



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

Welcome to the April issue of StrokeNet. This month we include articles, which describe how stroke survivors are reaching out. Rod Sparks shares the story of a "Walk for Stroke" in which he participated in Tempe, Az. Included in Gunter Wenzel's bio are photos from the "Stars for Stroke" event held by The Stroke Recovery Association of Manitoba. There is also an interview with Susan Cotter Marshall where she explains her work as a mentor for The Stroke Network

Also in the issue, Steve Mallory reports on two changes on the website: the Gallery for photos and Top Sites for sharing websites. David Ray reports on The Lower Hutt Stroke Club March meetings. An article is included with four notices of interest to readers. In her website review Janice Rodriguez focuses on seizures and epilepsy. Bios, which are now posted in the Gallery, are of Dorothy Bove and Gunter Wenzel. Have a good read.

Lin Wisman, Editor
LWisman@strokenet.biz



Organization Highlights

By Steve Mallory

March has brought change not only in the weather but to our message

board. The warmer temperatures are already evident in my home state of Maryland and my body cannot wait for the temperature to heat it up naturally. I am trying to make our web site as interactive with the members, as possible, so volunteers, or lack of thereof, are not the reason that the site is not updated regularly.

I want to speak first about the Gallery. The Gallery has always been a site feature but the method which photographs were added was limited to personal photographs of members. The previous Gallery was embedded within the site and most likely one of the least visited areas of our entire web site. Now, you click the Gallery link on the message board and you will find a number of Gallery forums, which are themes for members to add pictures to and any length description to tell everyone what that particular picture is about. You can show everyone pictures of a younger you, family vacations or even

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your bio. Bios can be typed in the description and then your personal photograph added. The nice thing is that you can do this all, and automatically -- within seconds you can add any number of pictures.

You can see that I have added many of the existing bios to the new Gallery. If you do not have digital photographs to add here your best bet is to take pictures to a local Wal-Mart, or some place equivalent, and for a minimal fee they can provide you back with a cd of digital photographs that you can share with friends and family. Getting digital pictures are no longer the hassle of the past.

What does a gallery have to do with stroke support?

It has EVERYTHING to do with! Many of us have been supporting each other in the forums or in chat rooms. Some of us would like to know who our friends are and know more about their family, hobbies, previous life, etc. The Gallery is the perfect way for the members of our organization to become more of a community, a community of stroke survivors and stroke caregivers. Where else can you do something like this? Instructions for adding pictures and bios can be found on the message board in a forum created for problems or feedback about the gallery in a forum call Gallery!

A second new feature is another message board link called Top Sites List. This feature previously existed and was limited to the Web Ring, only. The Top Sites has a web ring but it does several more things! It keeps a running list of sites, automatically selects a top site for you to review and allows others to rate, plus comment about the site. I understand that not everyone has a personal web page. Those of you who do should be proud of yourself and show us what you have done. Those who do not have a site can still show off by adding sites that they think may benefit other members. To add a site, go to the Top Sites link on the message board and click the Control Panel link. Just click the Add a Site link. This area has been in a preliminary state for the past week and will be upgraded in the next few days

Steve Mallory
President & CEO
SMallory@strokenet.biz



Life in New Zealand with a Stroke

by David Ray

Our Stroke Club had its first March meeting with a very interesting and entertaining talk by a lady who, with her husband, had spent 4 months traveling around Turkey. This retired couple, in their sixties, had traveled with a minimum of clothing etc, had stayed in backpackers accommodation and traveled on local transport throughout the journey. They had been to many ancient and historic sites and enjoyed the beautiful scenery of the Turkish countryside. The speaker had a great sense of humor and her experiences of many amusing instances keep us, her audience, very much entertained.

Last Tuesday we had our half-year picnic in the Otari Bush Gardens. This is an outdoor museum devoted to native New Zealand plants and trees some of which are very rare. Being a young country, early settlers cleared native forests to create cleared land for farms, towns etc. As a consequence many plants were lost or their number and availability reduced. The Otari Bush Gardens has over 10 kilometers of walking tracks with plenty of areas to sit and view the trees and plants.

