



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

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Greetings to all Stroke Network members in 2006. We hope you have a good year, full of improvements and fun. Steve updates all on the happenings at the Stroke Network. The editor located some stroke statistics on the internet which she calls to your attention.

Next, find part of a press release by Stem Cell Therapy International, Inc. Steve writes an article which introduces Kessler Institute for Rehabilitation. Kate Adamson writes about New Years Resolutions.

Then find the first announcement of a new column to begin in the spring. Start thinking about how you can participate. January Birthdays are highlighted. Bios are of Heather Strong and Simon Rogers.

Enjoy your read.

Lin Wisman, Editor
lwisman@strokenet.biz



Organization Highlights

By Steve Mallory

Recap of 2005

Happy New Year! I hope that 2006 is much better than 2005! What a year. I am so glad that it is over. Last year was probably my worst year other than 1994, the year of my stroke. It started fine but suddenly spiraled downhill after April 24, the day that my ITB pump prematurely failed. Let me recap some of the positive achievements of our organization, though.

- The blog feature created for the message board. This is basically a means for our members to type out their daily thoughts.
- A custom skin for the board was displayed. It was more of an accurate theme to go

- along with our website than the blue colors of the message board designer, Invision.
- We added a new Internet address for the Members Area, Internet address <http://www.strokesupport.org/>. Hopefully, everyone can easily remember this address and will frequently visit this web page.
- We began a calendar style Chat Schedule - Reminder e-mails can be sent at the member's option.
- We started the Language Disorders Chat series and also had several Guest Speaker Moderated Chat series with featured topics and speakers of Constraint Induced Aphasia Therapy by Dr Jen MD and Stroke and Depression by Dr Laura Cushman PhD.
- We added several new functions to our message board. Information about message board users including state, country flag, age, local time.
- After this point I had the dreaded Pump prematurely fail! Everything seemed to slow down drastically for several months after this point. I was in and out of the Emergency Room several times within one week and then admitted for a week. After release, I was essentially out of the game and could not function for another six weeks.
- The Member Donation barometer was created. This allowed and encouraged all members to donate just \$10 in hope that we could make the barometer rise up to meet our goal. This fundraiser still exists and is located at <http://www.strokesupport.org/members/donation.htm> in case you would like to contribute to our organization.
- Finally, we had a very successful Annual Stroke for stroke golf tournament fundraiser. We far exceeded our original expectations and brought in more than enough revenues to keep our website around for years to come.

Then, in November, my computer crashed! This blew my mind but luckily all organization files were backed up. This still meant purchasing a new computer and then transferring everything over. And then there is the issue of properly setting up the new computer and more weeks of aggravation and frustration.

You might know that my stroke caused quadriplegia and loss of speech. This problem only compounded the issues of 2005. Thank goodness it is behind us!

January 2006

There are a few new highlights to talk about. The first thing in the preliminary planning stages is to establish a Bracelet program. We would have some sort of bracelet made to establish that you are a stroke survivor and possibly a design that links you to our organization. The bracelets would be sold on-line and at a reasonable price.

Does this sound interesting and would you participate? A poll for this question exists in the Community Forum on the message board at <http://www.strokeboard.net/index.php?showtopic=4430>

One of our members e-mailed me last month and was very concerned that the other members may not be aware of our Members Map. The Members Map is a graphical image of each continent. When a person adds their name to the map they get to place a pin on the location where they live. You can get to the map by going to <http://pub16.bravenet.com/guestmap/view.php?usernum=1336723508>

If you went to our message board today you noticed that we are back to the Invision blue skin. What really happened is that the board was upgraded. You can explore the board and look for the improvements. Please do not e-mail me about the problems just yet because I already know what some of them are and am trying to get everything straightened out. I estimate that it will be about another month before we are back up to speed. Sorry for the inconvenience.

I received a request from a graduate student who would like to gather information from our organization. She will be submitting a survey questionnaire that hopefully can help her with school. Here is a summary of her information.

Hello! My name is Linda Bonk and I am graduate student in Speech Pathology at Saint Xavier University in Chicago, IL. I am currently working on

my thesis that focuses on caregiving for someone who sustained a stroke. I designed a survey that will address how the Speech Pathologist at the hospital handled sharing information with the caregiver, providing resources and assisting in the referral process. There is also a section that will allow the caregiver an opportunity to share experiences, if s/he chooses. I greatly appreciate your time and participation! Thank you

Steve Mallory, CEO
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Stroke Statistics

By Lin Wisman

As we begin a New Year let each of us take the opportunity to continue to educate ourselves about stroke and to be grateful for our own situation.

