



www.strokenetwork.org

February 2003

Greetings to all our readers.

In this newsletter Steve Mallory updates each of us on what is currently happening at The Stroke Network. David Ray reports to us on going to the beach in New Zealand. Those of us in the northern hemisphere are jealous! Michael Roberts contributes an article on reading aids. He explains various products and strategies he has used to improve reading. Next you will find an article that reminds each of us to take the time to have legal documents in order.

Readers are then directed to products listed on the web pages of The Stroke Network. You are invited share product data with other readers. Innovative Speech Therapy extends a special price reduction to Stroke Network members for their Rehabilitation and Technology Seminar to be held March 7, 2003. Barbara Layne reviews the website of the State University of New York at Buffalo Toshiba Stroke Research Center. Debby Griffin and John Stokes are featured in the month's biographies

Lin Wisman, Editor
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Organization Highlights, by Steve Mallory

Helping Hand

There was a fair amount of interest in the Assistive technology device, Helping Hand. Steve Flaherty, inventor of it, was in the chat room several weeks ago to answer questions. I'm sure that he is willing to discuss it further. You can email him at meexch@iserv.net or visit the web site at <http://hh-i.net/>.

Door prize Winners - Cynthia Ikens and Maria Camaratta. I will make sure that you receive your prize at your home address, congratulations!

Search for information, practical solutions to issues with stroke.

Use the search function on our message board or mailing list archives. You should select several keywords for the subject, which interests you. Chances are that the topic might have already been discussed and the answers to your questions were right there the whole time. This web site is not just an on-line stroke support group. We also have tons of information relating to stroke. The message board search engine is located at <http://www.strokenetwork.org/cgi-bin/ultimatebb.cgi?ubb=search> and the mailing list archive search is at <http://support.strokenetwork.org/SCRIPTS/WA-STROKE.EXE?REPORT&z=4>

Wanted!

We need your bios, caregiver testimonies and both survivor and /or caregiver photographs. We are also looking for web pages that you might have created. We understand that we have a very large group; lets get to know each other better. Some of us talk to each other practically every day. I read practically every single email and message board post so I know how much discussion goes on. Send your bios or testimonies to the Stroke Support Group Coordinator, Jay Marken-Bentzen, jmarken@strokenetwork.org and your photographs to me at smallory@strokenetwork.org, I will even scan your photograph for you if you cannot do it yourself. Just email me and I will send you my home address.

Bios -

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

Photographs -

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

Web Ring -

<http://l.webring.com/hub?ring=thestrokenetwork>

Printable version of Newsletter

I forgot to mention this last month, in addition to the on-line version of the monthly newsletter Lin is publishing a newsletter, which can be printed. It is available at <http://www.strokezine.org/newsletter/>. Take a copy to your local stroke support groups or if you know of other stroke survivors, or possibly a local hospital, we will mail color versions to them. Send the address to Lin at lwisman@strokenetwork.org.



Life in New Zealand with a Stroke by David G. Ray

January is the main holiday period in New Zealand when families leave their homes for sun, beach and adventure. Nowhere here is far away from a camping area, safe swimming beach or lake. We must however be aware when swimming in the sea of particular dangers, which exist such as jellyfish. This month my wife went for a swim in the harbour and was accompanied by hundreds of jellyfish. Some species can administer a nasty and painful sting and my wife did not wait in the water to find out which type was sharing the sea with her.

Some lakes are very cold as they are snow fed. A few years ago my wife decided to go for a swim in Lake Mavora in the South Island of New Zealand. The day was very hot but the water of the lake was so cold that it took her breath away and she was unable to call for help. Eventually she was able to get out of the water but she found the experience very scary. From this account you will gather that my stroke precludes me from swimming. I did try splashing about in a swimming pool but found it very difficult. Perhaps I should have persevered because I have been told that splashing about in swimming pools can be very beneficial for stroke victims.

