

the advocate

Sep to Oct 2010

A voice for equity, inclusiveness and empowerment

Wonder woman

Wendy Adams is making
a difference

 Spinal Injuries
ASSOCIATION
Empowering people for 50 years

Crossing over

How traffic lights brought a
community together

Power up

Claiming your electricity rebate

Here's to you

Paying tribute to carers

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What next for the Bill of Rights?

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Family fun in Townsville

The Association in the noughties

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the advocate is the official
publication of the Spinal
Injuries Association



'the balanced opinion'

"If you saw what we see every day ..."
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FROM THE CHAIR

In August we welcomed back the Governor-General Ms Quentin Bryce AC, to the Association's Brisbane office.

Ms Bryce served as our patron for six years while she was Governor of Queensland. It was a wonderful opportunity for Her Excellency to help us continue our 50th anniversary celebrations and for us to thank her for her ongoing support. While the Governor-General may no longer be our official patron, her commitment to disability issues remains strong. We continue to value Her Excellency's support and the time she gives to the Association.

This visit by the Governor-General also marked a new era for the Association. It was the first time we used our video link with the Townsville office for this type of event. Previously we have used the link for sharing information and staff communication. We will be using this link much more now to engage our Townsville area members and supporters and will continue to look to engage our other regional members and supporters.

In July, the State Opposition Leader, John-Paul Langbroek, Shadow Disability Services Minister, Andrew Cripps and Mr Cripps' policy advisor, Tim Barnett visited our Brisbane office. The visit was arranged after I met Mr Langbroek at a recent business function. CEO Mark Henley, John Mayo, Frances Porter and I took the opportunity to discuss the National Disability Insurance Scheme (NDIS) and help our visitors understand the challenges faced by people with a spinal cord injury on a daily basis. This is the first time members of the State Opposition had visited our offices. We look forward to continuing these discussions with both the Opposition and Bligh government.

Your board is going to be very responsive to the recommendations from our recent member survey. Some changes are already being implemented and I look forward to reporting to you our new initiatives in the next few editions of the advocate.

David Riley, President



Her Excellency and Robert Spencer

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FOCUS POINTS

MARK HENLEY
CEO

As this issue of the **advocate** goes to print, the results of the Federal Election are uncertain. What is known is that, throughout the campaign, each of the major parties made greater commitments to support for people with a disability than during any other election campaign. Both Labor and the LNP indicated their support of a proposed National Disability Insurance Scheme (NDIS), pending the outcome of the Productivity Commission's inquiry. While these commitments are encouraging, it is only post-election that we will see how well they are delivered. We will wait and see, and keep you informed.

At a State level, the June budget offered some good news. An extra \$3.2 million of funding for personal support and housing modifications (in addition to an extra \$1.5 million allocated to the Spinal Cord Injury Response program) is a welcome outcome that will help people with spinal cord injuries live with the levels

of assistance that they require. We will bring you more news of this soon.

More welcome news is the government announcement of the Medical Cooling and Heating Electricity Concession Scheme. This rebate is explained more fully on page 4. While it is not as high as sought, it is a start and we will pursue a better future outcome.

The Productivity Commission has ended the consultation period of its inquiry into a proposed long-term care and support scheme for people with a severe disability. The Association made a submission and I know a number of members responded individually to the Commission. The campaign for this scheme -- which may take the form of a National Disability Insurance Scheme (NDIS) -- is gathering strength with the appointment of both State and Federal campaign coordinators. Former New South Wales government minister John Della Bosca takes up the Federal role and brings a wealth of experience in disability, being responsible for the introduction of the New South Wales Lifetime Care Authority, which provides treatment, rehabilitation and care to people injured in motor vehicle

accidents, and Stronger Together, designed to better meet the needs of people with a disability, their families and carers in New South Wales.

We recently recognised and thanked those whose contributions make a real difference to the Association. In June, we recognised the many volunteers, including our SEAT presenters, member network facilitators, post polio support group convenors, and, of course, Board members and others, who willingly give so much of their time and energy to the Association. In July, we welcomed to the Woollongabba office many of our suppliers at a special event to acknowledge their work with us. Many of our suppliers, including TechnologyOne, Metro Ford and Tailored Consulting, deliver exceptional service and additional support and it was great to have a chance to thank them.

Results of the recent user needs survey, conducted by Griffith University, are being considered by the Association. You can read more about this on page 14. Thanks to everyone who participated in this important survey.

Your Orthotic Solution

Improved Comfort, Safety and Stability for Sitting, Standing or Walking

Orthotic Solutions help clients with weakness and instability resulting from Polio or spinal injuries. We design, manufacture and service Orthoses ranging from pressure relieving insoles to custom made AFOs, KAFOs and Calipers using plastics, lamination techniques or traditional metal and leather designs.

Services provided by Orthotic Solutions can be funded by MASS, DVA or Workcover for eligible persons, or by private funding arrangements including Private health insurance.

Please call us on **07 3356 4676** for more information and to make an appointment to visit our Stafford or Holland Park clinic.

 **ORTHOTIC SOLUTIONS QLD**

Power up

The Medical Cooling and Heating Electricity Concession Scheme: *what it means for you*



Get your form from www.qld.gov.au

Continued increases in electricity costs have put pressure on many households, particularly those that include people living on low incomes. The situation is worse for people, such as many of our members, whose medical condition makes them dependent on air conditioners or heaters to keep their core temperature stable and their health in check. Now a new rebate from the State Government will help ease the burden, offering \$216 a year to people whose injury or illness means they need to use electrical appliances to help control their body temperature.

What is the concession?

The concession provides financial assistance to low-income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. It is designed to assist individuals with the increased electricity costs incurred by frequent operation of an air conditioner in order to regulate body temperature. The concession is not limited to one person per household, but all applicants must meet all of the eligibility criteria outlined below.

Who is eligible?

The applicant must be a

Queensland resident and have a qualifying condition (which includes spinal cord injury) that requires cooling or heating to prevent the symptoms of their condition worsening. They must also:

- be residing at their principal place of residence which is fitted with an air conditioning unit.
- hold a current Pensioner Concession Card (issued by Centrelink or Veterans' Affairs), or a current Health Care Card (issued by Centrelink), and
- be financially responsible for the payment of the relevant component of the electricity bill

The rebate is worth \$216 a year.

How do I apply?

To apply for the concession, complete the application form and arrange for your medical practitioner to complete the Medical Certification part (you will have to meet any costs involved with this yourself). A parent or legal guardian can complete an application on behalf of children aged under 18 years. A legal guardian or person holding a power of attorney may also complete the application on behalf of an adult applicant. The person with the qualifying medical condition must be listed on the form as the applicant.

The form can be obtained from the Queensland Government website (visit www.qld.gov.au and search for 'medical cooling') or by emailing concessions@smartservice.qld.gov.au or calling 1800 460 849.

How do I receive the rebate?

Quarterly payments will be made by electronic funds transfer to the applicant's nominated bank account.

Do I have to reapply?

You will have to reapply for the concession every two years. Applicants with an identified permanent medical condition will not need to obtain a new medical certification, but will be required to confirm their concession card status or living arrangements remain unchanged.

You will be contacted six months before your concession approval expires.

How can I get more information?

To find out more, visit www.qld.gov.au and search for 'medical cooling', email concessions@smartservice.qld.gov.au or call 1800 460 849.



Don't miss Lisa Hunt!

Gala dinner goes gold

Celebrate Spinal Injuries Awareness Week with us

Join us on Saturday, 13 November at the Hilton Hotel, Brisbane to celebrate Spinal Injuries Awareness Week. This year's dinner – featuring the theme: a splash of gold – celebrates the Spinal Injuries Association's 50th 'golden' anniversary.

Soul singing sensation Lisa Hunt is returning for an encore performance; the popular giant raffle will create lots of excitement once again; and there will be special guest speakers to entertain and inform. Tickets go on sale this month – book online at www.spinal.com.au, email galadinner@spinal.com.au or call 07 3391 2044.

Crossing over

The opening of a highway crossing in a Queensland town is anything but pedestrian.

Home Hill is a North Queensland town, just south of Ayr and home to about 3,000 people, including several Association members. It's known as the water capital of Australia and its town logo boasts that the sugar cane town is 'the sweetest place in the world'. By all accounts, Home Hill has always been a pretty good place to live -- except that you couldn't get from one side to the other without risking your life. Association board member and Townsville Member Network coordinator Scott Stidston explains:

"The main street of Home Hill is the Bruce Highway (Highway 1) – it divides the eastern side of the town, where most people live, and the western side of the town which houses many businesses and services only available on that side. The lack of a safe, convenient crossing denied Home Hill residents equal opportunity to public facilities and services, while property owners and tenants missed out on sales."

