



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

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Welcome to the July issue of StrokeNet. Steve Mallory shares important network information and congratulates two staff members for recent contributions. David Ray shares data on New Zealand birds. Kathy Bosworth writes the second of a two part series "Getting your Affairs in Order." Jean Riva contributes an article on accessible housing.

Jean Kirshenbaum selects a newsfeed article on Botox Treatments for Stroke. Janice Rodriguez reviews websites focusing on aphasia rehabilitation. Bios of Janice Rodriguez, Wesley Cook and Jim Gerrish are highlighted

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help email them to Lin or myself. Our email addresses are listed on this newsletter.

We will be offering free email accounts in the next day or so. This free email account is similar in quality to hotmail! In some ways, even better quality! The email features are awesome, you can forward email from your regular email account, and it has auto-responders, powerful message rules and spam filtering system, and much much more. I am critical of most software but this looks fantastic!

To start with we will be offering email addresses, like yourname@strokesurvivor.net. This is the perfect way for members to tell everyone that they survived a stroke and now are part of our community. In the near future, caregivers can also choose the email address, yourname@strokecaregivers.net. This email is so cool! To create an account go to the message board, login and click on My Controls.



Organization Highlights

By Steve Mallory

I would like to begin by covering a few highlights from last month.

These are important issues and I think that our new members should be told about them. We average about 150 -200 new members per month so everyone should be constantly reminded.

Remember to enter the stroke support area through the Members Area button on the homepage, <http://www.strokenetwork.org>. If you haven't already, visit the Members Map and enter, or view, where other members are from. Place a pin on your location. Maybe, you will find another member in your neck of the woods and can become local friends, as well as cyberbuddies.

Have you been to the bio web page? Go to the message board and click on Gallery. Choose the Bio forum and click on the picture of the person you want to read about. While you are there, why don't you post a photograph? Add your bio or a family picture. Instructions for adding a picture are on the main message board or if you need

I need to recognize two staff members who are performing special tasks to keep this organization great! I would like to recognize all staff but I think these staff members are doing something special. First, Jean Riva, is organizing the message board and putting the posts in order. Message board management is a major task and Jean has been busy making sure that all posts are in the appropriate forums so members can make better sense of where to find certain types of discussions.

I also want to recognize Jean Kirshenbaum. Jean was instrumental with getting the article about the organization published on the national Business Wire. Her normal task is to screen the Newsfeed articles and to write a monthly newsletter featured article. Thanks to both

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Life in New Zealand with a Stroke

By David Ray

Last month I wrote about The Kiwi, national bird of New Zealand. This month I am going to mention some other birds that we have or used to have in this country. Many, many years ago, New Zealand was home to a number of very large birds all of which are now extinct. One of the largest was a type of eagle. Another was the Moa which was flightless and stood over the high of a man. Although extinct a few years ago a man who lived near Arthur's Pass in the South Island reckoned that he had seen a Moa and got a number of people excited. It was a hoax of course but there is a model of a Moa is on display outside the hotel that he owns.

My wife and I are woken up by the call of Tui, a black bird with a white tuft of feathers just under its beak. It is sometimes call the Parson Bird because of this. It delivers a grating noise at first but this soon changes to a melodious call. Tuis are especially busy in the spring when they get their nourishment from eating the nectar of the Kowhai tree flowers Kea is a cheeky parrot that lives mainly in the mountains. It is well known for its habit of ripping off the rubber trim around the windows and doors of vehicles. Many motorists has parked their cars, gone for a walk in the high bush, and returned to find the Keas have been at work. I can recall chasing Keas off the top of my car thus stopping them from pecking at the cars trim. They have beautiful orange feathers, which you can be seen only when they flap their wings.

Another flightless native bird is the Weka found mainly in the South Island. This a cheeky bird which is often seen coming out of the bush when you park your car. They are looking for a meal. These birds seem to have no fear and I have had one trying to undo my shoelaces while just standing on a bush track. Other interesting birds are the Fantail, which flits around just in front of you at eye level when walking in bushclad tracks although we have had them in our pear tree when the fruit are ripening. Another native bird, which we see almost every day, is the Pukeko, often seen on country roads near waterways. Although it seems to be flightless it is able to fly short distances. There are many other interesting native birds and since the arrival of Europeans another population has made their home in New Zealand,

some useful others such as the magpie and Myna, very unwelcome.

