http://www.strokenetwork.org/

February 2004

Welcome to the February issue of StrokeNet.

Steve Mallory explains The Stroke Network community outreach program with Good Samaritan Hospital in Baltimore Maryland. David Ray shares the story of a ferry, which capsized in the harbor. Joe Flasher writes about Peripheral Arterial Disease.

Stroke Network Information Sites are described to help readers find stroke information they can use. Joe Flasher reviews the product "The Fork" which enables one handed eating. Janice Rodriguez locates several sites, which address the issue of Music as Healing Therapy. Featured biographies are Susan Cotter Marshall and Don Williams.

Have a good read.

Lin Wisman, Editor
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Organization Highlights

By Steve Mallory

January has been an especially cold and snowy month. I hope that everyone has had his or her heat up high. Spastiscity usually becomes worse in colder weather and can become quite a burden!

We begin the month of February by welcoming our new friends from Good Samaritan Hospital in Baltimore, Maryland. Good Samaritan is the hospital where I received rehab, after my stroke in 1994. For those of you who do not understand what is going on, our organization chose Good Sam for its community Outreach Program and donated three new computers to their stroke ward, which were recently installed.

They will acknowledge the contribution with a ribbon cutting ceremony this upcoming week. Stroke survivors and their caregivers will have access to the computers while receiving inpatient care and going through their rehab therapy. Hopefully, the computers can be used by them to help them understand that people, like the members in our organization, are here on-line, and can assist and support them through their journey in the life of a stroke survivor or stroke caregiver.

We all learned AFTER our discharge that this community exists on-line and that local resources are not necessarily an option once settled back at home. We also would like to give them the capability of learning of some of the software and assistive technology resources that will potentially be available to help their transition into independence and with their neurological rehabilitation.

One of the objectives of our organization is to help develop the ways that computers can become valuable tools to hospitals with rehabilitation facilities and possibly assist the recovery and stroke support for their stroke patients and the families of the stroke survivor.

We have a position open for someone with technical abilities to screen and add articles about the latest stroke news, our Newsfeed. This job requires a person with the basic understanding of how to perform basic Internet commands. It will require approximately one to two hours per week of volunteer service.

Please use the Volunteer Request form at http://www.strokenetwork.net/questions/volunteerrequest.htm if you are interested in this position. You should refer to the request in the February newsletter.

Steve Mallory
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Life in New Zealand with a Stroke

By David G. Ray

This morning I went for a short walk to the beach just a few steps from our house seeking inspiration for a subject to write about given that the Lower Hutt Stroke Club is in recess for the Christmas/New Year period. A very strong northerly wind was blowing, a wind which gives Wellington its reputation as "The Windy City". As I looked over the beautiful harbour I was reminded of the morning of April 10 (the day before my wife's birthday) 1965. On that morning, in a horrendous storm, the interisland ferry "Waihene" capsized with terrible loss of lives. ("Waihene" means "woman" in the Maori language.) What follows is a personal account of that day.

The "Waihine" was one of two passenger ferries, which sailed overnight between Lyttleton, the port near Christchurch in the South Island and Wellington in the North Island. It was a modern vessel with modern navigational aids. It left Lyttleton on its 11 hour journey at 8pm due to arrive in Wellington about 7am on 10 April. During the night severe hurricane force winds arose which reached its peak of more than 120 miles per hour just the "Waihene" entered Wellington Harbour.

At home the roaring of the winds awoke my wife and me early and being a keen public servant, I caught my usual bus into Wellington from Eastbourne. Enid, my wife, took our school aged children to school at 9am and on returning home, listened to the radio which gave out the news that the arrival of the "Waihene" would be delayed but all on board were safe. However, on the advice of the schoolteachers, she went back to the school to bring our children home again. Enid then braved the strong winds and walked down to the sea front. She saw through the mist and rain that the ship was across the harbour but on its side, the other side being under water. She rang me at work to tell me not to believe the radio broadcasts and I decided to get the first bus that I could back home. News broadcasts still said that the ship was OK. You can't believe everything you hear on the radio,

By this time the road to Eastbourne had been closed by the strong winds and heavy large waves but eventually I heard on the radio that large vehicles, including buses, were getting through. Immediately I left my office and went to catch the bus, which was in fact just leaving. It took the bus over 3 hours to get to Eastbourne, a journey that normally took 40 minutes. On the way army trucks carrying stretchers and other rescue equipment passed us. When the bus reached the sea front we could see that the harbour was extremely rough. By this time the reports on the radio were giving accounts of the seriousness of the situation. Lifeboats full of passengers had been launched from the stricken vessel and were landing at Eastbourne and the beach at Seatoun across the harbour from Eastbourne.