Helen Basse and Scott Stidston (front) with Craig Wallace and David Atkinson



A three-year campaign that began with a cup of tea in the backyard of a member saw the Association's Executive Manager — Community Relations John Mayo join forces with Scott to advocate for what would be the town's first pedestrian crossing, a button-activated, time-controlled crossing that would stop traffic to permit the safe crossing of the main street by pedestrians.

Designing the crossing was a collaborative effort involving Main Roads, the Association and the Burdekin Shire Council. Main Roads Minister Craig Wallace described the process as a great example of 'what can be achieved when everyone pulls together'.

In June, Scott joined Mr. Wallace in opening the landmark crossing that, in being accessible to all, has effectively brought the Home Hill community together.

"It means we have a safer access for the whole community, not just for those of us in wheelchairs — it's been a long time coming," said Scott.

Resident Helen Basse said the crossing meant she could resume her volunteer work at the town's information centre.

"I have limited mobility and this crossing has opened up my life — I can come up into town now and easily use the public facilities and cross safely to the information centre."

Craig Wallace paid tribute to the efforts of the Association and others in making the crossing a reality.

"The real heroes on this historic day are those community members who drove this project from the start," he said. "It's an historic day for Home

Hill. In years to come, we'll be able to say we were here when Home Hill's first traffic lights were switched on."

John Mayo said the opening of the crossing had implications beyond Home Hill.

"It is hard to believe in this day and age that pedestrians are locked out of the right to participate in their town because there is no safe designated pedestrian access to cross the main street.

"It was critical for the Association to engage in this matter and establish the precedent in Home Hill to secure people's rights. As part of that journey we have discovered there are other Queensland towns with no pedestrian crossing in their main street — and those communities can now benefit from Home Hill's outcome."

John says the dilemma for any town without a safe crossing is that there will be some business services on one side of the main street that are exclusive, ie. not available on the opposite side. In Home Hill that included the only women's clothing shop, banking, insurance, information centre, post office and public toilets. John explained that the crossing was a long time coming because of initial reticence from Main Roads, the Council and the local business association.

"The matter had to be tested in the Anti-Discrimination Commission. When agreement was reached through conciliation, the funding and design took time.

"Now the crossing is installed, everyone is saying it's great — and Minister Wallace was genuinely happy when he and Scott Stidston jointly activated the crossing for the first time.

"The Association was pleased too".

bill of rights

WHAT HAVE WE GOT INSTEAD?

Members may recall the energy the Association applied in regards to Australia adopting the UN Human Rights Convention as part of the process to achieve an Australian Bill of Rights.

The Rudd Labor Government rejected the establishment of a Human Rights Act in Australia, its first official response to the 2009 report of the National Human Rights Consultation panel, chaired by law professor Father Frank Brennan.

The introduction of a Bill of Rights or Human Rights Act was what the disability sector wanted and importantly, such an Act was the major recommendation made by the panel. Instead, the Government's response, announced by Attorney-General the Hon Robert McClelland MP proposed a large expansion of Government spending on the human rights 'industry', in both the Government and non-Government sectors.

Mr McClelland said the Government believes a human rights framework, rather than legislation, is more appropriate, and that all new bills introduced to Parliament will have to be compatible with Australia's international human rights obligations.

"The Government believes that the enhancement of human rights should be done in a way that as far as possible unites rather than divides our community, and the framework is designed to achieve that outcome," he said.

"Nevertheless, as you'll see, the framework does reflect the key recommendations of the human rights consultation committee and we believe [it] will make a real difference."

Leading human rights activists have expressed disappointment in the Government's response. Law Professor, Father Frank Brennan stated that "the Rudd Government has

baulked at the recommendation for a Human Rights Act that would allow judges to assess Commonwealth laws, policies and practices for human rights compliance". (CathNews.com, 23 April, 2010).

"In the long run the question will be whether or not politicians, when dealing with complex and controversial issues such as asylum seekers or Aboriginal rights or detention questions with security, whether or not they will be sufficiently faithful to those obligations when there's not the prospect of some judicial oversight," he said.

Professor Brennan stated that if the Government's game plan proved to be ineffective, the case for a Human Rights Act would only become stronger.

Dr Helen Watchirs, ACT Human Rights and Discrimination Commissioner, along with the Australian Human Rights Group (AHRG), both agreed more human rights education and a new Parliamentary committee are a positive progression towards better protection of human rights, but stated that these actions by the Government are not sufficient without a federal Human Rights Act.

Liberty Victoria expressed further disappointment at the Government's rejection of key human rights recommendations made by the Brennan committee, describing the refusal to support a Human Rights Act as an indicator the Government does not consider human rights a top priority.

"We are profoundly disappointed that the Government has decided not to adopt a Human Rights Charter. The powers of the Australian Human Rights Commission, except in the area of expanding its education role, have not been enhanced. It also seems that a number of the committee's other recommendations have been ignored,"

said Centre Director Professor Sarah Joseph. Professor Joseph noted it was strange that the Government chose to establish the committee, only to reject its major recommendation.

The Shadow Attorney-General George Brandis has said the Government has thrown away \$2 million endorsing a concept which never had community support, stating that Mr McClelland backed the move towards a Bill of Rights, only to have his own party leave him out on the battle field.

"Robert McClelland nailed his flag well and truly to the Charter of Rights mast and he's been humiliated by his own Cabinet," he said.

Senator Brandis reaffirmed the Opposition's position on the human rights issue, stating that the Opposition was encouraged by the fact the Government did not endorse the Bill, reminding the public about the amount of time, energy and money that has been wasted in attempting to support the idea.

Points from the Government's proposed Human Rights Framework:

In October 2009 the Attorney-General, the Hon Robert McClelland, published a document called *Protection and Promotion of Human Rights in Australia*, upon receiving the National Human Rights Consultation panel's recommendations.

"The Consultation has demonstrated that there are strong views on the merits of a Human Rights Act. It has also shown that there are many other ways to protect and promote human rights including through enhanced education and improved parliamentary scrutiny.

The Government is committed to taking action to:

- foster an Australian culture where

- the fundamental human rights of all people are respected and protected, and
- ensure a range of mechanisms are available to promote and protect those rights.

The Government believes that:

- respect for human rights underpins Australian society and our future as a safe and inclusive democracy
- more can be done to ensure fundamental human rights are considered by Government;
- any change to enhance the protection and promotion of human rights and responsibilities

must preserve the sovereignty of Parliament

- access to information and education about human rights is critical.”

(The Hon Robert McClelland, MP Attorney-General, October 2009)

In April 2010 the Rudd Government issued a document known as *Australia's Human Rights Framework*. This framework document contains more transparent and specific explanations which describe exactly what this framework holds for the Australian public instead of a Bill of Rights. For more information, visit www.ag.gov.au/humanrightframework.



READ the advocate ONLINE.

If you would prefer to read **the advocate** online, go to <http://www.spinal.com.au/in-the-news/advocate-magazine/>

The Community Yellow Envelope

An exciting new initiative in North Queensland health care

*Do you find that doctors, ambulance and hospital staff often don't understand spinal injury or post polio syndrome?
Do you find that if you have to go into hospital you have to repeat the same information to every doctor or nurse that sees you?
Do you find that when leaving hospital, changes in your health needs are often **not** communicated to your support workers or service providers?*

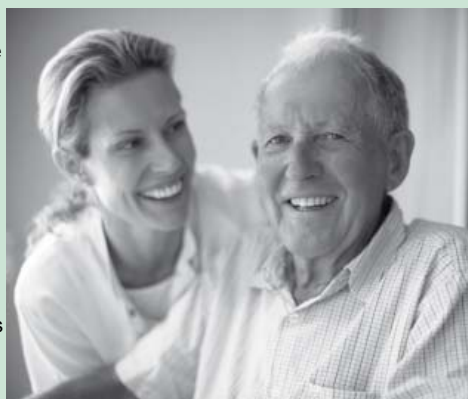
It is because of all these issues that Townsville health and community service providers have initiated the Yellow Envelope Project. The aim of the project is to improve communication and the flow of information between hospitals and a person's home. The initiative uses a yellow envelope to transfer the individual's relevant health information (eg. autonomic dysreflexia, medications, advanced health directive) from the person's home to hospital, and back again when the person is discharged.

The use of the yellow envelope in the Townsville district has been underpinned by significant education and training to public and private hospital staff (emergency department and ward staff), ambulance officers, local GPs, carers, aged care and disability service providers. Training commenced in May 2010 with all of these groups now trained.

Staff from about 20 disability provider agencies in Townsville (including the Spinal Injuries Association) have participated in the training, and the Association is using the envelope with the approximately 50 people we work with in the community.

The project will be evaluated in October 2010, incorporating feedback from people with disabilities, their carers, older people, community providers, GPs and hospital and ambulance staff.

