



<http://www.strokenetwork.org/>

May 2003

May is American Stroke month. Stroke is a leading killer and disabler across the world. We challenge each of us to find ways to increase stroke awareness.

In this issue Steve explains changes at the Stroke Network website. David Ray shares the story of a tragedy, which happened 35 years ago in New Zealand. Dr. Ted Cole explains Hyperbaric Oxygen Therapy and Stroke. He founded Cincinnati Hyperbarics.

Perry Davis raises the question of a Stroke Network pen pal program. Next, Rhonda Peterson reminds us of the basic facts of stroke. She completes her writings with two brief reflections. Michael Roberts shares the role of play in recovery. The website of The European Stroke Initiative is reviewed. Mike Sutton and Gloria Kamenske have provided bios for May.

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## Organization Highlights

By Steve Mallory

This past month has been very productive. More and more features are being added to our site in hopes of making you feel that this is a worthy support organization, which is worthy of your sharing, listening, understanding and then giving back to the others who require assistance and support.

Probably the biggest improvement has been the addition of the **Quick Links** web page. A member mentioned to me how difficult it is for him to negotiate the dropdown menu. Nobody has mentioned this before as being an obstacle to navigating the web site. Now, you can just click on the Quick Links button on the homepage and then click on the hyperlink of your choosing. The dropdown menu is nice for navigating to all the important web pages on our site but now hopefully everyone will have easy access.

- This just emphasizes the importance of needing your feedback. If I can I will do whatever I can to accommodate you and your limitations.
- The next addition has been a brand new message board. It has tons of neat features. One of the cool features is that you can now select your notification method of message board posts, including an emailed daily digest. You can get to know the other members by adding them to your list of contacts and keeping track of them that way. When you register, please take the time then to complete your profile, which includes a bio. If not at registration you can always go back and update it at your leisure. You can add your photograph instead of the cartoon avatar, if you like. You will need the URL for your picture. Just email me and I will give it to you.
- This is how we will get to know each other so please participate. We really need everyone to get involved with the board and post in the various forums. There are several that are specific to stroke survivors and several for our stroke caregiver members.
- Stroke caregivers are probably the most vulnerable to physical and emotional challenges on a daily basis so I have given them the forums where they can share their issues else and hopefully we will all benefit from their experiences.
- You will need to register with the message board before you can post to it. Just use the Message Board link from the dropdown menu or use the quick links. The registration link can be found on the message board.
- Use the Help link found in the Tools tab of the board in order to get to know all of the available features.
- Several people, including myself, have been experiencing difficulty with the message

board login. This is not something that I can fix myself. Technical support for our message board, at a very high level, is busy correcting the problem.

- O Our next new site feature is the addition of chat links to the message board. The nice thing about it is that you can click the "Who is chatting?" Link and take a peak at who is currently in the chat room and then sign-in and join them if you want. You now do not need to enter the room in order to find out if anybody is in there.
- O I have also added a small download program, free, that lets you sign-in to the chat room when you are on-line and then minimize the chat room window. You can forget about being in the chat room because you will hear it when somebody else enters the room.
- O The special feature about this program is that the chat room window does not actually minimize but it reduces to the traybar next to the computer clock.
- O You do not need to have a browser window open, chewing up the computer resources! The program keeps the chat room opened for you and runs with a minimum load on the computer.

My hope is that the addition of these new links, plus the new download program, will greatly increase the opportunity for our members to meet and discuss issues in real-time.



## **Life in New Zealand with a Stroke**

By David G. Ray

The southern part of the North Island and all of the South Island are both enjoying a sort of Indian summer. The weather has been sunny and warm and our stroke survivors have enjoyed quite a few outings such as picnics and walks in our parks. My wife, Enid, and I took off to the South Island for a family wedding and funeral. I will cover this trip in the next one or two newsletters. However one outing made by the Stroke Club during our holiday was to Pencarrow Lighthouse eight kilometres from Eastbourne where we live.

