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I recently received the results of our annual staff survey, and I was once again struck by the passion, commitment and dedication of our people. Some of our staff members have been with us for many years, while others have joined us more recently. However, no matter how long people have worked for us, everyone is here for the same reason: we can all see the impact that our organisation has on our clients (and on society at large) on a daily basis—which is not something that can be said of most organisations.

When we bring new employees into the organisation, we spend as much time exploring their attitudes and their ability to fit in with the Spinal Cord Injuries Australia (SCIA) way of doing things as we do looking into their skills and experience. While skills can be taught, attitude is everything, and if our people don't display the right attitude when working with our clients, or in their dealings with fellow employees, they don't stick around for very long. To allow people who are a threat to our strong values and culture to remain working here would be like allowing a poison to spread, untreated, through the body.

I firmly believe the success of an organisation such as SCIA rests on its people. An organisation can have great technology, unique products and services, lots of money in the bank, a watertight quality management system or the best ideas, but unless it has the right people, and the right culture, these positives can be wasted and never leveraged for good.

I also believe that if you're employed by an organisation such as SCIA, 100 per cent of your energy should be focused on the needs of your clients; there is no place for petty disputes, politics, lack of cooperation with colleagues, and infighting. Having seen those behaviours in many of my previous (mainly corporate) workplaces, I have applied much of my energy since taking over the leadership of SCIA to ensuring that all of our organisation's efforts are focused on our clients' needs. Based on the feedback from our clients and staff members, it seems to be working—although there is always room for improvement.

Here are some highlights from our latest staff survey (the numbers in brackets are the percentage of our people who agree with each statement):

- I believe in the overall purpose of this organisation (99 per cent)
- I believe in the work done by this organisation (97 per cent)
- Staff in this organisation treat clients with dignity and respect (96 per cent)
- My colleagues strive to uphold the rights of our clients (96 per cent)
- I am proud to tell people that I work for this organisation (96 per cent)
- I feel a sense of loyalty and commitment to this organisation (96 per cent)
- I take pride in telling people about what our organisation does (96 per cent)
- I believe in the values of this organisation (96 per cent)
- Our mission and values support person-centred approaches (96 per cent)
- I am aware of the values of this organisation (96 per cent)

These results are a testament to the passion and dedication of our people. Our commitment to all of our clients is that we will continue to find new and better ways to partner with our members and clients as they realise their dreams.
In 2017, a mere 18 months away, Spinal Cord Injuries Australia (SCIA) will be celebrating its 50th birthday. Not only is it a time to reflect on the past and current achievements of the organisation, it is also worth reflecting on our contribution to the disability rights movement in Australia. When the former Australian Quadriplegic Association (AQA) was created, unbeknown to its founders back then, Australia was on the cusp of a new social liberation revolution. The disability rights movement was born of the civil rights movements of the 1950s, 1960s and 1970s, including the fight for equality and the overturning of centuries of oppression experienced by black people, women and gay people, among others. In the words of Anne Manne, it was "a late flowering", but no less powerful and transformative in its messages of social justice, deinstitutionalisation, desegregation, personal empowerment, equality of rights and opportunities, and the removal of all barriers to fully realised dignity and independence.

Throughout the 1970s and 1980s, SCIA played a critical role in advocating for long-overdue legislative reforms in social welfare services, human rights and improved access to the community. Before 1981, for example, neither home nor attendant care existed for people with disabilities. Similarly, not only were all types of public transport inaccessible, there were also no modified taxis suitable for wheelchair use. In fact, if you didn't have private transport and couldn't transfer, the only option for routine medical appointments was an ambulance. As a result of a major protest at the opening of the Eastern Suburbs railway in Sydney, rallies outside federal and state parliaments, and extensive and painstaking backroom lobbying spearheaded by AQA/SCIA, gradual changes were introduced.

Today's wheelchair-accessible taxi service, now Australia-wide, came directly from the principled stand of our members who were no longer prepared to tolerate the poverty of transport choices. The public marches and impassioned speeches during the UN's International Year of Disabled Persons (1981) marked a turning point in public consciousness. Within a decade, anti-discrimination amendments were enacted, major community services were introduced and local councils began to take access seriously.

SCIA thanks and honours those whose contributions have made a profound difference.
LETTER TO THE EDITOR

Dear Editor,

As a Spinal Cord Injuries Australia (SCIA) full member and a person with quadriplegia, I nominated to be elected to the SCIA Board of Directors at the November 2014 Annual General Meeting (AGM). I was successful and very proud and excited that the SCIA members put their confidence in me to represent them on the SCIA Board.

I attended the first SCIA Board meeting directly after the AGM, but a few weeks later I was informed I could not remain on the Board as I live in SCIA-managed accommodation. Rule 48.(h) of the SCIA Constitution doesn’t permit more than two SCIA Board members living in SCIA-managed accommodation to be on the SCIA Board at one time. Two SCIA Board members currently reside in SCIA-managed accommodation.

It is extremely disappointing for me personally, and for the many SCIA members who voted for me, that this anomaly of Rule 48.(h) exists, and that it wasn’t raised at the 2014 AGM after the election results were announced. But if my nomination for the SCIA Board had been unsuccessful, this anomaly in the SCIA Constitution would not have become an issue.

I understand that Rule 48.(h) was added to the Constitution about 20-plus years ago when SCIA managed a large nursing home and was known as the Australian Quadriplegic Association (AQA). SCIA now manages a small number of group homes, with only a handful of residents receiving funded care support, for which SCIA gets government funding.

A group of SCIA members believes Rule 48.(h) is discriminatory and antiquated, and they petitioned to have the rule removed. This recently gave SCIA members the option to vote on a special resolution, which required a minimum 75 per cent of the votes to be ‘for’ the resolution, to remove the rule. Although a majority of 73 per cent of members’ votes was in favour to remove the rule, the 75 per cent criterion wasn’t met, and the rule remains.

Considering SCIA’s vision and mission statements, which include references to “a life without barriers and unlimited opportunity for people with spinal cord injury”, I hope one day this rule will be removed. Then that should enable all SCIA members the opportunity to represent the members on the Board, not to be excluded simply due to their accommodation situation, as I have been.

Yours sincerely,

Mark Tonga
Chatswood, New South Wales

Accord welcomes letters to the editor. Email your contribution to accordeditor@scia.org.au to be considered for publication. All contributions are edited and Accord reserves the right not to publish any contribution.

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Search ‘SCIA’

Heidz Haydon, Education Officer, Spinal Cord Injuries Australia

Sheree Hurley was a force to be reckoned with in the disability sector; a tenacious advocate for those with a spinal cord injury. Not many people were silly enough to stand in her way.

One of my earliest memories of Sheree was a couple of weeks after I sustained my injury, when I was in acute spinal rehab. Sheree was a peer support officer and came in to say hello with her beautiful assistance dog, Jade.

In the beginning I didn’t want anything to do with peer support, but as I got to know Sheree, I realised there was more in this world for me. She inspired me to pursue the life I wanted.

Watching Sheree change people’s lives was surreal. She was cool, calm, straight-up and no-nonsense. Patients and clients couldn’t get enough of her charisma and laid-back personality. Her cheeky smile and nature made us feel so comfortable; we put our trust in her. She changed lives; she certainly changed my life.

When we worked at Spinal Cord Injuries Australia (SCIA) together, Sheree wasn’t backward in coming forward. She was one of the people who reminded us why we were doing what we were doing: to improve the lives of those with a spinal cord injury.

