

Neurosurgery VICTORY IN THE SOUTH

After a long campaign that united the people of Southland and Otago who raised their voices against the proposed relocation of Neurosurgery to a centralised service in Christchurch, **victory was achieved** when on November 10th the Director General of Health announced that Dunedin would retain its Neurosurgery facilities.

The decision signals the conclusion of a debate that has been raging since the idea of the South Island having one centralised neurosurgery service was first raised in March 2009. Opposition has been vast and vocal and has gathered momentum this year, with public meetings, a large scale protest march, a Facebook page with over 20,000 members and a petition with 55,000 signatories - all calling for the rejection of the idea.

The announcement that not only would Dunedin retain its services, but that these would be extended and improved, has been welcomed by Cathy Mathews, Liaison Officer for Brain Injury Association of Otago, she states "Like everyone here in Otago and Southland I am absolutely ecstatic that the Panel has seen the light, listened to the people and



made a very clear proposal that ensures Neurosurgery is retained here in the south for the foreseeable future. This is a direct result of Southerners uniting to fight the loss of services. Our thanks to everyone who spoke up, to the survivors that bravely told their stories and others that marched or signed petitions."

How Wrong could they be?

Many **BrainLink** readers will be familiar with Richard Safey's story from the book, 'The Everest Within'. Richard sustained serious injuries when the car he was a passenger in was involved in a head-on collision in 1992. Doctors did not believe he would survive, however, after spending three weeks in a coma and two further months in hospital, Richard beat the odds to make a remarkable recovery. While he still lives with some side effects from the accident, Richard acknowledges he is lucky to have recovered so well – and makes the most of every moment these days!

Now almost twenty years on from his accident, Richard is working part-time, involved with the Supreme Dance Centre, active within the Brain Injury Association of Whanganui and has just become the first counter registration for the 2011 Masters Games. Richard entered his first ACC NZ Masters Games in 2001, where he won bronze in both the 500m and 2000m indoor rowing events. He has competed in every second Masters Games since then (each event that has been held in Whanganui) and was last year awarded the ACC Masters Games Life Award.



"With my busy schedule, it sometimes feels that there are not enough hours in a day. To think that in April 1992 doctors believed my future was bleak and I would continue to live in a 'Locked-in' Syndrome. Now look at me – how wrong could they be!"



BRAIN TREE TRAINING WORKSHOPS



IPH Ltd is pleased to announce that Kit Malia and Anne Brannagan O.B.E. of Brain Tree Training will be coming back to New Zealand in March 2011.

There will be three Workshops on offer:

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| 2 Day | Cognitive Rehabilitation for Professionals Workshop
March 14 and 15, 2011 |
| 1 Day | How to do Cognitive Rehabilitation Therapy (CRT)
March 16, 2011 |
| 2 Day | Insight Workshop
March 21 and 22, 2011 |

\$5 from every registration will be donated to Brain Injury New Zealand

All the workshops will be held at the Holiday Inn, Auckland Airport.

For further information and registration forms please go to www.iphltd.co.nz and click on workshops.

Recognising Effort and Achievement

Through the 'Holiday Fund' and 'Carer Koha', Brain Injury New Zealand has been recognising the value and effort of carers for a number of years. We have been fortunate enough to receive donations from a benevolent contributor which has allowed us to offer a short break to client's families who are nominated by their Liaison Officer. We have also been able to offer small gifts or treats to carers when their Liaison Officer has felt they have gone that extra mile or could really do with a small 'pick-me-up'.

Recently we have been looking at ways to revamp this fund and have decided to expand it to allow for gifts to recognise effort, achievement or hardship experienced by clients as well as carers. There will now be three funds: **Client Treats**, **Family Days** and **Carer Koha**, as well as an annual 'Carer of the Year', who will receive an all expenses paid weekend break for two.



We are actively seeking donations to fund these accounts so we can recognise the hard work and achievements of as many clients and carers as possible.

If you feel you would like to donate specifically to this fund, please contact the national office on **09 414 5693** or email national@brain-injury.org.nz

Further information is available on our website at www.brain-injury.org.nz

BRAINlink

A Newsletter of Brain Injury New Zealand

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A Newsletter of Brain Injury New Zealand

a marathon effort for Northland

Northland's Ken Williams came to compete in the Kerikeri Half Marathon the hard way.

