



# Brain Injury Matters Newsletter

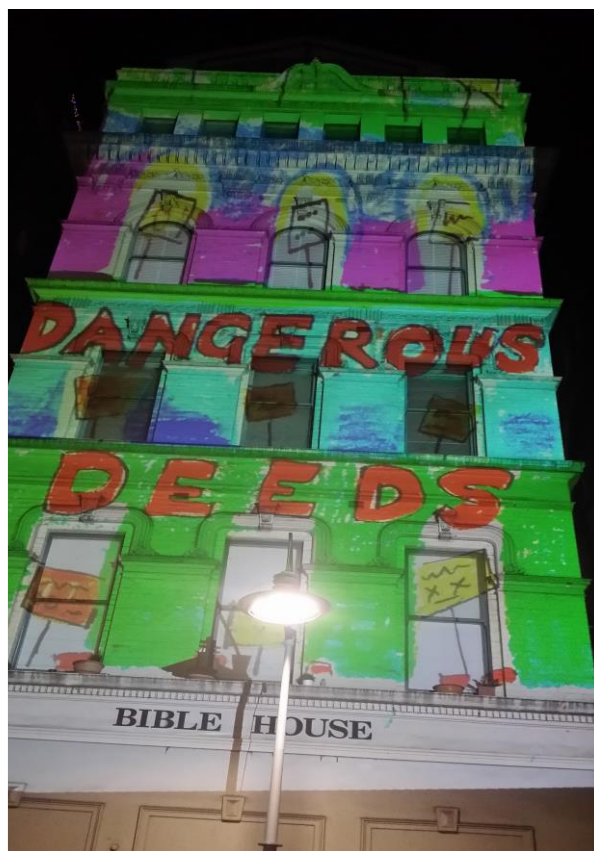
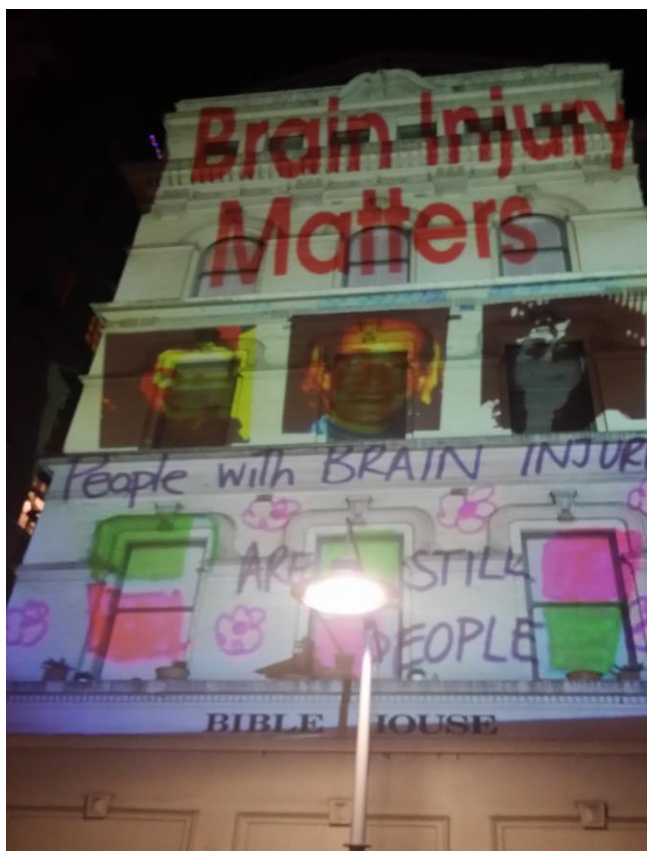
Issue 2 Feb-16

## *Wise Words for a Back Bending Life*

A hearty welcome from our newsletter team to our latest edition, and welcome to all of our new readers who have joined BIM since our last issue.

Included in this edition of our newsletter is:

- Details and photographs of the '*Dangerous Deeds*' project
- An informative look at *Acquired Savant Syndrome*
- A report on brain injury and family violence
- Details of the '1 Million Stars To End Violence' project
- and more!



