

AQA NEWS LINK

The Official Newsletter of AQA Victoria Ltd., & AQA Tasmania

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Plus much more...



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A.Q.A. NEWS LINK is the official newsletter of A.Q.A. Victoria Limited, and is published bimonthly. *NEWS LINK* seeks to publish material of interest to people with physical disabilities and their families, professional workers and other individuals and organisations concerned with the welfare of those who are physically disabled.

A.Q.A. Victoria Limited always welcomes articles for News Link. Please feel free to send in your contribution. Articles will be published at the discretion of the Editor who also has the right to edit all submissions as it sees fit.

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Volume 23, Number 1

From the CEO



Welcome to our first News Link for 2009. We're looking forward to continuing to offer you relevant and reliable information and to link you with the contributions of other members and subscribers.

Bushfires have dominated our hearts and minds throughout most of February. For our part, the Information team have been careful to only send members and subscribers the most relevant information, such as the announcement that the Department of Human Services is directing Aids and Equipment Programs Issuing Centres to assist people who have been affected by the Bushfires. They will be prioritising replacement of items of aids and equipment as 'no wait' and waiving the subsidy gap for any new item of aid or equipment for people who have lost or require A&EP as a result of the bushfires.

Our thoughts are with all our clients, members, subscribers and staff who have been touched by these extra ordinary events.

Largely overshadowed by the scale and impact of the bushfires, came the announcement during February of the Victorian Neurotrauma Initiative's (VNI) decision to award approximately \$19M for further research in brain and spinal cord injury.

Three significant grants were made to project teams in spinal cord injury who will run multi centre trials into:

- sleep problems following SCI with the aim of improving quality of life and ability to function better during the day
- new treatment to affect better bowel control, stable blood pressure, and bladder function.
- the effectiveness of early intervention, intensive activity-based therapy program on lower limb function and task-specific training for the arm and hand.

AQA welcomed this significant investment in clinical research as it shares our vision to improve the quality of life of people living with spinal cord injury. If proved effective these strategies will greatly improve a person's independence and reduce barriers to participating fully in community life. We look forward to keeping you informed about how these and other SCI research unfold in 2009.

Finally, please find enclosed a reminder that 2009 AQA memberships and NewsLink subscriptions are now due. Thankyou to those who have already renewed either as a member or NewsLink subscriber. You make an important contribution to AQA and your fellow members and subscribers.

Peter Trethewey
Chief Executive Officer

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From the Editor



First of all, I'd like to wish everyone of our readers a Happy New Year. I hope you have all taken a good long break and have some stories to share with us.

We all know the importance and benefits of sharing information between spinal cord injured (SCI) individuals, but a major barrier in sharing information is the fact people are scattered far and wide. In this issue AQA's forum moderator, Peter Van Benthem, talks about AQA Victoria's forum which connects SCI people together.

Tim McCallum's passion for musical theatre stems from his childhood, and he hasn't been put off since an accident left him with C4 incomplete quadriplegia - see page 7.

Reader Lucille Marks has been kind enough to share some of her handy ideas that she has found to make her life easier and more comfortable. The article is in the 'From a Woman's Point of View' column, but will appeal to many readers.

Spinal Cord Research is again in the news with the announcement of embryonic stem cell treatment for spinal cord injury. We have a view from *New Scientist* website as well as the Reeve Foundation.

It comes as no surprise that people living with a physical disability are at high risk of experiencing some form of depression or anxiety. One in five people will be affected by this disorder. Recently some AQA staff attended a workshop held by Wheelchair Sports Victoria in conjunction with Beyondblue. The workshop was aimed at giving participants awareness regarding depression and anxiety and ways it can be treated.

Some of you will recall from past issues Able Management Group's Norton House in Harrierville. Naz has finally got around to seeing it for himself and writes about his experience.

We look forward to hearing about your holiday adventures also.

Finally, our condolences go out to the Cizmadija family after the passing of long time AQA member Ivan. He will be sadly missed.

Simon Damevski

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The Reeve Foundation

After years at the forefront of the pursuit of new treatments for spinal cord injury - encouraging in particular the exploration of stem cell therapies - The Reeve Foundation has issued the following response to the Geron trial.

The Reeve Foundation watches, along with the rest of the world, as the first clinical trial using human embryonic stem cells (hESCs) moves forward after the FDA's January 23rd go-ahead for a Phase I study. The Geron trial will be a groundbreaking first.

Patient safety, not efficacy, is the endpoint in a Phase I study. A small number of acutely injured spinal cord patients (ASIA A complete) will receive Geron's hESCs. Acutely injured animals receiving the transplanted cells showed some recovery of function. Presumably this is because the cells prompted some remyelination and/or production of nerve growth factors.

Since the isolation of hESCs by Dr. James Thompson in 1998, they have been the object of intense research by

scientists throughout the world and have been imbued with magical properties by many who seek cures. Human embryonic stem cells could be used in regenerative therapies for diseases and disorders. Scientists are using them to better understand how humans develop and what happens in the course of injury and disease. They can be used to test and screen new drugs.

In spite of excitement about this trial, we should remember that the leap from laboratory to clinic is filled with challenges. There are rats "walking" in labs all over the world, the result of one therapy or another, none of which have yet been translated to the clinic. Many interventions that worked well in animals have failed in clinical trials. And in this instance, some experts have expressed concern about Geron's move to the clinic with these cells at this time.

So, while we hope for success in and new insights from this "Phase I" safety study, we acknowledge that it's a first step in what is essentially an unmapped journey down the regenerative medicine road.

Historic Trial to Treat Spinal Injury with Stem Cells

The recent announcement that stem cell treatment of spinal injury was finally moving from experimentation on rats to an actual human trial is the news that many people affected by spinal cord injury have been waiting for. This article written by Andy Coghlan from the New Scientist website details this exciting development.

