



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

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Welcome to the December 2004 issue of StrokeNet. We send Seasons Greetings. Hope everyone has a great and safe holiday. I would like to remind everyone to please submit your original writings for the Feb issue. Deadline is Dec 31. This month we introduce a new columnist. Kate Adamson is Public Relations Director for The Stroke Network. Kate will be sharing excerpts from her monthly newsletter "Postcards from Kate's Journey." Also in this newsletter, Steve lists new and improved features of the Message Board.

David Ray reports on the Lower Hutt Stroke Club November meetings. The Stroke Network's Caregiver Handbook is highlighted. Jean Kirshenbaum features three articles, which focus on new stroke therapies. Janice Rodriguez lists some of the websites, which have been featured in StrokeNet this year. December birthdays are listed. Bios featured belong to Kate Adamson and Tania Parson.

Enjoy your reading.

Lin Wisman, Editor
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Organization Highlights

By Steve Mallory

Happy holiday! Hope everyone can have a nice and relaxing holiday season!

The StrokeNet Email link has recently been added to the message board! In case you don't know already, the organization provides a free email account with every membership. Just login to the message board and click the email link. You can then register your free email account with one of

several name endings. Choose the one you want when you register.

Emoticons have recently been added to the message board. Just about every conceivable emotion can now be added to your post. Emoticons are a fun way of graphically displaying your feelings. You have to open all of the emoticons to see and use the new ones.

Another new fun feature recently added to the message board is the Country flag. You can now show everyone which country you are from and display a small waving flag under your name when you post a message. In order to show your flag click you must first login to the message board, click on My Controls and then edit your profile information.

Everyone should be receiving our weekly chat reminder. Chat has become a very important stroke support activity and everyone seems to want to chat. We have a top notch chat room with several internal rooms. They are all private and then we have several reserved for private, one-on-one, discussions. One room is reserved for stroke caregivers, one for stroke survivors, one for social discussion called the Coffee Shop and one called the Auditorium, which is where we plan to have guest speakers. Pam emails everyone in the membership each week to remind you of the week's scheduled chat meetings. A chat host will be in attendance for each scheduled chat. In you have questions about chat please email Pam Braidt at hostpam@strokenetwork.org.

You heard me mention having guest speakers. We have plans for 2005 to start having guest speakers. Hopefully, once/month we will schedule a guest speaker. These events are held in a chat room but the meeting is not for chat. In fact, the Auditorium is setup differently. You can ask questions and then the guest speaker will answer all questions in queue. You can only ask

questions and cannot chat with each other. This way, everyone will benefit from the guest speaker and will get to see them provide an answer to a specific question. It's all very orderly and well organized. Our intention is to provide a meaningful chat event where our members can listen to something interesting. Look for the schedule in coming weeks! Kate Adamson is the scheduled guest speaker for January.

Mentor certification is still one of my major concerns. We have had several people certify in this past month but we still have several mentors that are eligible to do this. Tania Parson, our Membership Administrator has been contacting those of you who can certify. I'm asking that you give this serious consideration. Our members rely on the posts to the message board from those who have the experience and can provide meaningful responses to their questions. Please consider doing this for our organization. If you have questions about the Mentor Certification Program please contact Tania at tparson@strokenetwork.org

A new help section has been recently been added to the message board. The Message Board Administrator, Jean Riva, has been hard at work rewriting our standard boilerplate help notes to something better in tune with real life questions that our members might have. She is making every effort to make your on-line experience easier for you so that you can use the board for its intended purpose of providing stroke support. Pam has even added a section for how to access the chat room! To browse through the Help section you must first login to the message board and then click on the Help link. If you need help with the message board please email Jean at jriva@strokenetwork.org

Important message from the Message Board Administrator – Jean Riva

You may have noticed that Steve added a new way to post to the message board, the "Fast Reply" Button. It's our hope that this new posting choice will solve some problems for a lot of people. Please try using the "Fast Reply" button. We think you'll like it!

