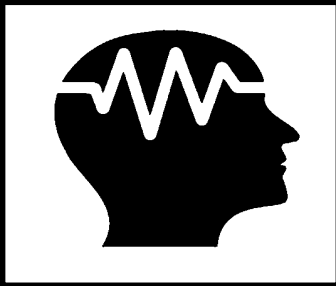


Stroke Recovery News

Volume 15, Issue 1

Summer Autumn 2015



Stem Cells Show Promise for Stroke in Pilot Study

Stroke therapy using stem cells extracted from patients' bone marrow has shown promising results in the first trial of its kind in humans. Five patients received the treatment in a pilot study conducted by doctors at Imperial College Healthcare NHS Trust and scientists at Imperial College London.

The therapy was found to be safe, and all the patients showed improvements in clinical measures of disability. The findings are published in the journal *Stem Cells Translational Medicine*. It is the first UK human trial of a stem cell treatment for acute stroke to be published.

The therapy uses a type of cell called CD34+ cells, a set of stem cells in the bone marrow that give rise to blood cells and blood vessel lining cells. Previous research has shown that treatment using these cells can significantly improve recovery from stroke in animals. Rather than developing into brain cells themselves, the cells are thought to release chemicals that trigger the growth of new brain tissue and new blood vessels in the area damaged by stroke.

The patients were treated within seven days of a severe stroke, in contrast to several other stem cell trials, most of which have treated patients after six months or later. The Imperial researchers believe early treatment may improve the chances of a better recovery. A bone marrow sample was taken from each patient. The CD34+ cells were isolated from the sample and then infused into an artery that supplies the brain. No previous trial has selectively used CD34+ cells, so early after the stroke, until now.

Although the trial was mainly designed to assess the safety and tolerability of the treatment, the patients all showed improvements in their condition in clinical tests over a six-month follow-up period. Four out of five patients had the most severe type of stroke: only four per cent of people who experience this kind of stroke are expected to be alive and independent six months later. In the trial, all four of these patients were alive and three were independent after six months. Dr Soma Banerjee, a lead author and Consultant in Stroke Medicine at Imperial College Healthcare NHS Trust, said: "This study showed that the treatment appears to be safe and that it's feasible to treat patients early when they might be more likely to benefit. The improvements we saw in these patients are very encouraging, but it's too early to draw definitive conclusions. about the effectiveness of the therapy. We need to do more tests to work out the best dose and timescale for treatment before starting larger trials."..... cont.....page 2

Welcome to
Stroke Recovery News
A publication produced
by the
Stroke Recovery
Association NSW

Inside this issue:

Stem Cells Show Promise for Stroke	1 - 2
Welcome to Our New Patron	2
When Couples Disagree on Stroke Recovery	3
Book Review	4
Research Opportunities	5
Electric Current to Brain Boost s Memory	6 - 7
TMS Research	8
Sydney Stroke Choir News	9
Dates for your Diary	9
It's a New Club!	9
Aphasia NSW Conference	10
We Want Your	10
Fingernail Issues	11
Thank You Team Larry!	11
SRA Annual President's Report	12 - 14
SRA Staff and Board 2015	15

(ContPage 1) **Stem Cells Show Promise**

Over 150,000 people have a stroke in England every year. Survivors can be affected by a wide range of mental and physical symptoms, and many never recover their independence. Stem cell therapy is seen as an exciting new potential avenue of treatment for stroke, but its exact role is yet to be clearly defined.

Dr Paul Bentley, also a lead author of the study, from the Department of Medicine at Imperial College London, said: "This is the first trial to isolate stem cells from human bone marrow and inject them directly into the damaged brain area using keyhole techniques. Our group are currently looking at new brain scanning techniques to monitor the effects of cells once they have been injected."

Professor Nagy Habib, Principal Investigator of the study, from the Department of Surgery and Cancer at Imperial College London, said: "These are early but exciting data worth pursuing. Scientific evidence from our lab further supports the clinical findings and our aim is to develop a drug, based on the factors secreted by stem cells, that could be stored in the hospital pharmacy so that it is administered to the patient immediately following the diagnosis of stroke in the emergency room. This may diminish the minimum time to therapy and therefore optimise outcome. Now the hard work starts to raise funds for this exciting research."

For more information please contact:

Sam Wong, Research Media Officer , Imperial College London

Email: sam.wong@imperial.ac.uk

Tel: +44(0)20 7594 2198

© Imperial College London. Reprinted here with kind permission.

Original press release can be read at:

http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news_8-8-2014-12-58-0

WELCOME TO OUR NEW PATRON

We are delighted to report that His Excellency General The Honourable David Hurley AC DSC (Ret'd) has accepted our invitation to be Patron of the Stroke Recovery Association.

His Excellency is the former Chief of the Defence Force, a post he took up on 4 July 2011, the culmination of his 42-year military career.