Lake Mavora is in the southern lakes area, and is a very good trout fishing area. It is situated in the fiordland area, a very popular holiday spot with locals and overseas visitors alike. Personally I find the whole area very beautiful and we like to visit there whenever

possible. Queenstown, the most famous town, is the centre of extreme experiences such as Bungee Jumping, jet boat rides and many other adventure type experiences. The mountain scenery is spectacular.

A couple of weeks ago I saw the movie, "The Lord of the Rings, The Two Towers", the second of the trilogy. The spectacular scenery depicted in this film was shot in the Fiordland area and also in Canterbury. A large section of this film was also shot in the Hutt Valley only about 20 kilometres from where we live. I remember seeing the film set from the road but there is no sign now of an area where a great battle was fought such being the magic of present day film makers.

Next month sees the beginning of the stroke club's year. We will soon meet to finally determine the programme for the first six months. Our programme will include the usual mixture of stroke related topics, general interest topics, entertainment and outings. We hope that the programme our committee has drawn up will be of interest to our members.



Reading Aids by Michael Roberts

Anyone reading this has probably already come to terms with the new technology and their disability but a thoughtful friend or caregiver might enlarge the font and pass it on to others who could benefit from information in this article. Information is the watchword. It can expand our horizons in so many ways and literally open doors for us. It can help with our day-to-day activities, make contacting our family easier and even entertain us. My wife regularly checks our bank balance online and exchanges email with friends and family near and far at a fraction of what the long distance telephone charges would be.

I check the public library's catalog and occasionally request a book I'm interested in having sent to my neighborhood library. We both sometimes shop. Last week I found a

place that sells aquatic sneakers in men's sizes. Those should make the adaptive aquatics class which I take more fun. We've searched for jobs online and made airline and hotel reservations. And those are just the Internet applications. I've written term papers and prepared classroom PowerPoint presentations on our PC. I'm a hunt and peck typist on my good days so having help smoothing the rough edges is a god sent.

My stroke left me with some visual impairment. I experience left neglect. My family still notices me eating entirely off of the right side of my dinner plate. I was already wearing bifocals before the stroke. Don't try to sneak up on me though. I used to be a meter reader and I listen for dogs. In a more serious vein, we read from left to right and neglecting the left side of a page or computer screen can make for slow going under those circumstances. I'm a librarian and can't function without reading so it was another situation I had to work through.

There were some helpful products and strategies for this work. A speech therapist who was working with me recommended a word processing program called Intellitalk. This program reads documents aloud and highlights each word as it reads it so I could follow text as I was supposed to and retrain my vision for reading.

This only left me with the question of what to read. Luckily, I had an idea of my own about that. I remembered that many books were available in electronic format at the Internet Public Library <http://www.ipl.org>. Many of these are classics that have become public domain. My wife copied a couple of my favorites to a CDROM and Intellitalk helped me re-read "The Warlord of Mars" and "Jungle Tales of Tarzan". Amazingly, the software had less trouble with the language of the Great Apes of Kerchak than I do. I, of course, am better able to manage a primate accent. Machines can only do so much. Some other useful accessibility aids are available. A different keyboard or mouse can simplify many computing operations. For a short time, I tried out a keyboard with brightly colored one-inch keys arranged in alphabetical order. It was much easier to use. Someone explained to me that the standard QWERTY

keyboard was designed to prevent the keys from jamming on mechanical typewriters. A classic case of people accommodating themselves to machines rather than designing ergonomically in the first place. It's also possible to purchase larger monitors and mice with joystick operation.

Public libraries and community centers are offering basic computer skills classes. These classes are often low cost or free. Ask your speech therapist about suggestions regarding equipment or instruction. Welcome to the 21st century.



Legal Documents by Lin Wisman

Necessary legal documents are sometimes confusing. The best advice we have found is to consult a lawyer locally. Laws vary from location to location. Although it is tempting to try to do this yourself professional advice is recommended.

