



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

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Welcome to the October issue of StrokeNet. Those of us at StrokeNet wish everyone a great fall. Steve opens this Newsletter by reporting on the annual Golf Fund Raiser, which took place on October 1. Sharon-dale Stone shares information on Pediatric Stroke.

Kathy Bosworth explores the issue of Caregiver Stress. David Ray reports on a talk on organic gardening at his Stroke Club. Jean reviews five newsfeed articles. Janice reviews two websites, which are resources for the stroke family. October Birthdays are listed. Featured bios are Penny Wohlford and Pam LeBlanc.

Enjoy your reading.

Lin Wisman, Editor  
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committed to playing again next year. Photographs will be posted at <http://www.strokenetwork.net/fundraiser/>. The problem with having an organization fundraising committee is that members may not realize that the future of the organization depends on the generosity of time and talent of just a few people, who aren't even stroke survivors or caregivers. This brings up the subject that I touched on last month, Rally Month. October is officially our Rally Month. It is the time of the year to raise funds for the coming year. What I'd like to do is make fundraising something where our members can get involved. This will give everyone the opportunity to feel they have a stake in keeping this organization alive. I've never asked this but I think that our members might agree with me!

One main ground rule is that I don't want our members to think that I'm asking them for money. Actually, it's just the opposite. I don't feel like our members should contribute, but I would like to ask their families and friends to do so. Anybody in his or her local community is welcome to contribute, especially local businesses. Some ideas are to have something like a bake sale, or you can just ask people contribute at <http://www.strokenetwork.net/donation/>. Contributions can be made on-line via credit card or can be sent via direct mail. Our mailing address is on the donation web page. Sponsor information is available by clicking on the "Donate to Us" button. Brochures are also available. Email me for more information.

There have been changes to the website. If you frequent the message board and chat room you might be asking what is going on? I want to start out by saying that the Internet addresses are changing. The message board is moving to <http://www.strokeboard.net/> and the chat room is going to <http://www.strokeboard.net/>. Chat will still be linked through the message board and



## Organization Highlights

By Steve Mallory

Sorry that the newsletter was delayed being released this month. Lin and I thought it would be a good idea to wait until after the golf tournament fundraiser. We had another successful fundraiser and I have to recognize the main volunteers. Without them this organization would not exist. I could still create the web site but unless we had them to raise funds for our bills we could not have our wonderful Internet web pages!

I would like to thank my beautiful sister, Jean, her husband, Tom, friends, Dave and Karen Lynch, and my mother, Marian! The fundraiser took months of hard work and preparation and the success was obvious on the day of the tournament. I got there before the golf event was finished and had the opportunity to talk with several of the player donators. Everyone was thrilled with our fundraiser and several already

Member Area. The reason for this change is to make the URL's much easier to remember.

Next, you are probably wondering why we are upgrading. I have to first say that I don't understand all the technical improvements, yet, but needless to say our members will soon realize many of them. Hopefully, the improvements will encourage many of our silent members to become more active.

Thanks to the efforts of our Chat Host and Message Board Administrators. They are making conscious efforts to make using the message board and chat room easier. Host Pam has been having Chat 101 class sessions to help those who don't understand and therefore might be afraid to chat.

Pam has already had several sessions and is planning more for October. Her next classes will be held on October 12 at 3 pm and October 13 at 5 pm. If you aren't a chatter, but would like to be, mark your calendar. Chat meets daily in the late afternoon to early evening. Both class times are EST and will be held in the chat room called, Class Room. Sorry for any technical problems that we have had recently but everything should be cleared up this week. The message board has similar training sessions, but Jean holds her training via private messages. You can send Jean a private message by logging into the message board and then click on her username, which is jriva.

Our staff is undergoing several changes. Janice Rodriguez will be leaving in December. We thank her wholeheartedly for the time that she donated. With her leaving we will need a new web site reviewer for the newsletter. Please email Lin for specifics. We had several additions to our staff in September.