Over the years I have often heard the comment "every stroke is different." This is true, but like most, I have the tendency to slip into the belief that all strokes are like mine. I decided to look for statistics which give more info about the outcome of stroke.

I stroked when I was 46. Many members of The Stroke Network, like me, were under 65. Each stroke age gives a different perspective on the event. I am in admiration of those who experience childhood stroke. I was lucky to have early adulthood unimpaired. I have also found an interest in those over 65 who have stroke.

Often it is a very different experience than I had. I imagine the experience is even different if you happen to be over 80. I recently read that stroke in those over 80 may be one way the body slows itself towards the end of life. Having a stroke in my 40s, I experienced that afterwards the trend was toward getting better. Each stroke is different.

The link below is to the website of The University Hospital, Newark, NJ, USA. The statistic categories are Consequences of Stroke, Current Statistics for Stroke Survival Rates, Risk Factors: Age, Gender and Ethnicity, Brain Aneurysms, and Economic Cost of Stroke. I'm sure there is data here which I already know, but more importantly there is probably data new to you. Take the time to educate yourself.

Stroke Statistics:

<http://www.theuniversityhospital.com/stroke/stats.htm>

Happy New Year everyone.



Stem Cell Therapy International, Inc. Press Release

To help keep our members up to date on Stem Cell research, The Stroke Network is reprinting part of a press release from Stem Cell Therapy International, Inc.

With the enactment of Proposition 71 in California in November 2004, a fund of \$3 billion dollars was created to promote stem cell research. Since that time, four other states New Jersey, Connecticut, Illinois and Wisconsin, have allocated significant funds for stem cell research. For additional information on SCTI's research and treatment programs please visit our website @ www.scticorp.com.

About Stem Cell Therapy International (SCTI)

Stem Cell Therapy International, Inc. is engaged in the field of research and development of regenerative medicine. SCTI manufactures biological solutions that are currently being used in the treatment of patients suffering from degenerative disorders of the human body such as Alzheimer's, Parkinson's Disease, ALS, leukemia, muscular dystrophy, multiple sclerosis, arthritis, spinal cord injuries, brain injury, stroke, heart disease, liver and retinal disease, diabetes as well as certain types of cancer. The Company has established agreements with highly specialized, professional medical treatment facilities around the world in locations where stem cell transplantation therapy is approved by the appropriate local government agencies. SCTI intends to provide these biological solutions containing stem cell products in the United States as well, to universities, institutes and privately funded laboratory facilities for research purposes and clinical trials. Their products, which are available now, include various biological solutions containing fetal stem cells, adult stem cells and stem cell which are extracted from umbilical cord blood.

Press Release by Stem Cell Therapy International, Inc. Dec 14, 2005. Reprinted with permission.



Kessler Institute for Rehabilitation

By Steve Mallory

Kessler Stroke

Rehabilitation Hospital is interested in telling us about them and their Stroke Rehabilitation Hospital. You may be aware that this is the hospital which provided Rehabilitation for Christopher Reeve.

In the Stroke Rehabilitation Research Laboratory at KMRREC, Program Director Anna M. Barrett, MD and her staff explore new means of helping people improve post-stroke cognition. The Stroke Laboratory's studies attempt to apply principles derived from experimental psychology, psychobiology, and cognitive neuroscience to unlock the brain's lost visual-spatial, and communication potential.

Spatial neglect is a failure to respond, report, attend, or orient to stimuli presented to the side of space opposite a brain lesion associated with functional disability. It occurs more commonly in patients with right hemisphere brain damage than in those with left hemisphere damage. For example, after a stroke on the right side of the brain, individuals may not detect objects on their left, or may asymmetrically represent or act on their environment. Spatial neglect may be a problem with coordinating perception, representation, and action. While the severity of spatial neglect usually lessens over time, it is still a major predictor of long-term disability, and thus may play a role in regaining independence in the chronic phase of post-stroke recovery.

Unfortunately, chronic spatial deficits might be difficult to detect reliably. In a study funded by the National Institutes of Health-National Institute of Neurological Disorders and Stroke, the Stroke Laboratory is working to standardize systematic detection of mild deficits, using a video testing method sensitive to small errors. A client might try to mark the center of a line while viewing his hand and a stimulus he is acting upon on a video screen. A video mixer can be used to right-left reverse the image, so that leftward movement appears on the screen to be moving to the right, and vice versa. As people with visual-spatial problems monitor their own bodies in this mirror-reversed manner, we can calculate whether errors may be primarily attributed to deficient perceptual awareness ("seeing or knowing where") or intentional action ("aiming"). These two error types may originate

from problems in different systems, mediated by different brain regions.