Brain Injury Matters facilitates self-advocacy and community education for people living with an Acquired Brain Injury. Our aim is to help people living with ABI to realise potential for a full life within a supportive community and increase community awareness about ABI.

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## Acquired Savant Syndrome

For an individual with an ABI, would it be a welcome finding to discover a talent or skill that was either latent or non-existent prior to acquiring a brain injury?

An article titled '*Hidden Genius Sometimes Unlocked by Brain Trauma*' published by Mr Lee Arnold in May 2014 on the website *mysteriousuniverse.org* explores and discusses a condition which most people would not have heard about, nor know exists, known as Acquired Savant Syndrome, which is found within a small population of those with acquired brain injury.

Mr Arnold discusses the work of Dr Darold Treffert, of Wisconsin, U.S.A, who has dedicated some of his professional life and focus as a psychiatrist to researching acquired savant syndrome. Many would know of savantism being associated with the rare genius-abilities of a very few people living with autism. Arnold notes that Dr Treffert "... *was an advisor on the set of [the film] 'Rain Man'...*" and is one of the "... *go-to experts on the subject of savantism in general*". The American film Rain Man, released in 1988, was perhaps one of the first vehicles of pop-culture in the 20th century to introduce savantism into mainstream culture, particularly in westernised cultures, in which Dustin Hoffman's character was an adult male living with autism and was portrayed as a savant.

Arnold's article draws extensively on Dr Treffert's research of savantism. Acquired skills in complex mathematics and aptitudes for vast memory stores not known to a person prior to attaining an acquired brain injury, as well as occurrences of artistic abilities such as drawing, painting, and playing music, are each some of the most commonly known genius-level skills that individuals have acquired as a result of acquired savant syndrome; these people are known as *acquired savants* who differ from those with autism who are perhaps considered as being *born* with savantism, the savantism manifesting itself as part of their autistic traits.

A noted commonality to all cases of acquired savant syndrome is damage to the central nervous system. 'It is believed...' this damage to the central nervous system '*...is what triggers the brains of those with Acquired Savant Syndrome ... to revive itself creating a new relationship between the left and the right hemispheres*'. Arnold states that Dr Treffert's studies show that some savants who have an acquired brain injury '*...show signs of left hemisphere damage...*' and that Dr Treffert's theory behind *acquired* savantism is that it occurs as a result of the right hemisphere of the brain compensating for the damage to the left. Mr Arnold's article further states that multiples studies of acquired savants have "*... shown most have suffered damage to the left side of the brain's temporal lobe. The temporal lobe is where we process visual and auditory data and make sense of it. The right side's compensation of the lagging abilities of the left side, is what some believe opens the door to the newly acquired artistic talents.*"

Also, Arnold's article enthusiastically echoes Dr Treffert's theory that the existence of acquired savants has led to a belief that many of us may have hidden talents and untapped genius, but parts of our brains may '*...get in the way...*' of accessing them. He quotes Dr Treffert as stating –

*"The fact that savant skills, entirely dormant before CNS (Central Nervous System) injury or disease, can surface by some 'release' (disinhibition) process raises intriguing questions about dormant capacity existing within us all. The challenge of course, if that is so, is how to access that hidden knowledge and skill without some sort of CNS catastrophe. And work to achieve just that is now underway".*

Acquired savant syndrome has been reported on more recently, in May this year, in Mary Jo DiLonardo's article '*What is acquired savant syndrome?*' published on the website *mother nature network* ([www.mnn.com](http://www.mnn.com)) within its health, fitness, and well-being pages.

Currently, there are reportedly about 30-40 verified cases of acquired savant syndrome.

Highly relevant is that savants are rare and acquired savants even more rare.

Nevertheless, acquired savants exist.