Tania Parson is our new Membership Administrator. Several of you have probably noticed that someone from our organization is mailing you a birthday card. This is just one of Tania's many responsibilities. If you know of anything that you think the organization might want to know about please email us. Tania can be reached by clicking on her name from the message board, tparson. Other additions are chat hosts, hoststephen, hostjerri and hostbette.

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## **Pediatric Stroke**

By Sharon-dale Stone

I can't tell you how many times people have said to me, "Oh my God! You were only 11 years old when you had a stroke! How is that possible?"

I've come to expect such remarks from people who don't know anything about stroke except what they've heard in the media, or who only know elderly people who've had a stroke. But it always surprises me when even people who were young adults at the time make the same kind of comments.

As any "young" stroke survivor should realize through personal experience, age doesn't protect anyone from having a stroke. Even babies, less than 1 month old, can have a stroke. In fact, according to research by the (U.S.) National Institute of Neurological Disorders and Stroke (NINDS), stroke is one of the top ten reasons for death in children.

Although no one can really give accurate statistics on how common pediatric stroke is, current estimates are that it occurs in one per 4000 live births and in at least seven per 100,000 children a year. As well, unlike the case with adults, where the ratio of ischemic to hemorrhagic stroke is approximately 4:1, some studies suggest that in the pediatric population it is closer to 1:1.5. In other words, children are more likely to have a "bleeding" stroke than a stroke caused by a blood clot. On the other hand, as diagnostic procedures improve (e.g., MRI and PET - positron emission tomography), it is beginning to look as though ischemic strokes in children are more common than originally thought.

A wide variety of problems can cause pediatric stroke. One of the more significant reasons for pediatric stroke has to do with an increase in chronic conditions such as congenital heart disease. As pointed out by Dr. Gabrielle deVeber, a pediatric neurologist at the Toronto Hospital for Sick Children, children who once died of heart defects now live, but they are more prone to stroke. Other neurologists also point to blood disorders, vascular malformations and viral infections as common causes. Probably the most common cause of hemorrhagic stroke in children is a ruptured arteriovenous malformation (AVM),

which is what happened to me when I was 11. Together with aneurysms and cavernous malformations, AVMs are responsible for up to 85% of hemorrhagic strokes in children. Other common causes of hemorrhagic stroke are blood disorders (including leukemia) and intracranial tumors.

None of this information, unfortunately, is widely known. Most disturbingly, much of it seems also to be news to general practitioners and emergency room physicians. In fact, just as I was initially misdiagnosed back in the 60s as having the flu (or possibly a drug overdose, so they pumped my stomach just in case!), it remains the case that children are quite likely to be misdiagnosed and not get immediate treatment. According to Dr. Donna Ferriero, chief neurologist at the University of California-San Francisco Department of Neurology, barriers prevent needed investigation into the cause and treatment of neonatal and childhood stroke. Most significantly, she points out, lack of awareness of neonatal and childhood stroke results in delayed and missed diagnosis, and approaches to investigation are not standardized.

Some neurologists say that prognosis for recovery is better for children than for adults, because a young brain can adapt more easily. Recent research shows, however, that up to 20% of affected children die, up to one third have a recurrent stroke, and more than half of all survivors are left with neurologic (e.g., one-sided weakness) and/or cognitive (e.g., aphasia) disabilities that are permanent. When you're one of the more than half of children left with permanent disabilities, as I am, then it's hard not to be skeptical of pronouncements about the greater capacity of the young brain to recover. In fact, there is precious little research on the long-term outcome of childhood stroke. What little research that exists tends to be based on extremely small sample sizes (e.g., one was just published based on 16 Swiss children, another was just published based on 29 American children).

