



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

Vol 4, No 6

June 2004

Welcome to the June issue of StrokeNet. Steve Mallory shares the news of hearing from two hospitals interested in the website. David Ray not only reports on his Stroke Club meetings but he includes info on Kiwis. Kathy Bosworth writes the first of a two part series "Getting your Affairs in Order." Frank Carl sent an article about the Rylyn Meacham not-for-profit center in Oklahoma City.

Jean Kirshenbaum provides her first selection from the Stroke Article Newsfeed. Janice Rodriguez reviews websites, which focus on aphasia. Dennis Martin's bio is highlighted. Have a great read.

Lin Wisman, Editor
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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 help email them to Lin or myself. Our email addresses are listed on the newsletter.

Have a good summer and hope you can help us make our organization even better!

Steve Mallory
President & CEO
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Organization Highlights

By Steve Mallory

Well, we are apparently finally getting some of the recognition that I think we deserve. I heard from two more hospitals that were very impressed with our on-line stroke support group. We owe it mostly to our members who are making us what we should be but I cannot forget the dozens of volunteer staff, many who are former members!

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 in your location. Maybe, you will find another member in your neck of the woods and can become local friends, as well as cyberbuddies.



Life in New Zealand with a Stroke

by David Ray

Although it is wintertime here we are enjoying warm sunny weather in the Wellington district. As a result our Stroke Club had full attendance at both meetings we held during the month of May. Our first speaker of the month was a very entertaining talk from a local identity on living between the 1st and second world wars.

Most of our members, including myself who was born in 1933, lived during these years and lived in the district, and were able to associate themselves with the events etc that our speaker described.

Our second session of May was a musical afternoon given by a well-known collector and piano player. He has played for us a couple of times in past years and was very popular as his repertoire consisted mainly of the songs of the first half of the 20th century.

He also produced copies of old music, mainly New Zealand songs. He played and sang many of these and he encouraged our members to join in singing the songs. Everyone received great joy from the afternoon.

Notice the photo selected to highlight this article. It is a photograph of the Kiwi, New Zealand's national bird. It is sometimes called "Kay one, W one" by the locals. It occurs nowhere else in the world and is unique because of a number of characteristics. One of these unique factors is the fact that they have their nostrils at the tip of their bills.

They are also flightless and therefore do not have a tail. They are a protected bird as the introduction of stoats and ferrets by the early settlers in the nineteenth century caused havoc among their population. Kiwis lay the largest eggs, in proportion to their body weight, of all birds. These eggs are laid in the nest in a burrow in the ground, which makes them very accessible to predators. The male bird is wholly responsible for their incubation, which takes about eleven weeks. The male Kiwi is also responsible for the burrow.

Kiwis are not easily seen in the wild because they live a nocturnal life. I have seen them in the Wellington Zoo where they are domiciled in a well designed building which is kept mostly dark during the day so that visitors can see them. I have heard them at night in the bush in the days when my wife and I were able to go tramping - those days are now over since I had my stroke.

The male's call is a rather mournful two-syllabus whistle whereas the female is lower and rather hoarse whistle - not really very tuneful. They mainly feed on insects, grubs and worms that they forage in the ground with their long bill. There are three species of Kiwi, the North Island Kiwi, the South Island

Kiwi and the great spotted Kiwi. The North Island species are small than those of the South Island but their name "kiwi" is based on the call of the North Island type.

New Zealanders are called "Kiwis" when travelling overseas. New Zealand has many other birds unique to the country such as the Tui and Morepork. Both these birds are spread throughout the country. We hear the call of the Morepork every night as it is of the Owl species.

The Tui we see every day as there are many in our trees growing on and around our property. On many mornings, such as this morning, my wife and I enjoyed a cup of coffee listening to its call as well of many other native birds. As I finish this contribution to the Stroke Newsletter I can hear the sound of the Tui foraging for berries among the trees.



Getting Your Affairs in Order

By Kathy Bosworth

Are you a baby-boomer having a difficult time talking to your parents about end of life issues? You are not alone. Are you a senior that wants to talk to your adult children about your funeral wishes and find they don't want to discuss morbid topics? Once again; you are not alone. There is a huge communication problem with parents and their offspring when it involves talking about subjects relating to death, dividing assets, and other issues that should be planned for. Families seem to have an easy time talking about world issues, religion, and child rearing, but cannot start dialogue about personal wishes regarding life support and funeral arrangements. Research by the National Hospice Foundation shows that boomers would rather talk to their teens about sex and drugs than to talk to their terminally ill parents about end of life issues. Yikes! That is pretty startling since I know how much I avoid talking to my kids about sex!

I have had the opportunity to talk to many boomers that are terrified to approach their parents to talk about end of life issues. Some have tried it once. When they brought up the subject, they were met with a frosty glare and their parent's comment, "You want my money before I am even dead, don't you?" The conversation is halted before it even begins. Are we so intertwined with our self worth, being measured by our assets, that we don't see the big picture? The big picture is this: we are all going to die and it is imperative that some arrangements are made beforehand.