Although the group traveled by bus the seven kilometres to the lighthouse on a sunny calm day, it

was just the opposite weather conditions thirty-five years ago on the 9th April 1968. Enid and I were living by the beach in Eastbourne (where we still live) with our four children. We awoke that morning to gale force winds, which lashed against the sea wall and our house. Our windows facing the gales moved in and out, threatening to break. I took the bus to work, a 15 kilometre ride to Wellington but really I should have stayed home. When I got to work I heard the radio broadcasts announcing that the interisland ferry "Wahine" had floundered at the entrance to Wellington Harbour in the extreme conditions - winds of over 130 kms.

Because Eastbourne was being battered by the gales I decided to return home and did so on the first bus. By this time the "Wahine" turned on its side and the hundreds of passengers had either boarded lifeboats or had been forced to jump into the sea. Although some lifeboats landed on the Wellington side of the harbour, two were forced onto the Eastbourne side. One of these was dashed against the rocks throwing out passengers. I arrived home from work and made sure the family was safe. Then I assisted the police search. All I found were two bodies, one of an elderly man the other of a small child. All told, 53 people lost their lives that day.

There is a memorial to those passengers who perished at the end of the road to Eastbourne. A similar memorial has been placed on the Wellington side of the harbour. Services were held to remember the day and some of the survivors were present to pay their respects to those who died. We all have to endure tragedy of one sort or another in our lives but we also have many periods of happiness. Enid and I had a wonderful three weeks touring the South Island and in the next two months or so I will tell you all about it.



## **Hyperbaric Oxygen Therapy and Stroke**

By Dr Ted Cole

Hyperbaric Oxygen Therapy (HBOT) has been around for a while. The first chamber used to treat patients was constructed in 1662 by Henshaw. And yes, that date is correct, making it almost 350 years old. Oxygen was not added to the chambers until more recently, but in the 1700's and 1800's chambers were being used as surgical suites due to the higher rate of positive outcomes.

In more recent times, HBOT has been mainly used by the military and diving industry. As a result, there has been reluctance on the part of the medical

community to accept it for many conditions. However, there is a great deal of scientific information available on this procedure, and stroke is one of the conditions that it treats very well. But first, let's describe HBOT and what it does. HBOT treatments proceed by placing you in a chamber, and then increasing the atmospheric pressure. During the treatment you breathe pure concentrated oxygen. This saturates the tissues with oxygen, and reverses any areas of hypoxia (low oxygen levels). As a comparison, the average person breathes in about 6 pounds of oxygen a day. During a single hour of HBOT, a person will take in about 3-4 pounds of oxygen, which increases the oxygen content of the tissues by a factor of 10-15. This has some dramatic and extremely beneficial effects, not only for stroke, but also for a wide variety of conditions.

Some of the effects are to promote the growth of new blood vessels, decrease swelling and inflammation, deactivation of toxins, increases the body's ability to fight infections, clears out toxins and metabolic waste products, and improves the rate of healing. In stroke, the practical effects are to help heal any damaged brain cells around the site of the stroke (this is known as the penumbra). It helps get rid of free radicals caused by the stroke, reduces swelling and pressure on the brain, helps stop bleeding if present, and helps stimulate the growth of new brain cells. This translates into improvement or recovery of speech, strength, coordination, memory, cognitive skills, walking, and other areas that might have been damaged.

Recovery from stroke can be dramatic, and we have seen patients become fully functional. The sooner HBOT is started after the stroke the better, but we have gotten good results even after 15 years post-injury. Results for each individual are unpredictable, and depend on a large number of factors, such as severity of the stroke, location, length of time since the stroke, etc. We also use a number of other therapies that complement HBOT, which provide even better results than HBOT alone. Like other conditions, a multi-therapy approach is best.

We typically treat each person 1-2 times a day for 1 hour each treatment, for a total of 40 treatments. Before further treatments can be given, the patient must wait at least 4-6 weeks. Then, another set of 40 treatments can be given. After this point, we usually limit treatments to 20 at a time. Some people will respond well to one or two sets of treatments, but most can count on getting from 100-200 total treatments for best results. We follow each patient's progress, and determine therapy based on his or her response.