She was instrumental in the creation of the SCIA Independence Expo and SCIA’s short-stay respite accommodation, CHOICES. These are legacies that will always remind us of Sheree. I only hope that I can make a fraction of the dent she made on this world.

Jack Seddon: 1945 – 2015

Alex Traill, former Regional Services Manager, Spinal Cord Injuries Australia

Jack was born in Salford, England, and immigrated to Australia in September 1969. He was a founding member of the former Australian Quadriplegic Association (AQA) Illawarra Resource Centre established in April 1986 (now the Spinal Cord Injuries Australia (SCIA) Illawarra and South Coast Resource Centre). Jack identified the need for the organisation to have a presence in the Illawarra region, as there were many issues within the community that required individual and systemic advocacy support.

I met Jack in March 1991 when I started in the position of Regional Manager at SCIA. It soon became apparent to me that Jack was a person passionate about issues that had an impact on the spinal cord injury community within the region. Jack was heavily involved on several community-based committees and the Wollongong City Council Access Committee. He was also a regular attendee at the weekly peer support group meetings, offering advice, support and adding a bit of humour to the day.

Jack had a strong interest in the built environment and design, so he set about attaining a diploma in drafting and put his new-found skills to work designing the amenities block located at the kiosk building in Killalea State Park, south of Shellharbour.

I recall Jack’s favourite saying, “I’m like a dog with a bone and I won’t give up,” and for those who knew him, this was very true. I was saddened to hear of Jack’s passing. To me, he was a genuine person full of passion and he will be missed by all his peers from SCIA. Our thoughts are with his family and, in particular, his wife Nancy, who supported Jack to achieve many milestones in his lifetime.
Citizens’ Jury hands down its verdict

The Citizens’ Jury has been unanimous in declaring the National Disability Insurance Scheme (NDIS) as a positive force for people with disability, but the NDIS is not without its challenges.

People with Disability Australia (PWDA) and Max Hardy Consulting led the Citizens’ Jury project with the support of the National Disability Insurance Agency (NDIA) between September 2014 and May 2015.

The Jury comprised 12 Australian citizens, including people with disability. They heard from NDIS participants and advocates about their NDIS experiences and considered the results of three focus group forums for people with intellectual disability and a social media forum. They were also able to question representatives from NDIA.

A Citizens’ Jury scorecard containing the findings of the Jury’s deliberations was published in May.

Among its findings, the scorecard revealed that many participants said the NDIS increased their choice and control, and there was more portability and less fragmentation of services.

The problem of unmet needs was also being addressed, and a number of participants pointed to achieving greater economic and social inclusion through living more independently, transitioning to mainstream study and employment, and gaining the means to choose mainstream social activities.

However, despite the successes, the scorecard also showed that there was room for improvement. Among its findings, the scorecard revealed that participants said the variability in the attitudes and skills of frontline staff resulted in some participants receiving variable service and outcomes. Also, because the previous block-funding model didn’t encourage people to think outside the square, many NDIS participants and planners were finding it difficult to think innovatively to improve rather than maintain lives.

For more details, visit: www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html

Be part of the SCIA Independence Expo 2016

The National Disability Insurance Scheme (NDIS) rolls out Australia-wide soon, and people with disability, their families and carers need to be informed about their options and what is available in the market.

If you are a service or product provider for people with disability, their families and carers, the SCIA Independence Expo 2016 is a great opportunity for you to get up close and personal with your audience from all over Australia.

The SCIA Independence Expo is a premier event and aims to provide an extensive range of lifestyle and disability products and services that will empower people with spinal cord injuries or similar disabilities to lead independent lives.

As the expo wants to touch all aspects of people’s lives, including daily living, social life, relationships, aspirations and recreation, a wide range of exhibitors is welcome to showcase products and services and present workshops and seminars. For-profit and not-for-profit organisations are welcome to exhibit.

A survey of exhibitors in the 2014 expo found that 100 per cent of them would like to come back in 2016.

“Great venue, lots of room for attendees, easy to drop off heavy items before set up, great to have access to discounted parking, lots of parking available [and] attendees very interested and happy to spend time [discussing] their specific needs,” according to one 2014 exhibitor. Most exhibitors said the 2014 Expo was very cost effective and the venue was great.

Exhibitors were also kept busy with a large volume of interested clients and networking with other exhibitors.

Visit www.scia.org.au/expo2016 to register your interest. For further enquiries email expo@scia.org.au or call 1800 819 775.

Newcastle Permanent injects $27,000 into the Beach House refresh

The refurbishment of the Beach House, an accessible holiday home in Coffs Harbour run by Spinal Cord Injuries Australia (SCIA), is underway thanks to a generous $27,000 grant from the Newcastle Permanent Charitable Foundation.

The Beach House provides a valuable service for people with spinal cord injury to enjoy a beach-side holiday with family and friends. But it requires a variety of minor repairs and needs a refresh. Newcastle Permanent Charitable Foundation Chairman Michael Slater says the grant to help refurbish the house will provide a high quality facility.

Peter and Lenore Brooks from Tamworth, parents to Dallas who has quadriplegia, say the Beach House is “a wonderful service that keeps ... families connected”.

Peter Perry, Chief Executive Officer of SCIA, thanked the Newcastle Permanent Charitable Foundation for the grant, saying the Beach House will be refurbished over the winter and will be ready for people’s summer holidays.

SCIA welcomes any local business interested in helping refurbish the Beach House by donating goods or services; please email SCIA at scia@scia.org.au or call 1800 819 775.
An extreme sports fanatic. Christophe says SpeediCath Compact Male catheters discreet design and secure packaging make it a natural fit for his active lifestyle.

Whether he’s kite-surfing, paragliding, skiing, quad-biking or sailing, Christophe often finds himself in some out-of-the-way places – places he wouldn’t dream of being in if it wasn’t for SpeediCath Compact Male catheters unique capabilities. Its ease-of-use, its discreet design and solid construction have rapidly made it indispensable. He says: “SpeediCath Compact Male has given me back my joy in my sports.”

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What do people with quadriplegia need to do so they can drive a car?

Technological advances are helping people with quadriplegia take to the open road.

Tony Varrall, Board Director, Spinal Cord Injuries Australia

The summer 2015 edition of Accord discussed the general requirements for a person with disability to obtain a drivers licence and suitably modified vehicle. For people with quadriplegia, here is some additional, specific information.

Driving is a key element to achieving greater independence and the freedom to go about life’s activities without having to rely on others. Many people say they would not have gained employment without having their own transport, and having the spontaneity that driving provides has given them a new lease on life.

There are vehicle modifications available that allow people with quadriplegia who don’t have good arm strength and range of motion to drive. This is usually in a van where the driver remains seated in the wheelchair, with the floor lowered and a ramp or hoist fitted for entry. A docking station on the floor in the driving position automatically connects with a plate fitted to the driver’s wheelchair. The doors can have electronic openers.

Driving controls are customised to suit the driver’s particular needs for the vehicle’s primary and secondary functions. This can include the following: a joystick or mini-wheel as an alternative to the normal steering wheel; adapted switches and levers for acceleration and braking; and a console of switches for functions like turning the ignition on and off, gear selection, indicating, switching on headlights and wipers, and applying the handbrake.

The process of getting a licence starts with applying for a learners permit. After an applicant declares they have a disability they need to obtain a medical certificate to show that they have no medical condition, such as vision impairment, seizures or heart disease, which makes them ineligible for driving. The results of the medical assessment will indicate if the applicant is medically fit to undergo off- and on-road driving assessments.

