

# Wise Words for a Back Bending Life

### Brain Injury Matters Newsletter

Issue 4 February 2013

A belated Happy New Year, and welcome to our newest readers.

In this issue, we have lots of contributions from our members, looking at the many and varied issues that ABI and Life presents us with! We have stories about the trials and joys of Christmas, family, exercise, about how informed are the ABI services and some words about returning to study with an ABI. We even try to explain some acronyms like SARU and PMG.

This year, we farewell Brent Alford, who has been on the BIM committee for the past 4 years. We wish him well with his future endeavours.

And we welcome Helen Caligiuri to the BIM committee. Helen was the feature guest writer for our last newsletter, and in this newsletter, she makes a short but very apt contribution about doing your exercises!

We also welcome back Ross Cottee, who returns to the BIM committee after some time away!

Don't forget that everyone is welcome to make contributions, so please send in your stories, news, poems, artworks, photographs, whatever! We'd love to hear from you!

#### **Stop press - New Arts Project!**

BIM/Wesabi will soon be running a new arts project, exploring linocuts, led by BIM member and artist Larissa MacFarlane. The project is expected to run for 6 weeks sometime during April-July. No experience is necessary. Workshops will be held at Ross House in the City. You can check out some of Larissa's linocuts in this newsletter as well as details of her upcoming solo exhibition. Please let us know at the BIM office if you are interested in being involved. It should be great!!

# BIM on 3CR

In November last year, BIM members, Lisa and Lara, went into 3CR with the lovely Pauline (from AMIDA), and did a radio show. We had a great half hour chat about brain injury and how it has impacted on each of our lives. We'd love for you to have a listen. You can find it on the BIM blog or listen on 3CR

http://www.braininjurymatters.org/wpblog/

http://pod.3cr.org.au/pod/3CRCast-2012-11-14-78314.mp3

We only really scraped the surface about all that ABI is, and hope to do another radio show in 2013. If you would like to take part and share your story and insights into life with ABI, we would love to have you!! Just ring or email us!

# **Do Your Exercises!!!!!**

A wise man once said, "You only have to until you want to!"

I believe the topic of discussion was vitamins and he was responding to another man's whine, "But you have to take them every day!"

Seriously, if only I had his problems!

I understand the point was that you only had to take vitamins every day until you start to receive the benefits. Once you reap the rewards you will be happy to down your medicine so to speak, no?

Perhaps, the same could be said for doing physiotherapy, Occupational Therapy or Rehab?

I heard a woman late last year that she had performed her rehab exercises for 15 years before she started to see the results. Blind dedication for sure. But if you have an ABI sometimes that's what you have to do. So, get to it!

This is an excerpt from the long awaited and long promised yet still forthcoming blog by Helen! Stay tuned!

**Helen Cailguiri** 



Epic Misadventures #34

Linocut by Larissa MacFarlane

# Christmas, family and ABI

I spent Boxing Day with my immediate family (father, stepmother, step-aunt, brother, sister and niece and nephew) on my father's farm, halfway between Benalla and Shepparton.

It is an annual event that I both look forward to and dread in equal measure. All those attending have partners, save my step-aunt who is very close to her sister – my stepmother. Strength in numbers, so I brought Larissa MacFarlane this time.

Most people have a touch of this; I notice I have an extreme version. My persona is shaped to a certain extent by those around me, vacillating between jellyfish and supreme confidence. For example, at BIM Committee meetings I am assertive and opinionated but if I meet someone in the field whom I wish to impress as president of BIM all my bravado vanishes and this squawking lump of blancmange appears.

This unwanted phenomenon regularly rears its ugly head at the family Boxing Day gatherings. Why? After all I'm quite familiar with all the participants.

The individuals in my immediate family are all high achievers. I'm like a breath of fresh air though sometimes, when I'm feeling exceptionally paranoid I feel more like an unwelcome gust. I fear the ABI has reduced my 'status' somewhat; biologically I'm the oldest of the children but at times I'm made to feel like the baby.



Epic MisAdventures #36

Linocut by Larissa MacFarlane

We cannot choose our family. Although I sometimes feel like the black sheep I must take at least fifty percent of the 'blame'. After all when it comes down to it I do love my family.

Peta Ferguson

#### Are ABI Services Ignorant?

ABI – Acquired Brain Injury – includes many different types of Brain Injury that is acquired at any age.

I have lived with this disability for 7 years, and experienced much about the associated complexities of a brain injury.

I recently gave a talk to some ABI service providers, but it wasn't until question time that I began to realise the level of ignorance about ABI. And this exists in the very people that are the so-called professionals that are in the position to potentially make your life better!

It's not that acquiring a brain injury means acquiring relevant intelligence: it's just that one has knowledge because one has the experience – probably because one begins to pay attention to whenever the brain, and its functions, are mentioned.

I really believe that service providers should know about ABI. Not everything, of course, but the major generalities, definitely. ABI does differ from individual to individual, and there are amazing diversities within this disability.

One thing is certain – this disability is one of, if not the most, complex disabilities around.

## Some Farewell Words From Brent

I was on the committee for a year then I became Vice President for two years. Then I stayed on the committee for another year. I have really enjoyed being part of the ABI community, having a voice for people with a disability and being an advocate for friends who an ABI. I will promote BIM wherever I go.

Milly Parker was our guest speaker at our 2012 AGM. Milly and I have both been involved with a program called Leaders for Tomorrow in 2012. After hearing Milly's story she has been through so much in which I have. Milly is the ultimate advocate for people with disability. She has been involved on a political stance with the National Disability Insurance Scheme. I'm very proud to call Milly a friend who has an ABI!