I have no evidence, but it seems to me that one of the reasons so many of us are left with significant disabilities – despite our youth at the time – may be precisely because we were not diagnosed or treated immediately. In my own case, I was in and out of consciousness when my father took me to the hospital, and the emergency physician told him to keep slapping my face to keep me awake! When I didn't get

any better, the family doctor was called and he recommended that I be kept out of bed and walking around! I can only imagine the damage that was done as a result of all this advice – damage that could probably have been prevented if the wise doctors had realized what they were seeing right in front of their eyes.

Stroke, of course, is a traumatic event for anyone no matter what their age, but what needs to be talked about more is the psychological damage that is done. In this regard, I've noticed that researchers of childhood stroke are starting to look at how it affects survivors as they grow into adulthood, and what they're finding is not good news. Most of us do return to finish school after a period of rehabilitation, and even go to college or university, and enter the workforce on a full-time basis. But in adulthood we tend to have poor communication skills (that's me!), we're not necessarily well-socialized (whatever that means!), and most of us, according to a recent Dutch study, have low self-esteem, emotional, behavioral, and health problems (no comment about me!).

I'm fascinated by these studies that have only just begun to appear in the literature, because they're about me, and never before have I ever seen research that so directly applies to my own situation. For too many years, I thought I was the only child who had ever had this happen. Even after I realized how relatively common stroke is in children, I still felt the lack of attention to the long-term outcome was a way of saying that I really should have just GOTTEN OVER IT a long time ago. So, I find it affirming to read these studies. I hope there will be many more conducted in the years to come, and I hope that awareness of pediatric stroke will become widespread.

### References and Selected Readings:

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Steinlin M, Roellin K, Schroth G. (2004) **Long-term follow-up after stroke in childhood.** In ***European Journal of Pediatrics* 163 (4-5):245–250.**

Children's Hemiplegia and Stroke Association  
<http://www.chasa.org/index.htm>

Pediatric Stroke Network  
<http://www.pediatricstrokenetwork.com>



## Dealing with Caregiver Stress

By Kathy Bosworth

More than one quarter of the adult population (26.6%) has provided care for a chronically ill, disabled or aged family member or friend during the past year. Based on current data, that translates into more than 50 million people! Sixty one percent of "intense" caregivers (those providing at least 21 hours of care a week) have suffered from depression. Heavy-duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three fourths of these caregivers are "going it alone". Is it any surprise that caregiver stress or burnout is becoming a critical issue?

Dealing with stress is not a new concept. None of us have immunity from the challenges of getting through life with the least amount of stress. Some people drink, over eat, smoke, bite their nails, yell at the cat, or retreat inside themselves when the going gets too tough. I'm sure you have your own ways of protecting yourself from

the ravages of stress. I have often thought my cat has the right idea when stress enters her life. After one loud meow and an angry swish of her tail, she retreats to another room to take a nice long two-hour snooze. Bamm! The stress is gone. Unfortunately, people do not have the same luxury.

Are you caught in the web of stress while being a caregiver? In the book, "Living with Stroke," there is an interesting section on stroke stress analysis. People list nine sentences that sum up all the different ways that stress exhibits itself in families of stroke survivors. Do any of these ring a bell with you?

1. Panic: "Ohmigod, I can't handle this."
2. Anxiety: "What if he needs me in the middle of the night and I can't hear him?"
3. Denial that leads to over-optimism: "Oh, he'll be fine. He just needs to come home."
4. Irritability and Anger: "It's all the rehabilitation team's fault."
5. Frustration: "I can't stand one more thing going wrong!"
6. Fatigue: "I'm utterly, completely exhausted from the experience."
7. Hopelessness and helplessness: "What's the use? Nothing's going to change."
8. Guilt: "How can I be so angry at him? It's not fair."
9. Ambivalence: "I don't know how I feel anymore. I can't make a decision about anything."