The Yellow Envelope Project is funded by Queensland Health through the Connecting Healthcare in Communities (CHIC), and is a community and health provider partnership. The Spinal Injuries Association is a member of the project working group in Townsville. The Yellow Envelope has been successfully undertaken and is operating across community and residential care services in New South Wales and now in Townsville. If the Townsville project is a success, the Association will explore ways to establish the Yellow Envelope Project in other parts of Queensland. For enquiries or further details, please feel free to contact Cathy Lengyel, NQ Manager on 07 4755 1755.



SPOTLIGHT ON RESEARCH

Why spinal cord injury research often disappoints

Interest in spinal injury research to protect and repair the damaged cord has intensified in the last two decades. We are all aware that there are unproven and experimental procedures being offered around the world, which have been attracting a lot of community, as well as media, attention. Nevertheless researchers and clinicians are still working hard on finding effective treatments for spinal cord injury. Often these treatments are felt to be just 'around the corner', although we have all heard of promising outcomes from pre-clinical studies which then fail when they reach human trials.

Canadian researcher Dr Brian Kwon and colleagues have published a survey of the opinions and perspectives of 324 clinicians and scientists working to develop promising interventions which will translate into effective treatments for people with spinal cord injuries. The aims of the survey were to establish what pre-clinical evidence is needed to get a treatment into a successful clinical trial, how this evidence could be obtained and to identify some of the biases that are involved in interpreting this evidence. They discuss the similarities with the stroke community, where inconsistent and sometimes inadequate pre-clinical experimentation resulted in many treatments failing in clinical trials.

As a response to these failures the stroke community introduced 'evidentiary milestones'. It is clear that spinal cord injury research lacks clear guidelines or a practical and realistic framework to maximise the chances of developing treatments that will work for individuals with a spinal cord injury.

The authors suggest the spinal cord injuries research community needs to establish 'how much is enough?'. There was no doubt about the necessity of live animal experimentation but it was apparent that rodent models were not always

enough to establish the appropriate pre-clinical evidence. The majority of respondents considered that large animal models, such as cats, dogs, rabbits, sheep, etc, were necessary to obtain meaningful pre-clinical evidence. In the case of invasive cell transplant therapies the addition of primate models was also deemed necessary. Some of the issues with this kind of comprehensive experimentation are the accessibility and availability of these types of models. The paper also discusses the enormous expense involved with conducting these types of experiments. Kwon and his colleagues commented that "the vast majority of scientists would find large animal or primate studies simply unattainable."

Kwon and colleagues surveyed clinicians and scientists about the types of models that were required to obtain clinically meaningful evidence and found there was a need for different types of models to be tested, as well as different severities of injury, so the variation in human injury could be replicated. For potential trials on cervical injuries there was seen to be an overwhelming need for confirmation in a cervical injury model. The contusion injury model was thought to best represent human spinal cord injuries due to the fact that most injuries in people are caused by a sudden blunt trauma that bruises, rather than cuts, the cord. Respondents were asked to predict the time window between injury and treatment in animals that would be relevant to humans. For acute (early) interventions, the time window of hours to days was thought to be similar in animals and people. However, for chronic trials, where treatments may be given 18 months after the injury, the majority thought a delay of six weeks to three months was acceptable in animals; however another large section of respondents required a delay of 12 months or more. Clinically meaningful evidence was thought to consist of an improvement in behavioural ability, which can include hind-limb locomotor function and reduction in neuropathic pain. There was a strong requirement to replicate results in an independent laboratory before a treatment is moved into a clinical trial.

Kwon and his colleagues also tried to pinpoint some of the bias in the way pre-clinical research results are interpreted. One issue was the problem that negative results are generally not published. One reason for this may be the poor reflection it can cast on researchers, especially when the research is the main focus of their career or place of work. Another reason may be the reluctance of high impact journals to publish such data. Whatever the reason, not publicising negative results slows progress because knowing what doesn't work can be as important as what does and, if it is unknown, the same studies may be repeated unnecessarily. The survey also highlighted concerns about modifying or repeating results to obtain the desired outcomes. Respondents were divided on the need for researchers being 'blind' when assessing experimental or control groups.

Spinal cord injury clinicians and researchers are driven by one goal – to discover effective treatments for individuals with a spinal cord injury. Currently, promising pre-clinical interventions often go to trial without replication by different labs or duplication in different animal models. Kwon and his colleagues have uncovered some interesting information on the opinions and perspectives of clinicians and scientists. They suggest that a framework for guiding pre-clinical studies would be helpful and stress that the extensive dialogue between spinal cord injury researchers and translators needs to continue.

This article is a review of this academic paper: Translation Research in Spinal Cord Injury: A Survey of Opinion from the SCI Community. By Brian K. Kwon, Jessica Hillyer, and Wolfram Tetzlaff. *Journal of Neurotrauma*, 2010 Jan; 27:21–33. You can read the abstract at: www.ncbi.nlm.nih.gov/pubmed/19751098.

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Please note that research news is included for information purposes only. The Spinal Injuries Association does not endorse or support any specific research findings and advises readers to seek professional medical advice.



GREAT WORK

The Association's SEAT at WORK program, which is all about sharing injury prevention messages and raising disability awareness, is helping reduce spinal cord injuries from the boardroom to the worksite.

The program's goal to reduce Queensland's rate of spinal cord injuries sustained 'on the job' has been bolstered by the ongoing commitment to workplace safety by Watpac and ENERGEX, SEAT at WORK's strongest supporters.

Construction and development giant Watpac has invited SEAT at WORK presenters Robert Spencer and Geoff Lemon to speak to staff on site and in the office about the importance of workplace safety and the consequences of sustaining a permanent spinal cord injury. Managing Director Greg Kempton said the program helped Watpac fulfil its goal of being a good corporate citizen.

"We're proud to be supporters of the Spinal Injuries Association, not just because of the good work the Association does but also for the value it adds to our organisation," said Mr Kempton.

"SEAT offers our employees a real-life example of people who've sustained a serious permanent injury who speak honestly about the trauma they've experienced and the challenges they face in their everyday lives.

"It helps them see the ramifications of a bad decision." Mr Kempton said Watpac believed that the ongoing relationship with SEAT would help keep safety at the forefront of workers' minds.

Feedback from staff has shown the impact of the presentation with one worker commenting: "It

has made me have a look at my life and where I can mitigate risks to avoid possible injuries occurring. It is easy to sit in a site induction and think you know everything but when you see the effects on a disabled person's life and realise it could happen to anyone, then it makes you have a closer look at your own life and pay more attention to inductions and safety issues in general."

Watpac also donates funds from its workplace vending machines to the Association.

ENERGEX invites the SEAT at WORK team to give presentations twice a year to each induction of new apprentices. The team has also visited depots to speak to other workers on the importance of not cutting corners. Workers have praised the 'honesty and genuineness' of presenters, while one described the presentation as 'the best I have had while working at ENERGEX'.

ENERGEX Training Liaison Officer Karen Tarvit said SEAT at WORK reinforced the messages given to apprentices during their initial six-month training which focused on safety.

"Seeing and hearing someone who has been injured brings it home to the apprentices and shows them the consequences of their actions. It makes them realise accidents really do happen."

SEAT Marketing Manager Sheila Andrews says the support of Watpac and ENERGEX is invaluable to the SEAT program and shows the companies' strong focus on safety.

"Watpac and ENERGEX have demonstrated their commitment to providing the highest possible safety standards for their employees and in driving home the message that every individual has a responsibility for their own safety and that of their colleagues.

"We applaud Watpac and ENERGEX for their ongoing commitment to reducing workplace injuries and their continued

support of the SEAT program."

Funds raised from SEAT at WORK presentations are invested into the school-based SEAT program which shares crucial safety messages with children throughout Queensland. The team of 18 SEAT Presenters are on track to speak to 120,000 primary and high school students this financial year.

At a glance

Of those people who sustain a work-related spinal cord injury:

- 70% never return to work
- 60% are aged between 25 and 34 years
- 95% are male



DISABILITY LIFESTYLES

A website for people with spinal injuries:
written by people with a disability

www.disabilitylifestyles.org.au

Check out our NEW online
Toolkit for

**Creating change in your
community**

You'll find tips and information on
how you can create inclusion and
equitable access in your area...
or read the personal success
stories written by people who have
created change in their community.

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Relationships • Coping
Personal Stories • Work • Study
Transport • Having Fun
Accessible Towns • Links

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Wonder woman



How much difference can one person make? Lots, when that person is Toowoomba's own Wonder Woman, Wendy Adams.