There are 100 hectares of forest made up of original and regenerating conifer broadleaf forest. Large conifers such as native rimu, totara, miro and matari can be viewed from a canopy walkway or on nature trails. There are about 150 species of flowering plants, conifers and ferns found throughout the forest. Perching plants sit high in the branches of mature trees. Climbing plants, including the New Zealand passion fruit, supple jack, and rata occur throughout the forest.

Kohekohe, rewarewa, tawa and mahoe trees dominate the upper slopes and merge with forest remains of older rimu and matai. In the valley areas tall pukatea can be seen with buttressed roots spanning streams or growing in wetter areas. On high south facing slopes, scrub is dominated by introduced gorse and Darwin barberry with colonizing native plants such as mahoe and rangiora.

The park has been cleared as far as is possible of possums, which have been introduced from Australia, and from aggressive weeds such as Old Man's Beard and Tradecantia. It was a very enjoyable and informative day for our members. We enjoyed our lunch and our drive into Wellington where the park is situated. We were lucky that it was a beautiful sunny autumn day.

Read about the Otari Gardens at
<http://www.wcc.govt.nz/recreation/gardens/otari/>

Mentor Interview



StrokeNet interviewed mentor, Susan Cotter Marshall. Susan shares with readers her experience of being a mentor with The Stroke Network.

StrokeNet: When did you have your stroke? What kind was it?

Susan: I had a Subarachnoid Hemorrhage in my brainstem. It was on Ash Wednesday, Feb 21, 1996.

StrokeNet: When and how did you first find The Stroke Network?

Susan: I can't remember when I found it; I found it by typing "stroke" into a search engine.

StrokeNet: When did you begin to mentor?

Susan: Maybe a month or two ago.

StrokeNet: What did you do first?

Susan: I visited the chat room and message boards; basically "jumping right in."

StrokeNet: What are the ways you currently mentor?

Susan: I respond to all entries in the "Stroke Network" guestbook, and if I have anything to "say" I either post replies on the message boards or start my own.

StrokeNet: How do you think mentoring is helpful to stroke survivors, caregivers and families?

Susan: Letting them know they're not alone, that there are many of us who have similar, (and different) stroke experiences, and that we're available to "listen", offer support, friendship and understanding.

StrokeNet: How is mentoring helpful to you?

Susan: Mentoring is helpful to me because it reminds me I'm not alone, there are so many survivors. I can also give something back; maybe sharing some of my own reality can help someone, somehow.

StrokeNet: Is there anything you would like to add?

Susan: Having a stroke regardless of what kind, how severe, where it is etc., changes a person for life - the quintessential 360. If "being there" for someone helps them to understand what's happened, I've been successful. (And I've helped myself too.)

Read Susan's bio at

<http://www.strokenetwork.org/newsletter/bios/smarshall.htm>



Walk for Stroke

by Rod Sparks

I am writing in this newsletter about an event that I attended, which was a fundraiser for stroke and heart disease survivors. The event happened at Tempe Town Lake in Tempe Arizona, which is east of Phoenix. Tempe is known for the yearly annual Fiesta Bowl, and has also accommodated the Super Bowl.

The day started off with registration at 7:30 in the morning and the walk started at 9:00. They had many sponsors that supported the walk. They included: Phoenix Suns; Subway, which provided a lot of the food; St. Joseph's Hospital, which is the top hospital in the valley that takes care of stroke survivors and spinal cord patients; St. Luke's Hospital; Arizona Cardinal's, who had two members of the team to sign autograph's; APS, an electric company in the valley, which provided entertainment with live music. There were so many sponsors -- it is hard to remember them all.

If you at the pictures you can see the number of people that showed up was unbelievable. The walk was 3 miles long around the lake, 8000 people participated. They raised \$700,000. As I wasn't able to walk the 3 miles, I had my 11-year-old daughter push me in my wheelchair. She did a very good job but was only able to last for 1½ miles, then another volunteer pushed me rest of the way. I was honored to have my daughter with me.

With events like this and the support groups that some of us attend, it is worth while for us as stroke survivors, that we know there is a lot of support out there. We all go through the same problems in our lives such as: having to depend on someone else to get us around to where ever we want to go. The best support that we have right now is The Stroke Network because of the many other survivors that have gone through the same problems as each and every one of us. I am truly thankful for all of you and the support that you give to me. It is always a sense of at ease in talking to those on the chat room knowing that we all have the same disability. I hope you will enjoy this part of the newsletter that I have put together.

