

The Nerve Centre:
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Message from the Chair and CEO

BrainLink continues to focus its attention on Carers: family and friends who provide 24/7 support to a loved one with an acquired brain injury or neurological condition.

Staff and the Board spend much time listening to many individuals in caring roles about what is important to them. Overwhelmingly they tell us it is getting a 'good response' (such as from the acute, rehab and community service sector).

When you consider that many individuals and families affected by an ABI are in need of a 'lifetime of support and care' it is not surprising a fair and reasonable response holds so much significance.

Carers need realistic help when 'they' need it, more than just encouraging words, flower gardens and journals. It is help at a time when it appears the world is crashing down. Supporting help is needed to survive, and it must be Guilt Free.

Caring is complicated and dredges up issues of loneliness, grief, anger, exhaustion, isolation, celibacy. Guilt can be overpowering and can lead to total burnout for some.

BrainLink seeks to offer practical advice to coach family and friends into taking charge of the caring role with a very realistic view. It's not about a lesson in delivering better care, but that Carers must take charge and not let a situation control their lives. Easier said than done!

So whilst we continue to spend as much time as possible listening to families' journeys and sharing their stories, we have also been reflecting on BrainLink's approach, to ensure we are a responsive organisation. Despite the difficulties we are filled with hope, and a desire to maintain strong families.

All our services need to be aware of what constitutes a 'good response' to our families in the first place, and then to ensure adequate resources to offer maximum assistance.

BrainLink can act immediately to improve service response, but what part can we play to ensure improved response from the disability sector and government as a whole?

On one hand, response is about how we deliver our services, and on the other about being an effective voice for systemic change to the disability system.

The Australian Government has asked the Productivity Commission to undertake a public inquiry into a long term disability care and support scheme. Focus will include investigating

1. how a scheme should be designed and funded to better meet long term needs of people with a disability, their families and carers; and
2. how to determine the people most in need of support, and the services that should be available to them, and service delivery arrangements.

Such an inquiry is indeed responsive and long overdue and we applaud the opportunity to be involved.

BrainLink is working closely with individuals and family Carers to ensure their voices are heard.

BrainLink is becoming passionate about a Vision that is:

- about servicing all of Victoria without funding being geographically restrictive,
- able to respond to anyone, anywhere, anytime who needs our support,
- a disability system with no waiting lists for Carers waiting for patient support,
- about Carers learning how to navigate the disability sector so they know and understand what services/support are available and how to access that support every time they need to.

For BrainLink, our future is about, "Focus, influence and standing for the people who need us."

We thank you and appreciate sincerely all your generous contributions but we do need your help to expand our service provision to meet a growing need and be truly responsive.

Philip Thomas,
Chair

Sharon Strugnell,
Chief Executive Officer

Raising Children and Awareness in 2009

Children and brain injury was the theme for Brain Injury Awareness Week 2009 – one that produced a number of wonderful speakers from families and professionals alike.

The launch was held at Melbourne Town Hall's Supper Room on Sunday 13 September with a delicious lunch for everyone to share. Families, people with ABI and professionals all turned out to hear guest speakers such as Franca Butera-Prinzi from the Bouverie Centre ABI Team talking about their Family2Family link-up program; Sarah Cocks, Team Leader from Melbourne Citymission's Paediatric ABI Team; BrainWave Australia, a great organisation that supports children with ABI from any cause; Dr Adam Scheinberg and Jane Galvin from the Royal Childrens' Hospital speaking on the importance of rehabilitation; and special guests Sue Reid and her son Blair.

Sue spoke about her daily struggles with the pain, guilt, endless rounds of therapy appointments and the need to look after herself as a carer, especially now that Blair is more independent. She also mentioned how friends dropped away, even though people saw her as a normal mother - meanwhile she was struggling to stay afloat.

Blair's story is more about hope than his accident (a TBI caused by a car accident at age 9). It took two years but he learnt to walk again, he has travelled, and now has dreams to open a coffee shop and for his beloved Collingwood to win a Grand Final – well, we can't wait to see his café!

BrainLink has many written resources available to help families better understand brain injury, including the "Parents' Guide – Growing Up with Acquired Brain Injury" booklet

NOTE:

Brain Injury Awareness Week 2010 has been moved to August 16-22. The theme this year is brain injury caused by falls, the leading cause of traumatic brain injury in Australia. Please check our website www.brainlink.org.au/news-and-events.htm for details closer to the event.