### Sources:

- <http://mysteriousuniverse.org/2014/05/hidden-genius-sometimes-unlocked-by-brain-trauma/>
- <http://www.popsci.com/science/article/2013-02/when-brain-damage-unlocks-genius-within>
- <http://www.mnn.com/health/fitness-well-being/stories/what-is-acquired-savant-syndrome>

## ***Brain Injury and Family Violence***

Recently, particularly within the last 12 months, family violence has been broadly discussed throughout many media genres and also within the broader society of Australia in general, and the topic – as well as debate and discussion about remedial actions and preventative strategies – appears to have featured in all levels of government. Raising awareness and discussing the outcomes of family violence as well as its prevalence is one thing – improving the quality of responses and treatments on an ongoing basis is another thing altogether.

A news article published on [www.abc.net.au/news](http://www.abc.net.au/news) on August 12 by Tracey Bowden quotes Brain Injury Australia's executive officer Nick Rushworth as stating it's a *'...matter of public attention that one woman is killed every week by her partner or ex-partner'*. He states that he now wants to *'...draw attention to those women who [have] to live with chronic brain injury...'* and that *'... three women are hospitalized each and every week in this country with a traumatic brain injury – the result of an assault by her partner or ex-partner'*. Ms Bowden also quotes him as saying that he believes this figure is just the *'...tip of the iceberg...'* because many women do not seek medical attention nor go to hospital and they *'...struggled on without diagnosis or support'*. Brain Injury Australia's fact sheet 'Acquired Brain Injury and Family Violence' states

*'In order to respond adequately to the needs of battered women with acquired brain injuries, clinicians, social workers, and domestic violence shelters etc must be aware of and trained to deal with the consequences of acquired brain injury.'*

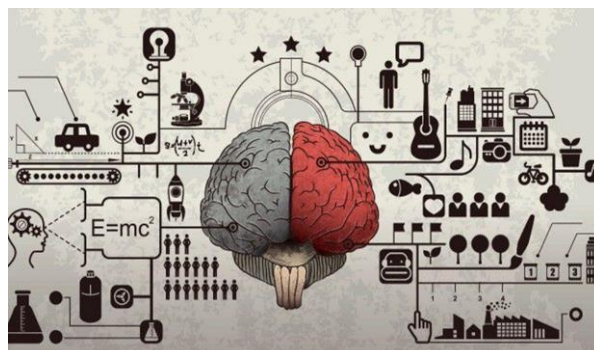
In stating this, Brain Injury Australia have drawn on research from 1999 entitled *'Head Injury and Battered Women: An Initial Inquiry'*; so, whilst research has been conducted and suggestions and strategies put forward, many concur that much more needs to be done, and on an ongoing basis. Having studied various publications, it appears that opinions vary widely as to the extent of – and the effectiveness of – the changes that have occurred in the 16 years since the aforementioned research was conducted.

In her article, Ms Bowden makes reference to neurosurgeon Richard Parkinson and quotes him as stating that *'...the impact of a blow to the head or repeated violent attacks could be dramatic...'* and that resulting injuries can include *'...anything from a minor concussion or an impairment of consciousness, to death...'*. In addition to this, he states *'...brain injuries commonly affect executive function such as planning, forethought memory, [and] emotional control...'* and that *'...can have knock-on effects with [their] children, with [their] relationships, and with [their] ability to get out of that relationship if it is an abusive one'*. Mr Rushworth is of the opinion that there should be *'...targeted screening for these types of problems...'* and that *'...there is really good rehabilitation for the most serious brain injury...'* but this *'...needs to be matched by services for women living with the cumulative effects of many assaults to their head.'*

As part of August's Brain Injury Awareness Week, Brain Injury Australia focused particularly on women who incur traumatic brain injury as a result of their experience of family violence.

### Sources:

- <http://www.abc.net.au/news/2015-08-12/family-violence-sees-women-hospitalised-per-week-with-traumatic-brain-injuries-advocate-says>
- "Abbott's Domestic Violence Policy re-announcement to 'cover up gaffe'", 28 January 2015; Dan Harrison and Judith Ireland
- 'Fact Sheet 6 – Acquired Brain Injury and Family Violence', Brain Injury Australia (from website: [www.braininjuryaustralia.org.au](http://www.braininjuryaustralia.org.au))



Picture: Mother Nature Network website: [www.mnn.com/health/fitness-well-being](http://www.mnn.com/health/fitness-well-being) via Doggygraph



## The 1 Million Stars to End Violence project

Featured on the flyer for our 2015 Annual General Meeting is artist Maryann Talia Pau's '1 Million Stars to End Violence' project. This project began on the steps of the Brunswick Baptist Church on Sydney Road in Brunswick in September 2012, when Jill Meagher was tragically raped and murdered. Within days the church steps became covered in a blanket of floral tributes and candles and became a place of public mourning.