In 2005, when he was 26 years old, Ken was struck hard in the temple in a collision with another boat, while racing his A-Class catamaran. The resulting brain injury left him with a multitude of difficulties including weakness in his left side, fatigue, headaches, dizziness and nausea, intolerance to light and noise, slurred speech, difficulties carrying out every day activities and depression. Ken notes "I went from clocking up 25,000 steps per day to pretty much collapsing after 200-metres. I had no option but live with my parents again, and did so for 2 years. It is really hard to describe, but it's like living in a fog, a very thick fog. Thinking just doesn't happen." Five years later, Ken has made huge progress in his recovery which he attributes to "grit and determination", but he says "despite my ongoing difficulties, life is good, and in some ways better than before. I have a much wider range of interests, and live for the journey now rather than the destination."

Ken's life changing experience inspired him to write a 'bucket list' and his positive attitude is reflected in this. "Two of the things on this list are to run a half marathon, and do more to help those less fortunate than myself." Competing in the Kerikeri half Marathon on November 20th to raise money for The Brain Injury Association of Northland ticked both of these boxes. Ken is full of praise for the Association that has supported him over this difficult time, stating "the staff are always there, no matter what. I can say, that being in the brain injury boat, I would not have wanted to tackle the journey without them. They actually care, and tirelessly dedicate themselves to the job despite the ongoing difficulties raising funds to maintain frontline services."

Ken faced a further challenge when, after months of training, he



Ken (centre) crosses the finish line

was struck down with a bad bout of flu the week before the event. Although it looked at one stage like he wouldn't be able to go ahead with the half marathon, Ken is a dedicated individual, and taking a cautious approach of a mix of walking and running, he completed the half marathon in an impressive time of two hours and twenty minutes, raising \$3,600 in the process. "I was very pleased to have my support crew there. Vanessa Gray and Vikki Herdman from The Brain Injury Association of Northland and my mother were there at several road junctions around the course to feed me and remind me not to over do it (a common theme of the last 5 years)."

Vanessa Gray, General Manager of the Northland Association states "Ken did amazingly well on Saturday considering he'd been unwell recently. With those long legs

he was walking past runners uphill at one stage, he was fairly good at keeping to the "walk only" rule until the last stretch where the temptation to run overcame him!"

Ken has been doing a fantastic job promoting his fundraising and worked really hard last Sunday taking photos for the Fred Ogle Cycle Ride - riders can obtain a copy of their photos by making a donation on Ken's FundraiseOnline page.

The extent of Ken's achievement is best summed up by Ken himself - "Looking at the bigger picture, after my brain injury I had to consciously think about moving my left leg to walk, and found it very hard to walk any more than 100-200m. On Saturday I did 21.1km. Given the far from ideal nature of the build up to this years event, my target for next year is 90 minutes".

For more information about Ken or to make a donation you can visit <http://fundraiseonline.co.nz/kennethwilliams/>

www.brain-injury.org.nz

Focus on Research

Stroke as a highly preventable and treatable brain injury

Prof. Valery Feigin, MD, PhD, FAAN

Director, National Institute for Stroke and Applied Neurosciences
AUT University, Auckland, New Zealand



After traumatic brain injury stroke is the most prevalent acquired brain injury. It affects over 7,500 New Zealanders every year and at any given time there are some 45,000 people living with stroke aftermath in our country. It is also the leading cause of disability in adults with 75% of stroke survivors experiencing some level of disability or reduced quality of life by one year post-stroke. Yet, it is a highly preventable and nowadays treatable condition.

Over 90% of strokes can be prevented if people would know and control their major factors predisposing to stroke, so-called risk factors. These are elevated blood pressure (blood pressure over 120/80, including fluctuations in blood pressure), smoking (even occasional and passive smoking), high level of "bad" cholesterol in the blood (total cholesterol over 5 mmol/L or low-density cholesterol over 2.5 mmol/L), poor diet with high intake of saturated fat and low intake of fruits and vegetables (less than 5 portions per day, more than 1 drink of alcohol per day), excessive weight (especially abdominal obesity), sedentary lifestyle (less than 30 minute exercise 5 times a week) and heart disease (including irregular heart beats or so-called atrial fibrillation). It is also important to know warning signs of stroke such as sudden loss of power or sensory loss in the arm and leg, especially on one side of the body, sudden language problem (e.g. slurred speech or difficulty of understanding of others), loss of vision in one eye or double vision. Anyone who observes or even suspects any of these symptoms should call an ambulance immediately.

However, if stroke happens it is not the end of the life. There are now highly effective treatments and rehabilitation strategies available for stroke patients. The important point is to get these treatments available as soon as the stroke symptoms appear, as time is brain, indeed, and wasted time means wasted brain. After hospital discharge it is crucial to continue rehabilitation and comply with all doctor's recommendations to improve your recovery and reduce the chance of recurrent stroke (20-25% of people can develop another stroke and the risk is highest within the first year after the initial stroke).