FAST REPLY BUTTON: Using this new button, the "Fast Reply" button, is the easiest and least confusing way to post. All you have to do is to remember to go to the **very bottom** of the

thread/topic you are reading in and you'll find a row of four buttons on the right. The first one is the "**Fast Reply**" button. Click on it and a bare bones text box opens up that is very simple to understand and very simple to use. (If you do not see the text box after clicking, scroll your screen up.) Just type in the box and click on the 'add reply' underneath the text box when you are done. This is a no-frills way to post that gets rid of all the confusing choices and gets rid of all the unnecessary quoting of other posters. Newbies and others who may be having problems posting, please try posting through the "**Fast Reply**" button!

For clarification, here is what the other three posting button choices on the message board are used for:

REPLY BUTTON: When you click on this button, a posting text box will open up that includes the written material of another poster which will appear within your post on the message board, along with what ever you write in that box. *If you do not want the other poster's material in your post, do not write your post in that text box.* Click back and look for the "Fast Reply" or the "Add Reply" button instead of the "Reply" button. Either one will take you to a clear text box to write in. If you do want to quote another person's post, but you are only addressing a few lines or a paragraph in a long passage, when the text box opens containing their post *please delete all but the portion you are planning to reply to.* It is NOT a desirable thing to use this button every time you post. It causes a great deal of confusion and wasted message board space. Use this ability to quote another poster sparsely.

ADD REPLY BUTTON: Using this button gives you a full array of choices to make when you post: the use of emoticons, different color or size print, bold print, etc. To use this button, go to the *very bottom of the thread* you are reading in and find the "Add Reply" button, which is in between the "Fast Reply" and the "Options" buttons. Click on the "Add Reply" button and another screen will open up where you can write your reply in the text entry box and make the other choices mentioned up above. When you are done writing click on the "Add Reply" button at the bottom. If you are new to posting, please stick with using the "Fast Reply" for a while.

NEW TOPIC: Click on this button when you want to start a brand new topic in one of the forums.

Read our 'help' section for the complete

directions on posting (which including definitions for newbies), how to finding lost posts, using the chat room, and 17 other topics.

Steve Mallory
President & CEO
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Life in New Zealand with a Stroke

By David Ray

At last winter appears to be over and we are enjoying spring/summer weather. My wife, Enid, has been for a few swims on the beach, which is about 100 meters or so from our house. She tells me that the water is still a little cool but she can put up with it. Our Stroke Club has had its last two meeting of the year. The first meeting in November was a talk by a Physiotherapist on ways we can assist our movement.

These talks are very beneficial to our members who all have movement difficulties of one sort or another. Our second session of the month was our Christmas luncheon, which we had at a popular restaurant. It was a very convivial ending to what had been a very successful year for our club and all look forward to meeting again in February 2005.

Sir Edmond Hilary, that great New Zealand explorer, together with Sherpa Tensing were the first to climb Mount Everest in 1952. Since that time Sir Ed has been involved in raising money for and building schools and hospitals for the Sherpa people. He was also the first man to lead an expedition over land to the South Pole to lay supply depots. The reason was to assist an English expedition, which was travelling across the Antarctic Continent. Later he was appointed New Zealand's Ambassador to India.

A few years ago, while I was still working, I was sent to India with a group of other public servants to discuss some aspects of trade. I met Sir Edmond in New Delhi when he was still New Zealand's Ambassador and in fact had the privilege of sitting next to him at an official dinner. St Ed is now 85 years old and is (at the time I prepared this report) paying a visit back to Scott Base in Antarctica.

I have prepared this paragraph about Sir Ed because he is a wonderful role model for all New Zealanders. He saw that there was much to be

done to assist the Sherpa people and set about doing it. Although he has not to overcome a disability such as ours, he is a great example of what can be achieved.

May I conclude by wishing all readers a very happy Christmas and trust that you all will enjoy a wonderful 2005.



Stroke Caregivers Handbook

A handbook is available which contains valuable information for stroke caregivers and families. It is especially useful for those new to stroke. Members of The Stroke Network wrote the handbook. Please have a look and distribute as you see fit.

The handbook is available online in pdf format. If you not already have Adobe Acrobat Reader it is available free of charge at <http://www.adobe.com>

Handbook can be found at <http://www.strokenet.info/resources/caregiver/StrokeCaregiverHandbook.pdf>. It can also be accessed through a direct link in the information section of the home page of The Stroke Network.