You probably recognise Wendy Adams. The vibrant Toowoomba member is a busy woman – she is a SEAT presenter, runs the Toowoomba Member Network, volunteers at Toowoomba's *What's Up in Disability* office, sits on the board of Warrina Services (an organisation that supports people with a disability to live independently) and has acted as an access advisor to the Toowoomba Regional Council. Why so much? "It keeps me on my toes," says Wendy with her ever-present smile. "And a lot of the things I do, I do because I like to help people. I find it rewarding."

Part of Wendy's drive to help people comes from her own experiences. Sustaining quadriplegia in a car accident at the age of 17, Wendy recalls the dark days following. "I always said I never got depressed. But I know now, looking back, I did."

"It was such a relief to get out of the hospital – I *hated* the hospital – but when I got home I didn't

want to go out. My friends invited me out but I didn't want to go. I wanted to stay home. After a while they stopped asking. And I didn't want to be around people in wheelchairs. I wanted to be around 'normal' people."

Early ventures to the shops with her mum and sister didn't bolster Wendy's courage. "We were at Kmart and I remember an old lady actually moved me out of the way to get to the red light specials!"

She laughs about it now (Wendy's always laughing) but those experiences left their mark and she is keen now to tell newly injured people, particularly young women, that 'there is light at the end of the tunnel'. She has visited Brisbane's Spinal Injuries Unit and spends a lot of time advising people by phone of the assistance available to them. "People are always taking my number down and passing it on to friends they know who need advice."

Wendy's a country girl, a shearer's daughter from Dirranbandi on Queensland's Western Downs, who moved to Toowoomba at 15 to work in the mailroom of the Heritage Building

Society. She loves Toowoomba and says it's a fairly accessible city, although it wasn't always this way. Much of its accessibility initiatives are due to Wendy's access advisory role with the Council as well as her own efforts to improve her ability to get around.

"I remember a friend and I went out and marked down all the broken ramps around town. Council fixed them all," she says.

Despite the rewards of being where everyone knows your name (especially Wendy's), regional living brings extra challenges for people with a disability.

"Getting help is harder," admits Wendy. "Getting equipment is one of the hardest things when you have to pay for the cost of shipping it to you."

"Transport is difficult. There was no access ble public transport when I was first injured. I don't know how we survived back then but we did."

Wendy notes that community attitudes towards people with spinal cord injuries have 'improved tenfold' since



her own accident more than 20 years ago.

"We're not hidden in our houses anymore. We're out in the community so there's more awareness. Sometimes people will still come towards me with a frown on their face; it's like they don't know how to approach me. So I just smile."



Wendy in Toowoomba's Ruthven Street

One of Wendy's great passions is her role as a presenter for the Spinal Education Awareness Team (SEAT), a program she discovered more than 10 years ago while living in Childers. "I love SEAT. I love going in and teaching the kids about being safe. I always say, if I can help one child from being injured, it's worth it."

While Wendy jokes that she was 'roped into' becoming Toowoomba's Member Network coordinator in 2005, it's a role she enjoys although admits 'it's a big job' and it can be challenging to engage local members. "Toowoomba's the sort of town where people don't want to come out of their warm houses and go to meetings!"

She says Member Networks serve a valuable role in getting information and updates out to people, citing the recent Government heating and cooling rebate as an example.

Wendy also works at Toowoomba's *What's Up in Disability office*, where she is currently the editor of the organisation's bimonthly magazine. "I go into the office once or twice a week. I absolutely love it. I enjoy meeting up with the other guys and providing advice to people."

It's hard to believe Wendy has much free time but when she's not fulfilling one of her many community roles, she's enjoying 80s music, watching her favourite shows (which include *Packed to the Rafters*, *Desperate Housewives* and *Home and Away*), going to the movies or feeding her addiction to Facebook.

"Facebook is the best thing that ever happened!" says Wendy, who says she's caught up with many old friends on the social networking site, including some she hadn't seen since before her accident.

Keeping up with friends is important for the self-confessed 'people person' who actively works to improve her community, not just for people with a disability but for everyone. Wendy dreams of a society where everyone is accepted for who they are, a sentiment reflected in one of her favourite sayings, featured in the Association's 2010 diary:

"One day I hope people don't see my disability. They just see me as a person and they don't see my wheelchair at all."

Tell 50 in our 50th year!

SEAT and the Motor Accident Insurance Commission (MAIC) were excited to last month launch the *Tell 50* campaign.

With the most common cause of spinal cord injuries due to road trauma and the most common demographic to sustain this type of injury between the ages of 15 and 30, *Tell 50* is aimed at high school students who view a SEAT presentation between August and November.

Our 18 SEAT presenters will encourage the thousands of students they speak to in that four-month period to download a short video from our website, which contains powerful injury prevention messages about the realities of road trauma. These students will then be encouraged to share this video with at least 50 of their friends (given it's the Spinal Injuries Association's 50th anniversary) via Facebook, Twitter, blogs or any other social networking site that they choose.

Students who share the video will then go into four monthly draws to win a \$500 cash prize!

Once the video goes online, it can be easily shared among young people throughout Queensland and beyond – an amazing legacy for SEAT and MAIC.

See the video at www.spinal.com.au.



Star of *Tell 50*, Finbar Mills (right), on the set of the video



Harry and Ellie Chalk

Ben says sometimes carers need to 'take a step back and realise it's up to the injured person to take control of their life. It's their journey'.

Harry Chalk
Injury: Post polio syndrome
Carer: Ellie (wife)

Harry and Ellie Chalk, of Goodna on the Brisbane-Ipswich border, have been married for 38 years and have two daughters, Tammy and Robyne and five grandchildren. Harry, 60, has been using a wheelchair for about the last 20 years and Ellie, 56, has been his carer 'since day dot'.

Here's to you

Carers are the unpaid – and often unsung – heroes of our community.

Most people with a spinal cord injury require at least some support as they go about their daily lives. For many of these people, the person who provides this support – their carer – is an unpaid spouse, family member or friend who often carries out this role continuously without a break. We spoke to three members about their experiences.

Ben Riley
Injury: Paraplegia
Carer: Teri (partner)

Ben Riley, 28, lives with his partner Teri and their daughter, Charli, 6 in Gympie where Ben works as an occupational health and safety officer for AgSolutions. Ben is also a SEAT presenter and does some other motivational speaking at events. He describes himself as '100% independent' – he lived by himself before he met Teri – but says 'when someone's there, I will use their services to the best of my abilities'.

While Ben can handle most of his personal care himself, he does need Teri to assist in tasks such as get the shower head off the hook so he can have a shower or hold his wheelchair still when transferring on a steep slope or gutter, and says these are examples of 'where give and take comes in'.

"I always let Teri know that I'd be having a shower in the next half an hour or so, so she has plenty of time to do it.

"I try not to be too heavily reliant on my partner, not that she would mind – she would go to the ends of the earth for me."

One of the things Ben loves most is when Teri gives him a massage. "Teri has shown me a lot about caring for my body, especially my paralysed area, and it's always good to have your muscles and posture adjusted." Ben says he concentrates on what he can do, not what he can't.

"I mean, when me and Teri and Charli can support each other throughout our lives, our possibilities are endless and all of a sudden the impossible becomes possible. There is no 'I don't think I can' – it's more 'How can I?'" Ben's mum works as a carer and he says he is full of admiration for the work they do.

"How can you put it into words? Carers offer so much more than just a clean bum and sanitised hands, it can be a deep level of companionship, trust and understanding.

"It's important for the person cared for to realise that that the support worker is working in a vulnerable and confronting situation as well and they, in turn, need to be supported."

"We've only had paid carers for about 10 years. We receive four hours help a day but it's not really enough. We've put in for more hours but we keep getting knocked back. They don't tell us why," says Ellie.

Harry's health is not good and he needs care 24 hours a day, leaving Ellie with few opportunities to go out by herself or look after her own needs. "I'm worn out. I don't get a break at all. I don't get resentful, because I'm not that way inclined but I do put myself last."

Harry describes Ellie as 'a terrific carer' and points out the difficulty in finding paid carers that are a good fit. "I like to do things fast. For me, carers need to be able to come in and pick up the job very quickly and understand what my needs are."

Harry and Ellie are critical of the amount of paid support available to people with a severe disability.

"It could improve," says Ellie. "Put the politicians in the same situation and I don't think they'd cope. They sit in their cosy offices and they've got no idea."

Despite the challenges of their situation, Harry and Ellie share a strong relationship, a great sense of humour and enjoy their life together. "I never worry about anything, I just get on with it," says Harry.

"There's no point sitting in the corner moping about it. Have a bit of fun. I don't get out much but we do all sorts of things at home. We've got the computers. I love music. And Ellie

often does little building projects. "Carers do a great job. It can be a difficult job. It's a two-way street and I try to be supportive of Ellie."