When I got home and took a look at the situation I could see that the ship was on its side. Lifeboats had come ashore but some had capsized in the heavy surf and passengers were tossed into the sea.

The police asked me to patrol the shore next to were we lived in case any passengers came ashore there and this I did. I will never forget finding the body of one elderly man, stripped naked by the raging waves. Helped by other men, we called the police who arranged for the body to be removed. Later we found the body of a small child and this has had a profound effect on me till this day. That night the army brought huge searchlights onto the beach to help with the search. The next day the wind had died down and it was hard, looking at the calm seas, to believe the tragedy that had taken place the night before. But the sight of the huge ship lying on its side across the harbour reminded us of this. The sea can be very cruel even in the safety of a harbour.

Fifty-one people of the 735 passengers and crew on board lost their lives that morning.

Peripheral Arterial Disease And Stroke

By Joe Flasher

Why are we considering Peripheral Arterial Disease (PAD? Because this disease can cause a stroke or a second stroke, or a stroke can contribute to this disease developing. Peripheral arterial disease may not sound familiar, but it affects 8 to 12 million Americans, and is one of a host of cardiovascular disorders that go beyond the heart. New data from the American Heart Association's Heart Disease and Stroke Statistics - 2004 Update reveal the burden of these often-chronic diseases.

Some of these disorders include congestive heart failure, peripheral arterial disease (clogged vessels

in the arms and legs), end-stage renal disease and venous thromboembolism (blood clot).

For the purposes of this article we are only concerned with Peripheral Arterial Disease. Peripheral artery disease (PAD) affects 12 to 20 percent of Americans 65 and older (4.5 to 7.6 million people). Despite its prevalence and cardiovascular risk implications, only 25 percent of PAD patients are undergoing treatment. PAD is a condition similar to coronary artery disease and carotid artery disease. In PAD, fatty deposits build up along artery walls and affect blood circulation, mainly in arteries leading to the legs and feet. In its early stages, a common symptom is cramping or fatigue in the legs and buttocks during activity. People with PAD have a higher risk of death from stroke and heart attack, due to the risk of blood clots

About 1 in 3 patients with PAD may experience intermittent claudication -the classic symptom used in diagnosing PAD 4,5 -most patients with PAD are asymptomatic (without symptoms) 6 Intermittent claudication is defined as ischemia in the lower extremities, experienced as an aching pain, cramping, or numbness, typically in the calf.. These symptoms are usually induced by walking and relieved by rest. Symptomatic or not, patients with PAD often have widespread arterial disease and therefore have an increased risk of myocardial inraection (MI), stroke, and other thrombotic events. 8 Studies indicate a 1% to 3% annual incidence of nonfatal MI in these patients, with mortality rates approximately 2.5 times greater than those of the general population. 8 Cardiovascular diseases are responsible for about 52% of deaths in the general population and up to 75% in patients with PAD. 8

Recognition and management of the risk factors in patients with PAD are of extreme importance. The risk factors for lower-extremity atherosclerosis include, but are not limited to, age, male sex, hyperlipidemia, and diabetes mellitus (DM), hypertension, and smoking. Additional factors to be addressed include physical activity and diet.

"Although patients with PAD have widespread atherosclerosis, atherothrombosis (formation of a thrombus superimposed on an atherosclerotic plaque) is primarily responsible for the arterial ischemic events such as MI, stroke, critical leg ischemia, and cardiovascular death. Clinicians need to treat both the increased cardiovascular risk and the symptoms, if present. Platelets have been shown to demonstrate shortened survival but increased activation in patients with PAD. 8

Antiplatelet therapy has been shown to reduce the risk of serious vascular events (MI, stroke, vascular death) by about 25% in patients with manifestations of atherosclerAosis, including PAD.

We have considered drugs used for cholesterol, Hypertension in previous articles. Those drugs used in diabetes mellitus are numerous and can be considered in another article.

The use of tobacco contributes the most risk of developing PAD. 3 It has been documented that smoking decreases patient survival and longevity of vascularization procedures and contributes to the progression of arterial disease.

Smoking cessation not only reduces the risk of death from vascular causes and MI, but also slows the progression to leg ischemia in patients with PAD. 4, 5 Estimates indicate that approximately 80% to 90% of patients who present for percutaneous or surgical revascularization due to ischemic rest pain, severe claudication, or gangrene are current smokers. 3 It is also estimated that the 5- year mortality rate for patients who continue smoking is about 40% to 50%. 3 Additionally, smoking cessation may reduce the progression of the disease from asymptomatic to stable claudication to ischemic rest pain and finally to amputation.