Kate's Korner

By Kate Adamson

This month I would like to emphasis the need for stroke survivors to reach out to others To do so I would like to introduce you to Cindy, who has been training for an upcoming marathon in Arizona next year.

Cindy, like me, is a stroke survivor. She had four strokes at the age of 40!

While participating in a "Train to End Stroke" marathon in Kona, Hawaii, for the American Stroke Association, another stroke survivor, Ray, and his wife, Gina, suggested that Cindy read my book, "Kate's Journey." She found my journey remarkable in its similarities to her journey. In fact, she related so well, she felt inspired to spread the message of hope and encouragement to others. Stepping out in faith, she sat down and typed me an e-mail thinking she would never hear back. Thus began our friendship.

On April, 2005, Cindy and I have our sights set on doing a "Relay for Life." I'll keep you posted on the details.

You never know what lives you will touch. Every thing you do can have an effect on others. Reach out to others.

This article is an excerpt from "A Postcard from Kate's Journey," November 10, 2004. See the entire article at Kate's website at <http://www.katesjourney.com/>.



Stroke Newsfeed Review

By Jean Kirshenbaum

The air is literally electric with new possibilities where stroke is concerned. Several articles in November deal with the use of electrical stimulation to treat strokes at the time they occur or in rehabilitation to regain movement. There is 1) ultrasound to help dissolve brain blockages; 2) magnetic brain stimulation to improve language impairment; and 3) electrical stimulation of the cortex to improvement movement.

For example, ultrasound is being tested as a booster to help dissolve brain blockages in stroke patients. Research was conducted at the University of Texas Medical School and the procedure was used recently at New England Medical Center in Boston. Specifically, "The same type of sound waves that pulsate from sonar fish-finders and ultrasound fetal monitors can dramatically boost the power of anti-clotting medicine and help it dissolve brain blockages in stroke patients, a study suggests.

This technique may one day offer a safe accessory for helping up to 100,000 U.S. patients a year, or 15 percent of the nation's stroke victims, doctors said." Imaging specialist Dr. Joseph Polak at New England Medical Center in Boston said more doctors should now consider adopting the technique. "It's a relatively big impact for a disease where we don't have many options," he said.

<http://www.rednova.com/news/display/?id=104048>

Additionally, researchers are studying a magnetic approach called repetitive transcranial magnetic stimulation or rTMS, which involves sending tightly focused magnetic pulses into the brain. "A lot of us believe that this is really going to be a turning point in intervention in neuroscience," said Dr. Randall Benson of Wayne State University and the Detroit Medical Center. While doctors have already shown that implanting electrodes in the brain to deliver stimulation can help control tremors, he said, rTMS offers a way to stimulate brain circuits without surgery.

Benson is just starting a study of using the magnetic stimulation to improve stroke-related language impairment,. British researchers, meanwhile, are beginning studies to see whether it can help stroke patients overcome problems with swallowing or using a weakened and clumsy hand. It "suggests we are opening up the possibility for the brain to establish and implement a new strategy to gain access to language," he said. He suspects the brain-circuitry suppression brought on by the magnetic stimulation is helping the brain abandon fruitless strategies to regain its language abilities, and explore new ones.

<http://www.thestate.com/mld/thestate/news/nation/10290268.htm>

Finally, doctors at the University of Arizona are testing a pacemaker like, brain-stimulating device for usefulness in restoring hand and arm movement in stroke patients. The clinical trial under way at UA and two other sites combines physical therapy with electrical stimulation of the cortex, the part of the brain that controls voluntary muscle movement, to take advantage of the brain's natural ability to rewire itself, said Dr. Martin Weinand, UA's chief of neurosurgery.

http://www.tucsoncitizen.com/index.php?page=local&story_id=110904a4_stroke



Website Review: 2004 List

By Janice Rodriguez

Happy holidays! These are some of the best websites reviewed this year.

January: Generation-S: Young Stroke Survivor
<http://www.orgsites.com/pa/generation-s/index.html>

February: American Music Therapy Association, Inc
<http://www.musictherapy.org/>

April: Epilepsy overview and medication
<http://www.neurologychannel.com/epilepsy/index.shtml>.