There are two types of chambers, multi-place and mono-place. In the multi-place, more than one person can be treated at a time. In addition, the atmosphere inside the chamber is air, and oxygen is delivered through a hood. In the mono-place, only one person can be treated, and the entire atmosphere is oxygen, so no hood is required. There is no difference in results between the two, and the main reason to have both is patient mobility. One simply lies down on a cot for the mono-place, and it is much easier to get into than is the multi-place chamber. There is a wide variety in quality and comfort between chambers. Some indications about the chamber can be the following: ask about the age of the chamber, if they've been bought second hand or salvage, and if they've been reconditioned before being able to be used.

The main safety consideration is fire. Remember, this is an oxygen environment, and there are strict rules about using the chambers. We require that all people entering the chambers be wearing 100% cotton clothing, with no jewelry or other items on. You should be given a list to follow before having a treatment. The main side effect is due to ear and sinus problems. You must be able to "pop" your ears, or damage can occur due to the pressure. It's much like going up in an airplane. If you're unable to clear your ears, steps can be taken to remedy this. All in all, HBOT is extremely safe and well tolerated with very few complications. It also should be a comfortable experience, both inside and outside of the chambers. The person administering the therapy should be a Certified Hyperbaric Technician, and I recommend that you use a center with a physician on site. The best way to find out if there is a chamber near you is to do a web search, using either "HBOT" or "Hyperbaric Oxygen" as your search word.

When all is said and done, the best place to be after a stroke is in an HBOT chamber. If I should ever suffer one, that's where you'll find me.

Read patient testimonials at <http://www.cincinnatihyperbarics.com/patienttestimonials.html>

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### **Are Pen Pals a Good Idea?**

By Perry Davis

I am a volunteer here, and my primary responsibility is to write people that sign the guest book. I have been asked about

whether we offer pen pals at our website. So O'Fearless Leader, (S. Mallory) and I discussed it briefly. I plan to post this as a Message Board topic, so I can feed your feedback. My first thoughts on this were:

**Pros:**

I remember wanting one as a new member. I was not at the point where I felt I wanted to talk publicly. I wanted to start with a pen pal, one-to one, and try sharing my story. Maybe that would ease me into chat and Bulletin Boards. The post-stroke life was new to me, and I was trying to get on with it, the best I could.

**Cons:**

Does it encourage isolation? Would it slow our individual journeys and the stroke network? Probably. I was stuck, until I started actively participating, and have made big strides since then.

Email me at [PDavis@strokenetwork.org](mailto:PDavis@strokenetwork.org).



### Facing Stroke Head On

By Rhonda Peterson

#### What is a STROKE?

A - golf swing

B - a cerebral vascular accident (CVA)

C - a swimming event

#### Stroke is a BRAIN ATTACK!

The third leading cause of death in the US. Someone suffers a stroke every 53 seconds. Approximately 750,000 people are affected by stroke each year in the US. Stroke affects ALL ages, ethnic groups, and both males and females. Stroke kills over 167,000 people a year. Approximately 4.6 million stroke survivors are alive today.

#### Types of Strokes

Ischemic or Occlusive - a blockage of blood flow to the brain caused by a clogged blood vessel  
Hemorrhagic - a ruptured blood vessel

#### Recovery is Ongoing

#### Team approach

Immediate and continuous therapy  
Affects the emotional, financial, social, spiritual, medical, and physical aspects of the survivor, spouse or caregiver, family, and their entire infrastructure.