70 Movies in 7 Days



Shane with Vanessa & Carolyn from BrainLink

When Shane Dunlop's cousin Julia sustained a severe head injury after being hit by a motorbike rider in early 2009, the aspiring movie maker decided the best way to support his cousin and her family was to do his favourite thing... watch movies.

While this may sound like a strange way to help, it turned into a marathon effort to raise money for BrainLink. He decided to attempt to watch 70 movies in seven days (do the maths!); and people could sponsor him to watch a movie of their choice.

So, 70 looong movies later, plus many emails of support from family, friends, and the ABI community who were highly impressed by his efforts, Shane had raised \$3430 for BrainLink and spread the word in The Age and on ABC radio about our cause!

And yes, he has been out to several movies since then, despite severe movie burn-out and chronic lack of sleep...

Thanks Shane for all that effort, and thank you to everyone who sponsored and supported him!

Multi-talented women honoured at 12th WOA Award



Winner Tania de Jong AM with finalists Bev Brock, Melissa Noonan & Mary Galea



Christine Nixon APM

The elegant Park Hyatt was once again home to BrainLink's Women of Achievement Award in 2009. Guest speaker Christine Nixon APM, Chair of the Victorian Bushfire Reconstruction and Recovery Authority, fitted the bill with her talk on leadership & her experiences as a woman in a man's world. She spoke of her previous role as the Chief Commissioner of the Victoria Police, outlining the need for a sense of humour!

A table of bushfire volunteers attended as Christine's guests, while Dr Sally Cockburn (aka Dr Feelgood) was MC, keeping the crowd in hysterics with her running patter on all the joys and pitfalls of being a woman.

While enjoying a delicious lunch, Lucky Envelopes became a sort-after item – everyone's a winner, including the lucky people who scored nights at the Park Hyatt and Flight Centre travel vouchers! Meanwhile, our four finalists waited nervously for the announcement...

Professor Mary Galea is a physiotherapist and leading neuroscience researcher in the ABI field. Always learning and always teaching, giving presentations around the world, Mary is also devoted to her family and a strong mentor to many physio students.

Losing her right leg didn't stop **Melissa Noonan** beating all predictions and returning to work under a year later. She then used her corporate marketing and volunteering experience to start Limbs 4 Life, an Australia-wide organization that provides information, peer support and systemic advocacy for amputees.

Bev Brock is known for tireless volunteering work for many causes, including the environment, youth work with the Peter Brock Foundation, and fostering children in crisis; all while raising her own three children. She is also an author, popular public

speaker, and patron of several causes, including the Fatality Free Friday campaign.

But it was singing entrepreneur **Tania de Jong AM** who won the close competition, with a unique ability to focus song power into practical programs. Tania started the Pot-Pourri and Music Theatre Australia companies to entertain people; then founded music programs to help them.

The Song Room has reached over 200,000 disadvantaged primary school students; while Creativity Australia combines choirs of people such as migrants, housing estate tenants and corporate employees, thus unlocking creativity, improving wellbeing and promoting a better understanding of each others' worlds through singing together.

So with another successful event over, BrainLink is looking forward to this year's nominations and another lunch to celebrate some quiet achievers!

Nominations for Women of Achievement 2010 will open soon: please check our website www.brainlink.org.au for nomination and attendance details.

If organizations can assist by donating prizes, please contact Vanessa Marrama on 9845 2955 or at info@brainlink.org.au.

Bending Over Backwards

What happens when someone has a stroke and wants to return to work? What happens when someone is diagnosed with a degenerative neurological disease like Multiple Sclerosis, but needs to continue working? Would you know where to go for assistance? Would your employer know?

People who suffer chronic illnesses or acquired disabilities usually still retain their essential knowledge and experience; and they also usually have the need and desire to continue working in the place that they know. Similarly, employers need to be encouraged to do everything they can to retain these valuable employees.

BrainLink and MS Australia organized the Bending Over Backwards breakfast forum to promote the importance of workplace retention of people with chronic impairments. It was a wonderful opportunity to participate in the Fringe Program held alongside the National Australian Labor Party Conference on July 31 2009 against the beautiful backdrop of Sydney's Darling Harbour.

Wendy Harmer was our fabulous and funny MC, directing the guest speakers as they told their stories. Guest speaker Prue Ward is a vet nurse who suffered an ABI in a car accident on her way to work one morning. She spoke eloquently about her return of confidence when her workplace,

Blackburn Animal Hospital, made every effort to accommodate her return to work, with part-time hours and education of her co-workers.