The point about writing about these native birds is that stroke survivors even if they are unable to move very far can get a lot of joy out of watching, examining the habits of, feeding or just reading about birds that frequent your neighbourhood. You can buy, borrow from your local library or just acquire books on the local wildlife. I have found such an activity to be very useful and personally rewarding and of course gets me, as far as possible out of the house and into the garden or onto the beach. I have found that feeding the seagulls on the beach near our house very relaxing.

Another relaxing time was spent at the Lower Hutt Stroke Club's half yearly lunch at a Chinese restaurant. We had a very enjoyable couple of hours of relaxing chat with each other. Two weeks before we had an hour of general knowledge questions between teams of four stroke survivors. As we found out at the end of the competition there was no prize for the winning team but it was a lot of fun and stimulated our brains.



Getting Your Affairs in Order

By Kathy Bosworth

If you are fortunate enough to break the ice and begin estate planning with your family, here are some issues that should be discussed.

Is there a will? Where is it?

I am often shocked that so many people I meet do not have a basic will. An estimated 57% of adult Americans do not have one. If you die without a will, your state has laws that will dictate how your possessions will be divided. It's a nightmare for your heirs. If you already have a will, make sure that someone knows where it is.

Is there a Living Will? Where is it? Does everyone understand what it is?

A Living Will gives someone you trust the authority to disconnect life support if you are unable to communicate and are brain dead. A Living Will is a must to me. I don't want to be kept alive on life support after my brain has ceased to function. If you don't care if you are on life support for ten minutes or ten years then you should do nothing. Doing nothing is the equivalent of saying you don't care. Living wills are often free

when a lawyer draws up a will for you. They can also be obtained from your local hospital. Some states are now mandating that all overnight hospital patients must have a Living Will.

Organ Donor?

How do you feel about being an organ donor? If you want to be one, you can have it put on your driver's license. If you don't have a license, it is important to tell your loved ones what your wishes are. It's a hard decision to make when there has been no dialogue on the subject. If your family knows what you want, the decision might still be hard, but not impossible.

Funeral Choices

Few people like to talk about their personal wishes for their own funeral. It's almost like they think talking about death will bring the Grim Reaper right to their front door. However, we are all going to die. Decisions like cremation or burial, to have a wake or not, and where people want to be buried will have to be decided by someone. Why not do it yourself? I know people that have planned every single detail, right down to the music they want played in the church. Now that is organization! People can also prepay their funeral expenses.

Where are the vital papers kept?

Items such as social security number, birth certificate, veteran information, marriage certificate, insurance policies (life and medical) should be stored in a place that family members can have easy access in an emergency. I have met many boomers that had been told by their parents they had life insurance. Yet, after the parent passed away, no policy could ever be found. Without the policy and insurance company's name and file number, no payment can be paid to beneficiaries.

Safe Deposit box?

If there is one, someone should know where it is and where the key is.

Bank Account

Where are bankbooks kept? Do you own stocks? Someone should have access to that information.

Pets?

If you have pets, whom do you trust to care for them if something happens to you? This is one that few people give thought to while organizing their final wishes.

A Living Trust

If you are fortunate enough to be in a high tax bracket, maybe a living trust might be in order. But **ALWAYS** consult a good, reputable estate attorney when making decisions about wills and trusts.

Being organized is the key to keeping updated estate documents. If the person you want to be responsible for carrying out your wishes can find all of your information quickly, it can save days, months, and even years. Hiding your important papers in the wall behind a picture might seem safe, but if nobody can find it, it's useless. Being unable to find documents can also lead to inflated legal fees, regardless of the size of the estate.

Communication is imperative! In spite of what we might want to think; **you cannot take it with you!**

Kathy Bosworth is the author of "Your Mother has Suffered a Slight Stroke"
<http://www.authorsden.com/kathybosworth>



Our Wheelchair Accessible Home

By Jean Riva

For most of our adult lives my husband and I had wanted to build a house. It took his stroke for us to finally take the plunge. We really had no choice. The two houses that we owned were not good candidates to retrofit for Don's newly acquired needs and there were virtually no wheelchair accessible houses on the market.