The father of three was born in Wollongong and raised in Port Kembla, attending Port Kembla High School until 1971, followed by a Bachelor of Arts and Graduate Diploma in Defence Studies.

He retired from Defence in June 2014 and succeeded Dame Marie Bashir as Governor of NSW on 2 October 2014. We enthusiastically welcome His Excellency's patronage!

Stroke Recovery Association Complaints and Feedback Process

Are you aware the Association has a complaints and feedback form? It is available from the Association on 1300 650 594 or by emailing info@strokensw.org.au. All complaints received are investigated by the Executive Officer and a report along with the original written complaint are presented to the Board of Directors.

We also have a quality improvement log where suggestions on how we can improve any aspects of our services are detailed and incorporated into our strategic planning processes, which happen from November through to February each year. If you would like a copy of any of these policies and forms contact Michelle on the number or email above.

When Couples Disagree on Stroke Recovery, One Partner Can Suffer

An innovative study from a University of Cincinnati (UC) social work researcher has found that when a stroke survivor and his or her caregiving spouse disagree on the survivor's rate of recovery, the caregiving spouse is more likely to experience depression and emotional distress.

Assistant Professor Michael McCarthy, PhD, working with co-author Karen Lyons at the Oregon Health and Science University, interviewed 35 couples in which one spouse had experienced a stroke within the past three years.

In separate sessions, stroke survivors and their spouses discussed the survivor's recovery, including the performance of daily functions, their memory and ability to problem solve. In the first mixed-method study in the topic, both quantitative and qualitative data showed that spouses rated rehabilitation progress as significantly worse than survivors—and that this discrepancy was associated with spouse depression.

"We found that spouses rated their partners' recovery worse than survivors rated it themselves, and that this discrepancy predicted depressive symptoms in the spouses," says McCarthy.

"So if the wife has a stroke," he continues, "and she believes, for example, that she can still drive but her husband doesn't—the difference in their perception is predictive of the husband's emotional distress. We were able to quantify and capture a different kind of worry and stress that caregiving spouses can experience and connect it to their outcomes."

He adds that the magnitude of the discrepancy in perceptions between survivors and spousal caregivers is key to predicting depression in spousal caregivers—which can then cycle back onto the survivors.

McCarthy says there is some evidence that wives may be particularly susceptible to caregiver worry, as are spouses in strong, fulfilling relationships. With studies demonstrating that stroke caregivers have higher rates of depression than the general public and may be at higher risk for stroke themselves as well as premature death, caregiver mental health has profound consequences.

McCarthy hopes the study can help social work and other rehabilitation practitioners working with stroke survivors. Overall, he says health care needs to broaden the conversation around stroke recovery: from focusing solely on the patient to considering the patient-spouse couple as a unit.

"How the spouse is doing matters in the equation," he says. "They need as much care, if not more in some ways, as the patient. We need to bring partners together in the rehabilitation process, to align each person's expectations and perceptions in order to achieve the best outcomes."

His paper, "Incongruence between stroke survivor and spouse perceptions of survivor functioning and effects on spouse emotional health," has been published online in the journal *Aging & Mental Health*.

© University of Cincinnati. Reprinted here with kind permission.

Original article published at <http://healthnews.uc.edu/news/?/24728/>

BOOK REVIEW

“FLATOUT”

Imagine yourself as a very physical guy, an ex-commando and skydiver, who has a stroke for no known reason and loses nearly everything but the functions of your mind and - thankfully - your sexuality.

You awaken from a coma to a gruelling, yet often funny, rehabilitation. You can't speak; you can only move your eyes.

You've never been an angel. You lose your marriage totally and are separated from your children.

Finally, new love, and you become a parent once more.

This is the true-life story of Danny Furlong's extraordinary journey from active life to the depths of mute quadriplegia, and back to the highs of life within that quadriplegia.

Danny Furlong has had a varied and very unusual life. At age thirty seven he had a stroke which left him a non-verbal quadriplegic. He has been this way for over thirty years and lives by himself. Carers come in the morning, noon, evening and late night for just an hour at a time to do the basics for him. For the rest of the time is alone, except for his six year old German Shepherd dog, Bruno.

Danny's rather un-ordinary circumstance have allowed him to concentrate on his writing - something he always longed to do but never had the time prior to his stroke. Early this year Danny decided to start publishing the best of his works including his autobiography, Flatout, and a young adult fantasy trilogy, Drinsighe.

Early on Danny led a life that included things like computer programming, professional running, time in the army as a commando soldier, parachuting, cliff climbing and mining to name just a few.

Then at the age of thirty seven things became interesting. Out of the blue he had a stroke that left him, after a few weeks of coma, a non-verbal quadriplegic. He has been this way for nigh on thirty years now. Years that also included things like bungy jumping and travelling the Australian outback in an old bus, bringing forth another new life into the world, and a lot of writing.