If you are a caregiver, I'm sure you find yourself nodding your head at more than a few of these stress indicators. I often say that caregiving is not something that people plan on or sign up for. It is a situation sort of plops itself in your lap totally unexpected. Caregivers are usually overwhelmed, untrained, and uneducated in the beginning. With time comes a sense of control that can help you through. Being out of control in any situation can knock a person off balance. Don't be too hard on yourself as you muddle through this. You are a rookie now, but you are getting some heavy *on the job* training.

Here are some tips that I have found to be helpful in getting your life in balance again.

1. When well-meaning people offer to help, accept their help. Be specific in things you could use help with. Now is not the time to show the world how strong you are.

You will only burn out quicker without help.

2. Watch out for signs of depression. Get professional help if you need to.
3. Educate yourself about your loved one's condition. Information is empowering!
4. Trust your gut feelings. I'm a firm believer in our innate instincts. If something sounds out of whack to you, keep asking questions until you are satisfied that the best care is being administered.
5. Find other caregivers to connect with. There are many caregiver websites and support groups. If there are none in your area, start your own. Believe me, you need somebody to talk to that understands what you are going through.
6. Be kind to yourself. Even if you only take a ten-minute walk around the block to alleviate some stress, DO IT. A caregiver with a lower stress level makes a much better caregiver. Getting enough sleep, exercise, and eating balanced meals reduces stress.
7. If you are caring for a parent and have siblings, be vocal about what they can do to help. Some people are not comfortable with the day-to-day care but they might be willing to grocery shop for you, pick up meds, or do a doctor's run or two. Don't be a martyr. Your emotional health cannot take it. Face it and get on with it.
8. Take charge of your life and continue to do things that you find relaxing or pleasurable. If a loved one's disability always takes center stage instead of your needs, you will become a resentful caregiver. Not good for anyone.
9. Write down things to keep your head uncluttered. Having ongoing lists of medications your loved one is taking will not only alleviate the stress of trying to remember what and when, but it is also a valuable tool when visiting the doctor. It's all written out and accessible. Doctor's are often rushed and cannot wait around while you try to remember which meds are causing what side effects, etc. Keep it as simple and easy on yourself in ways that you can.
10. Keep your sense of humor. It's the most important tool you have and it's free. Humor can be found in the most surprising places, even hospitals and nursing homes. Laughter is good for the soul.
11. Know your limitations! Don't let guilt get in the way of making the best decision for

your family member and yourself. Not everyone can be a caregiver no matter how good their intentions might be. If you cannot be a caregiver due to an emotional, physical, financial or locational burden, you do have choices. You cannot help another if you yourself need help. The medical needs might warrant the need for assisted living or long term care. If you must find alternative living arrangements, make sure they are ones you can live with and serve the best interest of your loved one! Stay involved and vigilant that the care remains good.

Caregiving is a huge responsibility. Keeping the caregiver healthy; physically, mentally, and emotionally is vital. Try to find the right balance in your life that allows you to care for your loved one while caring for yourself.

### Helpful websites for caregivers:

Family Caregiver Alliance:

<http://www.caregiver.org>

National Family Caregivers Association:

<http://www.nfcares.org>

National Alliance for Caregiving:

<http://www.caregiving.org>

Empowering Caregivers: <http://www.caregivers.com>

Caregiving.com: <http://www.caregiving.com>



### Life in New Zealand with a Stroke

By David Ray

I only attended one Lower Hutt Stroke Club meeting in September because my wife and I travelled to Timaru in the South Island to attend the 70th birthday party of an old schoolmate of mine. He is a Catholic Priest and he was using the opportunity to invite some of our old classmates for a reunion. More about this next month.

At the September gathering which I attended, our daughter, Catherine, gave a talk and demonstration on organic gardening. Catherine is the manager of a shop called 'Commonsense Organics' which has organic groceries for sale and well as other products. She has completed a course at the Wellington Polytechnic on organic

gardening. She demonstrated, using a bag of organic compost, how stroke survivors can grow their own organic plants such as lettuces, cabbages and other seeds and plants.