PAD is a serious disorder that is now considered a coronary heart disease (CHD) risk equivalent. Thus, patients with PAD carry a risk for major coronary events that is equal to that of patients with established CHD. Recognition and management of the risk factors in patients with PAD are of extreme importance. These factors include age, male sex, hyperlipidemia, DM, hypertension, and smoking.

The use of tobacco is the most important cause of PAD. It has been well established that smoking contributes to the progression of arterial disease, as well as decreasing the longevity of vascularization procedures and patient survival.

Because patients with PAD are at a significantly increased risk for cardiovascular events and death, antiplatelet therapy should be strongly considered in the management of these patients. Although the data are not strong for the use of aspirin, aspirin is still considered the primary antiplatelet drug for patients with PAD. Currently, clopidogrel is the only antiplatelet medication that has received FDA approval for the reduction of atherosclerotic events (MI, stroke, and vascular deaths) in patients with atherosclerosis documented by recent MI, recent

stroke, or established PAD. A formal exercise program is considered the most effective non-pharmacologic therapy for claudication.

I cannot emphasize the exercise and not smoking enough. It is extremely important to the prevention of stroke and other vascular problems

If there are any questions please notify me through the StrokeNet Newsletter.

Sources:
Pharmacy Times
American Stroke Association

Joe Flasher is a Pharmacist.

Stroke Network Information

This month we draw special attention to stroke information on The Stroke Network website. If you have specific questions you may find the answer. It is also a great place to extend your stroke knowledge.

The Information section can be found through the home page http://www.strokenetwork.org Click on the Information button. This information is also be found by accessing http://www.strokenet.info/.

Information is divided into the following sections:

Newsletter This is an archive of the monthly newsletter you are now reading, StrokeNet. Come here to read back issues from 2003 and 2004. A printable version in pdf format is also available. There is a search feature if you are trying to find information, but do not know in which issue the article is located. Alternatively contact the editor to help you find back data. She can also locate info, which was published before 2003.

Library This is a collection of web casts. In most cases transcripts are also available. Included is general stroke information. Subcategories are Stroke and TIA Overview, Stroke Risk Factors, Stroke Prevention, Stroke Treatment and Recovery, and Current Research on Stroke.

Specific items are featured. For example "How to Spot a Stroke" and "High Blood Pressure and Diabetes: Treating a Dangerous Duo."

In addition to general data on strokes there is access to data on Women's Health, Men's Health, and Healthy aging.

Bookshop Many readers are interested in locating books about stroke. They may be looking for specific help such as available assistive technology, or particular health information. They may be seeking reflections from stroke survivors. You will find a listing of books, which other stroke family members have found helpful.

Click the Buy Now button next to be book, which sounds interesting to link to Amazon.com's website. The book title will appear. Click on the title here and you will access information including both editorial and customer reviews. The customer reviews are most helpful as the reviewer is often a member of the stroke family.

Articles There are many articles available that can answer specific questions and expand your knowledge. Subcategories include Stroke, Brainstem Stroke, Stroke Repair, Central Pain, Stroke Caregiver, Assistive Technology, Disability, Prescription Drugs, and Traumatic Brain Injury

Product Catalog Products, which members have recommended, are listed. Links to manufacturers websites and prices are provided. There is a special section, which lists books that have been written by Stroke Network members.

This is a good place to come if you are looking for any information regarding stroke.

Product Review: The Fork

By Joe Flasher

When I first had my stroke, I lost the use of my right side. Not having the use of both hands proved to be a challenge and a humbling experience. I needed someone to cut my food at meal time, help me get dressed and many other everyday tasks. It was frustrating and humiliating. I frustrated everyone trying to help me by trying to do these jobs myself, when it would have been much easier to let them help me. I frustrated my wife and my inabilities frustrated me. Two frustrated people in the house at the same time is never an easy situation.

This leads me to my review of **"The Fork"**. This product solves one of the stumbling blocks to independence at mealtimes. It allows you to eat with one hand in a socially and personally acceptable manner.
It is absolutely perfect for right or left hand use, having a substantial handle, super lightweight but strong. It is re-usable and dishwasher proof.

I have given the **"The Fork"** to friends, relatives and professionals in the rehabilitation field and they are pleased and surprised that something that looks this simple is actually easier to use than a knife and fork. I even gave it to my 3 and 5 year old grandchildren to try and it was much less problem that a knife and fork.