Having plenty of alone time and being a non-verbal quadriplegic has allowed Danny to concentrate on his writing - something he has always wanted to do but never had the time to do (except for a time in his twenties when he spent many months living on a Greek isle writing the Great Australian Novel - which he hurriedly threw into the bin when he re-read it back in Australia).

Danny uses a special computer keyboard that is operated by a head laser attached to his reading glasses. It's good system, but very slow and the physical task of typing a book is interminable.

Finding the words to write has always been easy for Danny and over the years he has devoted himself to writing many things - novels, film and stage scripts, short stories and poems. He's had various short stories and poems published, but never really spent the time needed to find publishers for his bigger works.

Early this year Danny decided to publish the best of his works online.

Ten years ago Danny wrote an autobiography, Flatout, He then rewrote it as a play and it was performed in theatres in Bendigo and Castlemaine. Subsequently it was serialised on ABC Radio National and produced on double CD for ABC shops. This year Danny has added to it and only a few weeks ago put it up online for purchase at www.dannyfurlong.com

Many years ago Danny wrote a young adult fantasy trilogy, Drinsighe, which he has done work on every few years since. This year he has had book one, Ellydd Gate, now reworked, professionally edited and put up online for purchase at www.dannyfurlong.com. Book two will be edited and published within months, with book three online too, just months after that.



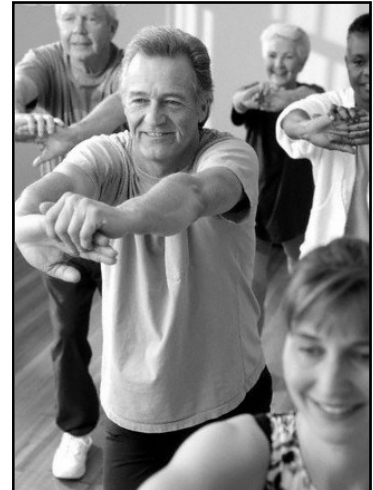
RESEARCH OPPORTUNITIES

Mapping and recovery of arm coordination after stroke

An important problem after stroke is an inability to coordinate arm movements. This project aims to identify which type of stroke causes coordination deficits of arm movements and to track and explore mechanisms of recovery over two years.

The study will result in new knowledge to increase understanding of recovery of coordination after stroke that will help to design new treatments to improve coordination of arm movement.

The researchers are seeking people whose arm movement has been affected by stroke. Participants will attend the Calvary Hospital in Newcastle three times for an MRI. They will also attend the Hunter Medical Research Institute three times for arm movement measurement. Participation will take place over a two year period. Assistance is available with travel and parking costs.



For Further Information Contact
Professor Paulette van Vliet
on 02 4921 7833 or paulette.vanvliet@newcastle.edu.au

myMoves

Macquarie University is excited to announce the launch of myMoves for ABI – a free self-management course aimed at improving physical activity after stroke or brain injury.

This 8-week course consists of 6 modules designed to give you the information and skills to create an active lifestyle that is best suited to you. Delivered via the internet with weekly telephone support with an experienced physiotherapist it can be undertaken at a time and place convenient to you.

We are looking for 40 participants who would like to test this exciting new course in early 2015. The first participants will commence in February 2015, with further participants to follow in March.

For further information and to apply please see
website: <http://www.mymoves.mq.edu.au>
or contact Taryn Jones on
taryn.jones@mq.edu.au

Electric Current to Brain Boosts Memory

Discovery may help treat memory disorders resulting from Stroke

Stimulating a particular region in the brain via non-invasive delivery of electrical current using magnetic pulses, called Transcranial Magnetic Stimulation [TMS], improves memory, reports a new Northwestern Medicine study.

The discovery opens a new field of possibilities for treating memory impairments caused by conditions such as stroke, early-stage Alzheimer's disease, traumatic brain injury, cardiac arrest and the memory problems that occur in healthy ageing.

"We show for the first time that you can specifically change memory functions of the brain in adults without surgery or drugs, which have not proven effective," said senior author Joel Voss, assistant professor of medical social sciences at Northwestern University Feinberg School of Medicine. "This noninvasive stimulation improves the ability to learn new things. It has tremendous potential for treating memory disorders."

The study was published August 29 in *Science*.

The study also is the first to demonstrate that remembering events requires a collection of many brain regions to work in concert with a key memory structure called the hippocampus – similar to a symphony orchestra. The electrical stimulation is like giving the brain regions a more talented conductor so they play in closer synchrony.

"It's like we replaced their normal conductor with Muti," Voss said, referring to Riccardo Muti, the music director of the renowned Chicago Symphony Orchestra. "The brain regions played together better after the stimulation."

The approach also has potential for treating mental disorders such as schizophrenia in which these brain regions and the hippocampus are out of sync with each other, affecting memory and cognition.