#### Warning Signs of Stroke

Trans Ischemic Attacks -TIA's  
Sudden numbness or weakness of the face, arm, or leg especially on one side of the body  
Sudden confusion, trouble speaking or understanding  
Sudden trouble seeing in one or both eyes  
Sudden trouble walking, dizziness, loss of balance or coordination  
Sudden severe headache with no known cause

### Turning Deficits into Assets

Everyone has deficits. During the natural course of aging, we seem to accumulate these irritations. Memory- "Where are my keys?" Vision- "This print is too small!" Hearing- "Turn up the volume on the TV." But when Stroke strikes, in many cases, minor irritations become major problems. Within very little time, you may lose the ability to verbally communicate. You may be disoriented regarding language, or sound, or balance. Vision may be permanently affected. The ability to remember and recall general information may become a tremendous lifelong challenge. After this major life-changing event, after the tears, after the rehabilitation, we continue to require helpful hints and brainstorming (excuse the pun) efforts in order to strengthen positive traits and discover new talents called our assets.

### Living with Stroke

I love the holidays! At Christmas time I can't remember what I've wrapped and during Easter I can't remember where I've hidden the eggs! Every day is an adventure.



### Playing to Recover

By Michael Roberts

"When I'm playful, I use the meridians of longitude and parallels of latitude for a seine, and drag the Atlantic Ocean for whales. I scratch my head with the lightning and purr myself to sleep with the thunder." Mark Twain Life on the Mississippi

Another approach to recovery and life in general is to play. I try to play everyday. Recently, I've begun to visit the home of some friends from my stroke support group for what my wife calls play

dates. This terminology brings great amusement to my daughter Allegra who has been earning extra money by baby-sitting while going to school at Barnard. The important thing about play is that it's best not to take yourself too seriously. Our friends Ceil and Dale have a well-appointed home gym, which they've set up to help Dale recover from his stroke. It includes a treadmill, a recumbent stair climber, a recumbent stationary bicycle, several bungee cords and gadgets which Ceil, who is quite inventive, has devised for different rehabilitation exercises.

One of these includes adapting an abdominal exerciser for tabletop ranging of the arms and shoulders. Dale's increased recovery of upper body range of motion from this. I get in more walking, so I'm there to egg him on and vice versa. It's just play. While we're working out we watch videos. I'd catch Hell if I spent too much of the day watching the tube at home but it's OK while visiting friends and getting some exercise. They've got a pretty good video collection. We've watched a couple of Indiana Jones movies lately and some films that I wouldn't ordinarily watch like Noble House and Shakespeare In Love. It's OK. Doing something different is a good way to stretch the mind. I plan on bringing over my copy of the Black hawk serial soon. If that one has you scratching your head, don't worry too much. I haven't watched the whole thing myself yet. Dale's the first person I've mentioned it to who had any idea what I was talking about. How will the Black hawks deal with Stan's evil twin Boris?



## Website Review: The European Stroke Initiative

To discover more about stroke, especially from the European perspective, visit the website of The European Stroke Initiative at <http://www.eusi-stroke.com/index.shtml>.

The European Stroke Initiative is a joint initiative of the European Stroke Council, the European Federation of Neurological Societies, and European Neurological Society. Its aim is to improve stroke management in Europe. The intended audience is both medical professionals and the general public.

In addition to providing basic info such as signs for stroke and basic stroke management information, some interesting categories are included. These include "Reasons Patients Don't Seek Help Immediately" and "Time: Traditional vs. Emerging."

Throughout the site changes in the understanding of stroke are covered.

The stroke prevention section includes articles, which will help the health care professional to understand prevention. The recommendation section includes papers, which outline the current state of medical understanding of stroke.

Links are included to various other stroke websites. There are sites listed within Europe and organizations outside Europe. Here you can located a variety of data and learn what is available.

This is a good site for basic information.