May: National Stroke Association
<http://www.stroke.org>

June: American Speech-Language-Hearing Association (ASHA)
<http://www.asha.org/public/speech>

August: Internet Stroke Center, "Reducing Your Risk of Stroke"
<http://www.strokecenter.org/pat/risk.htm>

Survivor, Marty lists has interests as fishing, hunting and golf.

12th SidneyJ (64) Colorado, US
Interests include music, gardening, cooking, computers, travel, and good music

12th Susan (50) Massachusetts, US
She is a farmer, was a financial director and VP Finance. Susan had a PFO, which resulted in a heart attack Aug 2003. She stroked in April 2004.

13th Pat Provost (50) Quebec, Canada
Pat is a survivor since 1997. She is VP Operations for The Stroke Network.

14th cnemec (57) Michigan, US

14th emmalibbie (55) Illinois, US
Liz is a survivor. She enjoys knitting, crocheting, sewing, and computer work.

15th tstone (55) Virginia, US
Survivor

27th Fish (48) Alabama, US.
Mike is a caregiver.

29th Priscilla (64) West Australia, Australia
Priscilla is a survivor. She lists her interests as talking to people, wining and dining, movies, family and animals.

29th Roberta (43) Ontario, Canada
Bobi is caregiver for her 20-year-old son. She is interested in becoming more knowledgeable about strokes.

29th Cher (46) Rhode Island, US
Cher lists interests of art, music, theater, museums, poetry, books, cooking, long rides, dining out, gourmet food, fairs and festivals, flea markets and shopping.

30th teawa (46) Waikato, New Zealand
Interests are listed as yachting, the arts, and collecting old books.

To be sure your birthday is included on the list of member birthdays, add the date to your profile. From the home page of the Message Board, select 'My Controls', on the left hand side of the screen look for the category 'Personal Profile.' Select 'Edit Profile.'



December Birthdays

2nd cindy253214 (32) Wisconsin, US
Caregiver to her mom.

3rd clc (55) Texas, US
Survivor

4th Gary Gray (56) PEI, Canada
Gary stroked August 10, 2002. He lists his interests as reading, walking, computer, chess, daily diet and exercise routine, meeting new people, movies and working on stroke recovery. He is a Certified Mentor and frequent participant in both the message board and chat.

7th hld (57) Wisconsin, US
Survivor since Feb 2000.

8th keyduplicator (39) Idaho, US

9th mjmlmommy (33) British Columbia, Canada
Caregiver for husband. She is a huge hockey fan, loves camping, fishing, and anything that has to do with kids.

12th martyhahn (51) Washington, US



Bio: Kate Adamson

In 1995, at just 33, Kate Adamson suffered a brain-stem stroke that left her with a condition called 'locked in syndrome.' She was

completely paralyzed, unable to even blink her eyes. Kate beat one-in-a-hundred odds just to survive; then beat the one-in-a-million odds to regain mobility and function.

After Kate's miraculous recovery she founded her own stroke survivor group, and became a board member of the Stroke Association of California and a national speaker for the American Heart Association. She is a member of the USC Department of Biokinesiology and Physical Therapy Board of Counselors, and a member of the National Health care Advisory Committee: for *Stroke Connection* Magazine published by American Stroke Association. She is Public Relations Director for The Stroke Network.

As a tireless promoter of patient's rights and disability rights, Kate is a devoted advocate for Women's Healthcare issues. She is a national spokesperson for the American Stroke Association and the subject of a major fundraising film produced in 1998 by the American Heart Association distributed nationally to each affiliate.

She is a member of National Speakers Association (NSA) and has delivered speeches for organizations as varied as the Bank of America and the United States Congress. In addition to representing the American Stroke Association and the American Heart Association, Kate also represented the United Way as a paid speaker and a fund-raiser.

