



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

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Welcome to the August issue of StrokeNet.

Steve Mallory describes detail of the Mentor Program. David Ray talks about the role of Stroke Clubs. Kathy Bosworth interviews Valerie Greene. Next is an article by Rhonda Petersen first published in 2001. She recounts an experience swimming to stay cool.

Jean Kirshenbaum selects five newsfeed articles concerning drug research. Janice Rodriguez reviews three websites, which focus on basic stroke information. August Birthdays are highlighted. All members are invited to add their Bios.

Have a good read.

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## Organization Highlights

By Steve Mallory

I have several exciting organization highlights to talk about this month!

➤ First, I want to introduce a new program called Mentor Certification. This is a program that I have wanted to see reach its potential for several years. I have had the basic concept in mind but did not know how to correctly implement it. Well, now it's possible!

Several of our members have already met the primary prerequisite. You must have posted to the message board at least 150 times. The board automatically keeps count and when you reach 150 your board rank becomes the Mentor designation. There is more to it, though, if you want to become a Certified Mentor!

You must go to  
<http://www.strokenetwork.org/support/mentor/>,

read the Mentor Guidelines and then submit the Certification form, which certifies that you have read the guidelines. The form submittal gives the organization the assurance that you are not only a frequent poster but have read and will hopefully follow these important guidelines, thus being certified. In addition to having your rank upgraded, you will receive a special Certified Mentor avatar that will display below your message board name.

Please help me implement this program so that it will make our organization have the most recognized members!

➤ The next exciting highlight has to do with StrokeNet web mail. Most of you know that we just introduced the free email accounts last month. What I envisioned is flooding the Internet with these types of email addresses. The email address is no longer limited to your-name@strokesurvivor.net but the address is now available as

- your-name@caregiver.strokesurvivor.net
- your-name@family.strokesurvivor.net
- your-name@friend.strokesurvivor.net

We need to make everyone aware of stroke and what better, and easier, way to do it than to paste our email addresses all over the Internet. This is not just a fly-by-night email service but compares to, or is better, than email similar to the likes of hotmail and yahoo. If you have your personal email on something like Outlook Express, you can have it automatically forwarded. Email me if you want to know how to do this! The login to StrokeNet email is located by clicking on the Members Area button when you go to <http://www.strokenetwork.org>.

➤ Several members have asked me about having instant message capabilities in our community. Did you know that we have it already? If you click on a member's name on

the message board it will take you to their profile. On the right is where their communication information is located. Besides being able to email or send them a private message, all their instant message information is displayed.

► I was recently contacted by a psychogeriatric, researching anthology, for KOPE Associates. She would like to receive information about stroke recovery. If you are interested, please email Liz Pearl at [lizpearl@sympatico.ca](mailto:lizpearl@sympatico.ca)

► The 3<sup>rd</sup> Annual Golf Tournament fundraiser is scheduled for October 1<sup>st</sup>!

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## Life in New Zealand with a Stroke

By David Ray

July sees the end of our 2003/4 twelve months of operation for the Lower Hutt Stroke Club. This month we had the annual general meeting where the members of our Club listened to our President's Annual Report of our activities. As Treasurer I presented the statement of accounts and sought the members approval for both reports. The election of the club executive for the 2004/5-year was conducted and, as seems to be usual, no one put their name forward.

It seems to me that as long as members do not want to be involved in any arrangements or committee work, they are quite happy. To me being involved in more than just appearing at twice weekly meetings. It is great therapy and makes me feel as though I am achieving a positive contribution to the welfare of the club and its members.

Our guest speaker this month was Keith Quinn who usually addresses us every year. He is a very entertaining speaker and always attracts a large turnout not only from the normal members but also from those who do not come regularly. Keith is a well-known rugby commentator. He commented on involvement in the Athens Olympic Games by New Zealand athletes. He has promised to return to the club and give us details of his experience in Athens. He is an excellent speaker and always attracts a full turnout of members.

The Lower Hutt club is one of a group of such clubs throughout New Zealand. As in other parts of the world, Stroke Clubs help members meet other stroke survivors, listen to speakers of both entertainment and informative value and go on outings to places of interest. Our club is part of New Zealand's central region. It produces a quarterly newsletter setting out interesting and general information of relevance to stroke survivors in the district.