TMS Boosts Memory

The Northwestern study is the first to show TMS improves memory long after treatment. In the past, TMS has been used in a limited way to temporarily change brain function to improve performance during a test, for example, making someone push a button slightly faster while the brain is being stimulated. The study shows that TMS can be used to improve memory for events at least 24 hours after the stimulation is given.

Finding the Sweet Spot

It isn't possible to directly stimulate the hippocampus with TMS because it's too deep in the brain for the magnetic fields to penetrate. So, using an MRI scan, Voss and colleagues identified a superficial brain region a mere centimeter from the surface of the skull with high connectivity to the hippocampus. He wanted to see if directing the stimulation to this spot would in turn stimulate the hippocampus. It did.

"I was astonished to see that it worked so specifically," Voss said.

When TMS was used to stimulate this spot, regions in the brain involved with the hippocampus became more synchronized with each other, as indicated by data taken while subjects were inside an MRI machine, which records the blood flow in the brain as an indirect measure of neuronal activity.

The more those regions worked together due to the stimulation, the better people were able to learn new information.

Contpage 7

How the Study Worked

Scientists recruited 16 healthy adults ages 21 to 40. Each had a detailed anatomical image taken of his or her brain as well as 10 minutes of recording brain activity while lying quietly inside an MRI scanner. Doing this allowed the researchers to identify each person's network of brain structures that are involved in memory and well connected to the hippocampus. The structures are slightly different in each person and may vary in location by as much as a few centimeters.

"To properly target the stimulation, we had to identify the structures in each person's brain space because everyone's brain is different," Voss said.

Each participant then underwent a memory test, consisting of a set of arbitrary associations between faces and words that they were asked to learn and remember. After establishing their baseline ability to perform on this memory task, participants received brain stimulation 20 minutes a day for five consecutive days.

During the week they also received additional MRI scans and tests of their ability to remember new sets of arbitrary word and face pairings to see how their memory changed as a result of the stimulation. Then, at least 24 hours after the final stimulation, they were tested again.

At least one week later, the same experiment was repeated but with a fake placebo stimulation. The order of real stimulation and placebo portions of the study was reversed for half of the participants, and they weren't told which was which.

Both groups performed better on memory tests as a result of the brain stimulation. It took three days of stimulation before they improved.

"They remembered more face-word pairings after the stimulation than before, which means their learning ability improved," Voss said. "That didn't happen for the placebo condition or in another control experiment with additional subjects."

In addition, the MRI showed the stimulation caused the brain regions to become more synchronized with each other and the hippocampus. The greater the improvement in the synchronicity or connectivity between specific parts of the network, the better the performance on the memory test. "The more certain brain regions worked together because of the stimulation, the more people were able to learn face-word pairings," Voss said.

Using TMS to stimulate memory has multiple advantages, noted first author Jane Wang, a postdoctoral fellow in Voss's lab at Feinberg. "No medication could be as specific as TMS for these memory networks," Wang said. "There are a lot of different targets and it's not easy to come up with any one receptor that's involved in memory."

The Future

"This opens up a whole new area for treatment studies where we will try to see if we can improve function in people who really need it," Voss said.

His current study was with people who had normal memory, in whom he wouldn't expect to see a big improvement because their brains are already working effectively.

"But for a person with brain damage or a memory disorder, those networks are disrupted so even a small change could translate into gains in their function," Voss said.

In an upcoming trial, Voss will study the electrical stimulation's effect on people with early-stage memory loss.

Voss cautioned that years of research are needed to determine whether this approach is safe or effective for patients with Alzheimer's disease or similar disorders of memory.

Other Northwestern authors on the paper include Lynn M. Rogers, Evan Z. Gross, Anthony J. Ryals, Mehmet E. Dokucu, Kelly L. Brandstatt and Molly S. Hermiller.

The research was supported by grants P50-MH094263 from the National Institute of Mental Health and F32-NS083340 from the National Institute of Neurological Disorders and Stroke of the National Institutes of Health.

© Northwestern Medicine

Original press release can be read at: <http://www.northwestern.edu/newscenter/stories/2014/08/electric-current-to-brain-boosts-memory.html#sthash.G9F4CwUM.dpuf>

NEW RESEARCH SUPPORTING STROKE REHAB

Using world-leading research methods, the team of Dr David Wright and Prof Paul Holmes, working with Dr Jacqueline Williams from the Victoria University in Melbourne, studied activity in an area of the brain responsible for controlling movements when healthy participants observed a video showing simple hand movements and simultaneously imagined that they were performing the observed movement.

Using transcranial magnetic stimulation -- a technique where a coil placed over the scalp delivers a stimulation to the brain, activates neurons in the underlying area, and causes a muscular contraction in the participant's hand -- the researchers found that combining imagery (imagining the feelings associated with performing the movement) with observation (watching the movement) created the strongest activity in the brain.

