when you set your mind to it and believe in a dream. It also emphasizes the necessity for continued support for research into finding a cure so people, like Shawn, might have the opportunity to walk away from brain and spinal cord injury.
Rick Hansen, C.C.; O.B.C.

President and CEO, Rick Hansen Institute

"Although the book focuses on Dr. Jennings' illness and recovery, the narrative is interspersed with vignettes of some of his most memorable and determined patients - all recorded from the perspective of a doctor who is now dependent on the medical system for help, and, at times, survival. Dr. Jennings' book will be an inspiration to other people whose lives are shaken by devastating illnesses, an eye-opener for the health professionals who care for them, and a testimony to the recuperative power of love."

Claire McIlveen
Weekend and Science Editor, The Chronicle-Herald, Halifax, NS

"I read a great deal - literally hundreds of books every year and Shawn's story is simply incredible. All the time I was reading the book I kept asking myself could I ever get through something like this with this amount of courage and then I vowed I would make sure I didn't live life with things undone."
Heather Erb Campbell

Executive Director, Heart & Stroke Foundation of New Brunswick

---

"Locked In, Locked Out is an important book for all of us to understand the challenges stroke survivors and their families face. This book offers hope and
inspiration, and clearly demonstrates that love and determination make a tremendous impact in recovery."
Patricia Nicholson RNBNMember Canadian Association of Neuroscience Nurses

---

"Locked In, Locked was published by Dream Catcher (Canada). Visit their website at http://www.dreamcatcher.nb.ca.

A Funny Thing Happened on the Way to Therapy

by Rhonda Peterson

I need to begin by telling you that I don't get out much. In fact, I've been chained to my computer for so long that I've outgrown my pants and can't get to the store to purchase a larger size. Over the winter, I have gained weight and seem to have shrunk due to the natural aging process so that very soon I will resemble the shape of a beach ball! This lack of exercise, except in my right hand that has developed a severe case of carpel tunnel from typing, pole-vaulted me into changing my routine.

I finished formal stroke therapy years ago but decided that any type of exercise could be called "therapy for the soul and body" and that the word "therapy" may psychologically motivate me enough to actually do it. Yes, I needed therapy. And probably a little professional psychological therapy as well! I could almost hear a psychologist asking me, "And how long have you been carrying on this relationship with your computer?" And answering " Is there a patch I can wear for computer withdrawal?"

Pulling on my big heavy winter boots was quite a chore as I've gained so much weight I can't even see my feet. I dressed in the appropriate traditional winter garb known to all Midwesterners as "the layered look" and trudged out into the snow. Yes siree Bob, I'm going to loose weight and see what's happening in the outside world.

"Wow! It sure is frosty out here. Better keep those extremities moving or I'll freeze to death," I muttered. "I can see my breath in the air! By Jiminy, it's bitter cold out here! I've heard on the news that exposed flesh will freeze in less than five minutes and my face is open to the elements! I better get back inside the house!"

Stomping the snow off my boots as I entered the door and removing my hat, scarf, coat, gloves, earmuffs, and five sweaters I figured that dressing, and undressing was about all the exercise I could manage on the first day. Maybe tomorrow I'll try walking to the end of the driveway. Maybe by next month I'll be able to walk to the end of the block. Ah, heck with it, I think I'll stay in and clean the house instead. Vacuuming, dusting, scrubbing floors, and doing laundry can be considered therapy too! I'll start that right after I peek in the office to check my e-mail.

Website Review

By Barbara Layne

The website for March is from the University of Iowa Hospitals and Clinics. http://www.vh.org/adult/patient/neurology/faq/strokетreatment.html

This is a link to a specific page answering questions about treatment for strokes. My strokes were linked to the severe migraines that I suffered most of my adult life and I am always looking for information. I found this article from the Virtual Hospital - a digital library of health information

There is a great deal of information at this website on all health topics. Being a stroke survivor has put me on a quest to find out about my particular type of stroke and other health information. It is absolutely amazing how much knowledge I have gathered in these last three years!!!

Editor's Note: Be sure to check out the links at the top of this webpage for additional health information.

Biography: Tony Boxer

My name is Tony Boxer. I'm 56 years old. I'm a software engineer, and am (now) self-employed as a computer consultant. At the time of my stroke I was a Senior Staff Engineer at a disk drive manufacturing company. I also am a principal in a software company that has created software for Real Estate agents to use on handheld computers. I'm an optimist, and my personal philosophy is to make someone smile and laugh every day.

I've had various medical issues most of my life. I've had a form of Reactive Arthritis called Reiters Syndrome since I was 17. It causes my immune system to periodically attack different joints and connective tissues. As a result, I have fairly little defense against infections. I also get migraine headaches, have a hiatial hernia, stomach ulcers, acid reflux disease, a torn retina in my left eye, and other things to make life interesting.

In March of 2000 I was diagnosed with a brain tumor. That's a fairly long story, so if you're interested you can read it at http://www.anarchive.org/tony_b.htm. A quick synopsis: The tumor is pressing on my brainstem, and since I have a history of serious infection following surgery I chose to have my tumor treated by Fractionated Stereotactic Radiosurgery at Stanford University. The radiation is working because the tumor is dying. The tumor left me with impaired hearing and balance, but otherwise no serious side effects.