Patients with spinal cord injuries will be the first humans to receive repair cells derived from embryonic stem cells.

The first ever clinical trial using stem cells derived from embryonic stem cells (ESCs) has received the go-ahead from the US Food and Drug Administration.

Geron Corporation, a company based in Menlo Park, California, hopes to mend the spines of patients paralysed from the chest down by injecting injury sites with stem cells that restore connections and repair damage.

"This marks the beginning of what is potentially a new chapter in medical therapeutics, one that reaches beyond

pills to a new level of healing: the restoration of organ and tissue function achieved by the injection of healthy replacement cells," said the company's president, Tom Okarma.

"My hat is off to Geron – this is what we've all been waiting for," says Robert Lanza, chief scientist at Advanced Cell Technology, a stem cell company in Worcester, Massachusetts. "It's been over a decade since embryonic stem cells were discovered, and this sends a message that we're ready at last to start helping people."

The trial had been "on clinical hold" for years over concerns that the cells could form tumours, but the FDA is now satisfied that this risk is low enough to allow the trial to proceed.

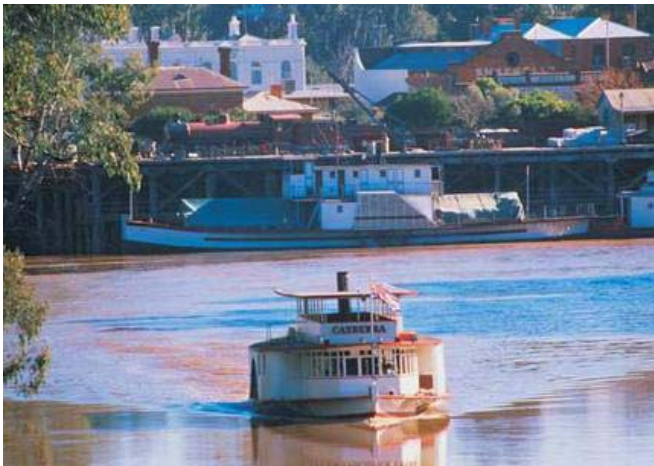
Note: To read the rest of this article you need to be a current member. Please contact AQA Victoria or download a membership form.



Me and My Town

Brendon Loftus, Echuca

Hi everyone, my name is Brendon Loftus, aged 69, living in the town of Echuca on the Murray River. I am an incomplete quadriplegic of some eleven and a half years with a C5,6 and 7 lesion. Prior to my accident I worked in the building trade doing renovations and extensions to homes in and around Melbourne.



About thirty years ago we decided to move with our two small children to Echuca where we initially ran a business selling tiles and bathroom accessories. At the time of my accident I was rebuilding a paddle boat on the slipway at Moama when I had a fall resulting in my quadriplegia. I have been lucky to have good carers on a daily basis (two of the original carers are still looking after me).

Echuca is a very friendly town to live in with a population, including Moama, of approximately 17,500. It is very popular with tourists as it is only a two and a half hour drive from Melbourne. The weather is very good most of the year. Winter can be very cold but it's very enjoyable in summer and autumn.

We live one block from the main shopping area which is great for me as I do not have to rely on transport to go to the shops.

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Able Management Group's Norton House in Harrietville

Some of you would recall past issues of News Link writing about the Able Management Group's Norton House in Harrietville. For years, Naz had made plans to go there and experience the place for himself. However, each time, something would 'come up' forcing him to cancel his plans. But not this time...

I have known about AMG's Norton House in Harrietville for a few years now. Each year, I have wheelchair rugby team mates and colleagues going up there during the summer and winter seasons for a few days. They come back each time with great stories about what activities they did while they were up there as well as the wheelchair accessibility of the property. Not only is the house accessible but the surrounding area as well. It is only a few kilometers to Mount Hotham heading to the east and you can back-track a few kilometers to the town of Bright.



The AMG is based at Norton House, three and a half hours and 348 kms from Melbourne, at the foot of Mt. Hotham, on the Great Alpine Road, in Harrietville.

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Tim McCallum - Following His Dream

As reported in SCIA's Accord magazine, Summer 2007, Tim McCallum is a name you can expect to see up in lights. Tim's passion and exuberance for musical theatre stems from his childhood, and he hasn't been put off track since a swimming accident left him with C4 incomplete quadriplegia.

I come from Geelong in Victoria and I've been singing since I was five years old. My best friend and I always wanted to do musical theatre together. We had dreams of being on Broadway playing opposite each other. He was accepted for the Western Australian Academy of Performing Arts (WAAPA) in Perth at the end of high school and I was lucky enough to join him the following year when I was almost 19.

In February 1999, the weekend before I was due to start at WAAPA I went swimming at a Perth beach with my best mate and three other friends from Geelong. I dived over a wave and hit a sandbar.

I remember the accident vividly- not being able to move or call for help. I blacked out in the water and woke up on the beach. My friends had brought me in on a surfboard – they knew that something was wrong, and they saved my life.

With spinal cord injuries, there's a six-week period where they know your level of injury but they can't give you a definite prognosis – with the swelling and stuff they don't really know. When they told me I would never walk again it was a huge shock.

But it was really only a couple of days after my accident that I started moving on. The next day was Valentine's Day, and I sang for the nurses through the oxygen mask! I started singing again from that moment on.



A lecturer who would have been my vocal teacher at WAAPA came to visit me all the time. He brought in tapes of my class and the songs they were singing. I've still got those tapes. When I was out of bed and in my chair he came into the hospital and we had a singing lesson. I sounded terrible!

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Please Note:

This copy of News Link is only a sample. The full version is 20 pages of great articles and other information. Current issues are available only to current members. Please contact AQA Victoria regarding membership or download a membership form.