



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

Vol 4, No 11

November 2004

Welcome to the November issue of StrokeNet. Steve Mallory discusses changes to the message board and chat room, recognizes members and talks of future plans. David Ray reports on two birthday celebrations. Members attention is drawn to the Active Forever website, which has items available to aid stroke survivors. Concrete Change, an organization which provides information on accessible housing, is described.

Jean Kirshenbaum reviews three stroke articles, which appeared this month. Janice Rodriguez reviews websites which provide stroke survivor education. November birthdays, which are in the member database, are listed. The only new bio this month belongs to Julie Burdyshaw.

Enjoy your reading.

Lin Wisman, Editor  
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The biggest adjustments were definitely the upgrades of the chat room and message board software. With any upgrade, the problem is not with the software, itself, but with the setup required for the software to function properly on a particular web site. Secondly, lots of members did not understand the new software so there were lots of reports of software troubles. Most of us took everything in stride and once the kinks were worked out our stroke support group was almost immediately operating at full force! From what I can see, from personal observations, is that the majority of our stroke support members love the upgrades now that they understand how they function. I have to admit, the upgrades are great and the chat room upgrade took our organization from a basic application to a room with several sub rooms and rich with features.

All members are invited to participate in chat. We meet several times everyday and discuss everything from the weather to serious stroke related issues. We have another new chat host, Host Smurf, aka, Gunter Wenzel or G. Chat has become such a common Stroke Network activity that we are trying our best to make the rooms as convenient and comfortable as we can. A special private Class Room has been setup in case that you would like a lesson prior to attempting to chat on your own. Host Pam will be glad to spend time with you and get you started properly!

I cannot say more about our chat rooms than that they are the perfect vehicle for stroke survivors and stroke caregivers to vent frustrations and get practical answers to questions that must seem extremely complex to them. You have to understand how nice it is to have experienced people to talk to 24/7/365. If nobody is in the chat rooms you can still post your issue to the message board and usually start receiving responses several hours later.

I cannot pass up a special recognition and give more encouragement to a stroke survivor and



## Organization Highlights

By Steve Mallory

Happy Halloween! October was a big month of adjustments for our organization. First, I want to remind everyone that we changed a few internal URL's for the message board and chat room. The Internet addresses are now <http://www.strokeboard.net> and <http://www.strokechat.net>, respectively. My objective with making the change was to have addresses that are easier to remember. You can still get to the message board and chat room by going to the old address but you will not be able to login if you go there. Clicking on the login link will redirect you to the new URL. You should actually bookmark neither one but access the site by starting at <http://www.strokenetwork.org/> and then clicking on the Members Area button. Every member benefit is available from this page!

friend, Peter Codner! I personally observed, in the chat room, Peter accomplish something that most people thought was a long ways off. I don't want to embarrass Pete anymore by singling him out but have to say that I was totally inspired to observe him begin to overcome a communication issue that is a side effect of having a stroke. Congratulations Pete, on a job well done and may your recovery continue at God speed!

I have to also recognize our 2004 season Certified Mentor Awards! The following members received plaques to recognize their personal accomplishment with achieving the certified mentor status. Pam Braidt, Marty Arlen, Janice Stern, Tania Parson, Jean Kirshenbaum and Steven Sanchez. They all deserve pats on the back for completing the final steps, as a Mentor, for becoming certified. I encourage all members to accomplish this goal and proudly display their special message board avatar, as being a Certified Mentor. We have started our 2005 season and have yet to certify a member.

It is a plan for our organization to encourage local hospitals to recognize the on-line stroke support group. We want to be known as a viable resource for discharged stroke survivors. What will set our organization apart from any other on-line stroke support group is that we have a Certified Mentor Program and have members who understand the important factors involved with supporting a newly discharged stroke survivor. Please support our organization by becoming involved in our Mentor Certification Program! We have many members with Mentor status who are eligible but, for some reason, are not taking that last step in the program. You can become certified by going to <http://www.strokenetwork.org/SUPPORT/mentor/guidelines.htm> and reading the information for doing so.

The last thing I want to talk about is our Community Outreach Program, called Computer Therapy. Many of you can appreciate the importance of the computer with your mental recovery. Many stroke caregivers have to appreciate the knowledge from the information gained from this site. Bottom line is that our site and organization is a valuable resource to many and could even have lots of potential uses if computers, and this web site, were on the therapy schedule of most hospitals with a stroke ward.

My plan for our organization is to donate several computers to hospital and then to establish

ourselves as a viable resource and be able to show them how valuable we are and be able to use the Mentor Certification Program as a model for how we benefit the stroke survivor. I have already begun testing my theory by donating computers to my local hospital and can say that the concept has definite merit! The plan is probably complicated to most but I feel that this is an unexplored frontier and we can make this happen.

I'm asking for your support with the following actions of you as members of this organization and members of society who understand that resources for stroke support, at the local level, are severely limited. They are not going to get better so we might as well get the on-line stroke support initiative established with a resource, like ours, that provides everything that an on-line stroke support group should have.