Catherine went on to say the organic agriculture and gardening is vital to the health of the environment and humans. Organic food is grown without the use of chemicals that can harm humans, animals and the soil. Organic growers build up and maintain the fertility of their soil and control weeds, disease and pests using both age-old remedies and modern tools and practices, which organic agricultural researchers are constantly developing. Catherine emphasised that, at least in New Zealand, one can be sure that the food is organically grown if it is certified organic.

So, she concluded, why eat organic food? Because organic food tastes like food used to taste. She bought some organic food with her for our members to try and Enid and I both strongly agree that organically grown bananas have much more flavour than those purchased in a supermarket. Catherine also stressed that organic food is safe, doesn't contain a cocktail of chemicals, because it was GE (Genetically Engineered) free. It helps the environment, which is very important in order to have a clean, green New Zealand.



## Stroke Newsfeed Review

By Jean Kirshenbaum

As usual, the month brought us a lot of interesting news about stroke. Right in line with the recent national concern about obesity, two articles warn that overweight children are at greater risk for stroke or heart attack before they reach 65. This is not so terribly surprising but it is disturbing, of course. Articles located at:  
<http://www.voanews.com/article.cfm?objectID=B8B93FF-6C7A-4FF7-858FC2B3CF0958BD&title=Obese%20Children%20Prone%20to%20Heart%20Attacks%20and%20Stroke%20as%20Adults>

<http://maconareaonline.com/news.asp?id=8473>

The article that really got my attention is the one about the woman who suddenly stopped dreaming after her stroke. That happened to me

as well. I remember telling my husband a couple of months after my own stroke in May of 2002 that I was no longer having dreams. Scientists believe that her case will help pinpoint where in the brain dreams originate. Article:  
<http://www.concordmonitor.com/apps/pbcs.dll/article?AID=/20040919/REPOSITORY/409190354/1013/NEWS03>

Another article covers research the umbilical cord as a source of stem cells, noting that President Bush and Presidential wannabe Kerry strongly differ on this issue. Article:  
[http://www.innovations-report.de/html/berichte/biowissenschaften\\_chemie/bericht-34052.html](http://www.innovations-report.de/html/berichte/biowissenschaften_chemie/bericht-34052.html)

Finally, the value of tPA in treating ischemic strokes is confirmed in a review by U.S. National Institute of Neurological Disorders and Stroke. I can attest to that since I was given tPA within 3 hours of my stroke and all my symptoms—left side paralysis resolved within 15 minutes. Therefore, I can walk normally today! Article:  
<http://www.ajc.com/health/content/shared-auto/healthnews/stro/520995.html>



## Website Review: Stroke Resources

By Janice Rodriguez

This month's topic is "Untangling the Web," which is the title of the late Steven Fullmer's award-winning website, [www.icdi.wvu.edu/others.htm](http://www.icdi.wvu.edu/others.htm), "Your complete listing of disability information on the Web." This great reference website is easy to navigate. The first part of the page is a Disability-Related Resource Menu, which points the user to a listing of interesting websites. Stroke survivors may want to check out the menu choices like Legal Issues, Orthopedic Disability, Agencies/Services, Employment and more.

The Stroke Information Directory, [www.stroke-info.com/fact\\_sheets.htm](http://www.stroke-info.com/fact_sheets.htm), is another good reference site. This website is very professional and covers topics like Pediatric Stroke, Deep Vein Thrombosis, and Spasticity. Many of the listed websites will point you to other sites to browse. As always, check your doctor and therapist for more information.



## October Birthdays

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

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>.



## Bio: Penny Wohlford

I've been contemplating for quite some time after reading other bios just how to approach my own. I want to share my story with others not only to hopefully give those who are new to this lifestyle some encouragement but to also share my struggle with those who have been there for a while.

While we all know that we have our crosses to bear some have a longer path to carry them while some have heavier crosses to carry I would like to put myself into the category of one who probably has a longer road to carry, but a road well worth going along however long it may take me.