Once declared medically fit, the applicant undertakes an off-road assessment. During the assessment, an occupational therapist takes the applicant’s driving history and assesses their physical and thinking abilities to determine their suitability for an on-road assessment.

For those applicants who progress to the on-road assessment, the occupational therapist will then determine the driving controls that are likely to best suit the applicant’s needs. Specialist organisations have vehicles that can be fitted with multiple systems. The occupational therapist and a driving instructor can take the applicant on the road to test out these systems. The driving instructor typically has access to dual controls so they can take over the driving operations at any time.

Once the right system has been prescribed, the vehicle can be used for initial lessons before the applicant decides to go ahead and purchase their own van. Dual controls can be used in that vehicle too, so the applicant can continue their lessons and reach the required number of driving hours before doing the drivers licence test.

After passing the test, the driver is issued with a licence that includes the vehicle modifications that are required for them to drive. Depending on the nature of the vehicle modifications, they may also be recorded on the vehicle registration.


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Working in partnership
CHILD’S PLAY

More kids can look forward to joining in the rough-and-tumble of the playground thanks to generous donations to set up the first locomotor training facility for children with spinal cord injury in Australia.

T

hree-year-old Talyn Reedy ran, jumped, danced and revelled in a world of make-believe, so when she complained about having sore feet, the last place her parents expected her to end up was in hospital. In what seemed like minutes, Talyn went from being a boisterous youngster to being ventilated in intensive care with no movement from the neck down. It was 15 April last year—the date is seared into the minds of her parents, Emma and Amron, and her older brother, Kaimana.

Talyn was diagnosed with a rare neurological disorder called transverse myelitis, which resulted in a spinal cord injury, and remained in hospital for almost four months. Now four years old, she has regained a lot of function but continues to experience increased spasticity in her legs, so her running, jumping and dancing are a long way from what they used to be. Although her hand function is considered age appropriate, she lacks strength in her fingers, which may affect her writing when she starts school next year. She also has a neurogenic bowel and bladder, requiring intermittent catheterisation every 4 hours.

When spinal cord injury takes away a child’s ability to revel in the playground, it not only diminishes their opportunity to have fun but also interferes with their ability to develop physically, psychologically and socially.

Exercise and play

Spurred on by wanting to give Talyn and other children every opportunity to meet their developmental milestones, Spinal Cord Injuries Australia (SCIA) is preparing to open a children’s exercise clinic.

A first for Australia, the clinic will deliver paediatric locomotor training (LT) that is based on extensive research and clinical experience from the US. The brains behind the US approach are Dr Susan Harkema, Director of the Reeve Foundation NeuroRecovery Network, Professor of Neurosurgery and Rehabilitation at the University of Louisville, and Research Director of the University of Kentucky’s Spinal Cord Research Center and Frazier Rehab Institute; and Dr Andrea Behrman, Associate Professor in Physical Therapy at the University of Florida and Assistant Director at the Reeve Foundation NeuroRecovery Network.

Together Susan and Andrea have developed a three-phase approach to LT: step training using body weight support on a treadmill and manual assistance from therapists to guide the child’s body through a walking motion; over-ground walking training; and community ambulation training.

During the step training, up to four therapists are required: one to steady the child in the harness over the treadmill; two to guide the child’s body through the walking motion; and one to engage the child in play. Play-based activities are integrated into the other phases of LT as well. To reap the most benefit it’s recommended that children participate for one-and-a-half hours per day, five days a week.

The US research shows that sensory information is repetitively sent to the spinal cord during LT. The sensory information comes from the stepping, the therapist guiding the client’s foot through the walking motion, and the sole of the foot making contact with the ground. Basically, this approach assists in rewiring the brain and the spinal cord, which helps to improve movement and function.

This type of early intervention is particularly beneficial because it can significantly improve functional independence after paralysis and decrease the associated health complications and social implications of a spinal cord injury, says Kierre Williams, National Manager Exercise
Programs at SCIA. If children don’t weight-bear through their lower limbs as they develop they can experience bone and joint deformities and other complications. “Our bodies are made to move and children love movement. So, what better way to encourage reaching their developmental milestones than by incorporating play and movement with intensive [exercise],” Kierre says.

**Increasing capacity**

Although there is already a small number of body weight supported treadmill training programs in Australia, including SCIA’s adapted kids’ Walk On program, none of them provides LT as prescribed by the US researchers and clinicians mentioned above.

Talyn is currently attending SCIA’s adapted program and has made significant improvements. She is now walking intermittently with assistance. She starts school next year, so applications for funding have been made to make the school accessible. These gains have been achieved despite the medical fraternity being unsure about what Talyn’s medical future holds, says her mother, Emma.

Also attending the program is two-and-a-half-year-old Aiden Sue. He has been coming once a week for one-and-a-half hours since he was 18 months old. He was born with a spinal lipoma, at the T10-S5 level of his spinal cord and has already had two major operations to remove as much of the lipoma as possible.

Since joining the program, he has literally made great strides, progressing from no movement in his right leg and little movement in his left leg to standing unsupported, cruising furniture and walking with assistance. His parents Ray

![Talyn Reedy (L) participating in kid’s Walk On with physiotherapist Terrey Sheumack.](image-url)
and Pearl also supplement the program with home activities, which include play to encourage standing and walking.

Aiden and Talyn are benefitting significantly from the adapted program, so if they and other children attend the more intense LT retraining, it is predicted that their achievements will be greater.

**Funding**

Spinal Cord Injuries Australia children’s exercise clinic will start post July—once the SCIA exercise physiologists and physiotherapists undergo paediatric-specific training in the US, namely LT Training Principles and Practice in Louisville, Kentucky. The training has been made possible by a generous donation of $55,000 from DOOLEYS Lidcombe Catholic Club. This will cover the training and also fund one staff member for six months to oversee the program when it begins.

Other generous donations for the LT program have come from Mazda, which donated $26,855 for a LiteGait exercise machine to facilitate over-ground walking, and IOOF, which donated $30,000 for other equipment.

No ongoing government funding is available to support the program and participants are not subsidised to undertake the program. However, a grant from NSW Ageing, Disability and Home Care will enable the LT program to get off the ground, as it will fund five children at $10,000 per child.

“We are hopeful that, upon the successes of these children in the program, the government may continue to offer support to other families so their children can also attend the program,” says Kierre.
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Rob Pyne, Member for Cairns, is blazing a trail as he wheels his way through the corridors of power in Queensland.

Tony Leggett, Member, Spinal Cord Injuries Australia

The late Stella Young’s hilarious “inspiration porn” speech reminds us that overusing the word “inspirational” can seem cheesy or even condescending. However, in the case of Rob Pyne, Member for Cairns in the Queensland Parliament and the first Member of Parliament (MP) to have quadriplegia, the label of “inspirational” may just be appropriate. At the very least, Rob is in many ways impressive.

How so? Consider the travel itinerary of up to 50 flights between Cairns and Brisbane that Rob estimates he’ll make in his first year in Parliament. While this may be routine for any regional MP, these MPs don’t have the extra ‘joy’ of wheelchair travel. Wheelchair flyers will know that negotiating check-in, aisle chairs and shepherding crucial equipment is no trivial task. Doing that on a regular basis when Parliament is sitting, frankly it boggles the mind.

But that’s not all. There are Rob’s regional trips on top of that. However, his Cairns electorate is geographically small and relatively accessible compared with some of the nearby larger electorates. Proof that he is mortal, though, Rob readily admits he’s not sure how he’d cope with the additional travel (on small planes) required in the big rural electorates.