Finding a builder who was knowledgeable about Universal Design in a town of 600,000 should have been easy, after all, the concept has been around since the 1980s. But it wasn't easy. The Home Builder's Association only listed one builder who built for that market niche and although his houses were beautiful customized homes, his starting price was twice what we had wanted to spend. But he was passionate about building for the disabled and, even though he knew we couldn't afford his services, he was generous with his time and gave us the confidence we needed to go forward with our project.

All total, we called twelve well-known builders. Some had never heard of the term Universal

Design. We were shocked! Other builders never returned our calls that we believe was a form of prejudice against the disabled. The building company we finally went with had built three wheelchair accessible houses, so they said, but we quickly found out that we had to bring our own research into the design stage of the process. They were willing and able, but WE were the experts when it came to Don's needs.

Universal Design is not rocket science, but there is a wide variety of choices to be made and just as every disability is different, every house for the disabled will be different based on the options taken and the budget you have to work within. The core, must-have features of Universal Design homes are:

- at least one no-step entry way
- one floor living
- 36" exterior and interior doorways
- thresholds on the doorways that are flush with the floor
- a five foot open radius in the centers of the bathroom and kitchen
- a roll-in shower stall or transfer tub that fits the special needs of your disability
- a roll under sink in the bath
- reinforced bathroom walls around the toilet with grab bars
- four foot wide hallways

Other features of Universal Design that we included thorough out our home were: lever-style door handles and lower windowsills than the norm, so that Don gets a better view from a seated position. Carpeted rooms have a very short looped carpet with a dense, commercial grade padding underneath that is glued on both sides. (The wrong choice of carpeting and padding can make it difficult for wheelchair and walker users.) In the kitchen, a side-by-side refrigerator is a must for people in wheelchairs.

We also included two microwaves---one low for Don, one high for me, and the cupboard below our kitchen sink opens up fully from countertop to floor so that Don can get his wheelchair up under the sink. A section of our countertop is also lower and open underneath so that Don has a workstation in the kitchen. There are lots of Universal Design options to use in a kitchen including hydrolytic cabinets that go up and down and oven doors that open side to side. But this is an area that will quickly drive up the cost of the home. The few options that we did use fit our life style perfectly with a minimal impact on our budget.

Our garage takes advantage of several common Universal Design features. The overhead doors are eight foot high, instead of the standard seven so that a pop-up van will fit. The garage is also large enough to unload a wheelchair from the side or the back of a van. We also have a parking space for an electric wheel chair with an outlet and a grab bar for transfers.

Another feature that is a favorite of Don's is that the entire garage floor is a gently slope, which eliminates the need for a wooden ramp. To push himself around in his manual chair, Don only has the use of one arm and one leg; with a conventional ramp, he would not have been able to roam freely from the house to the garage without my help. Our front sidewalk uses the same gentle slope principle, so there is no visible ramp advertising that a disabled person lives within.

Anyone who is thinking of building a Universal Design house will find a lot of information on the Internet. A few books and magazines of plans are also available. Your local rehab hospital may also put out pamphlet; ours did, as did the local Home Builder's Association. Most helpful was our local Advocates for the Disabled; they had a specialist in Universal Design, disabilities and local codes who reviewed our plans free of charge and made suggestions. He also gave us a scale model wheelchair to run around the blueprint to look for ways to fine tune things like the swing of the doors, furniture placement, turn spaces for the wheelchair, etc. This was a VERY useful little tool.

We also had my husband's occupational therapist go over the master bath plans, so that we got it just right for his needs. (We set up the master bath for a right-side disability and our spare bath for a left-side disability for resale purposes; but we've been told that most Universal Design houses sell by word of mouth, before they hit the open market, so resale value is not really an issue with these houses.) If you are thinking of building Universal Design, my advice would be to start your research early and take you time doing it. Don't sign off on your blueprint until you are satisfied with your choice of options and the price. The Universal Design features that we included added just under \$4,000 to the cost of building a conventional house and it was tax deductible.

Even now that our house is almost a year old, we still can't believe this beautiful, well-thought out and functionally perfect house is really ours. Our only regret is that it took a stroke to get it built.