For many stroke survivors the process of recovery goes far beyond the period of hospitalisation and for some it continues for many months and even years. Our recent research showed that as much as 60% of 5-year stroke survivors regain their lost functions virtually completely to the pre-stroke level. To facilitate better recovery, we also recently developed the world-first stroke rehabilitation DVDs that cover virtually all aspects of stroke rehabilitation (over 40 techniques ranging from proper positioning in the bed and feeding to physical and speech therapy), prevention and coping strategies. All the procedures are shown in easy-to-follow tutorial format and can be used by lay people (people without special medical training) at home or any other facilities. The DVDs are available for purchasing online at www.stroke-education.com (the website will soon be upgraded to have these techniques available for download for just a few dollars).

The Auckland Regional Community Stroke Study (ARCOS IV)

The Auckland Regional Community Stroke (ARCOS) IV; Measuring and Reducing the stroke burden in New Zealand, is a 5-year programme (2010-15) with 5 inter-linked objectives and 3 distinct study designs, providing a multi-perspective evidence-base to assess and reduce stroke burden in New Zealand. The study has been awarded funding by the Health Research Council, and is led by Professor Valery Feigin as the Principle Investigator, and Professor Kathryn McPherson and Dr Suzanne Barker-Collo as Co-Principle Investigators. **Stroke is the 2nd most common cause of death worldwide and a frequent cause of adult disability in developed countries. The aim of the ARCOS study is to measure and reduce stroke burden in New Zealand.** This unique population-based approach will allow examination of trends in stroke incidence, prevalence and outcomes for a 4th decade (flowing on from previous ARCOS I, II and III studies); examination of effectiveness of primary and secondary prevention strategies adopted over the last 30 years; and evaluate a novel, potentially widely applicable behavioural intervention to reduce stroke recurrence. In addition, a third, qualitative component of the study led by Professor Kathryn McPherson, will examine the long-term impact of stroke.

To find out more information about the ARCOS IV study, contact:
Senior Research Fellow Dr Rita Krishnamurthi on e-mail: rita.krishnamurthi@aut.ac.nz
or the ARCOS Programme Manager, Melissa Girling on Phone: 9219999 ext 7588, or e-mail: mgirling@aut.ac.nz

STUDY

Head Space: A Handbook on Brain Injury

A new publication from the New Zealand Spinal Trust

After four years of research and development, 'Headspace' - a handbook for people with brain injury - has finally been launched. Co-authored by Claire Freeman and Bernadette Cassidy, the handbook was produced through collaboration with Brain Injury New Zealand and staff of the Brain Injury Rehabilitation Service at Burwood Hospital. A number of focus groups were also held with people who have sustained a brain injury, and their families, which were integral to the development of the content and presentation of the handbook.

When a person is recovering from a brain injury, access to a wide range of information and resources is vital - this handbook is the first step in providing that information in a format that is easy to understand. Having the appropriate information about brain injury and the impact it has on a person can help to remove the fear and stress associated with it. It will also be a helpful point of reference for people who may need to take the next step in getting professional help.

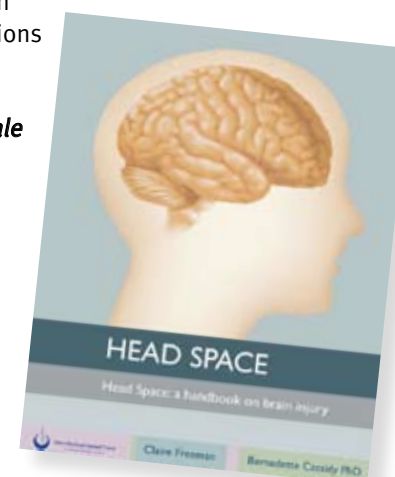
One challenging aspect of brain injury is that, depending on the severity, it can be a 'hidden injury' and the difficulties experienced by those affected, as well as their family and

friends, may not always be obvious to others. **Headspace** is a useful guide to anyone seeking information. It offers comprehensive explanations and suggestions that will satisfy the majority of questions and concerns.

Headspace will be distributed free to all hospital patients in New Zealand, available half price to people who are members of the Brain Injury Association and will be sold to organisations for \$50.

Copies of the book are for sale in the Allan Bean Centre at Burwood Hospital in Christchurch.

Please phone 03 383 9484 or email abclibrary@burwood.org.nz for information.



Farewell Neil...

After almost ten years of service in various capacities, Neil Bendall, Accountant to Brain Injury New Zealand and the New Zealand Stewart Centre Trust has decided to put away his ledgers and retire.