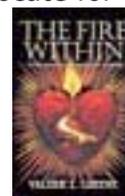
In turn on the national stroke scene the Stroke Foundation of New Zealand produces "Forward, Reducing the risks-improving the outcome", a publication of general interest to all stroke survivors. Finally I produce a monthly newsletter of relevance to Lower Hutt Stroke Club members only. Members who eagerly look forward to each issue welcome all publications.

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## Valerie Greene Interview

By Kathy Bosworth

I wanted to interview Valerie after seeing her story in the Stroke Connection magazine. After a massive stroke at the age of 31, Valerie has gone on to become an advocate for other survivors. Her newly released book, *"The Fire Within"* is a must read for survivors and loved ones of stroke. It details a deeply moving journey as Valerie went from being a victim to being a survivor. Valerie graciously consented to an interview with me.



Kathy: Many of our readers have read your story in the Stroke Connection magazine. One part that caught many people's attention is the fact that you had stem cell injections. Since they are unavailable in the United States, can you tell us where you received such a "cutting edge" procedure and how do you think they helped?

Valerie: Stem cells have been used safely and effectively in other countries for nearly 70 years. They benefit many types of neurological injuries such as a stroke, and in my case were extremely effective. My remarkable recovery clearly demonstrates its effectiveness.

Kathy: Do you think the United States will ever catch up with this medical break though for stroke survivors? Is there anything that the public can do to speed this process along?

Valerie: I believe the citizens of America need to make known that they want this treatment made available. I am personally doing my best to share my experience with as many people as I can. Nancy Reagan has also sent a strong message to Congress to expedite its approval. (see the article on my website listed under Stroke Resources)

It is very important that people be educated to learn that stem cells do NOT have to destroy a human fetus. They can be harvested for a human umbilical cord or from a lamb, which is where I received mine.

Kathy: Do you know of any other new medical approaches that are being tried right now?

I had the pleasure of reading your book and found it very poignant, educational and honest. How long did it take you to write your story? Did you find it therapeutic to write or was it painful?

Valerie: My book started out as my personal journal that I had been writing for years. It was an excellent way for me to release my thoughts and frustrations. When I showed it to a friend one day, she assured me that I had written a book. I quickly replied, "Don't be ridiculous." It was from that day on that nearly once a day someone would say, "You know, that would be a great book." So, I took that as a message to share my experience with the world hoping that it might help someone who might be going through a similar circumstance.

Kathy: Your determination to overcome and continue on in your life was true inspiration. How can others find that fire within?

Valerie: Seek, and you shall find it! It's within us all.

Kathy: What is the advice you give to other survivors that they seem to connect with the most?

Valerie: Never, Never give up!!!!

Kathy: After reading about your misdiagnosis on more than one occasion, it is painfully obvious that the medical world needs a lot more knowledge about recognizing the signs of a stroke. I hear many stories of patients sitting in ER rooms for hours on end with one side paralyzed and nothing is being done. If your stroke symptoms were properly diagnosed

immediately, what do you think would or should have been done differently?

Valerie: If my stroke symptoms were recognized earlier, I could have been started on a blood thinner. Even an aspirin might have made the difference.

Kathy: I understand that doctors were assuming that you could not be having a stroke due to your young age. Have you met other survivors in your age group that have had the same story?

Valerie: Yes, and it is heartbreaking to hear about. I know my life was spared. That is why I'm on a mission to warn people of the symptoms and demonstrate that it can happen at a young age.

Kathy: Congratulations on walking the marathon at Disney World in January. I am so impressed that you not only completed the 13 miles but also raised \$11,500 for the Train to End Stroke. Can you tell us about that program?

Valerie: Train To End Stroke is a marathon event to raise money for stroke research and education. Whether you walk or run, you have a coach that helps you train several months prior to the event. It is challenging, I cannot lie; but one worth accepting and doing. The accomplishment is very gratifying! If I can do it, so can you! Put on your walking shoes and reach deep. Find your fire!

Kathy: Please tell us what it felt like to finish the marathon when just a few years ago you didn't know if you would ever walk again?

Valerie: Exhilarating! I cried tears of joy! I DID IT! I DID IT!!!

Kathy: You have obviously accomplished so much already. Do you have any new goals set for yourself?