So it’s a good thing that Rob is a Cairns local. Rob grew up in Gordonvale, just south of Cairns, in Far North Queensland. While his father, Tom, was a prominent local politician, Rob was more interested in sports than politics before his injury in 1991.

However, a diving accident off a boat in Trinity Inlet left him with C5-6 quadriplegia and led Rob to the realisation that education was the key to his future. Since then Rob has completed a Bachelor of Arts in history and politics at James Cook University (JCU) and a law degree at Queensland University of Technology (QUT). University life gave Rob a taste for politics, with him becoming president of the student association. Rob married his wife, Jenny, in 1992 and they have a daughter, Katie, who is in Year 12 at high school.

Rob was elected to the Cairns Regional Council in 2008 and re-elected in 2012. As a councillor and now state MP, Rob is interested in the regional development of Cairns, particularly in the areas of health, education, small business, public housing and local infrastructure.

**Heritage access adventures**

In his maiden speech, Rob made special mention of the Clerk of the Queensland Parliament, Neil Laurie, for “providing him with ‘reasonable accommodation’ to allow him to contribute to this parliament on an equal footing with other MPs”. Rob felt the access changes were done proactively and without fuss, especially considering the heritage-building restrictions of Queensland Parliament House. Heritage requirements mean any changes must be undoable.

An expert consultant was engaged to assess both the Queensland Parliament and Rob’s electoral office. Rob’s Cairns electoral office needed a new accessible bathroom as well as the installation of electric sliding doors with swipe card access.

The Clerk of the Parliament said the parliamentary chamber was made accessible by reconfiguring some of the seats to create a space for Rob to manoeuvre his wheelchair into. Logistically, this needed to occur at the front (and therefore
Rob is aware of his minor celebrity status as a role model for people with disability.

Rob Pyne with his daughter Katie (L) and wife Jenny (R).

...ground level) of the chamber—so Rob is, in one sense, already a ‘frontbencher’. Rob also moved into a deputy whip’s office for quicker access to the chamber.

During sitting weeks regional MPs stay in rooms in the parliamentary complex. As a previous MP had injuries affecting their mobility, there was already a room mostly modified for Rob. The remaining modifications were just “lots of little things”, the Clerk of the Parliament said.

If this sounds too good to be true, there’s a catch. Visitors to the Queensland Parliament who use a wheelchair should know the public gallery remains one of the least accessible areas because of its steep, narrow steps.

Rough and tumble

Rob has a plain-speaking communication style in person and on social media. He believes people from a regional electorate wouldn’t tolerate anyone mouthing talking points and sound bites, so he doesn’t.

Moreover, being outspoken has its drawbacks, particularly as ‘troll fodder’ on social media. As reported in the Brisbane Times recently, Rob sought an apology over remarks that his predecessor, Gavin King, former Member for Cairns, posted on Facebook on 18 May: “Not really sure the current Member for Cairns knows much about preventative health or is an advocate for the many benefits of running and walking ...” In fact, just before this incident, Rob had taken a short, self-imposed leave of absence from social media when things got particularly heated.

Future possibilities

Many politicians will deflect tricky hypothetical questions with the good old “I don’t engage in hypotheticals.” However, Rob is happy to accept a hypothetical future position as Disability Services Minister assuming it becomes available. His main caveat is that his first term is 100 per cent about representing the people of his electorate. Cairns absolutely comes first.

Rob is aware of his minor celebrity status as a role model for people with disability. His advice for anyone contemplating following in his footsteps is to have a go, as he believes politics and public life in general need more people from diverse backgrounds. While not mandatory, a degree or two and considerable volunteer work (as in Rob’s case) certainly can’t hurt.

Finally, ‘Rob Pyne the MP’ is a team effort, with his wife, Jenny, travelling with him every sitting week of Parliament. Jenny complements Rob’s role as his personal organiser.

Already, Rob and his team are making quite an impression on the Queensland Parliament. ■

His advice: have a go, as politics and public life in general need more people from diverse backgrounds.
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Files in the cloud

I have been using a small hard drive to back up my files. This is okay, but it means I have to rely on carers to plug in the drive and then put it away at the end of the day. Having my files in the cloud could be better for me. What are the options?

Using a portable hard drive to back up your files is better than nothing. If your computer gets stolen the hard drive would probably go, too. There are several cloud-based systems that are popular and, from my experience, reliable. If you’re the only one using your files (i.e., files are not being shared simultaneously with others), your task is fairly simple. Some of the popular cloud-based systems are Dropbox, Google Drive, OneDrive (Microsoft) and iCloud Drive (Apple). These all work well and offer free storage up to a certain level. You need to be connected to the internet for the backup to occur, but each will appear as a separate folder on your desktop. The files are stored on your computer as well as in the cloud, but are synchronised when you connect to the internet. It can get tricky if more than one person is using the files, but that’s not your case. The beauty is this: if your computer fails through malfunction or is stolen, your files are safe.

Simple remote

My son has a disability and needs to be able to switch from Foxtel to free-to-air television simply. At present he has too many choices and gets lost when moving from one to the other. Is there a remote that could make this process easier for him?

The best solution for your son would be a remote control with a macro function. This means a number of commands could be stored under one button. Among specialised devices there is the HouseMate Lite ($990). Another option would be a generic device such as the Logitech Harmony 650 (about $90) or Logitech Harmony Ultimate One (about $290). These have customisable touch screens and the capacity to store a sequence of commands under one button.

Equipment trials

I would like to trial some computer devices, such as a trackball or joystick, and maybe speech recognition. It’s very hard to borrow such devices, so how can I be sure if they are suitable for me? It’s too late once you’ve paid your money.

We agree there is a big need for an equipment loan pool. Some suppliers do lend some devices, but in our experience there are often lengthy waiting lists. EnableNSW does have some equipment available in a loan pool if you are in New South Wales (see www.enable.health.nsw.gov.au/home/services/speech-generating-device-loan-pool). At Ability Technology we have also commenced our own loan pool to meet this need. It’s called TryIT and you can contact us at info@ability.org.au for details.

One phone to rule them all

I have a landline phone and a mobile phone at home. I get caught out if I’m in one room and the landline phone is in another room, or if my mobile is charging in one part of the house and I’m in another. The result is I miss a lot of calls. Is there a solution for this mess?

There is a solution: the Uniden XDECT 8155 Bluetooth Portable Phone. This interesting phone enables you to pair up to four mobile phones with the cordless landline phone unit. This means you can make and receive calls from either the landline or the mobile. It comes with three handsets (including one on the base). It has a power failure mode—when a power failure occurs the charged handset temporarily supplies power to the base unit. You can then make and receive calls using a handset.

Technology means

- Independence
- Productivity
- Connection

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What’s your story?

When people get to know each other a little better, it can break down fears and misconceptions to create potential employment opportunities.

Stephen Lowe, Disability Employment Manager, SCIA Workforce, Spinal Cord Injuries Australia

Generally employers in Australia have limited exposure to people with spinal cord injury (SCI), and their fear of offending (not knowing what to do or say) may unintentionally inhibit the access of people with disability to employment opportunities.

Employers aren’t seeing the person and their capability, rather they are seeing the disability and incapacity. This generally comes from a position of concern—almost being over supportive.

So when these fears and tendencies are combined with perceptions about the cost of employing people with disability, it’s too easy for some employers to say “It’s all too hard”.