Using electrodes on the participant's hand, the researchers found that muscle contractions in response to the cortical stimulation were larger when participants were concurrently imagining themselves moving their muscle whilst watching a video of a hand moving on screen, compared to when they used the imagery or observation techniques alone. or engaged in various control conditions.

This research, which is published in the open-access journal *Frontiers in Human Neuroscience*, may provide useful applications for the care of stroke patients who have restricted use of their upper limbs. If stroke patients practice the recommended techniques, it could potentially help maintain activity in movement-related brain areas, especially when used alongside more traditional physiotherapy techniques where the same movements are also practiced physically.

Dr Wright said: "The idea is that because imagery and observation techniques share some characteristics with physical movement in terms of activating similar areas of the brain, if someone can't perform the movements themselves physically, it might be possible to keep those areas of the brain active through imagery and observation techniques. This might help contribute to the recovery of motor function."

Currently, imagery and, less frequently, observation are used separately alongside physical therapy during the rehabilitation of stroke patients, but Prof Holmes suggested that combining the two techniques may support re-learning of movement patterns for some patients.

He said: "After a stroke, parts of the brain die and will not recover. To compensate, other parts of brain can alter their function to take control of the lost behaviour -- a form of brain plasticity. We think that combining imagery and observation, in addition to physical therapy, may allow the brain to speed up this plastic change as well as benefitting more psychological aspects of recovery such as movement confidence." He continued, "the research team's work in this area has the potential to make a real impact on the way physiotherapists, occupational therapists and nurses work with the stroke community"

"These changes may happen without the intervention -- it is certainly not a miracle cure -- but the combined imagery and action observation approach should speed up the process of relearning movements that have been lost."

The research was funded by Manchester Metropolitan University's Knowledge Exchange Innovation Fund and a Research Accelerator Grant awarded to Dr Wright (an early career researcher in the Motor Cognition Research section of the Centre of Health, Exercise and Active Living).

Future research by the Group will seek to establish optimal methods for delivering these psychological interventions for stroke rehabilitation by investigating the effects of different types of instruction given to participants and different video presentation methods on activity in the brain during combined imagery and observation. The team also expect to release a stroke rehabilitation App in early 2015.

This article is a news release, located at:

<http://www.sciencedaily.com/releases/2014/11/141127082350.htm>

SYDNEY STROKE CHOIR NOW UP AND RUNNING

Nordoff-Robbins Music Therapy Australia presents a new and exciting choir for people who have experienced a stroke. And they are looking for more participants!

If you are having difficulty communicating since having a stroke, feeling low, depressed or unmotivated, then this may be ideal for you. Benefits of choir participation have been demonstrated in areas such as confidence, communication, mood and motivation.

For those who are interested, there is the possibility of participating in a research project that explores the benefits of singing for people who have had a stroke.

Where: Northside Baptist Community Centre

63-65 Willoughby Rd, Crows Nest

When: Wednesdays, 11am - 12 noon

For expressions of interest or more information, please contact Kate on:

Phone: 02 4736 0240

or

Email: k.tabain@uws.edu.au

DATES FOR YOUR DIARY

APHASIA NSW AND SRA PICNIC: Tuesday 17 March

APHASIA NSW CONFERENCE: Friday 17 April

SYDNEY STROKE OLYMPICS: Thursday 11 June

COMBINED CLUBS MORNING TEA: Saturday 1 August

STROKE AWARENESS WEEK: 14 - 20 September 2015

LAUNCH OF STROKE AWARENESS WEEK: Monday 14 September

BURWOOD CONFERENCE: Tuesday 15 September

STROKE RECOVERY ASSOCIATION ANNUAL GENERAL MEETING: Friday 30 October

HUNTER STROKE OLYMPICS: Wednesday 14 October



IT'S A NEW CLUB!

We are delighted to announce that the Stroke Recovery Association has assisted in getting yet another affiliated Stroke Recovery Club up and running!

All are welcome at the inaugural meeting of the Bankstown Stroke Recovery Club on February 25, 2015, from 10:30am to 12:30pm, at the Revesby Workers Club.

Accessible parking is available through the entrance on Tarro Ave, there is lift access, and also accessible toilet facilities.

To RSVP please contact Post Acute Rehab at Bankstown Hospital, on 9722-8026 (and if it goes to message bank, please do leave a message).

Please spread the word about this new Stroke Recovery Club, throughout your networks!



SHARE YOUR GREAT RECIPES!

Here at the Association, we are considering a fundraising idea that will also be a great resource for the stroke-affected. We are thinking of putting together a cookbook full of stroke-friendly and healthy meals, and we'd like to get those recipes from the people who know what works. That means you, our readers, the stroke survivors and carers! We'd like the recipes to be fairly easy to execute, none of those complicated fifty-step jobs, and ideally able to be cooked by people affected by hemiplegia. We realise that's a big ask though, we all know that decent hemiplegia-friendly recipes can be scarce, so simple and healthy are the most important criteria here.