You can gain complete confidence and independence at mealtimes using **"The Fork"**. It is ideal for people with disabilities such as stroke, hand/arm amputees or arthritis, MS, Parkinson's to name a few.

Here are the instructions for use.
1 Hold the fork upright in the palm of your hand, PRESS DOWN on the food.
2 Roll your wrist towards you to cut.
3 Twist your wrist to pick-up. really that easy.

For information:
http://homepages.slingshot.co.nz/~bmee/
Email: BMee@slingshot.co.nz
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Website Review: Music Therapy

By Janice Rodriguez

This month's topic is music. First, I was interested in how the brain processes music (the science), how that might affect the brain in a stroke (the theory), and finally, could music therapy help stroke survivors to regain skills (the practical). Well, it's a huge topic, and I have no music education or skills other than singing with the radio. (And I lost the singing part in my stroke!) So I found some websites about the topic - it's a little "taste" of the topic, not a "feast!" And, of course, as I always say, some of the information on the Internet is old, incomplete, and just wrong. So be skeptical and always check with your doctor or therapist.

The first website is a article that my cousin sent me, "Brain Health: Music and the Mind." It is a good introduction for the topic although it does not focus on stroke. Another site is an article written by Dr. Oliver Sacks, "When Music Heals." No science or theory; just anecdotes from Dr. Sacks' practice. Check out Dr. Sacks' website also - it is not on the topic but well designed and informative. Now to the science and theory.

There are many scientists and scholars who specialize in the neural functions and music. I found a journal article authored by several German neurologists about the brain dynamics of music perception. The article is sort of readable, so I will paraphrase the discussion and the conclusion of the study.

The main components of music are harmony/melody, rhythm, and language. The test was to measure the differences in the perception of music among several factors: music experience (musicians and non-musicians), mode of listening (attentive and background) and gender. The conclusions were: Non-musicians used the right brain for harmony, left brain for language, and both for rhythm. Women, particularly female non-musicians, used the right brain more than men. But musicians and attentive listeners used the left brain during harmony perception. Background listeners used the right brain. Thus, music perception is a complex process involving different brain structures dependent of many factors.

So remember, that was for "normal" subjects. The next journal article is about people who have brain damage (usually from a stroke) in the left or the right brain; the study was to see if this damage affects the listening of music. One of the words the

journal article uses is amusia - the inability to interpret or appreciate musical sounds. Amusia might extend to impairments in music memory and recognition as well as in singing and the ability to tap in time to music. The statistics from the article: impairments in music processing were found in 62.5% of the patients with right brain damage and 75% of the patients with left brain damage. That supports the conclusion that the ability of listening music can be damaged in both the right and left brain because music processing is based on widely distributed neural networks controlled by individual aspects of musicality and music experience.

Can we as stroke survivors do something to help to regain our musical and other abilities? Probably I have some websites with interesting information about research (Center for Biomedical Research in Music), therapy (American Music Therapy Association.), and one product (Advanced Brain Technologies - this is NOT a recommendation!). All the websites mentioned are listed below. So if you are interested, browse these sites. Have fun and I will see you next month on a different topic.

1 Brain Health: Music and the Mind
http://www.intelihealth.com/IH/ihtIH/WSIHW000/9273/24261/349887.html?d=dmtContent
2 When Music Heals by Oliver Sacks
http://www.bobjanuary.com/hhh/oliver.htm
http://www.oliversacks.com/index.htm
3 The cerebral haemodynamics of music perception - A transcranial Doppler sonography study Evers, et al., Brain, Vol. 122, No. 1, 75-85, January 1999
http://brain.oupjournals.org/cgi/content/full/122/1/75?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&searchid=1073343963226_2221&stored_search=&FIRSTINDEX=50&minscore=5000&journalcode=brain#SEC4
4 Receptive amusia: evidence for cross-hemispheric neural networks underlying music processing strategies Maria Schuppert, et al. Brain, Vol. 123, No. 3, 546-559, March 2000
http://brain.oupjournals.org/cgi/content/full/123/3/546?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&andorexacttitle=and&andorexacttitleabs=and&andorexactfulltext=and&searchid=1073341352851_2117&stored_search=&FIRSTINDEX=0&sortspec=relevance&volume=123&firstpage=546&journalcode=brain
Home page link: http://brain.oupjournals.org
5 Center for Biomedical Research in Music
http://www.colostate.edu/depts/cbrm/
6 American Music Therapy Association, Inc
http://www.musictherapy.org/
7 Advanced Brain Technologies (ABT)
http://www.advancedbrain.com

Biography: Susan Cotter Marshall

I had my stroke on Ash Wednesday, (Feb. 21st) 1996. I was at work when it happened, and because of some basic medical knowledge, I knew what was happening. I had gone to the copier and started to feel like I was going to faint. I walked into the break room, heard a "rushing" sound in my ears. I told my boss to call 911 and my husband; then I fell over to my left, I couldn't swallow and my vision was messed up. I knew I had had a stroke.
I was brought to our local hospital and I remember arriving, but I don't remember anything else. No tests - nothing. I was then transferred to the University Hospital in our area, where I'm told the "fun" began. I write "fun" because I have no memory of the next three weeks.