Nevertheless, blaming employers for this lack of awareness doesn’t help. Instead, the situation needs to be viewed as an opportunity for greater education of employers and the broader community.

Learning about the skills and experience people with SCI can bring to the workplace and the challenges they have overcome just to get to the front door of a prospective workplace is enlightening.

Individual perspective

We’ve seen that the transition potential employees with SCI undertake post injury can challenge them in many ways—especially their sense of identity about what they can do. This takes time to work through; the length of which varies from individual to individual.

Those who are fortunate to have support, self-belief and confidence throughout their transition tend to seek and accept support in finding employment more readily than those who don’t. Again, it is an individual process. However, in our experience, most people keep in mind that employers look for employees with the right attitude.

Type of employer

There are large employers that actively seek the employment of people with disability. These organisations generally employ to a clearly identified strategy and in some cases to a quota, and have dedicated staff on hand to facilitate the process.

Small-to-medium sized employers generally don’t have the capacity to undertake the same processes due to the amount of time and other resources that are required. This is doubly so for those employers in regional areas.

This gap in employers’ ability—whether actual or perceived—to hire people with disabilities poses a significant problem, as small-to-medium sized employers constitute the majority of employers in Australia. It is these employers that often provide the opportunities for people in general to enter or re-enter the workforce.

Expectations

People with SCI who take on new job roles need to apply newly learnt skills like any person starting a new role. They cannot be expected to operate at the highest level immediately.

People also need to adjust to work after long periods of being out of the workforce. They not only have to learn their new job role but also manage the physical demands of the new environment. However, these barriers can be overcome for the mutual benefit of the employer and the new employee.

SCIA Workforce currently manages the transition back to work by partnering with people with SCI and employers to ensure a successful employment outcome for all parties.

This means developing and implementing individual programs, including accessibility, training and education, to satisfy the job requirements as well as the career aspirations of the person with SCI.

This approach can lead to fantastic new experiences and opportunities for employers and people with SCI.

To get back to work or hire top talent, email: workforce@scia.org.au or phone: 1800 819 775.
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Now you see it, now you don’t

Conjuring up laughter and suspense is easy when you have a number of magic tricks up your sleeve.

Wheels McCrudden

The people at Bunnings Warehouse are probably still scratching their heads after I wheeled into a local store with my straitjacket and asked to see the chains-and-padlocks aisle. Finding the right chain length and padlock for an escape trick is no easy task. The only option for ensuring I’d get the right type and size of gear was to don the straitjacket and be chained up, right there and then, in the store.

The Bunnings sales assistant was a little shocked, but he never wavered in his help—just like the ones in the television commercials. He brought out the chain cutters to ensure that I (and the friend who had accompanied me into the store) got the chain lengths right. I drew quite a crowd, particularly when I practised struggling free—which went off without a hitch. As we left the store the police came in—but we didn’t stick around to find out why they were there.

Creating scenes in hardware stores was not my first foray into magic. As a young child, whenever I visited my grandparents, my grandfather would show me this one magic trick. He would do the same trick every time, but he never divulged how it worked.

It wasn’t until I got to high school that the real magic started to happen. As a student I was also a television presenter for a community-based program and I was fortunate enough to interview a magician. After that I started taking magic more seriously and began practising.

Once I finished high school I started attending magic nights run by a group of local magicians. On my very first night I was told I had to perform. For most people, I suppose, being confronted with that would have made them a nervous wreck. But, for me, I spent the entire night performing without any problems. I only had to do one trick to be accepted into the group, but I really made an impression when I just kept on table-hopping and doing different tricks. Since then I’ve been going on a weekly basis.

I drew quite a crowd, particularly when I practised struggling free from the straitjacket.

The magic world knows me as Wheels—very few people know my real name. It’s all part of the illusion. Just like my tricks. I mainly do card tricks, such as Card from Box, Reset and Cannibal Kings. One that gets requested a lot is called ‘The Grandfather Special’. This was my very first trick—it’s a card trick I created and dedicated to my grandfather.

I perform at children’s parties, when I’m out with family, but mainly at the regular magic nights. However, I want to get back onstage so I can play to bigger audiences. A bigger audience lends itself more to including jokes in my act while still retaining the element of suspense. Performing on stage also draws a different sort of crowd, and I feel I can connect with my audience better than when I do ‘close-up’ magic.

I first appeared on stage in 2010 for a magic competition. This is the competition I was preparing for when I was at Bunnings Warehouse. I did the straitjacket escape and then the illusion of sawing someone into two. I made it to the second round as a ‘ wildcard’ entry.

Best of all, with these tricks up my sleeve, laughter and suspense are in great supply.

I drew quite a crowd, particularly when I practised struggling free from the straitjacket.

Pictured:
Wheels McCrudden
Sit skiing Grand Targhee in the US

Taking on the never-ending snow at Grand Targhee in the US and exploring its iconic surrounds brings a sit skier closer to becoming an adaptive ski instructor at home in Australia.

Sue Thomas, Peer Support Volunteer, Spinal Cord Injuries Australia

Flying out of Australia to the American ski fields on Australia Day may seem unpatriotic, but it means the holiday gets off to a good start because the airport is quieter and the traffic to the airport is easier to negotiate than usual.

Our flights ultimately deliver us to Salt Lake City, Utah, which is a four-to-five-hour drive to our destination in Idaho. As my husband and I are frequent visitors, these days we have our own car, which friends drive down from Idaho.

We spend a couple of nights in Salt Lake City adjusting to the time, cold and altitude. The city is beautiful and friendly, perched on the southern end of the Great Salt Lake and dwarfed by the rugged Wasatch Mountains. Spending time there not only allows us to enjoy the surrounds, but also to stock up on skiing supplies before driving off to the slopes.

Driving north to Idaho seems to take no time, thanks in part to the 130km/h speed limit in Utah and Idaho, and sunny weather—driving in blizzards in this part of the world is not recommended.

Before we know it, we’re in Teton Valley, Idaho. We stay in Driggs from late January to early April, skiing at Grand Targhee Resort, which is just across the border in Wyoming. Staying for so long in the one place allows us to minimise accommodation and skiing costs. I can purchase an early-bird adaptive season pass and pay only US$250. Our accommodation is a private rental, which is accessible enough.
Driggs is well serviced and generally easy to get around, depending on how much snow is on the ground. Using a FreeWheel and outdoor tyres on my wheelchair makes negotiating the snow a lot easier.

Grand Targhee is a wonderful, friendly ski resort that caters well for adaptive skiing (as do many American resorts), but there’s no accessible accommodation on the hill. However, the resort never gets too busy and has one of the best beginner areas in the west of the US. The views from the resort towards Grand Teton National Park are spectacular on sunny days, which we find are in good supply. A little-known secret is that Grand Targhee often has the best snow in the Rockies, which is the case this year.

Apart from continuing to improve and enjoy my skiing, I’m able to further work towards becoming a Level 1 adaptive certified ski instructor. I joined the Professional Ski Instructors of America (PSIA) last year and have been studying hard for certification. I’ve just about clocked up the hours required for observing lessons and assisting in lessons, and I hope to sit the certification exam next year. I’m hoping that I can then find a way to use my newfound skills in Australia, helping others to discover the joy I’ve found in learning to sit ski.

Mixing it up

Not every day is a ski day while we’re in the US. I take time off to recover, which can include attending local yoga classes and doing the odd side trip. A local not-for-profit organisation headquartered at nearby Jackson Hole can help to arrange lessons and equipment hire for Nordic skiing and other activities. The National Elk Refuge in Jackson is a great place to spot elk, bighorn sheep and the odd moose.