Valerie: After my book hits the bestseller list, and I'm on Oprah and all around the world, I plan on opening a health center for challenged individuals. It will be state-of-the-art facility and have every luxury you would find at a major health center all geared for special needs.

Kathy: It is important for caregivers to understand how a survivor feels immediately following a stroke so they can provide the best care and words to say for encouragement. What

would you tell a new caregiver, overwhelmed with worry about saying or doing the wrong thing?

Valerie: Be patient. A stroke is like a file cabinet being turned over. All the files are there; it's just going to take time for them to find their way back to the right place. This is not easy and is terribly frustrating for everyone. So, be patient with them and yourself. God bless caregivers. You are special people.

Kathy: What would you offer for advice to a recent stroke patient that is overwhelmed with doubts about their future?

Valerie: Manifest your future. Reach for the impossible. Set your sites high. Hang up pictures of things you can visualize on and stay focused on them. I had a wall covered in inspirational affirmations and pictures of walking, running, hiking, swimming, horseback riding, and I achieved them all! Don't sell yourself short! Go for it!!

Kathy: Most writers I know who write non-fiction or personal stories do not do it for riches and fame, but rather a need to connect with and touch people that are caught in a similar situation. If you could afford to give your books away, where would you most like it to be available?

Valerie: I give books to stroke survivors that ask because they are on a tight budget and cannot afford to purchase one, or to anyone who cannot physically see to read, I send an audio.

Kathy: Have you received interesting feedback from readers of your book or people that were present at functions where you spoke? Can you share any with us?

Valerie: I speak at so many functions. It is truly a blessing to hear the feedback. I recently received a manila envelope filled with letters from high school students that I had spoken too. I was taken aback as one by one they said how I had inspired and changed their life and were now grateful for their health and their life.

I also spoke at the 20<sup>th</sup> Annual Stroke Conference in Orlando where survivors lined up to meet me afterwards and say how I had restored hope. One lady even admitted she was suicidal until after hearing my story.

Kathy: Your writing is focused, passionate and personable. Do you think you will write a sequel to your book?

Valerie: Thank you. Yes, I am certain of it. The response has been so powerful that I realize people need inspiration and hope.

Kathy: Is there a question you wish I had asked or any other information that you would like to share with our readers?

Valerie: I think you covered just about everything.

Kathy: Please let our readers know where and when they can purchase your book, "The Fire Within." You can also list your website here if you would like.

Valerie: Thank you.

Kathy: Thank you so much for your time and for sharing your insight and knowledge. I wish you much success in your writing and all other areas of your life. You are truly an inspiration to us all!

Valerie: Thank you!!! Blessings

The First Limited Edition copies of *The Fire Within* can be ordered at: 1-800-247-6553, or it is available at <http://www.amazon.com>  
Book details are available at <http://www.bookmasters.com/marktplc/rr01129.htm>

Valerie's Website: [http:// www.thefirewithin.net/](http://www.thefirewithin.net/)

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## Staying Cool

By Rhonda Peterson

This article was originally printed in StrokeNet in

August 2001.

As a general rule, most people living in northern Minnesota, close to Lake Superior, do not require air conditioning. However, this past July, Mother Nature decided to play a trick on those living in Parka Land and turn up the heat. In an attempt to escape the blast furnace of 90 degree heat and high humidity I drove further up north to my family's cabin. After squeezing into my spandex bathing suit until my thighs bulged out like some misshaped circus balloon, I walked into the cool water dragging an air mattress.

The challenge was to situate by body on the flotation device without drowning in the process. I have no sense of perspective regarding the left side of my body and balance is not one of my

strong points. After a few rounds of wrestling the air filled mattress as if it were an alligator I precariously situated myself so that I was somewhat floating on the lakes surface. After paddling with one arm, I realized I was only going in circles so I began to kick and use my arm as an oar on both sides of my makeshift gondola. Finally reaching a raft anchored a few feet from the swimming beach, I grabbed hold of a rope that was secured to the stairs of the raft.

Regis Philbin had nothing on me as I held fast to my life line. At least I wouldn't float away. Soon two young boys swam out to the raft and began jumping off in cannonball fashion "Don't splash!" I ordered. This command was as useless as my non-water resistance SPF 20 suntan lotion. "I'm at the end of my rope!" I pleaded. Of course by uttering any objection to every mother's dream of healthy exercise for two adolescent boys, I realized the error of my ways and concluded that I was merely enticing them.