So if you have any great recipes to share, that we could include, please contact eileen@strokensw.org.au or ring (02) 9807-6422 or 1300-650-594 (or by mail to PO Box 3401, Putney NSW 2112). We are also thinking about a title, so suggestions for that are also welcome.



APHASIA NSW CONFERENCE

April 17 2015

We need YOU to present!

We are looking for:

- People with aphasia
- Friends and family of people with aphasia
- Health professionals

You can present about:

- Life with aphasia and your story
- Ideas and initiatives for aphasia
- Rehabilitation for aphasia
- New aphasia research
- Your organisation
- Something else about aphasia!



Please contact Aphasia NSW if you want to present!

Email	aphasiansw@gmail.com
Phone	02 9850 7960
Post	Scott Barnes, Department of Linguistics, Macquarie University, North Ryde, 2109
Closing	Please contact by February 28th!

DO YOU ALSO HAVE THIS ISSUE?

One of our members has brought to our attention an issue which others may have experienced as well, and has suggested we canvass our membership to find out. Advocacy is, after all, so much more effective when it is representative of greater numbers of people affected.

Geoff told us about the strange situation that arises when he goes for his check-ups at Aged Care and Rehab, Napean Hospital; while they check his hands for hygiene and make sure his fingernails aren't cutting into the palm of his hands, they don't actually offer any fingernail cutting service. Obviously it has 'fallen through the cracks', seeing how a podiatry service is offered, but not a manicurist to assist with the very issue that they do watch for. And as Geoff pointed out, this is not only an issue for those who have had a Stroke, but also people with arthritis and those in nursing homes. We were very excited when Geoff reported that he'd written to the Minister for Health, who had someone write a response!! Unfortunately, the suggestions in the response turned out to be inaccurate, and Geoff wrote back to say as much, but there have been no further replies - yet.

Let's put our voices together on this! Are you affected by spasticity in one or both of your hands, such that management of fingernail growth is becoming an issue? If so, we'd like to talk with you. Contact us! Email eileen@strokensw.org.au or ring (02) 9807-6422 or 1300 650 594 from country areas.

THANK YOU TEAM LARRY!

Last year the Stroke Recovery Association was lucky enough to be the beneficiary of an extraordinary fundraising event. Karen Ryan and her family set up an Everyday Hero page for their participation in the Sydney Morning Herald Half Marathon, with all funds raised coming to the Stroke Recovery Association. That meant an incredible \$7130.97 raised for us!

They called themselves "Team Larry" in honour of Karen's father who'd had a Stroke. Even more special was Larry's involvement - the team pushed him the length of the course (21.1km) in his wheelchair, which took two hours and ten minutes. What a mammoth effort, and an incredibly successful fundraiser. Thank you Team Larry!



Before



And after!

EXCERPTS FROM THE STROKE RECOVERY ASSOCIATION PRESIDENT'S ANNUAL REPORT JULY 2013 TO JUNE 2014

The following is part of the Stroke Recovery Association President's Report for the period July 1, 2013 to June 30, 2014.

The Association has continued to provide a comprehensive telephone helpline for carers, people affected by Stroke and the community over the past twelve months.

During the period July 1, 2013 to June 30, 2014 the Association's statistics reflect the high demand for our service:

The number of telephone calls has increased significantly over the last twelve months; counselling and information requests account for 36% of all calls received, with referrals registering 12%. Roughly 48% of calls were enquiries regarding Stroke Recovery Clubs, about conferences, publications and membership. Administrative matters account for the final 4% of calls.

The statistics above indicate that there was a small decrease in client contacts over the year; however, significantly less than the increase experienced in the 2012/2013 period.

This is due to the reduction in use of our Website (as indicated in our statistics) which has remained the same since we developed it some years ago with only minor variations occurring over the years. We are now in the process of upgrading the site to ensure its viability for service users in to the future. It is hoped that the new website will be up and running by Stroke Awareness Week 2014.

Our Facebook page continues to power along and our members are much more able to use it as we further advertise it through our publications. While our majority client demographic is the elderly, they appear to be accessing modern technology more. It is certainly more readily used by our members in the younger age range.

During the period July 1, 2013 to June 30, 2014 the Association's statistics reflect that there is still a great deal of demand for **Information Kits** (1059), an increase of 91% on the previous year's figures. These are provided to individuals, health professionals, community groups, and anyone who requests one through our information/counselling phone line. This figure no doubt reflects the addition of a second booklet, "A Practical Guide to Stroke Recovery with Exercises and Advice" which was included in our Programme Report in 2012 at Appendix 9. In addition we also provide **DVDs** (75), **pamphlets** (4,923), **posters, and relevant media articles**.