Maryann states on the website she has created for this project that she had

*'...never seen anything like it... Strangers were talking to each other, holding each other, and wailing without shame...'*, but *'...despite this grief, I remember thinking, this is human nature at its best.'*

She was inspired by a quote which someone had placed within the hundreds of tributes and thousands of flowers, words spoken by Dr Martin Luther King which read –

*'Returning hate for hate only multiplies hate, adding deeper darkness to a night already void of stars. Darkness can not drive out darkness, only light can do that. Hate can not drive out hate, only love can do that.'*

Ms Pau explains that her personal response to this tragedy was to return to her studio with these words resonating in her mind, and commence weaving stars from ribbon and other materials. She states that she decided to weave stars as a

*'...way to bring more light into the world at this sad time and as a reminder that we need to have navigating stars that call us to hold onto hope and courage to end violence in our communities, including violence against women.'*

Maryann explains on the 1 Million Stars website that this is a self-funded project which aims to collect one million specially-made woven stars that will culminate in an installation featuring the stars in Queensland in 2018. Thus far, Maryann's website notes that over 500,000 stars have been made and collected. She states that she chose the number of one million as a

*'...reminder that ending violence is a massive and global issue and that ending it can only be done if we work together.'*

Maryann also states that we

*'...need to believe we can end violence'* and that these stars represent that *'...we are hopeful, active and we are encouraging our networks and communities to do the same.'*

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## ***Dangerous Deeds project***



The '*Dangerous Deeds*' project commenced at the end of 2013 and is a joint project of Diversity and Disability (DnD), Self Advocacy Resource Unit (SARU), and stART community arts. The project was developed

*'...featuring art developed by people with disabilities which explores their passions and tells the stories of their involvement in the disability, advocacy and self advocacy movements.'*

A video art installation was exhibited in the foyer of the Department of Health and Human Services (DHHS) building at 50 Lonsdale Street, Melbourne from August 10-14th, the exhibit being launched on August 11<sup>th</sup> by the Hon. Martin Foley, Minister for Housing, Disability and Ageing.

BIM was one of the self-advocacy groups involved as were Reinforce, and Deaf Blind Victoria. Larissa MacFarlane (BIM member) was one of the artists employed in the project and made several art works in collaboration with disability activists. Gordon Prior who has been involved in a long legal battle with the Australian government to get fair wages for people with a disability was part of the project.

BIM's part in this project was a projection on the building 'Bible House' (next door to Ross House, in Flinders Lane in Melbourne's cbd) on the evening of April 6<sup>th</sup>. Some of the BIM Committee members involved in the composing of the artwork to be projected included: Lisa Brumtis, Ross Cottey, Peta Ferguson, and Larissa MacFarlane. The images were well-received by members of the public on the evening they were displayed.



## **BIM goes to the 2014 Disability Sector Awards**

Finally it pays off to have an ABI and a disability – I got to meet Tim Ferguson again!

At the recent Disability Sector Awards some of us at the BIM office had the pleasure to meet Tim Ferguson. You might know him as the comedian who has MS. I understand he managed to avoid disclosing this for many years. You may also know him for his years with the Doug Anthony All Stars alongside Paul McDermott. Tim Ferguson has a book out which I recommend you to read. I haven't actually read it but wish I could and will recommend it all the same.

To his credit, it must be really challenging to be a public figure where everyone knows you have a medical condition. At our meeting he was obviously at a disadvantage because he didn't know what our disabilities were. He could have worked out that we had brain injuries, however that's not really narrowing it down very much.