Safe and adaptive movement in complex environments is the basis for functional independence and daily life competence. Spatial function is clinically assessed only in near space, although we are often required to distribute attention over large spatial areas beyond arms' reach (sports, navigating in a mall or an airport, driving). Dr. Barrett and her collaborators are among very few laboratories in the world examining the neuropsychological mechanisms of far bias and distractibility in brain-injured post-stroke patients. When problems are identified in far space, however, it is not clear what treatments would be most appropriate. In the current set of experiments, the group will investigate whether people with far space deficits improve while wearing an eye patch, a treatment Barrett and others have reported may benefit near space symptoms.

The long-term goal of this work is to translate spatial science to new and more effective treatments of post-stroke spatial attentional disorders. The laboratory recently proposed a follow-up group of studies in this direction, attempting to assess effects of several other available treatments. The aim is to determine if specific therapies targeted to deficits may be more effective. Although there are not known benefits to the video assessment performed as part of the NIH-funded spatial neglect studies, behavioral stimulation and visual-motor practice theoretically might improve performance. The mirror-reversal apparatus is also similar to prism and virtual-reality treatments being used at other centers for spatial neglect. Our laboratory is working to examine whether using the video apparatus may benefit performance, and if so, to adapt the video apparatus to wide use in clinical settings where prism prescriptions or virtual reality equipment may be impractical.

A second study being performed in the Stroke Laboratory, funded by UCB Pharma, Inc., focuses on the pharmacological treatment of stroke-related aphasia. Effective approaches for patients with aphasia may often be limited to management (e.g. family counseling) and vicariation (e.g. computer devices). The more than one million people with acquired speech, language and communication disorder in the United States need remedial therapies to improve their symptoms and return them to their previous activities.

Piracetam is one of the few medications reported to improve aphasia in previous studies, but is not available in the US. Dr. Barrett proposed to UCB Pharma that she perform a pilot study investigating whether levetiracetam (Keppra), currently approved for treatment of epilepsy, may improve aphasia symptoms. Levetiracetam, related to piracetam, has been associated with memory improvement in a scopolamine-induced amnesia rodent model. In an open-label, multiple-baselines prospective pilot study, the stroke laboratory will administer levetiracetam to fifty patients with chronic aphasia and serially examine their speech and language function to determine if any improvement in spontaneous speech, verbal fluency, naming, repetition, discourse and memory occurs.

Quality care is integral to the cognitive recovery process. Rehabilitation therapy is an important part of this care. Scientific treatment approaches are extremely valuable in planning care and in counseling individuals and their families about adaptation to the disabling conditions associated with stroke. Dr. Barrett and her team are working collaboratively with other scientists at KMRREC, as well as at UMDNJ-New Jersey Medical School, Montclair State University, Seton Hall University, Penn State University and other institutions to remain in the forefront of progress towards helping people maximize recovery after stroke.

The above information was provided by:

Siby Varughese, MA, RN
Research Nurse Coordinator
Stroke Rehabilitation Research
Kessler Medical Rehabilitation Research and
Education Corporation



Kate's Korner
By Kate Adamson

Decide this instant on something you have always wanted to do. What is it? What is that something you know is possible, and you have wanted to do for a long time, but just never have done? What has you paralyzed? What is stopping you? You can overcome your paralysis by simply focusing on what you want (not on what you don't want) and what you can do (not on what you can't).

Are you tired of a messy house? Then focus on it being clean. Are you tired of being overweight and out of shape? Then focus on being trim and fit. Are

you tired of being disorganized? Then focus on how it will look and feel to be organized and energized.

Keep that image in front of you. Every time you look at a messy house desk or office, close your eyes and visualize it clean and organized. Every time you look in the mirror with dissatisfaction close your eyes and visualize how you will look trim and fit, dressed in clothing that complement a more attractive, energized and successful "you." Do this EVERY time – without fail – always focusing on what you DO want. Soon you will move to that new ideal because the old condition simply will no longer fit how you see your life.

Sound simple? It is. Incredibly simple. Yet it works, incredibly well.

That attitude of focusing on what I wanted – with the blessing of God – brought me from total paralysis, where I couldn't even blink my eyes, to a fully functioning life. I now have the blessing of making a difference in the world by helping others overcome the paralysis that keeps them from moving to their next level of happiness and accomplishment.