Peter Hamilton
Injury: Paraplegia
Carer: Mary (mother)

Peter and Mary Hamilton live in Sunnybank on Brisbane's southside in a house they bought for its accessibility after an accident left a then 21-year-old Peter with paraplegia in 1964.

The house marked their move to 'the big smoke' from home town Jandowae in the state's west. While eligible, Peter has never had any paid carers and he and his mother describe themselves as 'very independent'.

"I have a routine and I'm quite capable," says Mary. "We've lived as normal a life as anybody could. While we can do it ourselves, we will."

Mother and son are 'always laughing and smiling', says

Mary. "We have our arguments and disagreements," offers Peter but, says Mary, "We've over it in a moment."

Peter, who worked for many years, can handle a lot of his personal care himself and still drives to the local shops. He keeps busy with computers, music and TV while Mary spends most mornings volunteering as an English teacher at the local Baptist Church or working in the canteen of the QEII Hospital. She was involved in the Sunnybank Theatre Group for 20 years and still enjoys going to see plays.

"There is so much you can do if you want to," says Mary. "People should never say they're bored."

While happy in her role as carer of her 67-year-old son, Mary admits that she hasn't had a holiday since 1975 ("to be perfectly honest, I'm quite happy to be at home") and doesn't want to consider what will happen when she is no longer able to look after Peter.

"I don't think about it. I know it's there but I don't think about it."

While Peter and Mary say they 'have everything we really need', they agree that the carer's pension could be more and that they are lucky that a friend and Peter's sister, Helen, help with some home maintenance tasks such as mowing and vacuuming.

"We're lucky. Some people could have problems."

Fast facts: Carers

- *More than one in eight Australians are carers*
- *Women are more likely than men to be carers*
- *42% of carers are caring for a spouse/partner; 26% are children caring for a parent; 23% are parents caring for a child*
- *More than one-third of carers have a disability themselves*
- *While one-third of primary carers reported negative effects on their relationship with their spouse or other family members, an equal proportion felt that caring drew them closer to the person they were caring for.*

Source: Carers Australia.
www.carersaustralia.com.au

Announcing new sponsor Medilaw

The Spinal Injuries Association is thrilled to announce it has a new sponsor – Medilaw, a national company with its head office in Brisbane that specialises in independent medical assessments and medico-legal reports for state and national clients. Medilaw's partnership with the Association will see it supporting our education and injury prevention work and sponsoring **the advocate**.

Association CEO Mark Henley said that Medilaw's sponsorship would help the Association advocate for people with a spinal cord injury and continue to share injury prevention messages with Queensland children.

"We are delighted with Medilaw's generous support and are particularly excited about their desire to build a long-term sustainable partnership," said Mark.

"Our long-running SEAT program is on track to share safety messages with 120,000 students around the State this financial year. The more children our presenters can reach out to with their personal and very powerful stories, the better our chance to further reducing injuries that will have a lifetime of consequences.

"It is fantastic that Medilaw shares our commitment to injury prevention and education. As we are celebrating our 50th anniversary this year, they are also celebrating a special anniversary – their 10th anniversary."

Medilaw CEO Chris Blair said the firm was delighted to be involved with the Association. "Every day we see the devastating results of injuries, illnesses and disability, including spinal cord injury," he said

"We look forward to the opportunity to work with the Spinal Injuries Association to make a difference to those people living with a spinal cord injury and to support the education of children to help prevent future injuries."

Medilaw's sponsorship of **the advocate** will also help improve the content of the magazine by making available a pool of medical experts. Medilaw's specialist consultants include orthopaedic surgeons, pain specialists, neurosurgeons, psychiatrists, urologists and respiratory physicians. www.medilaw.com.au

MEMBERS' SURVEY REVEALS BIGGEST CONCERNS



Housing, access and equipment top the list

A survey of more than 1,700 members and clients of the Association has revealed the major issues facing people with a spinal cord injury, as well as their thoughts on the Association and the support it offers.

The survey, conducted in collaboration with Griffith University during June and July, covered a wide range of topics including the Association; services available to people with a disability; policy and funding; healthcare; regional needs; and the experiences of families of people with a spinal cord injury.

The Association's Executive Manager — Client Services Frances Porter thanked everyone who had completed the survey and said findings would help guide the Association's future direction.

"We appreciate the time people have taken to contribute their thoughts on how we can improve and best support and empower people living with a spinal cord injury in Queensland," she said.

"Understanding what our members and clients are most concerned about will help focus our advocacy efforts and decide where our services can be enhanced and expanded."

Frances said that one of the most striking points to emerge from the survey results was the high number of members who reported that their meets were not being adequately met.

"About one-third of members are not getting all the services they need, with many saying cost is the reason," said Frances.

"The researchers who carried out the survey noted a big difference between the ability to cope of people injured before 2005, when the Spinal Cord Injury Response (SCIR) program was introduced, and those eligible for this funding. People without SCIR support find life much more difficult, with researchers describing many as 'burnt out' and 'exhausted'.

"This issue highlights the urgent need for the introduction of a National Disability Insurance Scheme (NDIS) to provide long-term support for people with a severe disability and ensure they do not have to go without the services they need to enjoy a good quality of life."

The survey was supplemented by focus groups held in Cairns, Bundaberg and Brisbane, including one with families of current Spinal Injuries Unit patients. The families, all of whom had come from outside Brisbane, spoke of their stress, isolation and alienation and suggested that opportunities to meet with others in a similar situation might be helpful.

The Association's Executive Management team have been analysing the information from the review to formulate future strategic plans to address the issues raised by members and clients. Lack of services or coordination of services in regional areas was particularly highlighted by the focus groups as well as in the survey, so different strategies are being investigated and considered to increase the services to people outside the Southeast corridor.

CEO Mark Henley says he appreciates the honesty of members who participated in the survey and focus groups.

"This information will ensure that we take on board, not only the positive feedback but also the negative, and we will continue to keep people updated with future developments through articles in **the advocate**."

What you said about:

Travel and Transport: "I would pass laws to make transport available to us all. We can't have community access if we don't have transport that is reliable to get us out of our homes. Taxis can pick you up three hours late and often not at all. Buses are also unreliable. The taxi fares are too expensive even with the taxi cards. Our limited income is taking this out of our reach."

Parking and Parking Permits: "Parking permit system needs revising."

In-Home Care/Care/Respite: "[We need] more caring in-home carers with more flexibility and autonomy from their employer."

Accommodation and Housing: "Ensure all people with disabilities have appropriate housing and personal care support."

Vocational support: “[We need] more opportunities for people with disabilities to achieve financial independence outside of mainstream employment.”

Regional services: “We pay the same membership, we are the same members but we don’t get anything in return. We need a base closer.”

Association’s advocacy: “Sometimes you feel like you are just a ‘little person’ and they (service providers) can walk all over you but knowing the Association is there to advocate for you, back you up, makes you feel more confident.”

Key survey findings

- 62% respondents were male; 38% were female
- Brisbane and Moreton regions were home to the highest number of respondents (65%), followed by the Wide Bay/Burnett region and Far North Queensland
- Most respondents were aged over 40 years
- Almost half of respondents sustained their injury more than 30 years ago
- 79% said the Association benefited them personally
- Approximately one-third of respondents had some needs that are not being met. About half of these people cite cost as the reason, while more than a quarter say that the services they need are not available where they live
- When asked to name the main issues facing people with a spinal cord injury, housing (63%) topped the list, followed by access (61.4%) and equipment (60%).
- 91% of respondents would recommend the Association to someone else
- Respondents said the Association’s main strengths are advocacy; service; and employment support
- Respondents said the biggest gaps in services available to them were in the areas of physical therapy; personal care; and gardening and home help/maintenance
- When asked if they could change one thing to make life better for people with disabilities in Queensland, accessibility; policies and funding; and public awareness were the top responses

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CELEBRATING 50 YEARS

New millennium: the 2000s

The noughties saw the Association become a force to be reckoned with and a recognised leader in disability advocacy.

The first decade of the new millennium brought challenges and was marked by milestones that highlighted the Association's increasing effectiveness in influencing government and advocating for members.

Growth was a key theme of the decade with the Association adding several more services such as its Peer Support program, the Community Linking program and expanded others such as Employment Options and the Spinal Advisory Service. By 2002 the Association was outgrowing its Kangaroo Point building and the search was on for bigger premises. The Association sold the property for more than four times what it paid for it and moved to what was then known as Allgas House and what is now the Association's current office in Woolloongabba.

The building's official opening on 24 February 2005 coincided with the launch of the Association's new name. After years of debate, the Paraplegic and Quadriplegic Association of Queensland became the Spinal Injuries Association. Recalled Des Ryan, who was Association President at the time: "The previous name – wow, what a mouthful! And people didn't know what it was. We needed to rebrand ... It was one of the best things we did."