Many of our readers have already had personal experience of legal problems arising due to stroke. For example, a family may face the problem of needing to access bank accounts where only the patient is a signature. The bills continue to arrive even though the survivor may be incapacitated. Others may have had the experience of a loved one dying without having their legal affairs in order. That poses additional problems.

Unfortunately each of us can be vulnerable legally. Luckily there are ways protect yourself. The time to decrease this vulnerability is while one has the capacity to do so. One lawyer tells the story of receiving a phone call from a family needing to make legal decisions. His first question was "Can she still sign her name?"

Many of us have experienced various problems because we (or someone else) thought they had lots of time left before serious illness or death. As uncomfortable as it may be to deal with these legal issues now, you or someone else will be grateful in the future.

There are a number of legal documents which each of us should investigate. It is important to have them in place in case of illness or death. These include a will, power of attorney and health power of attorney. These go by different names in different countries and are even different between states and provinces. It is always wise to check with a lawyer locally.

Many figure they do not own enough assets to make a will worth the time, effort, and money necessary. In most places if you die without a will, the government will make decisions about your assets, usually to the government's advantage. Having a will assures that your assets are transferred to selected heirs. It is not wise to assume that your assets will naturally transfer easily to spouse or children. This is especially true in today's world of blended families.

It is important to have an inventory of all your assets. If possible, share this inventory with others in your family. Be sure that they know where it is located.

Most of us would like to avoid or minimize taxes. Estate or death taxes do exist in most localities. In the US, currently the first \$675,000 of the estate is not taxed. This amount is scheduled to increase to \$1,000,000 by 2006. Most individuals have fewer assets. However, to avoid any problems it is worth the time, effort, and expense to see a lawyer and to have proper papers.

A power of attorney is needed if for any reason you are unable to attend to your finances. The downside is that the person who you grant power of attorney can do anything with your finances, so you want to be sure that the individual is trustworthy. In many locations an alternative is to be sure all your accounts are joint accounts. In some locations you can simply add someone as a signature to your accounts without making them an owner.

Power of health is needed if for any reason you are unable to make health decisions. It is wise to talk with your family ahead of time about your position regarding life support and organ donation. Although laws vary from location to location, this document insures

another has permission to make medical decisions on your behalf if you cannot. Often such a document allows your family rather than the medical system or government make the decisions.

There are many questions. What is a Living Trust? What is probate? How can I avoid probate? What about life insurance? Should I have long term care insurance? If I die who takes responsibility for my underage children? What about making a will myself using online or offline software? What are the rules about organ donation? What about funerals?

As stated earlier, it is smart to contact a local lawyer and have him/her help to sort out these issues. In the mean time it is also smart to do your own homework. To bone up on the issue see these sites:

<http://www.mtpalermo.com/>
<http://www.nolo.com/lawcenter/index.cfm/catID/FD1795A9-8049-422C-9087838F86A2BC2B>

<http://www.sentex.net/~lwr/> (Canada)
<http://www.wills.com/index.htm>

There are many more sites available. Like everything else on the web you must be willing to gather the info and research what works locally. Do the research. Don't be unprepared.



Products on our Website

What products have been helpful in your recovery? Each stroke is different. Each individual finds gadgets, rehab equipment, and other devices which are helpful in their situation. Ideas come from many places including therapists, catalogs, the Internet, and friends. Aids make it possible to complete some tasks, become more independent, or make life more pleasant.

There are a number of devices featured on Stroke Network's web pages. Visit <http://www.strokenetwork.org/products/index.htm> and see how a listed item could help and to see what items are missing. Drop me a note at lwisman@strokenetwork.org and share what you have found of benefit.