Now it is your turn. Do it. Today. Right now. Choose one or two New Year resolutions; focus on what you want, not on what you don't – this is something anyone can do. Take that first step and begin immediately to enjoy your journey by doing what you can do, not on what you can't.

Want to know more about the process on how to do this? Want to create a movement where you and your group actually move to your next level of life and living? Invite me to speak to your church or community organization. Invite me to your business meeting or convention. Ask me to tell you about "Pink Pumps and Green Gatorade" and I will show you that you can overcome your mental, emotional, spiritual and business – as well as physical – paralysis. Let's start now while the year is new.

This article was first published Jan 10, 2005 by Kate Adamson on her website. Reprinted with permission.



January Birthdays

The following Stroke Network Members included their January birthday in their profile.

1st agleb02532 66 FL, USA Caregiver

1st MikeCoane 63 Germany Survivor

1st rosetta 67 CA Caregiver
Enjoys motor sports, gardening, hiking and travelling.

2nd brezie 45 GA, USA Caregiver

3rd jgritz 62 MD, USA
Janet is a Speech-Language Pathologist in private practice in Montgomery County, MD. For many years she has worked with stroke survivors and caregivers in her office; through contracts with local hospitals, nursing and rehab facilities, home care agencies; and as a consultant to the Montgomery County Stroke Association since its inception nearly 25 years ago. Janet is Speech Therapy Expert for The Stroke Network.

4th JerryTaylor 61 NY, USA Survivor
Jerry enjoys computers, golf, golf, and more golf, basketball, tennis, and gardening.

5th JaneA 64 TX, USA Survivor
Jane lists her interests as brainstem stroke, and cavernous malformations.

5th Marylee 58 IL, USA Caregiver
Marylee's interests include aphasia, cognitive struggles, finding solutions, camp for stroke survivors, and caregiver support.

5th hostbonnie 57 WA, USA Survivor
Bonnie enjoys animals, crocheting, crafts, cooking, 4 grand children, 6 dogs, one cat, goats, chickens, 2 geese and a fish. Bonnie is Chat Host for The Stroke Network.

5th slowe 55 CA, USA Family
Enjoys reading, cooking, scrapbooking, grandchildren, hiking, backpacking, travel, and wine.

6th Seagull173 55 OH, USA Survivor
Tom enjoys chess, soccer(futbol), sailing, fishing, high school football, Ohio State Football, Youngstown State Football, and reading.

7th embersflame 31 TX, USA Survivor
Tania likes to cook, read, surf the net, walk, crochet, and spend time with family. She also enjoys golf and bowling. She likes chatting online and playing pc games.

7th rassymom 36 CA, USA Caregiver
Interests include theatre, movies, music, teaching, cooking, and gardening.

8th Neil S. 75 FL, USA Survivor
Lists interests as configuration management, real estate, and health.

9th Florida Nick 57 FL, USA Caregiver
His only interest is trying to find anything that will bring wife out of a persistent vegetative state. She had a brain hemorrhage on January 1, 2004.

9th motherhen962 35 VT, USA Survivor
Wendy likes writing, reading, sewing, cooking, and playing with her three children ones. She enjoys watching old movies with husband.

9th Bil 60 NJ, USA Survivor
Bil lists his interests as writing and reading.

9th RodD 54 NY, USA Survivor
Rod enjoys cars, and antiques.

14th nmf1973 33 QLD, Australia Family

20th nzeekerikiwi 52 New Zealand Caregiver
Anne enjoys her dog, and garden.

21st carolLynn 71 OR, USA Survivor

21st Nina 41 PA, USA Survivor

22nd teal 53 CA, USA Survivor
Interests include reading – especially mysteries, and Harry Potter. She also enjoys photography, rubber stamping, book binding and other crafts.

23rd susancm 46 VT, USA Survivor
Susan enjoys music, dogs, reading, crosswords, and cooking. She is Guestbook Administrator for The Stroke Network.

27th Miss.Diagnosed 31 MI, USA Survivor

28th wmoyers 54 MS, USA Survivor
William enjoys chatting, casinos, online games, fishing, Eastern Philosophy and poetry.

28th screspo 33 FL, USA Caregiver
She enjoys her children and husband.

29th Tonya0129 37 AL, USA

29th Barnell 63 FL, USA

29th livingrace 50 NE, USA Survivor

To be sure your birthday is included on the list, 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.'

Bio: Michael Hennessey



It was February 28, 1994 and I was 27 years old. It was about 8 Pm and my girlfriend, Cindy and I were sitting at the table drinking coffee and talking when my right eye began to hurt. The pain quickly increased from a dull pain to an intense sharp pain, which felt like a metal skewer was being driven through my eye. Then my speech became unintelligible, the left side of my body went numb and I fell to the floor in a heap.