A highlight this year is a full-day trip into Yellowstone National Park. The weather is great, though cold; and thanks to an early thaw, a lot more is wheelchair accessible than usual. In winter more of the thermal features are evident (Old Faithful geyser is true to its name) and we see plenty of bison and the occasional elk and coyote. The tour operator caters well for wheelchairs (there are two of us with wheelchairs on this trip), but the early thaw makes the road conditions a little tough to handle.

We end this year’s ski trip with another couple of days in Salt Lake City and a side trip to Antelope Island on the Great Salt Lake.

After a final meal of good old American barbecue, our hearts and minds are ready for home—but already with a thought to next year’s return.

I’m hoping to finish my instructor certification next year and help others in Australia to discover the joy in learning to sit ski.

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INFORMATION AND RESOURCES

Don’t Push Me: Walking the Wheelchair Walk by Ed Hooper. The author speaks with his alter ego, Spokes Ableman, about stigmatisation and the pressure to acquiesce to second-class treatment simply because he has quadriplegia. Visit: www.booktopia.com.au/don-t-push-me-ed-hooper/prod9781507843321.html (or borrow from the SCIA Library)

Reconnecting: Relationship Advice from Wheelchair Users by Lisa Wells. Six people who use wheelchairs share their perspective on friends, family and relationships, including dating, marriage and parenting. Visit: www.amazon.com/Reconnecting-Relationship-Advice-Wheelchair-Users/dp/1508437890 (or borrow from the SCIA Library)

Shepherd Center Personal Care Manual and website by the Shepherd Center. The manual provides information on the effects of spinal cord injury (SCI) and detailed instructions on personal care procedures. The centre also has other comprehensive online resources for people with SCI, including video instructions. Visit: www.myshepherdconnection.org/sci

Resting Easy in the US: Unique Lodging Options for Wheelers and Slow Walkers by Candy B. Harrington. This guidebook discusses access to more than 90 properties across the US, ranging from bed and breakfast, guest ranches and lakeside cottages, to boutique hotels, rustic cabins and deluxe yurts. Visit: www.amazon.com/Resting-Easy-US-Lodging-Wheelers/dp/0692430571 (or borrow from the SCIA Library)

CareCure Community is a US-based online resource consisting of more than 70 forums where people can talk and give and receive information on a wide range of topics. You are welcome to browse and if you register you can contribute to the forums. Visit: http://sci.rutgers.edu/forum

Apparelyzed website and forum is a UK-based resource where people can go to share their experiences and learn about spinal cord injury (SCI). Visit: www.apparelyzed.com

Reusability is an Australian website with classifieds for disability, aged care and rehabilitation aids and equipment. Visit: www.reusability.com.au

Life after a Spinal Cord Injury, Series 1 & 2 Video podcasts produced by a group of people with spinal cord injury (SCI) to help newly injured individuals address various aspects of life. Visit: www.rippleproductions.co.uk

These publications and resources are available for loan or download from the Spinal Cord Injuries Australia SCI Resources Library. For details, and to borrow, visit library.scia.org.au, call 1800 819 775 or email library@scia.org.au. In addition to the library and a comprehensive range of topics delivered through publications and SCI Resources on our website, SCIA offers help and advice to people with a spinal cord injury (SCI) and similar disability, their families and carers through their SCInfo service. SCInfo can be contacted by phone on 1800 819 775, email information@scia.org.au, or visit scia.org.au/information-services
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INDUSTRY EVENTS 2015

**JULY**

28 - 30
TRANSED 2015: 14th International Conference on Mobility and Transport for Elderly and Disabled Persons, Lisbon, Portugal
www.transed2015.com

29 - 30
Australian Community Workers Conference and Exhibition, Pullman on the Park, Melbourne, Victoria

**AUGUST**

11 - 14
ICORR 2015: International Conference on Rehabilitation Robotics, Singapore
www.icorr2015.enabling-technology-festival.org

12 - 14
International Convention on Rehabilitation Engineering and Assistive Technology (i-CREATE 2015), Singapore
www.icreateasia.org

**SEPTEMBER**

2, 9 & 16
Gearing Up Living Your Potential Expos: 2 September, Princess Wharf 1, Hobart; 9 September, Tailrace Centre, Launceston; and 16 September, Arts and Function Centre, Burnie

6 - 9
www.academyscipro.org/Public/Conference2015.aspx

**OCTOBER**

7 - 9

16 - 17
Wellness Through Leisure: 2015 National Diversional Therapy Australia Conference, Mercure Gold Coast Resort, Gold Coast, Queensland
www.diversionaltherapy.org.au/Professional-Development/Conference

**NOVEMBER**

8 - 14
Spinal Cord Injury Awareness Week
www.rebuildinglives.com.au

**DECEMBER**

3
International Day of People with Disability
www.idpwd.com.au

28 - 30
National Housing Conference, Perth Convention Centre, Perth, Western Australia
www.nhc.edu.au
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SMALL. IT’S KIND OF A BIG DEAL
The recent New South Wales (NSW) state election and cabinet re-shuffle have opened up a new front on the Taxi Transport Subsidy Scheme (TTSS).

After the election in March, Gladys Berejiklian was promoted from Transport Minister to Treasurer; Andrew Constance (a former Minister for Disability Services) moved from being the Treasurer and Industrial Relations Minister to Transport Minister; and John Ajaka remained as the Minister for Disability Services.

Before the election, the Transport Minister and the Disability Services Minister issued a joint media release stating there would be improvements to transport services, including “possibly” an increase in the TTSS subsidy. In light of this and the Cabinet re-shuffle, I wrote to the three Ministers seeking their support to increase the TTSS subsidy.

As the Transport Minister, Gladys Berejiklian often stated that the transport portfolio only received a limited budget from the Treasurer so she was unable to increase the TTSS subsidy. So my letter suggested that now she has been promoted to NSW Treasurer it would be appreciated if she could allocate the funding to increase the TTSS subsidy.

The Treasurer responded, saying she had forwarded the letter to the Transport Minister. The Transport Minister’s Department responded, noting the issues raised but did not address them. The Minister for Disability Services responded but only provided details of services related to the National Disability Insurance Scheme (NDIS), not about the TTSS.

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**Goods and services tax**

Spinal Cord Injuries Australia (SCIA) continues to advocate to expand the variety of items with a goods and services tax (GST) exemption for people with a disability. SCIA’s submission to the GST Policy and Administration Subgroup (GPAS), which comprises state and territory government representatives, was due to be considered in April, but was rescheduled to May. At the time of writing this column, the GPAS hadn’t met. SCIA will report the outcome, when it is known, on its website, in other media and the next issue of Accord.

An exemption from the GST will have great benefits for many people with disability—in particular, those people who are ineligible for any government-funded or government-provided services or programs, including the NDIS. Those who are ineligible for such services have to fund their own items, including vehicle modifications and maintenance, home modifications and maintenance, purpose-made adaptable clothing and so on. An exemption from the GST would make these products and services more affordable.

**NDIS sustainability**

More people are eligible for the NDIS and more people have had NDIS plans approved, according to the National Disability Insurance Agency (NDIA) sustainability report on the trial sites that was released in February.

From July 2013 to December 2014, the NDIA report says 13,646 participants were eligible for the scheme. This is an increase of 2,707 participants since 30 September 2014. Also, 11,029 participants had an approved plan and $565.3 million of support has been committed to these participants. This is an increase of 2,149 participants since 30 September 2014, the report adds.