I have also heard the other side of this mystifying coin. Seniors, knowing they have a terminal illness, have shared with me the dismal conversations they had with their adult children. When they approached their family, they were met with a look of horror as their offspring said, "You are going to be fine. I don't want to talk about such depressing things." Do they honestly think by not talking about it, the outcome will be different?

Talking about the issues can be similar to tiptoeing through a landmine with all the excess baggage that exists within each family. It can be a scary journey to embark on. Yet, the journey can only be started with open, honest dialogue.

If you fall into the category of an adult child that cannot allow their parents to talk about these issues, you have to face reality. Statistically, you will outlive your parents. Nobody wants to talk about death, but it is a fact of life. While there is life, you can ease your parent's worries about things that are important to them, even if you find them morbid and depressing. A few hours of your time in an uncomfortable setting can be a positive experience for three reasons. One; you will get a clearer insight into parts of your parent's personality they often do not share. Two; you will give your parent a sense of comfort and peace. Three; when you open up those huge doors that inhibit most families, you may find other issues being discussed that are personal and ultimately create a closer relationship.

How important is it to get your affairs in order? Personally, I think it is very important. There are many situations that can come along in life we cannot foresee. We can all do things to make it easier for our loved ones in the event of an unexpected crisis. September 11th was one of the most catastrophic days the US has ever experienced. I pray we never see another one like it. Yet, one interesting fact kept emerging. Since the average age of the victims was well below retirement age, the majority did not leave a will. There were no instructions on assets, children, and other personal wishes. Not leaving a will can tie up probate over a year. Getting your affairs in order is something that people of ALL ages should address.

Plain and simple: People cannot carry out your wishes if they do not know what they are. It is hard enough to make decisions for a person that is incapacitated, or dies unexpectedly when you know what they want. It is impossible to do when you have no idea what their wishes are. People tend to think they know what loved ones want. We incorporate our own feelings and beliefs into what we assume others want. Take a piece of paper and write down the names of five people you are the closest to. Next to their name, write what you think they want regarding a living will, cremation, organ donation, etc. Then ask each person how he or she really feels. Their answers might surprise you. I know when I did it; I was surprised how far off I was. It was enough to make me dig deeper into their feelings on other issues.

So, what do we do with this inability to communicate? I'm not sure I have the answers, but I do think that some of the communication problem lies in the delivery. If a boomer wants to initiate a discussion about end of life issues, they should probably NOT approach their parents with a statement like this: "I think you are getting old. How much money do you have? I think it's time for you to make out a will." Parents don't take advice too easily from their kids, especially about their money. It might be better to say, "My spouse and I went to a lawyer today. We had a living will made up. This is what it is and

this is why we did it. We also had a will drawn up because we want to be responsible parents if something should happen to us." Mom and Dad might not jump over to the phone to call their lawyer, but it will give them food for thought. They can ask you questions and you can share your knowledge with them without it becoming a personal situation for them. Two generations have now opened up a line of communication. Communication is imperative!

Next month I will list the topics to discuss when you are talking to your loved ones about end of life issues.

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



Stroke Article Newsfeed Review

Stem Cell Research

By Jean Kirshenbaum

There is always news about stroke and this month was no exception. I posted 10 articles in my first month as a volunteer screener with The Stroke Network. Having started my professional life as a newspaper reporter, I like to be in the know and that hasn't changed now that I am 57 and a stroke survivor. It's even more important to me now. So, as the articles screener, I am certainly in the know about stroke.

To me, the most interesting article posted in April (April 29 <http://www.scienceblog.com/community/article2680.html>) has to do with new research, from the American Academy of Neurology, which "shows that cells taken from adult human bone marrow can be converted into brain stem cells that meet the criteria for transplantation into the brain." These cells have the potential to restore functioning. Also important is the fact that the "use of the cells from adult human bone marrow, called stromal cells, eliminates the ethical and logistical issues that arise with the use of cells from fetal tissue."

Join other members in a discussion about this article on Tuesday, June 8, 2004 at 8:00pm EST. The discussion will take place in The Stroke Network chat room.

The newsfeed area of The Stroke Network website can be accessed through the Information section. Access <http://www.strokenet.info>. Select Articles.

DISCUSSION

Join other members in a discussion about this article on Tuesday, June 8, 2004 at 8:00pm EST. The discussion will take place in The Stroke Network chat room.



Rylyn Meacham Center

Rylyn Meacham Center is a non-for-profit organization in Oklahoma

City, Ok, USA. IT provides free services to those who have exhausted their medical insurance.

This is an article sent in by reader Frank Carl. It originally appeared in The Oklahoman newspaper on May 24, 2004.