See pictures of the event at

<http://www.strokenetwork.org/newsletter/event/arizwalk.htm>

Notices



Quilting Group

Jean Crawley earlier contacted several Stroke Network members about starting a quilt group. Several showed interest. Unfortunately because of family health problems Jean was not able to continue. She is now ready to begin. Contact Jean at JCRAW44196@aol.com if you are interested in a Stroke Network Quilting Group.

Wheelchair Registry

Human Engineering Research Laboratories is currently organizing a "Wheelchair Users Registry".

The Registry is an informational service that uses an interested participant's profile as a wheelchair user to qualify for approved wheelchair research studies. Anytime a wheelchair user is qualified for a study they are notified. The wheelchair user has the option to participate or decline. They may decline participation in any of the research studies, but remain an active participant in the registry and receive notification of other studies. The participant can remove their name from the registry at any time.

Interested individuals can contact the lab and receive a consent and questionnaire packet by mail. Once the consent form and questionnaire is completed, the survivor will be called to answer any questions about the registry and potential studies. The wheelchair user will be entered into the database and notified of any potential studies. All of the information is confidential and only accessible by the investigators. Individuals do not need to live in or visit Pittsburgh to participate in research, as many of the studies can be conducted by mail and telephone.

For more information email Amy Boyles, Clinical Coordinator Assistant, at boylesa@herlpitt.org. Learn more about the lab at <http://www.herpitt.org>.

Hyperbaric Oxygen Therapy Presentation

The Cole Center for Healing and Cincinnati Hyperbarics will host a presentation explaining Hyperbaric Oxygen Therapy.

Date: Thursday, April 22, 2004

Time: 7:00 p.m.

Location: The Cole Center for Healing
11974 Lebanon Road
Suite 228
Cincinnati, Ohio 45241

Hyperbaric Oxygen (HBOT) is a simple, powerful therapy with a wide range of applications. It saturates the entire body with oxygen, which has profound effects on every aspect of metabolism. It promotes the growth of new blood vessels, decreases swelling and inflammation, deactivates and clears out toxins and metabolic waste products, increases the body's ability to fight infections, and improves the rate of healing.

HBOT has been used to treat numerous conditions, including difficult wounds, in preparation for and recovery from surgery of any type, burns, bone infections, radiation effects, **stroke**, cerebral palsy, MS, head injuries and concussion, infections of all types (Lyme's, hepatitis, etc.), heart attacks, chronic fatigue, ADD/ADHD, sports injuries, autism, migraine and other headaches, cancer, HIV, trigeminal neuralgia, Raynaud's, vascular disease and areas of decreased circulation, Crohn's disease, fibromyalgia, decreased immune function, wellness/anti-aging, and others.

Dr. Cole will describe the indications, cautions, side effects, and methods of treatment for various conditions. He will also cover other therapies that can be used in conjunction with HBOT. Participants will be able to see state of the art HBOT chambers and how they are used to provide treatments.

There is NO COST, but please register ahead:

On-line: www.colecenter.com; click on Lecture Schedule link at the bottom of the home page.

By phone: (513) 563-4321 ext. 8302

We are located on Route 42 in Sharonville, just north of I-275, across the street from PNC Bank. We are in the middle of Crystal View Plaza.

Technology Training Workshop

Technology Training Workshop is a two-day intensive hands-on workshop, limited to 6 speech pathologists. It will be held in Potomac, MD on these dates:

March 29-30, 2004

May 23-24, 2004

July 12-13, 2004

Personal attention and consultation to meet participate needs will be provided. Affordable solutions and startup suggestions will be investigated.