Stroke Article Newsfeed Review

Botox Treatments

By Jean Kirshenbaum

I may have spoken too soon in the previous issue. There isn't **always** plenty of news about stroke. Not much of interest has appeared in the past six weeks, unless, of course, you are into golf. And who among us is on the PGA tour these days? Most of the headlines I scanned were about golf because one player or another was ahead or behind by one stroke. So why am I talking about golf (a game I used to play)? Because our news feed service picks up articles with the word "stroke" in the first paragraph. So many stories are about golf, (despite the fact that those articles are supposed to be screened out before they reach my strokenetwork.org mailbox).

But there was something of note about botox treatments for spasticity from stroke. Here's the summary of the article I posted on June 2:

BOTOX Stroke Treatment --A high-tech needle is directing Botox treatment to the right muscles in stroke patients. Rehabilitation specialists at the Medical College of Wisconsin are using Botox to relax, but not paralyze, muscles that are too tense to move in stroke patients. Doctors use an electro-magnetic guided needle to identify the best place for the injection. An audible "squawk" lets them know they've found the right spot. Following the injection, study patients have their motion analyzed to measure progress. Results last for about three months before patients need to have another treatment.

Read the full article at:

<http://rdu.news14.com/content/headlines/?ArID=48364&SecID=2>.



Website Review:

Aphasia

by Janice Rodriguez

July is for the second part of our discussion on aphasia, apraxia, and other communication problems, focusing treatment and rehabilitation. First, I will point you a link from the National Aphasia Association website: "Research Update 2002: Aphasia Therapy in the New Millennium" by Kristine Lundren and Martin Albert, <http://www.aphasia.org/newsletter/Spring2002/ResearchUpdate.html>. The references in the end of

the "Research Update" article will lead you to the original research article.

For example: You want to see the research on the last entry, "Walker-Batson, D., Curtis, S., Natarajan, R., et al. (2001). A double blind, placebo controlled study of the use of amphetamine in the treatment of aphasia. *Stroke*, 32, 2093-2098." Now, enter the National Center for Biotechnology Information (NCBI)/National Library of Medicine (NLM) website: <http://www.ncbi.nlm.nih.gov/>. Click on the first word after the logo in the top left, "PubMed." You are now ready to find the original article. Enter two or three search terms from the reference entry, like "amphetamine aphasia" and click GO. You should see the article listed. Of course, this does not mean that amphetamines are an accepted or safe treatment of aphasia, however, you and loved ones could discuss these treatments with your doctor.

There are aphasia programs all over the world. Again, see the National Aphasia Association website, <http://www.aphasia.org/NAAweblinks.html#ac> to see a lengthy list. Add this "Constraint-Induced Aphasia Therapy" program in California, also, <http://www.advancedrecovery.org/>. In the June Web Review, we learn how to find a speech therapist in your area. As you know, you must discuss these programs with your doctors and therapists.

With the help of Joan Green, M.A.CCC-SLP, from www.innovativespeech.com, I want to close this review with computer therapy, which I have used successfully. Computers are not for everybody and you should discuss software tools with an experienced therapist. Here are three websites where you can find good, inexpensive software tools:

- * Universal Reader - Reads text from anything you highlight.
- * Ultimate Talking Dictionary - Reads definitions and helps you think of words.
<http://www.premier-programming.com/Products.htm>
- * Rosetta Stone - comprehensive program for listening comprehension, reading, speaking and writing; look for the free demo at the site www.rosettastone.com
Amazon.com has "Rosetta Stone English Explorer" for \$19.95

*Talk Now! English - \$9.95
<http://store.yahoo.com/software-blowouts/talnowamenje.html>

This is just a sample from Joan Green's list - if you have any questions about these software tools, email me at <mailto:jrodriguez@strokenetwork.org> and I will forward them to Joan. Thanks, and see you next time!.



Bio: Janice Rodriguez

I am an attorney for the firm Arnold & Porter, Washington, D.C. I graduated magna cum laude from Georgetown University Law

Center in 1999 and have a Bachelor of Science from University of Maryland University College. Before law school, I had a successful career in information technology. I am a stroke survivor. My stroke, in September 2000, left her with severe aphasia and apraxia. With the help and encouragement of a loving family, several terrific speech therapists, and a supportive employer, I was working part-time. However, I am now in recovery at home after suffering a series of seizures. I live in Alexandria, VA, with my wonderful husband, Jose (and of course, Pepe, my silly chihuahua and Rudi, my mischeivous cat). Our sons, Stephen (24) and Michael (23), live nearby.