I was pushing the rules of swimming etiquette. The unwritten rules of water safety flooded my mind. 1) Never holler "help" unless you really need it. 2) Children can be in the water as long as there is an adult present.

Apparently, in absentia, I had been christened the "Official Lifeguard." I let go of the rope and drifted with the waves. Suddenly, I heard a low gurgling sound and noticed little bubbles coming up from beneath the air mattress. Ever so slightly I shifted my weight to one side in order to inspect the damage. Whoosh! The splash caused a tidal wave that resonated around the lake causing the boys to grab what was left of the air mattress and ride the waves while I miraculously synchronized my body parts in Esther Williams fashion and swam to shore.

"One small step for man. One giant leap for..." stroke survival.



## **Stroke Newsfeed Review Drug Research**

By Jean Kirshenbaum

In June I focused on news about stem cell research and harvesting stem cells from bone marrow. With the death of President Reagan the subject of stem cell research became topical once again when Nancy Reagan came out strongly in support of stem cell research in hopes of finding a remedy for Alzheimer's disease, which is what ultimately killed President Reagan.

My focus this month is on new drug research, some of which is very exciting for stroke survivors. See item 4 about a drug that could improve motor function after stroke. Other news is contradictory and confusing – all of it related to aspirin therapy. And then some of the news is simply old hat, i.e. our diet can put us at risk for stroke.

### **1 Study: Patients should not rely only on aspirin to prevent strokes**

This article states that use of aspirin therapy alone may not reduce the risk of stroke. It says that "aspirin may not prevent a stroke, and patients should not rely on aspirin therapy alone to reduce the risk of stroke." This was the message that researchers want to publicize, following a study in which almost half of patients were found to be "aspirin resistant." Researchers from Northwestern Memorial Hospital studied patients who were on aspirin therapy. <http://www.heartcenteronline.com/myheartdr/home/research-detail.cfm?reutersid=4557>

### **2. Study Questions Combo Therapy for Stroke Patients**

This study states that using aspirin with a clot-preventing drug for people at high risk of artery problems after a stroke does slightly more harm than good. There is a small benefit in terms of reducing the risk of another stroke, myocardial infarction [heart attack] or death, but there is a significant increase in bleeding complications," said Dr. Hans-Christopher Diener, a professor of neurology at the University of Essen, Germany. <http://www.ajc.com/health/content/shared-auto/healthnews/stro/520248.html>

### **3. Aspirin Resistance Test Now Available Nationwide**

At the same time, there is a new test that can indicate whether a patient is resistant to aspirin therapy. Creative Clinical Concepts, Inc., has announced that its aspirin resistance test is now available nationwide. The company says that its new test, called Aspirin Works®, is "ideally suited for patients on long-term aspirin therapy and can be ordered by any doctor's office or hospital laboratory in the U.S." [http://biz.yahoo.com/prnews/040726/lam064\\_1.html](http://biz.yahoo.com/prnews/040726/lam064_1.html)

### **4. Boston Life Sciences Files Investigational New Drug Application ...**

But by far the best news is about a new drug that could enhance motor function recovery after stroke. It's now being studied. Boston Life Sciences, Inc. has announced that the Company

has filed an Investigational New Drug (IND) application with the FDA for the use of Axosine(TM) to enhance motor function recovery after stroke. The IND includes a proposed human Phase I study protocol to test the safety of Axosine administered to stroke patients for 28 days by continuous infusion into one of the fluid compartments of the brain (intracerebral ventricle; ICV). Pre-clinical efficacy and safety in animal testing has shown that Axosine, when administered in this manner, is safe, well tolerated, and highly effective in promoting motor function recovery after experimentally-induced strokes in rats. The results of these efficacy studies, as well as studies demonstrating compensatory axon growth in experimental spinal cord injury, have been published in numerous prestigious scientific journals during the last few years.

[http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news\\_view&newsId=20040726005475&newsLang=en](http://home.businesswire.com/portal/site/google/index.jsp?ndmViewId=news_view&newsId=20040726005475&newsLang=en)

#### 5. **Western diet could increase stroke risk**

Finally, there is a report that it's what we eat that puts us at risk for stroke. Is this even news? According to one new study, the diet we eat in the West could increase stroke risk. A long-running study compares a healthy diet and a 'Western' diet with respect to stroke risk. The Nurses' Health Study has been looking into the risk factors that affect health since 1984 and a new report now finds a link between diet and stroke. Researchers at the Harvard School of Public Health have found two dietary patterns in the group of nearly 72,000 nurses, which they terms 'prudent' and 'Western'. The prudent diet comprises higher intakes of fruit, vegetables, fish, legumes and whole grains.