Then, on October 10, 2001 I was at work when I got a slight headache on my left side and suddenly felt like I was drunk (and I don't drink). I had trouble speaking; my vision was impaired, and other typical signals of a stroke. Unfortunately, I didn't recognize the signs, so I got into my car and drove home. It was 4:30, so I had enough sense to not drive the freeway during rush hour, but the trip home was interesting.

When I got home my wife called 911, and over my objections, off to the hospital I went. I was sent home at about 9:30 PM, having been told I had experienced a TIA. About three hours later, I began to sweat profusely and have uncontrollable spasms in my left arm and leg. I woke my wife and told her to get me back to the hospital. As we were walking across the parking lot, I collapsed and she had to drag me into the ER. A full-blown brainstem stroke was in progress.

This was my introduction to the world of brainstem stroke survivors. I initially had very little use of my left side, including facial and speech issues. I had difficulty swallowing, major balance problems (I'm sure the tumor damage contributed) and incontinence problems. I was supposed to go to a rehabilitation hospital for 2 - 4 weeks of therapy, but I guess I'm an extremely lucky brainstem stroke survivor since I was sent home after two days because I could get out of bed and walk myself across the hospital room with a little support from the bed table.

Since the stroke I have regained almost full use of my left side. Being ambidextrous probably helped quite a bit. I had to teach myself how to use my left hand again, and how to type. I still make mistakes typing, and sometimes experience "brain freeze" when I can't think of a word or remember something. You couldn't tell I am a stroke survivor by looking at me unless I am tired. Unfortunately, I get tired very easily now, so I take lots of naps during the day.

I still need a cane to help with my balance but I'm working on not using it and can get around without it as long as there are things I can use for correcting my balance (like walls, chairs, cars, people, etc). I still have trouble swallowing, so have to dip my chin down when swallowing, and of course I have to control my fluid intake when I

know I'm going to be away from home for any time.

I think a positive attitude, a good sense of humor, and a refusal to give up has been what made my recovery a success.

Biography: Shawn Jennings

I was a 46-year-old male physician, when I had my brainstem stroke. I was subsequently 'Locked In' for months; as many of you know, that means paralysis on both sides of the body, no speech or swallowing ability, and no facial muscle movement. The eyelids offered me my only voluntary movement. My cognitive ability was fine.

The stroke arose from a dissection (tear) of the inner lining of my left vertebral artery. That tear arose from a simple whiplash two weeks before. I avoided an accident-a truck pulled out in front of me. I thought nothing of it, until, that afternoon an ache arose from the back of my neck. I assumed it was a whiplash, and treated myself over the next two weeks with heat and Advil. (You know-'Physician heal thyself'-yeah right!)

A week prior to my stroke, I had a bout of severe vertigo, and ended up in Emergency. I have a problem with chronic fluid in my middle ear, and the Doc thought this was the probable cause of the vertigo. I mentioned the whiplash, and asked if he could see a connection; he couldn't and neither could I. But I felt uneasy and secretly wished for more investigation, but I was a patient now, so I kept my mouth shut.

I continued to be a bit off-balance, despite having my ear drained, so one day while I was seeing my patients in hospital, I mentioned my symptoms to a neurologist friend of mine. He did a cursory exam and thought something wasn't quite right either. He thought we should get a CT scan.

It probably wouldn't have shown anything, but in any case, we were not aware of the urgency, because three days later I had my stroke.
In Emergency, bad luck continued to follow me. I lapsed into a coma just as I entered the department; if I had been awake, I could have told them I was having a stroke. Bad luck-the first CT scan was negative, because I was so deep in coma, my head shook, resulting in a poor picture.

Hours went by while they watched blood results, and took other tests; hours my brainstem could ill afford, as it was being starved for blood and oxygen.

After a few hours, a neurologist came, declared me locked in, and arranged an arteriogram, where upon tPA was given. It opened the artery 25% before it started to bleed, and they had to abandon the procedure.

I as given Heparin, sent upstairs to ICU, but prognosis was poor: death was a definite possibility. I did awake-'locked in'-but alive.
I spent ten months in rehabilitation. And as I'm writing this, it will be my fourth anniversary in May.

I can eat everything now-I have to be careful, but I can eat! I speak a sort of 'Drunkenese', as though I've had a few, with low volume. My left arm is functional; my right spastic, but I can write with it. My trunk is spastic. After two years I finally took my first step! And it continues to improve. I still need a minimum assist with the walker, as my balance is not great.

I wrote a book-"Locked In Locked Out"-to create something positive out of a negative situation. I try to point out to my fellow survivor that bad things happen-it isn't fair, but there is no fairness in this world. I try to convey to them, to accept, but never, ever, give up.

The Stroke Network is a registered 501(3)c non-profit organization. We are an on-line stroke support organization and are available to everyone worldwide. Since 1996 we have provided stroke support and information to nearly 10,000 people and to hundreds of thousands of visitors to the site. The Stroke Network is the homepage for a network of several other smaller web sites owned by The Stoke Network Inc

Copyright © March 2003
The Stroke Network, Inc.
P.O. Box 492 Abingdon, Maryland 21009
All rights reserved.

This newsletter is distributed free of charge via email monthly. Visit the website to subscribe.