Some of my stroke activities are: Stroke Network Newsletter Web Review contributor; founder of Speech Directions; and Chairman of the Consumer Advisory Committee, Stroke Comeback Center. Speech Directions is a peer-directed, self-help group for people who have aphasia and related disorders (apraxia and dysarthria). Stroke Comeback Center will provide ongoing, high-quality, professional, supportive therapy for stroke survivors.

This picture was taken in our vacation in Arizona. We had a tour of a old copper mine in Bisbee. Fun!!!



Bio: Wesley Cook

On March 7, 2001, at age 58, he had a bilateral pontine stroke. In January and February he had episodes of what we now know were TIA's but both times the doctors diagnosed him as having panic attacks because they did not find anything wrong! This seemed ridiculous to us because he is not the type of person to be having panic attacks. Both times he had garbled speech, then become unable to speak and unable to move his arms and legs and both times he completely recovered. Nothing showed up on any of the tests.

As a result of his stroke in March, he was totally locked-in for 2 months, only being able to move his eyes. We learned that he had a PFO (patent foramen ovale), which is a hole in his heart, and the neurologists believe that a clot went through the hole causing the stroke. He was given a tracheotomy and feeding tube, and placed on a ventilator. I exercised his arms and legs continuously and used foot reflexology on him.

After discharge, he spent two months in a rehab center receiving physical therapy, speech therapy and occupational therapy where he slowly began to recover. Speech therapy is essential, I believe, in the recovery process with strokes like my husband's. The speech pathologist suggested the use of a laryngeal mirror to stimulate the swallowing mechanism in the throat and this really seemed to help. The feeding tube was removed after 6 months but due to the dysphagia he has to be careful eating because of choking. Overall, he does quite well though. He ambulates well without a walker or cane but says he feels off balance some of the time, especially when tired.

However, he is constantly in pain from the stroke and I am searching for some way to help him. He was left with tracheal stenosis (scarring) in his windpipe, which is about 50% blocked, and he can't get enough breath to be as active as he could be. We have considered tracheal dilatation but from all we can learn the procedure, itself, can cause even more scarring, so he is afraid to have it done. I have searched your site and others hoping to find someone else who has this problem and if there is anything they have done which makes breathing better. We are so thankful for the recovery that he has made and he continues to work on strength building. Life changed for us forever on March 7th but we are so thankful for the recovery he has been able to achieve.



Bio: Jim Gerrish

My name is Jim Gerrish. I am 57 years old and had my stroke while working down at

Ground Zero in May 2002. Up until that time, I was a chief in the FDNY, but after that, they let me go (they said I could have a desk job, but I refused). I had what is called a left basal ganglia CVA, while I was working the recovery effort at the WTC. Thinking back on it, I fell down and hit my head, then got up (I don't know how long I was down) and drove home. I was dizzy but I thought something was wrong with the car.

When I got home, I woke my wife and told her that something was wrong with the car, and that I fell at work and injured my right wrist. You see, I couldn't write well and thought the problem was

my wrist. I then went to sleep. Later, my wife told me that I didn't look well and when I couldn't walk up the stairs, she and my son insisted I go to the hospital. I insisted on showering first, and they drove me to the hospital. Then, right after they left, I couldn't get out of bed or talk. Somehow, I called my wife and insisted she return. I was a basket case, unable to walk or talk.

Fortunately, I was in a good hospital. After a week there, they sent me to a rehab center in another hospital, which was also good. After several more weeks, I was able to go home. I still couldn't drive or do much, but I continued with therapy on an outpatient basis. Now, I can drive and do most things and most people don't see my disability. But I know about it. I continue to improve and hope that someday, I will get everything back.

New Stroke Statistics

- Median time from stroke onset to arrival at eh ER is between 3 and 6 hours
- Fourteen percent of those who have a first stroke or TIA have another incident within one year.
- Average hospital cost of an ischemic stroke within 30 days of the acute event:
 - Mild event - \$13,019
 - Severe event - \$20,346
 - Average lifetime cost of ischemic stroke (hospital, rehab, and follow-up care) - \$140,048
- The estimated direct and indirect cost US nationwide \$53.6 billion

Source: Heart Disease and Stroke Statistics – 2004 update

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.

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