After selling the graphics printing company he had owned for fifteen years, Neil started his tenure with the two organisations back in 2001 when he took on the role of Accountant for The Brain Injury Association of Auckland, Brain Injury New Zealand, Northern Stewart Centre Trust and the New Zealand Stewart Centre Trust. It wasn't until he began working in this environment that Neil realised he himself had an acquired brain injury, which had resulted from surgery he had undergone to remove a benign tumour from his brain.

Neil had his first foray into a life of leisure in 2007, however this retirement proved to be very short-lived as a few months later he agreed to return one day a week to act as Accountant to Brain Injury New Zealand now located at Albany. However, soon after taking up this role, it was expanded to incorporate the New Zealand Stewart Centre Trust accounting responsibilities, and for the past four years Neil has been a four day a week fixture in the National office. "This was the first job I actually enjoyed coming to. I was here because I wanted to be here, doing the job I wanted to do. I have felt valued and enjoyed the team I have worked with."

Graham Menary, the National General Manager comments. "While this is a richly deserved

retirement, Neil will be sorely missed in the role he so successfully filled, as will his sense of humour and quick wit. We have greatly valued his infinite wisdom and the emphasis he places on work ethic and the team spirit. Our office culture has been the better for his contribution."

Far from putting his feet up, Neil is looking forward to spending the first few months of his retirement travelling, with a month long holiday to the UK planned for Christmas, a tramp in the South Island immediately upon his return. Neil is also Treasurer of the Morgan Sports Car Club and will tour the South Island with his Morgan, thirty other Morgans and their enthusiast drivers! Neil is also looking forward to spending time with his wife Pauline, his grandchildren in New Zealand and visiting his other grandchildren in Melbourne.

While Neil will be greatly missed by all he has worked closely with, and those he has supported from a distance, we are grateful for the decade he has given us and wish him well for his retirement. In keeping with his historical inability to make a clean break from his role here, Neil has accepted a request that he be co-opted onto the New Zealand Stewart Centre Trust Board, where his experience and knowledge of the organisation and the sector will be highly valued.



Neil (with Monique) fundraising earlier this year

Carers. Our 'unsung heroes'

Brainlink often features amazing stories of determination and hard work, generally these focus on the experiences of those who have sustained a brain injury. Carers are so often the 'unsung heroes' in our community, they work so hard and face many difficulties that are rarely acknowledged. So in this edition, Alison McLellan, Liaison Officer for Auckland, shares the experience and value of her Carer Support Group.

Our **Carer Support Group** meets every first Wednesday of the month to catch up on where everyone is at with their challenging situation. Each member brings to the table either a report, a request for information - or a humorous episode to relate, which the group pack into their survival kits for when life becomes really tough.

I personally am grateful for the situation I am in as convener of the group, having had personal experience of being a carer I am not only able to deeply empathise with all who come but also give out first hand information and advice.

As the group has gradually grown closer, an evening out at a restaurant or pampering oneself at the House of Camille with a facial massage or getting our nails done has become such fun. It is heartening to watch all these unsung heroines allow their resentments and irritations to slip away. Giggles and laughter gently replace pain and for the evening they gather strength to go back in peace to the challenges that await them.

The bond amongst them has grown deeply and anyone who is absent is missed.

Through the years, many carers have come and gone from the group, but the spirit remains the same. Selfless, loving and tired souls who come together to soothe one another while searching for answers to their own lives.



I am reminded of a poem from my childhood:

**If I can stop one heart from breaking
I shall not live in vain;
If I can ease one life aching,
Or cool one pain,
Or help one fainting robin
Unto his nest again,
I shall not live in vain.**

Emily Dickinson

See the back page for ways you can donate to help us reward worthy carers

Community Advocacy Service

Brain Injury New Zealand has won a contract to provide independent advocacy and advice to ACC clients who are experiencing difficulties with their entitlements. The new service is a **phone based 'hotline'** which is available to any client of ACC who requires advocacy - not limited to clients with brain injury. ACC are aware of the rise in cases going to review and have implemented this service as an independent third party who can assess decisions, explore their rationale and intervene where necessary in order to avoid, where possible, the need for clients to follow the lengthy review process.

The service went live on 1st November and there has been a steady flow of calls in the period since then. This is a phone based service, however we will still refer those more complex cases that require face to face advocacy to our Liaison Service and, for those clients that have other injuries, we are forging links with face to face advocates around the country. We have found that a fresh approach and, where necessary, early intervention has in the majority of cases so far resulted in positive results for our clients.

*If you believe your entitlements have been unfairly revoked and you require advice or assistance regarding how you can appeal this, please call the **Community Advocacy Service** on 0800 273 464*