Thanks

**Brent Alford** 

Lisa Brumtis

### ABI and the Justice system

On 30<sup>th</sup> November 2012, a small group of the Brain Injury Matters committee attended the Office of the Public Advocate in Lygon Street, Carlton for the official launch of a Paper funded by VCASP (Victorian Coalition of ABI Service Providers).

The paper was called the 'Issues and Inequities Facing People with Acquired Brain Injury in The Criminal Justice System'. The report is very comprehensive (56 pages), and if you want more info it can be downloaded from http://www.vcasp.org.au/resources.shtml

Here are 2 key issues that were raised

- 1. ABI is present in 30% of Females and 40% of Males in the criminal justice system.
- 2. Given that the prevalence of ABI in the general population is about 2%, ABI is well over represented in our prisons and justice system.

#### **Paul Kefford**



## **United Brains Update**

United Brains is a network of self-help, support and self-advocacy groups for people with an ABI throughout Victoria. We have joined together in order to share ideas, lobby for change and raise community awareness about ABI. United Brains was officially launched in May 2012, at the DARU/SARU conference. It currently meets bi-monthly at Ross House. Last year, United Brains used the network to promote both the 2012 Global Picnic and Brain Injury Awareness Week. They also facilitated members to give presentations in Bendigo and Geelong. And their new website will be launched soon. In the meantime, check out their great new logo.

If you would like to be part of this exciting new network, please contact Neil at <u>unitedbrainsneil@gmail.com</u>

**Neil Cameron** 

### Studying with an ABI

#### Yes, Yes, Yes. If you have any inclination at all to study, then do it!

Studying with an ABI can be very rewarding, but also incredibly challenging. It can take much effort to discover the new ways in which we must learn with this new brain, post ABI. We experience more tears of frustration and loss as we discover that learning is not what it once was. But studying encourages our brains to grow, and that is always a good thing when learning to live life with a brain injury. Another upside is that our actual improvement in the skills we learn is much greater, in comparison to the other students without ABI!! Sure they start out better at the beginning but their learning curve is so much smaller than compared to ours!

My ABI was 14 years ago, and over that time, I have tried lots of study. I have done courses with disability groups, at community centres, TAFE's, and finally I started university last year. So my advice is to start small and build up. Try not to have expectations that it will be like what it was before. You will probably get very tired, so fulltime may never be possible. And it will most likely take longer to complete the course than 'normal'. But there is no reason why you can't learn and complete the set tasks. It will just take time to work out how you are going to do it. Recognising what are the unique challenges that your ABI gives you, is crucial, and will often be an ongoing process in itself. Getting support can be very useful, but unfortunately not always easy to get. But I think it is always good to ask.

Since starting university, I have found myself trying to pretend to be like everyone else...and I am not. So learning to stand up for my differences has been really important. Most formal education offers some form of disability support and whilst it is limited, it is worth registering with them. For example, my university's Disability Liaison Unit is assisting me to apply for funding for a hearing assistive device. It won't solve my problems, but it will help a bit!

So go for it. Whilst study is definitely hard work, especially if you have an ABI, the benefits are huge. You will get to learn more about who you are, as well as those around you and the rest of the world. There are new conversations to be had and new friendships to be made. Give it a go!!!

Larissa MacFarlane



*Chasing Street Shadows,* Reduction Linocut by Larissa MacFarlane This artwork recently won the 2012 Macedon Ranges Post Your Art Award. Congratulations!

#### What is the SARU, the PMG, & what does it have to do with BIM?

The SARU is the Self Advocacy Resource Unit. It is funded by the State Government to support the needs of people with acquired brain injury, intellectual disability and complex communication needs. The SARU has 7 jobs: to strengthen self advocacy groups; to support new groups to start; to support networking; to resource self advocacy groups; to make sure people with a disability are involved in managing and running the SARU; to support advisors and self advocacy groups to work together; and undertake evaluations of their work

The SARU is managed by 4 community groups: Brain Injury Matters (BIM), Action for More Independence and Dignity in Accommodation (AMIDA), Reinforce and sTART. Two members from each of these groups, as well as state government and worker representatives make up the PMG, the Project Management Group. The PMG meets once a month to oversee the SARU. At the moment, BIM's representatives on the PMG are Lisa Brumitis and Peta Ferguson.

Hence, BIM gives advice to SARU via the PMG. BIM also provides peer workers and advisors to support and work for the SARU. In return, the SARU helps BIM with planning and project development!

Hope that makes it all a bit clearer!

Lisa Brumtis & Lara MacFarlane

### **Diary dates!**

#### September 21 – 2013 Global Picnic

This worldwide event to raise awareness of brain injury is this year registering with the Guinness Book of Records! There are two picnics planned for Melbourne: The City and Berwick. Stay tuned for more details and in the mean time, check out their website. <u>www.biglobalpicnic.org</u>

#### 12-19 August, Brain Injury Awareness Week

This annual event features several events across Australia. To find out what is happening in your neighbourhood, check out this website, closer to the date. <u>www.braininjuryaustralia.org.au</u> Or contact the BIM office.

#### Hot tip!

Did you know there is a great quarterly Australian magazine about brain injury called *Bridge,* that is free to all people with an ABI. Contact them to get on their mailing list... www.synapse.org.au/shop/ magazines



A Crisis is a Terrible Thing To Waste A Crisis is a terrible thing to waste Linocut by Larissa MacFarlane

#### **Art Exhibition**

BIM member Larissa MacFarlane, invites you to attend her solo exhibition of her linocuts and other artworks, at Cocoa Latte, 24 Ferguson St, Williamstown, from April 5-May 5. Open everyday 9-5.30. And they do a fabulous hot chocolate! Contact Larissa for more info at larissalice@gmail.com Sender

### **Brain Injury Matters**

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