Natalie Burns, the Hospital's Practice Manager, told the audience how Prue's experience and bond with clients made it natural for her employers to want her back. Mike Symon MP, ALP member for the Deakin electorate, spoke about previously hosting a BrainLink/MS roundtable earlier in the year to showcase local employers, such as the vet hospital, who have shown initiative and flexibility in retaining employees.

Then followed a lively discussion of the needs of employees and employers alike by our panel: Skilled Group's GM of Workplace Relations, Paul Duckett; Jason Clare, MP, Parliament Secretary for Employment; Chris Simpson, Senior Industrial Advocate, Australian Workers Union; and BrainLink CEO Sharon Strugnell.

They pointed out the importance of providing a source of information and advocacy for both employers and employees to turn to. The need for positive examples and assistance was illustrated; as was the need to foster enlightened leadership in corporate Australia, so that businesses from the head down recognize the importance of their employees' experience and confidence against the costs of training replacement staff.

Questions & answers flew between panel, audience and guest speakers, and the forum ended on a positive note for future improvements in holding on to people who value their jobs not only financially but emotionally.



Mike Symon MP, Nat Burns, Prue Ward, MC Wendy Harmer, Jason Clare MP, Sharon Strugnell, Chris Simpson.

BrainLink Groups:



Carers enjoying a day on the links

Life Moves

(presented by Peers Inspiring Peers)

BrainLink is proud to welcome Life Moves back to the Nerve Centre! Run by Peers Inspiring Peers, Life Moves is a structured 8-week peer support program run for people with an ABI, by people with an ABI. Sessions are run without carers or professionals and are a wonderful way to share your story, discuss issues and strategies to deal with them, and improve confidence, self-esteem and community participation.

- When:** Thu 26 Aug to Thu 21 Oct (excluding Thu 14 Oct), 12.30-3pm
- Where:** Betty Cuthbert Room, The Nerve Centre, 54 Railway Road, Blackburn, 3130
- Cost:** Free (tea, coffee & biscuits provided)
- Bookings:** Call 9376 6669 or see www.peersinspiringpeers.org.au for further details.

Brain Tumour Support Group

BrainLink in conjunction with Southern Health runs a support group for those with a primary malignant brain tumour, and for their carers (family & friends). Facilitated by a nurse, these sessions allow people to share their experiences and information with people in the same situation.

- When:** Third Tuesday of each Month from February to November, 1.30-3.30pm
- Where:** Betty Cuthbert Room, The Nerve Centre, 54 Railway Road, Blackburn, 3130
- Cost:** Free
- Bookings:** Call Brainlink on 1800 677 579 or email admin@brainlink.org.au

BrainLink Writers

BrainLink conducts creative writing workshops for people with or without an ABI, and with a keen interest in writing once a month at Collingwood Library.

Guest speakers cover topics from exploring your creativity to writing poetry.

- When:** Second Tuesday of each month from March to November, 2.30-4.30pm
- Where:** Meeting Room, Collingwood Library, 11 Stanton St, Abbotsford, 3067
- Cost:** Free (light lunch provided)
- Bookings:** Call Brainlink on 1800 677 579 or email admin@brainlink.org.au

OMABI Performance Group

BrainLink sponsors the performance group, OMABI, which welcomes new performers and particularly singers who are confident about singing in a small group. Sessions explore improvisation where the creative input of participants is both invited and encouraged in the development of new material.

- When:** Regular Friday sessions
- Where:** Ross House, 247 Flinders Lane, Melbourne
- Cost:** Free
- Contact:** If you are interested in joining, or asking for a performance, please contact Lyn MacDonald on 0418 811143 or email om.abi@hotmail.com.

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ABI Resources

Contact Brainlink on 1800 677 579 or admin@brainlink.org.au for an ABI, Stroke or Brain Tumour Information Kit or one of our many other resources to help people with an ABI, their families and professionals.

Speaking From Experience: ABI DVD

This Speaking From Experience DVD offers first-hand accounts from ten people living with ABI. They discuss the impact it has had on their lives and the ways they manage the condition.

Price: AUD\$29.95 (Personal use) or AUD\$77.00
(Professional use)

Contact Realtime Health on 9620 2233 or
info@realtimehealth.com

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In Memorium

Ken Bieg

In 2009 BrainLink director, Ken Bieg sadly passed away after a long illness.

A much respected and dedicated board member for more than 6 years he was a courageous and dignified gentleman.

Ken is remembered fondly for his integrity, passion for our cause, hard work and practical input supporting the work of BrainLink.

His sense of humour will never be forgotten.