A new name helped raise the Association's profile which is certainly stronger now than at any other time in its history. The support of high-profile patrons, such as the Governor of Queensland, and ambassadors including the Classic Wallabies, who came on board in 2005, has helped increase awareness of the Association and what it does.

Throughout the 2000s, the Association became a much stronger political advocate that was not afraid to speak up for people with spinal cord injuries in Queensland. In 2002, the Association campaigned against proposed cuts to

disability, urging people to 'stand up to a government that is under-nourished in both knowledge and spirit.' The Association also lobbied for increases in the Medical Aids Subsidy Scheme (MASS), with John Mayo talking to the media about a 16-year-old boy waiting seven months for a new wheelchair and a woman faced with being admitted to hospital when she was forced to wait four months for a shower chair.

During the 2004 Federal election campaign, disappointed by a lack of commitment from both major parties regarding disability, CEO Mark Henley wrote letters to then Prime Minister John Howard and Opposition Leader Mark Latham describing their stance as 'disgraceful and embarrassing'. Pressure from the Association and the Unmet Needs Campaign saw every political party then releasing a disability policy – a first in an Australian Federal election campaign.

Later that year, the issue around adequate support for people with a spinal cord injury reached a dramatic climax. Supported by the Association, six patients of the Spinal Injuries Unit, all with quadriplegia, refused to leave the Unit until adequate at-home support was available to them. It was a stand-off that received national media coverage on programs including *A Current Affair* and Channel 10 news, and resulted in what would be a milestone for both the Association and people living with a spinal cord injury in Queensland. The introduction, in 2005, of the Spinal Cord Injury Response (SCIR) program changed lives, allowing people injured from that date to receive support that would allow them to live in their homes. Malakai Tava, one of the 'gang of six', who had helped convince then Minister for Disability Services Warren Pitt to make the funding available, said of the meeting with Mr Pitt: "He listened. I didn't want him to only give me a funding package. I wanted the people who left hospital after me to get it too." The Association continues to work to secure better funding for people injured before

2005.

While post polio syndrome (PPS) members will tell you that the battle to make the medical profession fully recognise their condition is ongoing, much effort during the noughties was put into increasing knowledge of PPS among doctors and other health professions. The beginning of the decade saw Christine Tilley and other post polio members work with Queensland Health to develop an educational and training package that went some way towards increasing awareness of the condition in the medical profession and saw a significant drop in members reporting a lack of awareness of their health issues.

The Spinal Education Awareness Team (SEAT) continued to grow throughout the noughties, visiting its one-millionth student in 2005. SEAT entered the 21st century with the beginning of its multi-media presentations and the release of its *Consequences* DVD. In 2010, one of SEAT's founding presenters Wayne Leo reached the milestone of speaking to 250,000 Queensland children.

Over the last 10 years, the Association has worked hard to increase its regional presence. In 2001, the Association bought land in Townsville to build a new North Queensland (NQ) office. After impressive fundraising, particularly by Judge Bob Pack, Fraser Montgomery and others in the NQ Supporters Committee, the office opened in 2004. Board member and Townsville Member Network Facilitator Scott Stidson said this was a 'huge' leap forward for NQ members. "It meant we were really establishing a presence in NQ. It was amazing getting that office."

Access has always been an issue for people with a spinal cord injury but during the noughties, it seemed that attitudes were finally changing – though not without what Executive Manager, Community Relations John Mayo described as 'gentle assistance'. In the Southeast, John led the



Julie and Malakai Tava with Association Ambassador Tim Horan in 2008

Association's push for equitable access for Brisbane's Roma Street Parklands, the newly redeveloped Queen Street Mall, Brisbane's busway tunnels and Suncorp Stadium. Member Ben Lawson initiated the action against the State Government-owned stadium when the seating area allocated to people using wheelchairs meant he couldn't sit with his friends at a State of Origin game. Said Ben: "I wasn't going to be treated differently just because I get around in a wheelchair."

In the regions, access improvements were achieved in Kingaroy, Noosa, the Whitsundays, Mt Isa, Maroochydore and in the North Queensland parliament in Toowoomba. In 2010, a landmark pedestrian crossing in Home Hill ended years of inequitable access in that town (see page 5). The Association, with

Tourism Queensland, also conducted regional tourism workshops.

In 2005, the Association supported a member who won her action against the body corporate of her prestigious apartment to provide her with equitable access to the building. At the time, the Anti Discrimination Commission Susan Booth described the decision as the most important legal precedent since the Convention Centre case in 1994. In the latter part of the decade, the Association also worked with airlines to improve their policies regarding passengers with a disability. The Association also supported and welcome increased State Government funding and allocation of maxi taxis in regional areas without accessible transport. Said Mark Henley: "This will change people's lives."

As the decade ended, the Association was continuing its work towards creating an inclusive community, which includes backing the proposed introduction of a National Disability Insurance Scheme (NDIS). In 2010 Mark Henley said the top priorities of the Association included 'making sure our members have appropriate levels of support, the equipment they require, and that hospitals and health services are meeting their needs'.

"We also want to influence the broader community regarding the inclusion of people with a disability."

The '90' event in November 2007



At a glance

In 2000, members Kelvin Haller and Scott Stidston (both from Ayr) carried the Olympic torch on its way to Sydney

In 2002, the Governor of Queensland (Major General Peter Arnison) became the Association's first patron

To mark Spinal Injuries Awareness Week in 2007, 50 members helped create a human stop sign around 90 empty wheelchairs, representing the number of Queenslanders sustaining spinal injuries each year

In 2006, Louise Yates became the Association's first female President, after Des Ryan resigned after seven years in the role. Current President David Riley took up the post in late 2007.

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Virtual playground for all abilities

Children with a range of different abilities can now all play in a virtual playground. Located at www.allabilitiesground.net.au, the All Abilities ePlayground is a free, online play environment offering fun and games in new, innovative and accessible ways. It can be played using a range of devices, including touch screens and assistive technologies like single switch and Puff2Play, in addition to the more traditional gadgets like keyboards, mice and joysticks. A Gold Coast City Council initiative, the ePlayground was created by non-government organisation Sonokids Australia with support from the Department of Communities (Disability Services). Its concept emerged as a result of community participation in creation of the Kurrawa All Abilities Playground – a project the Spinal Injuries Association was involved with in contributing its access knowledge. The ePlayground's accessibility features have already been recognised as best practice by international awards program ACCESS-IT.

Access action

Following some fine advocacy by member Andrew Briggs, the Charters Towers Central Business District has undergone an access audit in August. In Brisbane, the Association has been engaged in the design of three new City Cat terminals which should influence pontoon and terminal design across the State. In Rockhampton, Des Ryan and Rebecca Rodger are linking transport services with shopping centres. In Brisbane, Queensland Rail has agreed to a workshop to overcome station lift failure issues experienced by wheelchair users, following advocacy by member Ben Lawson.

Door latch design

Arising from a design brief for an automated public toilet, a NSW

industrial designer who has been consulting with the Association has designed an excellent door latch for people with limited hand dexterity. The design combines a D-shaped door grab rail on the back of the toilet door with lift-up, lift-down door latch that works perfectly every time and requires minimal force from any part of the hand/lower arm to operate. Bitz hopes to publish a photo in the near future.

Robotic exoskeleton option of walking

A small New Zealand company, Rex Bionics, has spent NZ\$10 million (AUS\$8,146,000) developing a product for the past seven years which it believes could potentially benefit millions of wheelchair users. The robotic exoskeleton known as Rex is basically a pair of robotic legs that strap around the user's legs and move the user's legs via hand controls situated near the user's waist.

Hayden Allen, a motorcycle racer who sustained paraplegia in an accident and is now an employee of Rex Bionics and a recent Rex user, says that being able to talk to someone at eye level has made a big difference to his life socially and that Rex has delivered valuable changes medically. "In a wheelchair you're prone to getting infections. Now I've had time on the Rex I don't seem to have those complications anymore," he says. The device will be available for sale in New Zealand by December 2010 and will come with the price tag of US\$150,000 (AUS\$172,000).

Epic TM outcomes

The Transverse Myelitis Day (17 May) USA video link up with the Association's Brisbane office opened new vistas for access to information, awareness and contacts. University of Texas SouthWestern Director Dr Bill Greenberg provided an exceptional

guide for lay people into TM. His presentation has been recorded and members can request copies free on DVD. Contact Bernice Quinn: bquinn@spinal.com.au.

Sir Leo Hielscher Bridges access

The new \$2.12 billion Gateway Upgrade Project in Brisbane is nearing its finishing point, with the new Sir Leo Hielscher Bridge duplication complete with pedestrian and cycle path providing cross river connectivity for pedestrians and cyclists.