The report also says that in the December 2014 quarter, plan reviews represented more than half of the plan approvals in the following trial sites: NSW (58 per cent), Victoria (63 per cent) and Tasmania (78 per cent). But only 35 per cent of the plan approvals were plan reviews in the South Australian (SA) trial site.

The average annualised package cost across all trial sites at the end of December 2014 was approximately $35,300, excluding trial sites in the NSW Hunter regions of Stockton and Colanda, the report says.

Also, to improve clarity around the NDIS, the scheme’s three tiers have been
renamed as follows: Public awareness and general information (previously Tier 1); Information linkages and capacity building (previously Tier 2); and Individual funding packages (previously Tier 3).

Citizens’ Jury report

The NDIS Citizens’ Jury results were released by People with Disability Australia (PWDA) in May.

The Citizens’ Jury was an independent, user-led (participant) evaluation of the NDIS. The jurors, who were randomly selected from across the country, heard directly from participants in the NDIS trial sites about their experiences to date.

According to PWDA, the Citizens’ Jury found the NDIS was already successful in enabling quality-of-life outcomes for some people with disability that would otherwise not be possible. However, the jury also reported areas in need of improvement, such as planners needing to be appropriately resourced and have the right skills. Turn to page 6 for more details.

For the report, visit: www.pwd.org.au/admin/ndis-citizens-jury-scorecard-project.html

Federal Budget 2015

The Federal and NSW governments have agreed to provide disability support under the NDIS for up to 2,000 people under 18 years of age in the Blue Mountains and Penrith from July 2015.

This agreement includes $20 million allocated in 2015/2016. It will cover access to information, referrals and capacity building through the NDIA from July, while access to individualised packages of support will start from September.

According to the Federal Government, the agreement allows for testing of the NDIS in advance of “the ramp-up” from July 2016.

Quality and safeguards

To protect vulnerable people with disability who are participating in the NDIS, a new quality and safeguarding framework is being developed.

The Australian Government has been seeking input from the community in the development of the framework through its consultation paper, A National Framework to Quality and Safeguarding for the NDIS. The consultation paper proposes a three-pronged framework: building individuals’ own natural safeguards; measures to ensure people with disability are safe from harm; and actions that participants and governments need to take to respond to incidents after they have occurred.

SCIA has lodged a submission in response to the consultation paper. In regard to the screening of staff to ensure they are safe to work with people who may be vulnerable, for example, SCIA supports Victoria’s approach. Victoria has a register of people barred from working in state-funded disability accommodation services, based on their convictions or past work history. SCIA would like this scheme to be extended nationally.

For other details about the framework, visit: engage.dss.gov.au/ndis-qsf

Submissions closed 30 April 2015.

Policy and Advocacy survey

People with disability and their families, friends and carers have been having their say in an online survey developed by the SCIA Policy and Advocacy team. The survey asks them about the barriers they have faced when accessing services and programs, how they have responded to these barriers, and what resources they need to better address barriers.

Once the responses are analysed, they will be used to develop resources to assist all people with disability.

SCIA thanks those who have participated in the survey.
SCIA Events

**JULY**

18  
Duo: When Elishia Met Tommy  
Prince of Wales Hospital (POWH) Spinal Unit, Randwick, NSW

25  
Wild Life Sydney Zoo, Aquarium Wharf  
Darling Harbour, Sydney, NSW

**AUGUST**

1  
Singer: Dan Demos  
Prince of Wales Hospital (POWH) Spinal Unit, Randwick, NSW

8  
The Australian Museum  
College Street Sydney, NSW

22  
Singer: Eileen McCann  
Prince of Wales Hospital (POWH), Spinal Unit, Randwick, NSW

29  
Comedy Store and dinner  
Fox Studios, Moore Park, NSW

**SEPTEMBER**

5  
Singer: Jae Haydon and BBQ  
Prince of Wales Hospital (POWH), Spinal Unit, Randwick, NSW

12  
Archery and BBQ, Sydney Olympic Park Archery Centre, Homebush, NSW

19  
Singer: Billy Demos  
Prince of Wales Hospital (POWH) Spinal Unit, Randwick, NSW

26  
Shooting, Sydney International Shooting Centre, Cecil Park, NSW

**OCTOBER**

24  
Picnic, Royal Botanic Gardens Sydney, NSW

To find out more or to join an event, visit www.scia.org.au/events, email events@scia.org.au or call 1800 819 775.

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**New roads to travel**

The Assistive Technology Industry is growing with advances in the complexity of products and also the solutions it offers end users. GMS Rehabilitation, which is based in Melbourne with agents around Australia, is launching a new range of lifestyle products that will enable you to travel to places that you haven’t been able to before.

The Hippocampe is a beach wheelchair, which has been designed in France by a person with paraplegia. It folds up to fit easily into your car and allows you to self propel or be assisted over paths, sand dunes and into the water. It floats and is made of foam-covered aluminum for superior rust resistance. Have a look today? Visit: www.vipamat.com

The Zoom is a new Swedish designed and manufactured off-road mobility device. Not actually a wheelchair, but it allows users to travel off-road on farms, beaches, snow, bush settings and other hard-to-get-to places. It is designed for people with lower limb issues and is used by people with paraplegia and quadriplegia, who have reasonable hand function. It is groovy and a heap of fun to use. Why not look at the Zoom website? Visit: www.zoomability.com

The Genny is the first generation of self-balancing wheelchairs being made by Genny in partnership with Segway. This amazing two-wheel wheelchair will revolutionize travel for many people with spinal cord injury. With a short footprint and zero centimetre turning circle it is a must have. What could you do with this solution? Visit: www.gennymobility.com
New catheter provides a step towards a fuller life

Hollister, specialising in continence care

Linda’s life was always busy with family, travelling for work and juggling social commitments. After encountering some serious health complications and undergoing a major operation a decade ago, her lifestyle changed substantially and led to her becoming reliant on intermittent catheters to manage her urinary incontinence.

“As a young woman, this really changed the way I looked at my life—and, initially, not for the best. Mentally, having to deal with the process of catheterising regularly was a big challenge. I found myself deciding not to travel long distances or visit certain places because of my concerns around cleanliness and the potential for contracting urinary tract infections,” Linda says.

Linda recently began using Hollister Advance Plus—an innovative and easy to use ‘touch free’ pre-lubricated catheter system. “Advance Plus has removed many of my concerns about hygiene and health. I worry less about carrying around bulky catheter kits and finding clean restrooms—and can focus more on my lifestyle and the freedom that this product offers me instead;” she says.

Having worked with and cared for Linda for a long time, Debra McCormack, Continence Nurse at Gold Coast University Hospital, confirms that Linda’s concerns around health, cleanliness and privacy are universal amongst many patients who use catheters. “Ease of use is critical to the general wellness of patients when it comes to using catheters regularly. Advance Plus intermittent catheters are an easy-to-use, intuitive product. Educating patients to catheterise with this system is simple, as the closed catheter system allows there to be less of an intense focus on their carrying around multiple products and looking for clean, private bathrooms,” Debra says.

A key focus for Debra and other healthcare professionals who work in urology and continence education is helping their patients to perfect their catheterisation technique, as patients can initially find this process both uncomfortable and confronting. “Infection control is a major issue—Advance Plus is a fully-contained system which removes the concerns around ‘touching’ that patients have—particularly if they are prone to urinary tract infections, or simply can’t get to a clean restroom in which to catheterise,” Debra says.