Her amazing, inspirational story has been featured in various national magazines, including *Redbook*, *Vim & Vigor*, *Caregiver*, *Keeping Well*, and *The Female Patient*. She has done numerous radio and T.V. interviews including both local and national. The Bill O'Reilly Factor, The Abrams Report, Fox News, MSNBC, ABC, NBC and the 700 Club, Coral Ridge Ministries, Trinity Broadcast Network (TBN) with Jay Jones on the Joy Program. She was featured recently on Lifetime T.V. 'Speaking of Women's Health' segment, getting a second opinion. Kate is a published author of the book *Kate's Journey: Triumph Over Adversity*.

See her web pages at www.katesjourney.com



Bio:Tania Parson

I am a 29 yr. old stay at home mom. I had my stroke on New Years Day 2004. On Christmas Eve '03 I went to a Chiropractor for the very first time and had my neck adjusted. I had been having neck spasms after having the flu and thought a Chiropractor might help.

After the adjustment I got real dizzy, nauseated and broke out in a cold sweat. I asked if this was normal. The Chiropractor said "NO, but it's probably just a shock to your system" He offered to let me sit in the office until the dizziness passed. I knew he was getting ready to close for the holidays so I told him I'd just set out in my car. It took around an hour or so for me to be able to drive. I went home and went to bed. When I awoke I felt fine and figured that the Chiropractor was right. I went back for a 2nd visit on the 29th of Dec. He adjusted my neck but not near as sharply as the first time. I got a little dizzy but not anything too bad.

On New Year's Eve I started getting real dizzy, but again didn't think too much about it. When I awoke on New Years morning it was like I was on a merry-go-round and could not get off. I told my husband, Lee, that I felt funny and he told me to get up and see if it would go away after a while. Well it just got worse. I started to slur my words when I talked, and I couldn't swallow. That really scared me. My balance was also off as I couldn't seem to use my left side, and I had double and blurred vision. I also had a dull ache behind my left ear.

Brain Aneurisms run in my family and I was terrified that that was what was wrong. I didn't know the symptoms of a stroke. My husband rushed me to the local "Minor" E.R. where I started getting the hiccups every 15 min. or so. There I was examined and told I just had a Upper Repertory Infection. The doc. prescribed a cough syrup with codeine and some antibiotics for me to take even though he was told that I couldn't swallow. I was released (by this time I couldn't walk at all) and went home where I started to vomit and dry-heaved all night. The next morning on the 2nd, we went to the "Main" ER and I was diagnosed with "Bells Palsy" due to the left side of my face had started to droop. They gave me a bag of fluids through an I.V. and prescribed steroids and herpes medication (I still could not swallow anything). Again I was sent home.

On the 5th (after the weekend) we were able to get in to see my Mom's family doc. He said that I had been diagnosed wrong at both E.R.'s. He said if we pinned him down right then he would say I had either suffered a stroke or had the beginning stages of MS. He wanted to run an MRI to make sure. On the 6th I had my first MRI, which came back with swelling on my brain. I was referred to a neurosurgeon in Dallas. I went to see him on

my 29th b-day, Jan. 7th. He immediately admitted me to the Hospital where 3 more MRI's (this time with dye in it) were run. It was confirmed that I had had a brainstem stroke due to trauma to the back of my neck. The left main artery had been completely severed and the right one had been damaged.

LINKS

Organization Schedule	http://www.strokeboard.net/index.php?act=calendar
Caregivers Handbook	http://www.strokenet.info/resources/caregiver/StrokeCaregiverHandbook.pdf
Newsletter Archive	http://www.strokenet.info/newsletter/index.htm
Stroke Awareness	http://www.strokeawareness.org
Donate to Us	http://www.strokenetwork.net/donation
Message Board	http://www.strokesurvivor.net/



Holiday Greetings From the Stroke Network

This newsletter is available online at <http://www.strokenet.info/>. It link can also be found through the Information Link at the home page of The Stroke Network. Copies can be printed from the web page. Contents may not otherwise be reprinted without the organization's permission. Please contact the editor.

Monthly newsletter distribution via email is free. Visit the website to subscribe.

The Stroke Network is a registered 501(3)c non-profit organization. An on-line stroke support organization, it is available to everyone worldwide. Since 1996 The Stroke Network has provided stroke support and information to nearly 10,000 people, 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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