I find people who know about ABI think that I have had a stroke, which is not the case. In some circumstances I introduce myself as "A High Functioning ABI" but that is still not saying what my ABI is.

So my point is that ABI covers a wide range of causes and consequences and that even in a community of people with ABI or disabilities, it is not always easy to ask 'what exactly is your disability?'

So I tip my proverbial hat to Tim Ferguson who puts himself out there and is happy to answer well meaning but naive questions without suggesting that we buy his book!

Now I want to write my own book and start charging my Helen Tax for all those repeated questions that I get asked. For example:

What happened to your arm? (That's \$2) What's an AVM? (That's another \$2) Will it get better (That's \$5 and also the 'Million dollar question') Do you regret it? Can you sue the doctors? Do you have a husband? Do you have children? The list goes on, so I suggest you stay tuned for the answers!

Meanwhile, congratulations to BIM for the recognition for a job well done!

Ps. On the subject of favourite comedians... I often see Frank Woodley in my local shopping centre and I think my facial expression gives me away as very excited to see him. I am told that he is quite happy to talk to people. Unfortunately, when I see him, I blink and he is gone. Frank is obviously unaware that I am well known for saying 'I cannot do stalker or stealth"! But if I ever do get the chance, I'd say, "Hey, I just want to say Hello and tell you, you are awesome!"

Helen Calligiuri



## ***Update: BIM's Committee of Management activities***

### ***'Speak Up Bayside' – self-advocacy group***

- BIM continues to be involved in supporting the ABI self advocacy group in Beaumaris, 'Speak Up Bayside'
- Both BIM and SARU have been directly involved in assisting the formation of this group

### ***KIT News/Update***

- The final stages of the collation of the kit 'Hitchhikers Guide Through The Brain Maze' are complete
- The final component, a book of stories about ABI by people living with an ABI titled 'Stories of Brain Injury', features artwork by Larissa MacFarlane on its front cover
- 100 kits have been produced, with many thanks going to some volunteers from CAE (Council of Adult Education) who assisted in collating and assembling each kit
- BIM is currently in consultation with DHHS (the Department of Health and Human Services) about announcing the kit's release and supporting its launch

### ***BIM's 2015 Annual General Meeting***

- Our AGM was well attended and included, after the formalities, the making of stars in support of the '1 Million Stars to End Violence' project under the tutelage of Larissa
- Lisa Brumtis retired from the position as vice president; our appreciation and thanks to Lisa for her years with BIM and also our best wishes to Lisa as she embarks upon her next journey
- Fran Lea was elected to the position of vice president

### ***Grant – Melbourne City Council***

- Late in 2014 BIM received a small grant from Melbourne City Council
- The grants purpose being to proactively provide educational speakers from within BIM's Committee (and membership base) to the youth of the geographical catchment area of Melbourne City Council and other inner-Melbourne council areas
- The primary purpose is for these speakers to talk with inner-Melbourne's youth about risk-taking behavior and acquired brain injuries

### ***NDIS Working Group***

- BIM continues to be diligently involved with an NDIS working group, one of its key focusses being the issue of future funding for self-advocacy groups

### ***Victorian Equal Opportunity and Human Rights Commission (VEOHRC)***

- Early in 2015 BIM was visited by VEOHRC which sought to consult with BIM about the use of language in publications with the view to enable greater accessibility for all, inclusive of greater accessibility of information for people with an ABI
- Part of that consultation included discussion about how the use of language should be relevant, and indeed used, in all forms of communication inclusive of audio visual communication tools
- The consultation included discussion about how long published material is used and also how technology is used to make resources and information accessible

### ***BIM continues to develop and enrich its partnerships with bodies such as:***

- Department of Health and Human Services, Victoria
- Action for More Independence and Dignity in Accommodation (AMIDA)
- Disability Services Commissioner
- Human Rights Commission
- Melbourne City Council
- Melbourne metropolitan councils and shires
- Office of the Public Advocate, Victoria (OPA)
- SARU
- Transport Ombudsman
- Victorian Equal Opportunity and Human Rights Commission (VEOHRC)