I was taken to a nearby hospital only to be sent home several hours later. The doctors said there was nothing wrong with me. I spent about four days at home with no treatment and went from weighing 126 lbs to 106 lbs. I was finally seen by a doctor at a local clinic who sent me to another hospital for testing. A CAT scan showed a large bleed in the right hemisphere of my brain located in the basil ganglia and thalamus.

I spent several months in rehab then went back home. Two months after I returned home I was told to leave because my girlfriend found someone else. I then moved in with my mother until I was approved for SSDI. Then I obtained my own apartment.

One year after I had my stroke I won custody of my daughter, Kala, who was four-years-old at the time. I have raised her on my own ever since. She is now 16, an A-B student and cheerleader. I am now 39 and finishing my senior year at a local college majoring in sociology.

The last 12 years have been painful and challenging to say the least but I can honestly say I have learned a lot about life as well as about myself. Prior to the stroke I had very low self-esteem and a

very negative attitude. Now I am the complete opposite. I have wanted to write a book about my experience but I have no idea how to write it. Maybe I'll meet someone who is a good writer who can help me out. Even though things are negative there is always something positive to come out of it.

Bio: Heather Strong



I stroked in July 2003, at the end of my first year of grad school. I had a huge headache on Sunday and on

Wednesday, my left arm was still asleep, when I decided I might need to see the doctor. I remember thinking that if my arm didn't wake up after two nights, then I should do something since once it had already been asleep.

I was 25 and never thought I might have a stroke. Luckily, it was a minor one. Because I was so fit before, I never noticed that my leg and arm didn't have strength left, I was compensating with the right side, so it was a shock for me when the doctor could just push my limbs down, like I was not trying to resist.

They found out I had a hole in between my atrias (most common reason for young people to have strokes). It was closed January 2004.

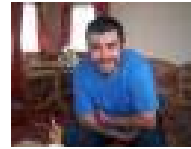
I spent a lot of time in PT to regain strength. I was told that everything would be back in 6 months. This did not happen. At first my memory was terrible. I was ranked at the 10th percentile at my first test, which isn't the best way to get a PhD. Luckily that has come back to nearly normal.

I went horse riding, which really improved my balance and back/leg strength (I can saddle the horse alone now and get on it without help). Now, I have pain in the left shoulder, the muscles are not

holding my joint together correctly, so the head of the bone gets out of the shoulder. I'm back in PT to try and get a little bit more strength.

I was really lucky that the stroke wasn't any worse. I always try to find a good side in everything, and the good thing about my stroke is that I am less shy and less inhibited. It is actually quite interesting to see how my personality has changed in some ways. I'm less high strung, things happen and I go along with them instead of fighting them and getting upset about it. It makes my life in the lab so much easier.

Bio: Simon Rogers



My name is Simon. I'm 34 and from England. I stroked when I was 31, in May 2003. The stroke

was very bad. I couldn't move from the neck down.....it was scary!! I was in hospital for 7 months, boy was that boring!! I had physio & OT galore, but, the worst is over. I now walk out to the car (on crutches). I eat with a knife/fork. to help with the chewing action.

I found a website where they do 80s retro candy from when I was a kid. I ordered some classic BAZOOKA JOE bubblegum & got chewing.....that helped a lot, because now I eat whatever I fancy. My speech was totally taken away for 3 weeks. Now I'm starting to talk on the phone. Things are now looking up. I'd say I've got about 70% of my arm back, and about 50% of my leg. They both improve everyday. My reading has been affected, so I try not to read if I can help it!!

This picture of me was taken on Hols in Torquay in September 2005. I was just about to go out with some mates, and have a few beers. My doc is baffled at my recovery speed. I get better/stronger everyday!

COMING THIS SPRING

Ask Uncle 007

A not so serious advice column for everyone. Watch for details.

This newsletter is available online at <http://www.stroketnet.info/>. It can also be found through the Information Link at the home page of The Stroke Network. <http://www.stroketnetwork.org>. Copies can be printed from the web page. Contents may not otherwise be reprinted without the organization's permission. Please contact the editor.

Monthly newsletter distribution via email is free. Visit the website to subscribe.

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.

Visit the frequently used Message Board to ask questions and help others in the Stroke Family. There are also regular chats. Both of these services can be accessed through <http://www.stroketnetwork.org>. Just click Support at the top of the home page. If you are already a member click Members Area on the left.