Members wishing to access the new path can do so from either Lavarack Avenue and Kingsford Smith Drive on the north side of the bridge (limited street parking available), and Lytton Road on the south side of the bridge (additional access and off street parking available in late 2010 pending construction of new park under Sir Leo Hielscher Bridge).

Members should be aware that until at least the end of November, there will be no disability parking available at either the northern or southern sides of the bridge for those wishing to access the new path. Disability parking will be available in the Queensport Rocks Park under the southern side of the bridge once construction of the park is completed in late November. Those wishing to park and access the new path can do so from this park. There will only be on-street parking available on the northern side of the bridge on Kingsford Smith Drive and Lavarack Avenue.

When using the new pedestrian and cycle path, members should be aware that:

- The pathway has a width of 4.25m. The cycle and pedestrian path will be divided by a 200mm solid white line and associated pavement markings
- The pathway has a length of more

than 3km from Lytton Road to Kingsford Smith Drive

- There are four rest areas offering shade and views east towards Moreton Bay
- Access to the path is on both the north and south sides of the Brisbane River
- There is a constant grade on the cycle path and variable grade (rest landings for mobility device users) on the pedestrian path
- There are CCTV cameras, help phones, lighting and drinking fountains for path users
- Be careful when entering

the path – intersections and corners feature a banded surface treatment to alert users to the changed conditions

- Use the correct side of the path – pedestrians are to stay on the eastern side and cyclists to the western side of the pathway
- Pay attention to signage – it will be at eye-level and on the path
- Remember water and sun protection
- Advisory speed limit of 10km/h

For more information and a map, visit www.gatewayupgradeproject.com.au, click on 'Features and benefits', then 'Pedestrian and cycle'.

PLEASE HELP

I am completing studies to become a registered psychologist and am required to complete a small research project. I myself have complete paraplegia and have always been curious if people cope better if they were to blame for their injury.

The below link will take you to a very short 10 questions to help me assess this hypothesis. Please visit the following website. The questionnaire should take no more than five minutes. Thank you!! *Brenda Kerr*

www.surveymonkey.com/s/THC6LQM



INFO NEWS

MARION WEBB
Coordinator, Information Service

Emergency REDiPlan – Household preparedness

Emergency Management Queensland (EMQ) joined with Australian Red Cross to develop a booklet for preparedness in emergency situations.

The booklet is aimed for people with disabilities, but in fact the booklet is for every person — we each should be prepared for the unknown, and have plan/s in place in preparation for the unexpected.

Four main factors form the basis for an emergency REDiPlan:

1. Be informed: Ensure everyone in your household will know what to do in an emergency.
2. Make a plan: To be prepared in advance assists emergency situations to be less stressful, and assists to limit unnecessary events.
3. Get an emergency kit: To ensure you are ready and

equipped if evacuation is determined to be essential. As well, an emergency kit will be beneficial if you become isolated.

4. Know your neighbours: A supportive strategy on two fronts — one for you and your household, and reciprocally for your neighbours.

The booklet can be downloaded from this website: www.emergency.qld.gov.au/emq/css/REDiPlan.asp.



Each chapter covers most imaginable possibilities, including checklists, and has pages for personal details, emergency contact numbers, and to record information for each component of your plan.

Red Cross has a series of booklets relevant to specific groups in the community, eg, seniors and children. Booklets are available in Easy English format, so check the following website for more information, or to download a booklet:

www.redcross.org.au/ourservices_acrossaustralia_emergencyservices_resources.htm#household_emergency_plan.

Medical Cooling and Heating Electricity Concession Scheme

A reminder to ensure you claim your rebate under this new scheme that can save you some of the costs of running your air conditioner. Check page 4 for more details.

POST POLIO AWARENESS WEEK

Rehabilitation physician **Dr Stephen De Graaff** visited the Association's Brisbane office on Tuesday 3 August to give a presentation on post polio syndrome (PPS), which included information on managing the condition and surgical options.

About 50 members attended the presentation which was also video-linked to members watching from the Townsville office. Feedback by members was universally excellent with comments including 'what a knowledgeable person — when is he moving to Brisbane?!' and 'very pleased and very impressed — he spoke our language'.

Dr De Graaff, who is the Director of



Gold Coast post polio group convenor Lyn Glover with Dr De Graaf

Members at Dr De Graaf's presentation



Pain Services at Epworth Healthcare in Melbourne, explained to members the importance of modifying their lifestyle to better cope with PPS.

"There are no magical cures," he said. "We have to adapt and adjust ... You don't have to vacuum the house every day, you don't have to wash the car every week.

"We want quality not quantity."

He remarked that 'polio survivors' often struggled with adopting this mindset after a lifetime of pushing themselves and working hard after dealing with the challenges of polio. Dr De Graaff said that while many people with PPS were reluctant to use orthotics or wheelchairs, he reminded them that orthotic devices have come

a long way from the 'horrible calipers' of the 1950s. "Using orthotics is not an indictment — it's about protecting the energy you do have."

He said that most medications to treat PPS were 'very disappointing' and encouraged people with PPS to minimise their deteriorating function by pacing themselves.

"If you know walking 500 metres to your favourite coffee shop is going to wear you out, stop halfway and take a breather for five minutes. You'll enjoy your coffee much more in the end."

Wisdom from Dr De Graaf

- People who contracted polio when they were younger than five years old and experienced a mild form of the disease are less likely to develop PPS
- In the past, people with PPS may have been advised to avoid exercise but 'sensible' exercise can increase strength
- Some people with PPS have found Coenzyme Q10 lessens fatigue. It's expensive, so Dr De Graaff advises trying it for two months while keeping a diary of how you feel. You can buy Coenzyme Q10 from health shops.
- Statins (prescribed for high cholesterol) can increase muscle weakness. Talk to your doctor about the risks.

SOMETHING TO SAY?

If you have a story you'd like to share with other members, or some feedback on the magazine, please don't keep it to yourself. Email vmannixcoppard@spinal.com.au

PARAVILLA MACKAY

The Mackay District Spinal Injuries Association provides supported accommodation and respite for people with a spinal cord injury.

The five bedroom house has been purpose built and is close to shops, doctors surgery, hotels and the base hospital.

**For further information phone or fax the co-ordinator on (07) 4957 2180
Email mssia@mackay.net.au**

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FAMILY FUN DAY

An initiative of the Townsville Burdekin Member Networks

By Cathy Lengyel and Scott Stidson

The Family Fun Day was held on 29 June 2010 at Riverway, Townsville, after the Townsville/Burdekin/Bowen Member Networks secured funding from the Department of Communities. Approximately 35 people with spinal cord injuries (including post polio syndrome and Transverse Myelitis), their friends and family attended the event, and from all reports, had a fabulous time!

Member Garth Brimelow and his young grandson were assisted by Association staff with the BBQ. Boat rides on the Leisure Accessible boat *Rosie* had everyone clambering to be Captain, while the pool and accessible playground provided a great distraction for the younger ones amongst us.

The media were present, and judging by the photos, there was a fair bit of

competition to be the next Australian top model!

The aim of the day was to provide people with spinal cord injuries an opportunity to get to know others in a social and fun setting, provide them with new or different experiences (ie. a boat ride) and raise broader community awareness of spinal cord injury.



Scott Stidson (centre) surrounded by friends

Many in attendance also took the opportunity to visit the Townsville City Council's Community Plan display and provide feedback as to how they want their community to look into the future.

MEMBER NETWORK NEWS

The day was a highly successful one and we look forward to organising an even bigger and better event later in the year.

We couldn't have done it without the support of our colleagues and local businesses. Thanks go to Ken and Joy Turner; Horizon Gourmet Meats, Garth, for his cooking skills; Scott and Col for their humour and coordination of members and activities; Townsville City Council for assistance on the day; transport services – TOTTs; and Burdekin Centre for Rural Health; and staff from the NQ office and Bernice Quinn (Member Networks Coordinator) for assistance with planning and organising the day.

To indicate your interest in a similar event, please contact Scott Stidson (Member Network Facilitator, Townsville/Burdekin/Bowen) on 07 4783 1150, stido@internode.on.net or Cathy Lengyel (NQ Manager) on 07 4755 1755, clengyel@spinal.com.au.