Stroke Information Sheets on topics relevant to the Stroke Survivor continue to be distributed widely. During the 2013/2014 period 16,889 were distributed by mail and 4,603 were downloaded from our website. We have also initiated another four new information sheets bringing our total number of information sheets available to 25. These will be uploaded to our website once our new website format is applied. In addition a sample pack of our information sheets has been sent to all health services in NSW for distribution during Stroke Awareness Week 2014.

Over the past twelve months our staff and volunteers have been involved in 49 instances where we have been called upon to provide talks on Stroke to various groups, agencies or training institutions. This is a significant increase in the number of talks given in the previous year. With the assistance of members of my Board and other members of the Association we have utilised their talents in this area of service delivery which has been impacted most from my injury. Stroke prevention talks given to CALD groups has remained static in 2013/2014.

The Stroke Recovery Carers Handbook "**It's 4am**" was launched by Her Excellency Professor Marie Bashir AC CVO at the Launch of Stroke Awareness Week 2013. A copy of the booklet and pamphlets in a plastic stand have been distributed through the Agency for Clinical Innovations Stroke Network to all Stroke Units in NSW. Thus far we have distributed over 300 booklets out through the Stroke Network and our sales figures indicate that we have sold 960 copies throughout the state. We are now talking with the

Stroke Networks in Queensland and Victoria about the suitability of distributing them through their networks.

The booklet has met with widespread acclaim and Tom Crow, the author, will be chairing the consumer forum at the Smart Stroke Conference in August and Allergan will be selling the booklets as well.

The Stroke Recovery Association now auspices **45 of the 52 Stroke Recovery Clubs in the state** which meet on a regular basis throughout metropolitan and regional NSW. In the past twelve months new clubs have commenced operation at:

Mouya

Revitalisation of Merimbula

Interest has been expressed in establishing Stroke Recovery Clubs in the following areas:

Inner West (Petersham)

Bankstown

Fairfiled (Considering affiliation)

We have again held two regional telephone conferences involving all our Clubs during 2013/2014 which functions to increase interaction in and between Clubs in each region. This has proved overwhelmingly successful. These teleconferences will continue to be held twice a year.

The combined "Clubs Friendship Day" organised on the Central Coast in July 2013 involving Clubs from the Hunter, Central Coast and Sydney areas was an enormous success and was attended by 5 different Clubs and 94 members. All were well attended and resulted in a great day being had by all. These friendship days will be again organised in the next twelve month period

The Annual **Hunter Stroke Olympics** was held on the 11th October 2013. This was again a great success. There were over 110 people in attendance. The Olympics continues to grow and we are enormously lucky to have the support of the University of Newcastle physiotherapy department who provide us with student volunteers to assist with the running of the games. The students are enormously popular with the participants. Plans are well underway for 2014. Unfortunately due to a transport issue the Singleton Club was not able to join us on the day and this resulted in a last minute rearranging of the games draw. However as usual the good nature of the contestants and the support received from the excellent organising committee meant that this was rectified very quickly and the day went ahead without further disruption.

The South Coast Stroke Olympics was held at the Lake Conjola Community Centre on the 16th of May 2014. Over 50 people were in attendance from our Groups in Nowra, South Illawarra, Ulladulla and the new group at Eurobodalla (Moruya). A Stroke Olympics Games Day is organised for Thursday 11th of September 2014 for the Sydney metropolitan area. This will be held in partnership with Royal Rehab and will take place at the new community centre in Putney. This will be open to our Stroke Clubs as well as all Stroke Rehab patients, both inpatient and outpatient, from Royal Rehab

Our Authority to Fundraise or Charitable Fundraising Number (CFN) was renewed with the NSW Office of Liquor, Gaming and Racing for another 5 years in March 2014 and this has been distributed to the Stroke Clubs for them to utilise in their fundraising activities.

We have updated the three booklets we use for new Stroke Clubs. These documents give volunteers and Club Coordinators a very valuable reference tool to the day to day running of a Stroke Club:

- How to Start a Stroke Recovery Club
- How to Manage a Stroke Recovery Club
- Activities for a Stroke Recovery Club

The Board and Staff continue to utilise all feedback processes when undertaking the annual review of services and Planning Day. This year we also incorporated members of our stakeholder organisations and individuals in the review.

The biannual "Clubs Satisfaction Survey" was undertaken by staff in the first quarter of 2014. The final document has yet to be presented to the Board but it will happen in the second half of 2014. It will then be distributed to all Clubs for comment. Its findings and recommendations will also form the basis of the workload of the Stroke Clubs Coordinator when appointed.

This year we will be undertaking Third Party Verification through the Department of Human Services - Aging

EXCERPTS FROM SRA PRESIDENT'S ANNUAL REPORT...Cont'd from page 13

Disability and Home Care. We are preparing for that now and the Verifiers are scheduled to review the organisation in December 2014.