The workshop includes:

- Phone consult with Joan Green prior to and after the seminar to maximize effective targeted learning
- Extensive written materials and demo software

Objectives include:

- Become familiar with software to help improve talking, listening, reading, writing, cognition, memory, thinking, organization and attention.
 - Identify a variety of characteristics to consider when selecting software and hardware.
 - Explore the use of text readers, word prediction software, adapted email programs and scanners to lessen barriers to e-mail for people with communication issues.
 - Discover valuable Internet resources and learn to use them as a powerful tool to promote self-advocacy.
 - Review local, regional, in print and online resources for people to continue learning more about improving computer literacy and overall quality of life.
 - Learn about a variety of additional tech items that can be integrated into daily life to assist with rehabilitation.
 - Gain practical insight into how to establish a computer lab and offer tech related services on a shoestring budget.
 - Become familiar with a variety of accessibility options with computers and software and dedicated communication devices.
 - Learn tricks to preparing engaging therapy materials using technology.
- For more information email Joan Green at Jgreenslp@aol.com. Read more information on the workshop at <http://www.innovativespeech.com/fasttec.html>.
- 
- Website Review:**
Seizures and Epilepsy
by Janice Rodriguez

The topic this month is the development of seizures and/or epilepsy after having a stroke. First, what are seizures or epilepsy? The Centers of Disease Control and Prevention says "A seizure happens when abnormal electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness, or behavior." Epilepsy is diagnosed when a person has more than one seizure. For more information see <http://www.cdc.gov/nccdphe/epilepsy/index.htm>.

What about the connection of seizures and strokes? The Epilepsy Foundation has a great website which has a wealth of information. For example, click on the "Answer Place" at <http://www.epilepsyfoundation.org/answerplace/>, and then "Epilepsy and Seizure Statistics" for the answer: "The basic, underlying risk of developing epilepsy is about one percent. Individuals in certain populations are at higher risk. For example, it is estimated that epilepsy can be expected to develop in ... 22 percent of stroke patients." See <http://www.epilepsyfoundation.org/answerplace/statistics.cfm>. There has been a great deal of research about the risk of seizures after stroke. In an ischemic stroke, the risks of late (7 days after a stroke) seizures are associated with three factors: acute early seizures, cortical signs ("cortical" is in the cortex or "grey matter" - one "sign" is aphasia) and large strokes. For example, individuals with just one of these factors have a 4.6% risk of seizure after one year, but those with two or three factors have a 33.3% risk. See

http://www.aesnet.org/currents_pdf/epc_03408.pdf at the American Epilepsy Society website. So this is especially significant for stroke survivors.

If you experience a seizure, the Neurology Channel has a good website for the diagnosis, treatments and medications for epilepsy. See <http://www.neurologychannel.com/epilepsy/index.shtml>. Medications are the most popular treatment for epilepsy, so you might want to research the different drugs used. A great general website (not just for epilepsy) is MedLine, which has over-the-counter and prescription drug information. See <http://www.nlm.nih.gov/medlineplus/druginformation.html>. And finally, see the website Drug Information Online, <http://www.drugs.com/>, and click on "Drug Interactions Checker." You can create a list of all your medications and then check for interactions between medicines in your list.

Remember, the information on the Internet may be old, incomplete, or just wrong. So always check with your doctor or therapist, especially on any seizure and epilepsy information - it is critical! Thanks, and see you next month!



Biography: Dorothy Bove

I realize I am not the only one who has had this experience. I am 32. How did the time disappear? I spent the last 2 years in rehabilitation.

Where did that time go? I want that time back so I could do what other people my age do when they are 28. I was an art therapist with children with cancers and blood disorders.

On September 11, 2000, I had an aneurysm, had surgery, and went to ICU. I was in an induced coma. Everything was "ok" but two weeks later, I had a stroke. I stayed two months at this hospital and then went to inpatient rehabilitation for two more months. I also had a tracheotomy during that time. I was still in a wheelchair but I went to outpatient rehabilitation for speech, physical, and occupational therapies for another year. I also had acupuncture, which really helped. I got rid of the wheelchair, cane and I can slowly walk- not the way I used to walk. I have a brace in order to walk long distances. And finally, I can DRIVE. I was nervous but I am driving.

I realized that I had aphasia. People thought I was from another country because I was unable to communicate what I was trying to say. I thought my words would come back but I did not realize it was permanent. That is when I realized what aphasia means. My long-term memory is good and so is my ability to self-monitor what I am saying.