The Western diet is focused more on red and processed meat, refined grains, sweets and desserts. Those with the highest Western diet score had a 58 per cent higher stroke risk than those with the lowest score. Those with the highest prudent diet score had a 22 per cent lower risk of stroke than those with the lowest score (but the researchers find this result not to be statistically significant). Women on the Western diet with high blood pressure were also three times more likely to have a stroke than those who ate the Western diet but did not have high blood pressure. These results are quite likely to apply to men. A shift towards the prudent diet and away from the Western diet could, therefore, cut the risk of having a stroke.

<http://www.healthandage.com/Home/gm=1!gid1=5996>



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## **Website Review: Stroke Information**

By Janice Rodriguez

This month we are going to think about stroke as one of the leading health risks faced. Many websites cover this topic. Some of my favorites are the following:

The Internet Stroke Center, "Reducing Your Risk of Stroke,"

<http://www.strokecenter.org/pat/risk.htm>, is a wealth of information on stroke. The risk factors of stroke are categorized as: 1) medical conditions, 2) controllable, and 3) uncontrollable factors. The site has links to other great sites. On the left side of the web page, you can browse other topics like, "How a Stroke is Diagnosed," "Recovering After a Stroke: A Patient and Family Guide," and "Recent Stroke News." I found the information in this site very instructive and up-to-date.

"Separating Myth From Fact: Women and Stroke," <http://www.healthatoz.com/healthatoz/Atoz/hc/wom/life/womstrk.html>, is a good general site. If you have some time, you can read articles on other health subjects, from "A to Z."

Finally, check out "Your Disease Risk - The Source on Prevention,"

<http://www.yourdiseaserisk.harvard.edu>. It is an "interactive tool" to estimate your risk of stroke (cancer and heart disease are covered also). The format is a questionnaire. The resulting rank helps you understand the your general risk. On the same page with your rank, you will see "tips" -- things you can do that impacts your risk. While the result may not be accurate for a person who has already had a stroke, the site is still interesting.

Have fun, eat your vegetables, exercise, and I'll see you next month!

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## **Stroke Warning Signs**

- 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



## August Birthdays

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

- 2<sup>nd</sup> – steve (47), Maryland  
David Ray (71), New Zealand
- 5<sup>th</sup> JackieE (55), Nevada
- 8<sup>th</sup> eatc7402 (58), Michigan
- 9<sup>th</sup> blackhills (53), South Dakota
- 10<sup>th</sup> jimg2000 (58), New York
- 12<sup>th</sup> sandy byrne (57), Ontario
- 26<sup>th</sup> HavanaFIBill (52), Florida

Look in the Member bio section of the Gallery to see bios of steve (Steve Mallory), David Ray and jimg2000 (Jim Gerrish). Click on the photo to read the bio. Steve's website is also available through the 'Top Sites' button at the top of the home page of the Message Board.

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.'

The Message board can be entered through the home page of The Stroke Network,

<http://www.strokenetwork.org>, or click <http://www.strokesurvivor.net> to directly access the message board.



## Bio Invitation

The Stroke Network invites you to include your bio in The Gallery. To visit the Gallery, click the 'Gallery' button at the top of the Message Board. The Gallery can be accessed through the home page <http://www.strokenetwork.org>. Or click <http://www.strokesurvivor.net> to directly access the message board.

Add the bio yourself or send it to the editor at the address above.

Instructions for entering the bio yourself:  
From the Members Bio page click the button at the top 'New Image'  
Enter the following data:  
Caption: your name  
Large text box: Enter the bio.  
Upload photo: At the bottom of the page upload your picture from your computer.

If you do not have a digital photo contact the editor at the address at the top of this newsletter. She can send you a snail mail address where you can send a paper photo to be scanned.

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/>. It is also available through the Information Link at the home page of The Stroke Network. Contents of this newsletter may not otherwise be reprinted without the organization's permission. Please contact the editor.

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