The Association has also assisted in the distribution of information for five Research Projects in 2013/2014:

Latrobe University – Exercise After Stroke – Do You Like It?

University of Western Sydney – Receiving Bad News – The Perspectives of Stroke Survivors.

Wollongong University – Balancing While Reaching After Stroke.

Macquarie University – Increasing Physical Activity for People With Chronic Mobility Limitations

University of Technology Sydney – The Use of the Tongue in Speech Post Stroke

Members can be assured that the Board and Staff of the Association continue to meet all legislative and organisational requirements as determined by our constitution and the funding bodies. In summary we are well managed and organised adhering to the vision and goals as determined by our Board and members.

The Board is aware of the changing face of the funding landscape and with the guidance of our Executive Officer we continue to steer the organisation through these uncertain times to a more stable future. The Board will complete a third party verification process in December as required by Ageing Disability and Home Care to ensure that we are eligible for continued funding however we have no guarantee from either funding body after June 2015.

As we move into 2015 we can look back on the past twelve months with some pride in the achievements of this Association. New Stroke Recovery Clubs are emerging and it is expected that this will continue. Stroke Recovery Clubs are and will remain the focus of our work. It is anticipated that by the appointment of a Clubs Coordinator in early 2015 that we will have the resources to support new and existing Clubs in an enhanced dimension.

In 2014 your staff and Board of Management will remain committed to working with Stroke Survivors and their carers to ensure that the interests and the voice of Stroke Survivors are well represented within NSW as well as to work cooperatively with Stroke Associations from all around Australia to expand and diversify our services. We will continue to be involved with NSW Health with the provision of consumer representatives. This is to ensure that we **have a seat at the table** and to ensure that the voice of Stroke survivors continues to be heard in the provision and planning of services in NSW.

In closing I would like to inform the membership that while I am hoping to stay on the Board of the Association, I will not be contesting the position of President for the 2014/2015 period. It has been a privilege for me to lead this wonderful organisation for 11 years now and it is time I handed over the leadership to another. I have enjoyed my time as President and it has been wonderful to be part of the organisation as it has grown and developed over that time. I will still remain on the Board and involved with my Stroke Recovery Club but ill health has meant that I have had to pass on the responsibility of President. I wish my successor every success in the position and trust that he/she will enjoy your support as I have.

Robyn Artlett
President
7 November 2014

**A FULL COPY OF THE ASSOCIATION'S ANNUAL REPORT IS AVAILABLE TO ALL MEMBERS
TELEPHONE 1300 650 594 TO REQUEST A COPY**

THE STROKE RECOVERY ASSOCIATION

PO Box 3401
PUTNEY NSW 2112
(Level 1, Hodson Building, Royal Rehabilitation
Centre Sydney)

Phone: 02 9807 6422 or 1300 650 594
Fax: 02 9808 6173
E-mail: info@strokensw.org.au



We're on the web!
www.strokensw.org.au

The Stroke Recovery Association
wishes to thank
NSW Health and
Department of Ageing, Disability and Home Care
for their financial support.

The Board of the Association

President: John Garbutt
Vice-President: Robyn Artlett
Vice-President: Pat Weir
Secretary: Linda Glanfield
Treasurer: Paul Wheeler
Public Officer: Stuart Chalmers
Directors: John Tass

The Staff of the Association

Executive Officer: Michelle Sharkey
Stroke Clubs
Coordinator: Vacant
Information Officer: Eileen Leather
Accounts Clerk: Cheryl Smith

MEMORIAL DONATIONS

The passing on of a family member, friend or loved one is a very sad and stressful time. Sometimes, symbolic gestures and actions provide great comfort to those who are grieving.

It is with gratitude that the Stroke Recovery Association receives donations in memoriam.

These donations, which assist us to continue our valuable work, are a wonderful remembrance of the person who has passed away. It honours their memory to help someone in the present, more completely than flowers ever can. And the benefits will last far longer than any blooms.

All donations received by the Association are tax deductible and can be forwarded to our postal address above. Acknowledgement will be sent to the family of the deceased, and the amount of the donation is not disclosed.

The Association is happy to provide memorial donation pamphlets, which can be made available at a funeral service, with pre-paid addressed envelopes. Thank you for your support.

DISCLAIMER

The views expressed in Stroke Recovery News are not necessarily those of the Stroke Recovery Association nor its Board. No liability or responsibility is accepted by the publisher for any consequences resulting from any action taken based on information or advertisements included herein. All care is taken to ensure the accuracy of the contents, but this cannot be guaranteed and should not be relied upon.

COPYRIGHT

The Publisher of Stroke Recovery News is the Stroke Recovery Association of NSW.

No part of this publication may be reproduced, either in print or any other media, including the internet, without the written authorisation of the Executive Officer of the Stroke Recovery Association. Permission should be sought by writing to PO Box 3401 PUTNEY NSW 2112 Australia.