See the article at <http://www.strokenetwork.org/newsletter/articles/okcenter.htm>



Website Review: Aphasia

by Janice Rodriguez

June is National Aphasia Association's (NAA) Awareness Month, so this is a great time to find websites on aphasia and related communication deficits. The NAA, www.aphasia.org, is a good start. Click on the link called "Facts and Reading" on the home page. You will have a list of information - my favorites are "Questions and Answers About Aphasia - What Is It?" and "Selected Resources." Also on the NAA home page, you will see links for nationwide support groups, NAA state representatives, aphasia research and finally, "Web Links." The Web Links are comprehensive, so dig in!

Another good site is the Aphasia Hope Foundation (AHF), www.aphasiahope.org, especially the "Input -Forums" and "Research - Articles" found on the home page. Also, a good general site is the American Speech-Language-Hearing Association (ASHA), <http://www.asha.org/public/speech>, where you will find information on speech and language disorders like aphasia, apraxia, and dysarthria.

On the left side of the web page, you will see a link called "Find a Speech-Language Pathologist," which is a great resource. Use the 'state' selection (not 'city' or 'zip') to view all the professional ASHA members in that state.

The final site for this month is the National Institute on Deafness and Other Communication Disorders (NIDCD), <http://www.nidcd.nih.gov/health/voice/index.asp>, which has a list of voice, speech and language disorders. Because communication deficits are a huge problem for stroke survivors, I will continue this article next month, focusing treatment and rehabilitation.



Bio: Dennis Martin

I was 56 years old when I had my stroke. I was an engineer, part owner and one of the founders of a small engineering consulting company

I stroked on May 21, 2001. It was a Saturday. I worked very hard all morning building a raised bed garden at our home, and riding my bike down a long hill into our local town center, then a long hard ride back up. Near the end of the ride I was getting a bad headache and a little dizzy.

I got home, showered, took headache med then left with my wife to visit some friends. On the way there I was getting a little disoriented. I normally could just drive in autopilot to familiar places. That day I had to think through every turn. The wives were doing boring stuff. So we guys decided to go to the local Home Depot & look around. While walking through the store I had trouble concentrating.

I was getting a little wobbly on my feet. I told my friend I had to go. I had him drive me in my car back to his house. I went home to bed. My wife came to bed a little later and found me lying funny with my right arm hanging out of the bed. I still believed that I would be better any day, big time denial. I remember doctors saying it might be as much as a year until I was fully recovered. Maybe they were trying to keep me from getting despondent if I knew then it would be many years. I was moved to another hospital in town where there was a floor devoted to rehab, mostly stroke survivors.

My insurance covering hospital in-patient time was becoming depleted. It was decided to move me to a nursing home near our house where I could still get PT, OT & speech therapy. To preserve my in patient benefit, I was to go back to the hospital as an in patient after 2 months for 2 more weeks to "finish off" my therapy with more qualified therapists working directly with my rehab doc.

They had me walking after two weeks in the nursing home, soon with a cane, what excitement! I had an almost continuous stream of visitors of family & friends. What a blessing and support. I was still not making any progress with my left arm. I was briefly blind in my left eye while in the emergency department, but my speech was never severely affected. I was given numerous mental cognition exercises and tests; they concluded that my reasoning capability was, surprisingly, to them, at pre- stroke levels. This was very reassuring to me, meaning I could still work as an engineer

I was finally released from the hospital and returned to part time work out of my home office. Capability was, surprising to them, at pre- stroke levels. It was very reassuring to me that I could still work as an engineer. I decided at the recommendation of my doctors to begin to go onto disabled status and begin to receive disability payments (60% of my pre--stroke pay) from our disability benefit coverage at work.

I was finally released from the hospital and returned to part time work out of my home office. I was not able to work full time. So, I did not qualify, according to the insurance company, for the medical & other aspects of our benefits plan. With the agreement of my company co-owners, I retired from the company. My co-owners began buying back my share of the company. I formed my own small consulting company to run out of my home. So I could keep all of the hourly billing

to my clients & not have any of it go to an overhead pool for benefits I was not receiving. I still could not afford medical insurance on my own. So we decided for many reasons to sell our waterfront dream home and move into a less expensive home suited to sharing with our son & his family. Then we could share expenses and I could watch our granddaughter grow up. I had worked day & night on our home to rebuild it and make three additions. Unfortunately, there were many things not yet completed when I stroked.

About a year into my recovery I began having seizures that are related to the dead parts of my brain not being able to carry electrical signals through the brain. The signals get diverted and cause havoc. My last seizure was about 4 1/2 months ago. I'm now on a very good seizure med. The state says I cannot drive until I'm 6 months seizure free. I so badly want to drive again.

I feel bad that I can't do any of the yard work. My wife has been cutting down trees. We hire people to do things that I used to do without a second thought. But, we are blessed beyond measure

See Dennis' resume at <http://home.comcast.net/~martin.dennis/Resume.htm>.

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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