### Biography: Mike Sutton

My name is Robert M. (Mike) Sutton. Better known as slack. I stroked on Feb. 5th 1995. It was on a Sunday morning at about 6:00 a.m. I was using the bathroom and started to feel bad and sat down. I was setting on the commode and all of a sudden I was on the floor. The door was shut to the bathroom. My poodle dog was outside the door having a fit and woke my wife. She called an ambulance. They carried me to the emergency room where they ran tests, MRI etc. and didn't find anything, so they sent me home. Somehow my wife managed to get me in the house. I lay on the sofa all day and never got any better, so my wife called the ambulance again. They took me to the emergency room again. They decided to send me to Memphis, about 60 miles away for another MRI. When my wife arrived I was flailing my arms wildly and the doctor told my wife I had a stroke. During the next couple of days I had two brain surgeries where they removed about 40% of my cerebellum. My memory is kind of fuzzy after that. My wife says I spent some time in critical care and rehab. I was in the hospital and was starting to get depressed. My wife noticed this and told my Neuro that she was going to take me home. After I got home my condition improved. I had some people come to my home and give me PT and speech therapy. With the help of family and friends and God, I made it through. I go to the gym now 4 days a week and drive occasionally but not very often. I am pictured with my wife in the strokenetwork gallery. [Click here to see. \(http://www.strokenetwork.org/memberzone/gallery/gallery1.asp\)](http://www.strokenetwork.org/memberzone/gallery/gallery1.asp)



## Biography: Gloria Kamenske

Gloria Kamenske's stroke took place at 4 in the morning. I had been asleep when somebody called It was

a wrong number. I told my husband something was wrong. He gave me oxygen (which he had on hand for himself) and called an ambulance. I had a left cerebral stroke and a brain-stem stroke. I threw up. The ambulance people took me to a local hospital where the doctor figured I had a stroke. My husband suggested they give me clot busters, but they said they didn't give them for stroke (now they do). This was in 1989 and I was 57 years old. I understand that I had a seizure then. I haven't had one since, didn't have any before, and don't remember it. They did a brain scan to be sure I had a blood clot and not a bleed. Then I was put on a respirator, a feeding tube was inserted and I was catheterized. My husband was told I wouldn't make it. (Wrong).

As the days passed, they were able to remove the respirator and the feeding tube. I couldn't talk at all and swallowing was difficult. I was put on solid liquids and my food was put through a blender. I couldn't feed myself. I stayed that way for about three weeks. A speech therapist worked with me. Suddenly one day when my boss was visiting, I said her daughter's name. Everyone was surprised! After that, I gradually could say more and more until I could speak normally except my voice isn't very good. This is bad for a person who used to have a pleasant speaking voice and a good singing voice. Now I can't sing at all.

I received my A.B. degree with honors from the University of Michigan and my M.A. and Ph.D. from Michigan State University. I always worked in the field of public Health (with the Department of the Army, the Office of International Health and the National Institutes of Health). I am a psychologist. I have traveled to most countries of the World and to just about every major city in the USA. My husband worked for the Voice of America, so we were able to

go on many trips abroad. We have been married 42 years and have no children. I was an only child but grew up with some cousins. My father was Chief of Police in my hometown. Both of my parents have now passed away. We have a cat. Now both my husband and I are retired.

I can no longer walk and am confined to a wheelchair, although I do what I can. I have a personal care attendant who helps me take a shower and dress and does my hospital bed and the laundry and cooks so we only have to warm up food for dinner. I graduated to chopped food and then regular food and beverages, although someone still has to cut up food for me. I can now feed myself. The personal care attendant also serves breakfast and lunch and puts me in bed at night. My husband helps me all he can but since he has had heart attacks, a four way by-pass, several angiograms and now has cataracts. there is a limit on what he can do.

I can no longer drive, nor walk, which bothers me a lot. I was in one hospital about three weeks and then in The National Rehabilitation Hospital about five months. I hear such long stays are unheard of now. When I got out of the hospital I was able to sit up and use a sliding board to get into a wheelchair. I was told that was all the progress I could expect. (Wrong again). Since then I have learned to move my chair myself, lift my affected leg a bit (which helps in dressing) and can transfer in and out of bed, to and from the shower and in and out of the car. So much for the theory that "if you haven't got it in 6 months, you won't get it").

My whole right side is affected. My face looks normal now (it drooped in the beginning), I can move my right thumb and lift my right leg a little. I had double vision at first, but that's gone. That's it. Thank Goodness for the computer and books, which keep me busy and relatively happy. My life has changed a lot and the lives of those around me have changed but there is nothing we can do about it.

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 Stroke Network Inc

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