You can help by providing donations that are planned to purchase computers for stroke wards and support our Mentor Certification Program. I need to get you all involved more so you can understand that this is not just the best on-line stroke support group but we are an organization that is going to make society better.

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

By David Ray

My long time friend from my early school days is a Catholic priest and at the end of September celebrated his 70th birthday in Timaru. We were both born and went to school in Timaru, a city about half way between Picton and Invercargill in the South Island of New Zealand. In other words we have been friends since about 5 years of age. Also at the celebration were two other old school friends who started school at the same time and have remained mates all of this time. It was a wonderful occasion.

We exchanged old stories of our times at the three schools we had attended over these years and following years until the present time. It is amazing how much we remembered, how many tales of fun we had had etc. Those of us who had married had our wives with us and it was an eye

opener to them to find out the pranks we had got up to during our schooldays. All of us were now retired from our working lives and it was wonderful that we could get together and remember our school days.

Unfortunately I missed one meeting of our Stroke Club because of illness and it was a meeting I had been looking forward to. It was a talk by a retired lighthouse keeper. The main road through the town where we live has its official end at its south end and has a gate to prohibit ordinary traffic from driving on further. However a rough road carries on about another 16 or so kilometers. About 8 kilometers along this road are two lighthouses, one at the top of a hill and the other on the beach itself.

They are on a point known as Pencarrow Head. This latter lighthouse is still in operation and guides ships into Wellington harbour. The lighthouse above it at the top of the hill is the oldest lighthouse in New Zealand. In my running days I used to train for marathons by galloping to that lighthouse and back along a very picturesque but rough track. There have been a few shipwrecks on the beach but except in very low tides these cannot be seen.

I was able to attend the 23rd birthday party of our club at which we were entertained by a group of elderly performers which was very much appreciated. These were not professional performers but a group of retired men and women who get together for their own enjoyment and the enjoyment of others. Not only did they sing old songs but also performed amusing action pieces. It was a most enjoyable afternoon.



## Active Forever

Have you perused the product catalog, which is linked in the Stroke Network Information site? Go to <http://www.strokenet.info> and click Product Information on the menu. This link is to <http://www.activeforever.com/>.

The Active Forever catalog contains of hundred of products, many of which are of interest to the stroke family. There are two divisions: Solutions For... and Departments. In the first section, Stroke Rehab is the last on the list. Check here for products designed with the stroke survivor in mind.

The Department section includes categories such as Bath Safety, Ergonomic Products, Kitchen Aids, and Medical Alert.

You will find hundreds of products, including a talking caller id, touch tronic lamp converter – which lets the user touch a lamp to turn it on and off, and large print crosswords. Kits are included including a Stroke Kit, which focuses on eating, writing, and reading.

Search this site to find solutions to particular problems. Look to find answers to questions you did not even know you had. Now that the holidays are close you may want to check for gift ideas.



## Concrete Change

An interesting website has been brought to the attention of StrokeNet. Concrete Change at

<http://www.concretechange.org> provides information to aid those building a new home or redesigning their home to increase visit-ability, to increase accessibility. From their website "To change that reality, three essentials can become routine:

- One ZERO-STEP entrance
- All main floor interior doors--including bathrooms-- with 32 inches of clear passage space
- At least a half bath, preferably a full bath, on the main floor

In other words, *get in and out of the house and be able to use the bathroom--the essentials for visiting, and for surviving in your house with a temporary or long-term disability."*

Their handout, which you may wish to use, is located at <http://www.concretechange.org/handout.htm>



## Stroke Newsfeed Review

By Jean Kirshenbaum

October gave us a variety of news of interest to stroke survivors and caregivers. One of the most recent items is about a therapy to restore vision lost after stroke. Another item affirms the value of MRIs over CT scans in stroke diagnosis. And

finally, one item is the text of a speech given by Dana Reeve, the widow of the late Christopher Reeve, in which she advocates stem cell research.

So, in summary, NovaVision, Inc. announced a non-invasive, computerized treatment that can help restore vision lost as a result of stroke, traumatic brain injury (TBI) and optic nerve injury, conditions previously considered untreatable. VRT is now available to qualifying patients at the clinic of Dr. Richard Legge in Omaha, Nebraska. A specialist in neuro-ophthalmology, pediatric ophthalmology and strabismus, Dr. Legge has gained a regional reputation as the premier provider of neuro-ophthalmology consultation services.

See the article at

[http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news\\_view&newsId=20041021005405&newsLang=en](http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news_view&newsId=20041021005405&newsLang=en)

Regarding MRIs, a new study says that in the "critical hours after a stroke, magnetic resonance imaging (MRI) pictures of the brain give doctors more valuable information than computerized tomography (CT) scans do." CT scans "have been the standard brain-imaging technique used in emergency rooms when stroke is suspected because they can quickly show whether a brain hemorrhage has occurred, according to study co-author Dr. Jeffrey F. Saver, a professor of neurology at the University of California, Los Angeles Medical Center.