Member Networks across Queensland

Brisbane

Meeting: 11am, 1st Wednesday of the month
Venue: Spinal Injuries Association, 109 Logan Road, Woolloongabba
Robert Montocchio T: 07 3379 4771
Email: rmontoc@bigpond.net.au
George Dougherty T: 07 3844 2949
Email: georgedou@optusnet.com.au

Bundaberg

Meeting: 10.30am 1st Tuesday of the month
Contact acting facilitator for time and venue
Luke Gale T: 07 4159 5668
Email: gales1@bigpond.com

Burdekin/Bowen

Meeting: contact facilitator
Scott Stidson T: 07 4783 1150
Email: stido@internode.on.net

Far North Queensland (formerly Cairns)

Meeting: Last Tuesday of the month.
Contact facilitators for time and venue
Lynne Barnes T: 07 4055 6675
Email: laquarius1@bigpond.com.au

Nita Carling T: 07 4045 1009
Email: nita.carling@bigpond.com

Gold Coast

Meeting: contact facilitator
Jim Clements T: 07 5522 7172
Email: jim@wheelietravel.com.au

Mackay

Meeting: 1st Friday of the month
Venue: contact facilitator
John Smith T: 07 4942 5445
Email: jh2smith@bigpond.com
Alan Elliot T: 07 4954 8646
Email: alanell@datacodsl.com

Maryborough

Meeting: 12 noon, 3rd Wednesday of the month
Venue: Carriers Arms Hotel, Maryborough
Brian Willcox T: 07 4121 4358
Email: brianwillcox@bigpond.com

Moreton Bay (formerly Pine Rivers)

Meeting: 1pm, 1st Monday of the month
Venue: Kallangur Memorial Bowls Club
Jim and Kay Considine T: 07 3283 8787
Email: kay.considine@bigpond.com

Rockhampton

Meeting: contact facilitator
Des Ryan T: 07 4926 4551;
0417 775 365 (work)
Email: dryan@heyer.com.au

Tablelands

Meeting: contact facilitators
Mark Taylor T: 07 4093 3821
Email: vireya123@gmail.com
Russell Dafforn T: 07 4091 7975

Toowoomba

Meeting: 12pm, Friday following Pension Day (17 Sep, 15 Oct, 12 Nov, 10 Dec etc)
Venue: contact facilitator
Wendy Adams T: 07 4637 4160
Email: wenadams@aapt.net.au

Townsville

Meeting: 10:45am (for 11am), last Tuesday of the month
Venue: Spinal Injuries Association, 488 Ross River Road, Townsville
Scott Stidson T: 07 4783 1150
Email: stido@internode.on.net

GET REVVED UP FOR CRUISE FOR A CAUSE

SUNDAY 7 NOVEMBER, THE STRAND, TOWNSVILLE

Proudly sponsored by Graduate School of Motoring

The Spinal Injuries Association's annual Cruise for a Cause will kick off Spinal Injuries Awareness Week (8-14 November) in North Queensland. This year the major sponsor for this terrific event is Graduate School of Motoring. This popular, free event will see more than 100 classic vehicles – from hot rods and utes to custom cars and bikes – gather at Willows Shoppingtown at 9am. At 10am, the convoy will cruise to Strand Park where the vehicles will remain on display until 2pm for the public to admire.

There will be a BBQ, music and many displays, including those of emergency services vehicles such as police cars and fire engines. Trophies will be awarded for

winners in eight categories: best car; best ute; best hot rod; Aitkenvale Auto and Dyno Best Engine Bay; best bike; people's choice; judges choice; best youth entry (under 21) and 'sponsors choice'.

The Association's North Queensland Manager, Cathy Lengyel, said Cruise for a Cause was a fun way to raise awareness of spinal injury and the Association in the North Queensland community. "We are really excited by the great ideas and practical contributions from our Association Members in this event, and believe it is going to be the best yet!" said Cathy.

Townsville Member Network facilitator and SEAT presenter Scott Stidston said he hoped the event would raise awareness of the Association and highlight the importance of road safety.

"In Queensland, one person will sustain a spinal cord injury every

four days and almost half of all these injuries are the result of road trauma," said Scott. "We are proud that motoring enthusiasts of all ages bring along their pride and joy to join with us in highlighting the safe motoring and injury prevention message of Cruise for a Cause."

The Association thanks the event's major sponsor, Graduate School of Motoring, as well as category sponsors, and the Cruise's organisers, the North Queensland Supporters Committee. The Committee is made up of leading business men and women in the Townsville community who are passionate in their support for the Association.

For more information, to sponsor, or to register for Cruise for a Cause, visit www.spinal.com.au/cruise-for-a-cause-2010/, email cruiseforacause@spinal.com.au or call the Townsville office on 07 4755 1755 (freecall 1800 024 422).

Post polio support groups around Queensland

Brisbane

Meeting: 2pm, 2nd Saturday every second month, (June, Aug, Oct)
Venue: Spinal Injuries Association, 109 Logan Road, Woolloongabba
Hugh Banney T: 07 3355 3298
Email: hughban@dodo.com.au

Cairns

Please contact
Bernice Quinn Ph: T: 07 3391 2044
Coordinator Member Networks
Email: bquinn@spinal.com.au

Gold Coast

Meeting: 10.30am, 1st Monday of the month
Contact facilitator for details
Lyn Glover T: 0448 206856
Email: lyn.glover@hotmail.com
Graeme Johnson T: 0407 750 626
Email: graron1@dodo.com.au

Sunshine Coast

Meeting: 10am, 1st Friday of the month
Contact facilitator for details
Cathy Newman T: 07 5447 6608
Email: cathynewman@tadaust.org.au

Toowoomba

Meeting: 2pm, 2nd Thursday of the month
Contact facilitators for details
Venue: Lourdes Activities Room, 227 Spring St, Toowoomba
John Bryant T: 07 4613 4102
Genevieve Payne T: 07 4633 5920

Townsville

Meeting: 2pm, 1st Sunday of the month
Venue: Spinal Injuries Association, 488 Ross River Road, Townsville
Mary Gibson T: 07 4779 8838
Email: emarygibson@bigpond.com

12-18 September	Disability Action Week
17-23 October	Carers Week
19 October	Carers Day
November	Spinal Injuries Association Annual General Meeting (date to be confirmed)
2 November	Melbourne Cup lunch, NQ office
8-14 November	Spinal Injuries Awareness Week
7 November	Cruise for a Cause, Townsville
13 November	3rd Annual Spinal Injuries Association Gala Dinner

SEEKING YOUR CHAMPIONS

Don't forget to nominate your Inclusive Community Champions by 30 September.

To celebrate the Spinal Injuries Association's 50th anniversary, our organisation is keen to recognise and celebrate the service providers and facilities who foster a truly inclusive community in the following 13 Member Network and Post Polio Support Group regions: Brisbane, Moreton Bay, Gold Coast, Sunshine Coast, Toowoomba, Bundaberg, Maryborough, Rockhampton, Mackay, Tablelands, Townsville, Burdekin and Far North Queensland.

There are five categories in the Inclusive Community Champion awards:

- Best sporting organisation/facility
- Best local business/community service provider
- Best government department or agency
- Best recreation/leisure/entertainment organisation, venue or precinct
- Best tourism or accommodation organisation or provider

We invite members in those 13 regions to nominate their local Inclusive Community Champions and outline the reasons why they are Champions on forms available at: www.spinal.com.au (in the new Members Only section) or by calling the Brisbane (07 3391 2044) and Townsville (07 4755 1755) offices.

Each category winner will be named the Inclusive Community Champion for their region and will be recognised at a morning tea in November, to celebrate Spinal Injuries Awareness Week (8-14 November).

A full list of the winners will be included in the November-December issue of **the advocate**.

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FOR SALE: Holden Crewman Ute with Hand-controls 2006 model VZ MY06 S, original owner, excellent condition, only 57,400 kms. Current RWC, colour Odyssey (dark grey), 4 speed automatic. Has Holden tubliner, towbar, soft tonneau cover, seatcovers, floormats, new rear tyres. Always serviced by the local Holden Dealer. Rego 02/11. \$23,500. Phone 07 4159 9188.

FOR SALE: Vitaglide wheelchair exercise machine for upper body workout. Just roll in and roll out, fits virtually any manual wheelchair and most power chairs with foldaway or removable arms. System raises or lowers depending on your needs. System also has intensity from one to seven — one being a good cardio work out and seven good for strengthening muscles. Natural pushing and pulling motions. One year old, still like new. I paid \$2,200 AUD from the US, sell for \$1,500 ono. Ph Debbie 07 4951 2710.

FOR SALE: Quickie R2 in very good condition. Purchased through Sunrise Medical. Willing to sell with wheels if requested. \$1,850 (paid \$4,500). Fits cushion sizes 16 x 16 inches and 17 x 17 inches as I use both sizes on it now. Purple/black splash frame colour. Backrest valued at \$800 will be included. Call Asti 041 4417466

FOR SALE: 1998 Ford Transit campervan. Exc condition. Hand controls. Engine recon. 4 spd auto. Rear wheelchair hoist plus driver's side access hoist. Solar panels. Vacuum toilet. Shower. Flat screen TV. Rear reversing camera. Prof fit-out. Ideal for active person with paraplegia. \$52,000. Call Rob 044 7798579.

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