Other strengths are my good social communication and articulation skills. I still have some difficulties with word retrieval. I can think of things but cannot always say them but I can find the right word when I am given a choice. I will be working out at a gym instead of physical therapy because they feel that they have done everything that they can do. Unfortunately, I don't agree with plateaus. You can always go further. Sometimes, I get stuck and depressed but I snap out of it.

I hate the idea of "disability" or "handicap" or "damage." I feel that something from "me" was taken from me. I worked so hard to get a masters in art therapy and now it is gone. I dislike the idea that I get sad about this. When will I move on? I am scared that I will not move on. I know that I need "to discipline myself in a totally new way, learning everything all over again, constantly adapting, adjusting or doing without." (Return to Ithaca, Barbara Newborn)

It is also so special to meet people on the board sharing experiences. That really, really helps. So Thanks again for giving me the push to go forward.



Biography: Gunter Wenzel

January 5th, 2003, just into the New Year, brought a change to my life. I was sitting in the kitchen relaxing after supper. My daughter Kristin was downstairs, my wife Heather was having a bath, when all of a sudden the ceiling started to rotate and I knew that something was up. I yelled for my wife. Suddenly a sharp pain hit the right side of my body. I thought I'd had a

heart attack. I thought to myself "why now" as my wife rushed to phone 911 and the medics came. The medics gave me a shot, carried me to an ambulance, and rushed me to the Health Sciences Centre. To say I was scared was an understatement. I was left with no feeling on my right side, double vision and some paralysis on my left. Basically at that time I thought life really "sucked".

The doctors told me I'd had a stroke. My father died of a stroke so I knew this was really serious. They stabilized my condition. After a few tests the Doctor told me that in the next few days I would start therapies that would allow me to hopefully return to a somewhat normal life. I thought no problem; boy was I in for a surprise. It was agony everyday without the help of The Health Care Aids. When you have a stroke you have many hours to think "now what." How am I going to support my family? Will I work again? How will my wife and others see me now? Anxiety in abundance.

I was transferred to the stroke rehab unit under the care of Dr. Daniels. She basically said: "Do your exercises, work hard everyday, and hopefully some feeling will come back and you'll walk again." I thought to myself, I'm going to do this come "hell or high water."

For months I worked hard with the help of staff and my loved ones. I met other stroke survivors who were worse off than I was. I did lots of stuff that wasn't according to their protocol but the doctor let me "think outside the box."

One day I was going past the desk and I picked up a pamphlet from the Stroke Recovery Association of Manitoba (SAM). I read it and asked Dr. Daniels about the organization which she highly recommended. When I got home on March 1st I phoned SAM and said I would come out to their office and see what they had to offer. They gave me a tour and explained their programs. After mulling it over I paid the fee and was told to come to the

general meeting. At that time I also joined the support group "In Your Prime." I went to a general meeting and I was enlightened to say the least. Here was a small group struggling to carry on the good work. It reminded me of another support group I belonged to before and that was for sleep apnea.

Some, after a stroke, experience an epiphany. I thought that I could help the organization in some way. I met with Marybeth Gilroy. She has a subtle way to get you to volunteer. With my past experiences with fund raising I felt this would be a perfect job for me. I have met a lot of great stroke members, each telling their stories with feeling and emotions. You look in their eyes and their eyes seem to tell their story. "You know."

My wife Heather, a nurse, is very supportive and so are my daughter Kristin and all my "normal friends." I can't work any more because of the stroke so I have free time to give. So reflecting back to "why now," now was my time to reassess and move forward. I have good days and bad days but one thing I can say, I don't cry or laugh alone. Friends are there to pick me up and give me "a boot in the rear end" when I feel sorry for myself.

My first grandchild Velorian makes all the family are proud, especially Grandpa. He gives me so much support that he doesn't even know about yet. I am looking forward to many "slow walks with Velorian." I hope I can keep up.

I would like to thank you for taking time in your busy life to read this. I hope all members, staff and their loved ones have lots of good health and as you know that's more important than anything money can buy.

See pictures of Stars for Stroke, a program of Stroke Recovery Association of Manitoba at
<http://www.strokenetwork.org/newsletter/event/wenzelstars.htm>.

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 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.

This newsletter is available online at <http://www.strokenet.info/>. Contents of this newsletter may not otherwise be reprinted without the organization's permission. Please contact the editor.

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