IST Conference

Join Innovative Speech Therapy at this unique and stimulating one-day seminar to explore ways to move forward into the world of technology to help yourself, your clients or loved ones benefit from the recent explosion of new techniques available to help people maximize their potential. Experts who use technology to provide a variety of solutions for people with disabilities and learning differences will offer three tracks of simultaneous presentations. Exhibits for hands on trial of new products will also be present so that you can try products and discuss their appropriateness for your situation. This seminar will be enlightening whether you are a speech pathologist, occupational therapist, special educator, doctor, nurse, administrator, case manager, caregiver or person with a disability. A delicious and nutritious breakfast and lunch will be provided.

IST Rehabilitation and Technology Seminar 2003
University of Maryland Shady Grove Conference Center
9630 Gudelsky Drive Building 2
Rockville, MD 20850
Friday March 7, 2003 8:00 AM-4:30 PM

Registration closes 2/15/02.

To receive a \$20 discount note that you heard about the seminar through the Stroke Network.

To view a list of presenters see http://www.strokenetwork.org/newsletter/event/IST_seminar_final_notice.htm

For more information or to register visit <http://www.innovativespeech.com>.

Contact:
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 301-602-2899/ 703-531-1161
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Website Review

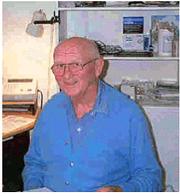
by Barbara Layne

State University of New York at Buffalo
 Toshiba Stroke Research Center
http://www.kaleidahealth.org/patient_care/toshiba/toshiba2.html

This is an informative site explaining some of the research taking place at the Toshiba Stroke Center. The external links take you to some familiar places and some new. It shows some of the procedure that take place at KALIEDA HEALTH in Western New York State, as well as providing information on the services offered.

Biography: Debby Griffin

My name is Debby. I am 54 years old and had an ischemic stroke on Memorial Day, 2000. I am lucky that I really do see improvement every day, thanks to some intensive rehab and the love and support of my family. My whole world changed that "holiday" weekend and in many ways for the better. I was just about to graduate college, with a degree in human services and my youngest was to graduate high school in June, it was finally MY TURN. I had my future all planned out and I was ready to see the world! WHAM!! Boy, did things change. Here I am, still in the small town I grew up in and always hated, dependent on my beautiful sister and kindest brother. I never realized before how blessed I really am. No longer do superficial things have any meaning at all and for the first time in my life, I really do "see" now. Hard as it's been sometimes, I really wouldn't change a thing now. I think God wanted me to "be still and listen. "God bless all of you stroke survivors, and know there was a reason things happen the way they do.



Biography: John Stokes

In March 1990 I had two strokes. They happened on the same day, and on the same side of my body. The first stroke hit about 1.15am. I went by ambulance to our hospital about 25 miles away and went straight to the emergency ward where I laid on a bed for about six hours before being sent to a ward with an empty bed. About 30 minutes later the second stroke hit, and it was a dandy! The whole right side of my body was completely dead. I wasn't very happy with my situation, nor do I remember much about those first two or three days.

A very pleasant physiotherapist evaluated my chances of recovery. I made the grade and was transferred to the Rehab ward for rehabilitation treatment. After forty days in the hospital I was discharged, being able to walk and talk well enough to go home where I worked hard at further improvement. Within four months my wife Dottie and I were on our way to a three-week stay in Ireland! And it was great therapy! Everywhere you go in Ireland you are either going up or down

steps! It was excellent exercise and very helpful.

I was fortunate to make a very good recovery. It has been so successful most people cannot tell which side of my body was affected. Twelve years later, except for the fact I have limited daily energy, I'm very happy with my lot. I had a pacemaker implant in March 1993 and since then my condition is very stable. There is much more I can tell you about my self-invented exercises and encounters but I'll save that for another time!

As a result of all this I have visited stroke patients at my hospital every week for the past eleven years. Our stroke recovery group has grown as a result of my contacts. In 1990 there were about twelve "stokers," now there are over twenty-five! I am a very fortunate person!

--John Stokes, Qualicum Beach, BC, Canada

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 hundreds of 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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