My husband called my family together because my neurologist wasn't sure I'd pull through. In the ER the doctors placed a shunt in the front of my skull, put me on a ventilator, and inserted a nasal-gastric tube. I was then sent to Intensive Care. After I was weaned off the ventilator, I had a tracheotomy, and a more permanent feeding tube called a "peg." Everyone knew I was going to pull through when I ripped out everything; the shunt, trach and all IV's. Of course I had to be placed in restraints after that, and apparently I wasn't amused.

This whole time as I wrote earlier, I have no memory of. What I do remember are what I call "dreams." In my head I was everywhere but a hospital. (Must have been the morphine!)

After I "came to" I was transferred to rehab. At this point I couldn't even sit up without help, couldn't speak because of the trach, and was getting all my nourishment through a tube. My days consisted of two hours of physical therapy, two hours of speech therapy, and two hours of occupational therapy. They were all relentless and I'm better off for it today.

My entire hospital stay, including rehab, was two months and two days. I've relearned how to walk, talk and write. I came home in a wheelchair, which lasted about a month; I then used a cane, and even though my balance is gone I don't use any type of aid when I walk now. It has now been almost eight years. I'm unable to drive or work outside my home. My independence has been lost and I think that's one of the hardest losses I've faced. I am alive though. A decent sense of humor has helped - immeasurably.

I'm married for the 2nd time and have two children, Lisa 21, and Corey 18, by my 1st marriage. I have two labs also - mother and son, yellow and black respectively.

Biography: Don Williams

My husband Don, who is 70 yrs old, went into the hospital in April 2003 to have bi-lateral knee replacements. The next day he suffered a severe right brain stroke that left him paralyzed completely on the left side of his body. He was hospitalized for 3 months and then 3 wks at a rehabilitation hospital followed by 3 weeks of outpatient therapy and then we were on our own with wheelchair, walker, tub bench and raised toilet.

What I did I learned on my own. While he was hospital I stayed with him 24 hrs a day, with relief from our adult children. I always made sure to sit on his left side so it would force him to try and turn his head. I used a knee mobilizer machine 6 hours a day for 3 months to keep his knees from locking up. I painted his left index finger with nail polish and also his big toe on the left foot and constantly made him aware of the left arm and leg and worked them all the time. I kept a journal of every doctor who came in on consultations. I knew every pill they gave him and when.

He couldn't swallow for 6 weeks so he had to have a G tube implanted. To keep him hydrated and less frustrated I asked that he be allowed to use a suction machine with sponges to keep moisture in his mouth but would not allow him to swallow. Touching a person in stroke is so very important. Massages were a great therapy both for of us and I learned to do massage from a massage therapist from whom I purchased aroma therapy massage oils. We would get him up every day onto a cadillac wheelchair and take him on walks throughout the hospital, even when he hated it.

After 2 months the Doctors brought in a physical therapist who got him up with a walker and in the next month he walked from 3 steps forwards and 3 back to 50 ft, then 100 ft, then 300 ft and finally 500 feet before resting. When he came home from the rehab hospital I had investigated taking him to a doctor who practices stroke care using a hyperbaric chamber treatment. However the distance was too great, and so I went online again and found a doctor locally who practices Neurolink, which is non-invasive stroke treatment. Within 2 weeks he was walking and swallowing, and was more responsive.

I took him gradually off of the mood elevators that his doctor had him on, which were making him more depressed and zombie like and opted to give him St. Johns Wart for depression and other nutritional supplements from the health food store. Finally, I enrolled him in a local gym with a trainer and now he walks with only the assistance of a cane. He is not losing weight any longer and is getting stronger.

We returned the rented wheel chair and life is getting back to normal, because I will not let him or myself dwell on what happened, but give all the credit to God for his awesome healing powers. We live every day for today, and refuse to worry about tomorrow or yesterday. Strokes can be devastating to the affected as well as to their family members. Learning everything you can about stroke, being in support groups and daily prayer make this frightening illness less frightening. Sincerely, Cynthia Williams.

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

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