<http://www.ajc.com/health/content/shared-auto/healthnews/stro/521838.html>

The speech by Christopher Reeve's wife, Dana Reeve on Oct 24 went as follows: "Hello, I am Dana Reeve. Thank you for your warm welcome. I know we all wish Christopher could be with us today, he would be honored, as I am to introduce our long-time friend and ally, Senator John Kerry. Chris and Senator Kerry's relationship goes back to a time when they worked together to advance this country's commitment to preserving the environment. Today, as an advocate and also as a wife, mother and caregiver I stand next to John Kerry to do my part to help advance this country's commitment to medical research. You can see the full text at:

<http://www.medicalnewstoday.com/medicalnews.php?newsid=15416>

If, in addition to getting news from the [strokenetwork.org](http://strokenetwork.org) news feed, you may want to get stroke news via Google. Here's what you do:

Go to the Google home page and click on News. Look on the left side column for News Alerts. Follow the instructions there: Put the word stroke in the news search blank. Enter your email address. Click create your news alert. You will then begin to receive news items about stroke (and golf). The alerts will begin to arrive pretty quickly. If they stop, then create the alert again. I had to do that several times to keep getting it.

Good luck and remember to stay informed about stroke. You may learn something from the news that applies to you!



## Website Review: Stroke Survivor Education

By Janice Rodriguez

This month's topic is "stroke survivors." This is a broad topic so the subjects covered will be wide-ranging.

### UK Stroke Survivors:

[www.stroke-survivors.co.uk](http://www.stroke-survivors.co.uk) "Stroke Survivors" is based in the U.K. and focuses on cerebellar stroke.

### Rehab for Stroke Survivors:

[www.stroke-survivors.com](http://www.stroke-survivors.com) - focuses on rehab information. Check out the newsletter, "Stroke Line." Click on the large picture to go to [www.stroke-cva.com](http://www.stroke-cva.com) "New Stroke Treatment for the Arm."

### Educational Video Series:

[www.strokehelp.com](http://www.strokehelp.com) - stroke education video series for families. Each video is filled with suggestions to help improve independence and ease the care of stroke survivors.



## November Birthdays

The following Stroke Network members are celebrating their birthdays in November. The Stroke Network sends birthday greetings to all of these members.

1<sup>st</sup> TLShark (38) II. Tammy is a caregiver.

5<sup>th</sup> Lainy (23) Ks. She stroked in April 2004. Lainy enjoys swimming, reading, movies, and reality TV.

9<sup>th</sup> Anniebarb (60) Ca. Barbara stroked Mary 1997. She is a Social Security and SSI disability advocate.

9<sup>th</sup> Cyndip (39) Ar. Cyndip is caregiver for her mom. She enjoys NASCAR and antiques.

11<sup>th</sup> rstalneck (47) Pa. A survivor since October 2001, rstalneck enjoys classical rock and science fiction.

14<sup>th</sup> oldwoman (44) Tx. Debbie stroked in 1998. She lists her interests as TV, computer, and feeding fish in the pond.

16<sup>th</sup> Debbi (47) Ga. She is a survivor since Nov 2003.

23<sup>rd</sup> Cinder (38) In. She is a caregiver to her father and enjoys creating and inventing reading, mowing 4 acres, and taking care of her dogs.

26<sup>th</sup> PerryS (46) Ky. Perry Stevens stroked on Christmas Day 2000. He stays connected to the world through his computer. He enjoys TV, and church. His wife and he created a web page. He keeps a journal, which he used to help write a book, "I'd Like to Return this Gift," which was recently published.

27<sup>th</sup> Vickie (53) Il. Vickie is a caregiver to her father who had a stroke July 2000. She lists her interests as bird watching/feeding, reading, travel, and antiques.

27<sup>th</sup> trubrat98 (33) NJ. Trubrat is a caregiver. The mother had the stroke. Trubrat lists interests as 5 ferrets, 2 cats and 3 dogs.

28<sup>th</sup> Lin (54) Il. Lin Wisman is the editor of this newsletter and is Director Information Resources for The Stroke Network. She had a brainstem stroke March 6, 1997. Lin enjoys reading, computer work, cooking and caring for her cat, Cleopatra.



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## Bio: Julie Burdyslaw

This is my second surgery on my ArterioVenous Malformation. (2004)

21 years ago, I had 3 strokes and a bleed from this AVM, WHILE I WAS PREGNANT with my oldest daughter. Cleveland Clinic did a resection as far as they could go, and I had a difficult recovery. For the next 20 years, I lived my life as "free" from the AVM. In April, I had a MRI done for an epilepsy check, they said "You have an AVM." I laughed and said, "no, that is just where it was. Well, the look on his face told me exactly what I was in for... I will find out in December if the AVM has shrunk. Oh, by the way, the beautiful girl in the picture is Jamie. She survived and today, she saves people's lives as a Paramedic!!!

GOD surely DOES exist, and there are times when it seems he is sitting right next to me!  
Julie Burdyslaw, OHIO

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