On May 21, 2002, my life as I knew it came to an abrupt halt. While I was taking a dressage lesson on my horse I experienced a mild stroke. Fortunately my horse was very gentle with me and walked me over to my instructor. Because of her I am alive today. She immediately took me off my horse and got me to a small hospital. They did a CAT scan and knew I was in big trouble and took me directly to the University hospital in Salt Lake City.

It was there when I came out of the MRI, my AVM ruptured. Because the neurologist stayed with me instead of looking at the results of the scan they were able to get me into the operating room right away to stop the bleeding from permanently damaging my brain stem. They had

to completely resection veins in my brain that were in this mass that I probably had at birth. The surgeon said that it was the worst that he had ever seen yet he expected me to fully recover. I was in critical care for ten days on life support.

I did about one year of physical therapy in my town of Park City Utah. From there I pretty much took it upon myself to do my own therapy at home. I did purchase a neuro-move and an e-stem unit which I have been using for two years. The only reason I still use them is because the therapists say that they are beneficial for keeping the muscles active. At this stage I can use my left hand minimally in assisting me with carrying things. I can't open it at will unless I'm in a certain position. Because of this I have great hopes that I will get more function back. I can move my fingers too.

I guess I'm fortunate in that I have very supportive friends, husband and family. It's because of them that I continue to push myself to get better.

We all say we USED to be able to that, what I say now is that I still do that just in a different way. I've been riding my horses since five months after I got out of the hospital. I needed help getting on and saddling them but now I do it completely by myself. However I always ride with a friend. One year after my brain incident I entered a dressage horse show and managed to show successfully in a little different fashion, but we did it.

I've also been on many trail rides in the mountains and have had no trouble with any of it. I also ski, not as aggressively as I used to, but I can still enjoy the mountains and the cross-country trails. I try to keep fit by swimming. When I first started last fall I could barely swim 100 meters, four lengths. I now swim a half a mile, which is 36 lengths. I just started swimming without a floating device. My next goal is to swim without fins, which gives my weak side an advantage so I will eliminate one then two.



### **Bio: Pam LeBlanc**

Pam LeBlanc is 43 years old and had a stroke 3 years ago after 15 years of abusing cocaine, She went to visit her mom looking for a new place to live to get away from old friends... the day she went to my mothers house the migraine hit- She had never had one before and had no idea what was going on. The headache was there for two weeks before she stroked.

She went to the doctor once and the emergency room twice where they asked where it hurt, and gave a painkiller that didn't work, and sent her home. She did get away from my old habits and

friends!!!! My whole left side was paralyzed. She couldn't swallow and she almost went completely blind before the downhill slide slacked up. She can walk quite well now, left hand does better on big things than small stuff, but it works. She still has trouble swallowing, vision is pretty horrible, and she does not like the way she talks. Her mother calls her a miracle child!! She was unemployed and real poor at the time of the stroke so she had to go on county public assistance, the doctors they sent me to were 3rd or 4th year med students who know nothing about strokes, but thanks to determination and prayers and a mother who wouldn't give up, her she is a 2nd semester college student at our local community college, hoping to graduate in a year or year and 1/2..... Life is hard, but life is good!!!!!!!!!!!!!!

### **Stroke Network Connections**

Organization Schedule:

<http://www.strokesurvivor.net/index.php?act=calendar>

Newsletter Archieve:

<http://www.strokenet.info/newsletter/index.htm>

Donate to us:

<http://www.strokenetwork.net/questions/donate.htm>

Caregivers Handbook

<http://www.strokenet.info/resources/caregiver/StrokeCaregiverHandbook>

Stroke Awareness

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

Message Board

<http://www.strokesurvivor.net/>

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.

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. Copies can be printed from the webpage. Contents may not otherwise be reprinted without the organization's permission. Please contact the editor.

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