Linda has used both traditional catheters and the Advance Plus closed-system catheter. “Being pre-lubricated and totally hygienic, I prefer to use Advanced Plus catheters. Before using this product, I really restricted my lifestyle—I based my movements and activities around when and where I could use a catheter safely and comfortably. I am very prone to urinary tract infections, and so feel a natural caution about using a catheter outside of my home. Few public restrooms are hygienic, and I can’t risk getting infections continually. Advance Plus helps me live a more active and engaged life by easing my worries about hygiene and privacy—it’s simple to use, requires no touching and is discreet,” Linda says.

“Using catheters is something I’ll have to do for the rest of my life ... Advance Plus makes this process easier and safer for me.”

Debra is pleased that her patients can return to living full lives with the help of a product like Advance Plus. “When patients first start self-catheterising, they can feel really stigmatised and excluded from a society that literally has no idea of the complexity of their daily healthcare. The process around using traditional catheters not only takes a lot of time from one’s day, it is multi-step and requires immaculate hygiene, which the real world rarely offers,” Debra says.

Advance Plus is an ideal solution. As Linda says, “Using catheters is something I’ll have to do for the rest of my life ... Advance Plus makes this process easier and safer for me.”

The views expressed herein are those of the user and nurse only. Always consult your healthcare professional prior to using any catheter.

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Ensuring equitable and effective services

Leanne Cowan, Regional Services Manager, Spinal Cord Injuries Australia (SCIA)

We are starting to see the rollout of the National Disability Insurance Scheme (NDIS) extend beyond the Hunter trial site, with people under 18 years of age in the Blue Mountains and Nepean areas set to be included over the coming year. As the NDIS catchment expands, we haven’t lost sight of the fact that not everyone will be eligible for the NDIS or, in some limited instances, need the NDIS.

We understand that one size rarely fits all. In doing so, Spinal Cord Injuries Australia (SCIA) is committed to ensuring that our services are delivered equitably and effectively, no matter where you are or how you are funded.

Furthermore, we are looking to have a greater presence in a number of New South Wales regional areas that we haven’t previously engaged directly, including the Hunter, Central Coast, Western Sydney, Southern Inland, Riverina, Murrumbidgee and Far West areas. These are exciting times.

If you have any ideas about what you think might be useful in your area, please contact me at lcowan@scia.org.au

NORTHERN RIVERS

Lee Clarke, Regional Officer, SCIA, northernrivers@scia.org.au

Over the past 12 months I have been working with the Mid North Coast Local Health District Community Reference Group and the Hastings Macleay and Coffs Harbour clinical networks. My role is to advocate for people living with spinal cord injury or other severe physical disability and their carers and families, to ensure better outcomes from hospital stays and experiences.

One project we are currently working on is policies and procedures that allow carers to assist their loved ones while in hospital with tasks such as showering, toileting and transferring using a hoist. This may be done by a paid care worker or a family member who usually does it at home for the person. Currently there is no risk assessment to cover these tasks if they are done by people other than the relevant hospital staff members. Therefore, some hospitals will not allow a carer to do it, while others realise the benefit of continuity of care for the person.

Casting a line

Mark Tanner, our local Peer Support Volunteer, is organising a fishing competition and outing for people with spinal cord injury and other severe physical disability. The Nambucca Heads Offshore Fishing Club Inc. is hosting the event. The club is currently looking for sponsors to make this an outstanding event with great prizes for all participants. You may even be able to get out on the river in a boat on the day. A barbecue will be provided at the weigh-in.
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NEW ENGLAND
Glenda Hodges, Regional Officer, SCIA, newengland@scia.org.au

As changes to the disability sector loom in New South Wales, I have attended a number of meetings with other service providers, and it is evident there is still a lot of uncertainty for people working in the disability sector, which adds confusion to the information provided to the many people needing assistance and care. Services such as Home Care and a few local block-funded services are still unsure of what’s going to happen after 30 June.

The regional representative for Home Care was invited to speak at our Tamworth information session earlier this month. But the talk was rescheduled for after 1 July, when the outcome of the tender submitted for the privatisation of Home Care will have been released.

The Armidale group has continued with its card sessions every second Tuesday. A number of people have been attending and enjoying the informal get-together at Armidale Bowling Club.

At last, a drive-through postbox will soon become a reality in Armidale. It has been on the agenda of the Armidale Dumaresq Council Access Advisory Committee for about 10 years. The postbox will be included in the next Armidale Dumaresq Council financial year budget. This will be the second such postbox available in NSW. The other, in Queanbeyan, has been in service for a number of years. Congratulations to the Armidale Dumaresq Council Access Advisory Committee for its consistent and committed work to achieve such a useful and well-considered project.

CENTRAL WEST
Craig Lees, Regional Officer, SCIA, centralwest@scia.org.au

In response to lots of interest from people in the Central West about home automation to reduce dependence on carers, here’s an overview of what is available.

In the smart phone era, environmental control systems can be less expensive to set up than in the past. Particularly for people with high-level spinal cord injury, environmental control can help minimise dependence on carers for many tasks.

Current smart phones come with a variety of technologies for connectivity. These often include infra-red, Bluetooth, Wi-Fi, near field communication (NFC) and voice recognition control. Mounted on an electric wheelchair, this technology can help a person take more control of daily tasks, no matter where they are.

Using a current-generation smart phone with the appropriate app, you can control remote-controlled appliances, including lighting, air conditioning, audiovisual gear, remote-operated doors and locks, and security systems. If an appliance doesn’t have remote control, plug-in remote receivers are available to allow control via infra-red, Wi-Fi, radio frequency signals or NFC.

A commonly asked question is: which type of smart phone operating system is best? In the past, Apple was the first choice, primarily because of the advanced voice recognition system, Siri. However, the voice recognition system used in current-generation Android phones is nearly as good as Apple, plus Android has a big advantage with its USB On-The-Go (OTG) connection. OTG allows a greater range of generic switch controls to be used, such as a computer mouse or a sip-and-puff switch. Being open source, Google also has the greater range of apps for free or very low prices; the Tasker app, for example, is very powerful and costs only a few dollars.

Where should I start in building a system? If money is no object, there are commercial applications that already exist. However, if you’d like to build your own system as cheaply as possible, a lot of internet research is required to work out your needs and what you may want from the system. The smart phone or tablet should be the starting point.

More information and ideas about technology can be found on page 17.

VICTORIA
Nazim Erdem, AQA Victoria (support for people with spinal cord injury in Victoria), nazimerdem@aqavic.org.au

This year at AQA, we’re excited to launch our regional networks program for people living with spinal cord injury (SCI) in regional Victoria and Tasmania, as part of the Spire launch. The Spire vision for regional networks is based on partnership, and we are looking to set up these networks progressively across regional areas in Victoria and Tasmania. The Ballarat SCI Regional Support Network, based in the Grampians Region, was the first group to launch.

You can follow the rollout on AQA’s Facebook page (search for AQA Spinal Injury Info & Support) and on the Spire website (www.spire.org.au).
Taking on the town
Heidz Haydon, Education Officer, Spinal Cord Injuries Australia

The World Famous Comedy Store Showcase
Comedy Store
Moore Park, Sydney

We had front-row seats at The World Famous Comedy Store Showcase: seven comedians back-to-back, finishing with headliner James Smith from the television series, Flight of the Conchords. Staged at the Comedy Store at Moore Park, Sydney, the show was a great laugh. The Spinal Cord Injuries Australia (SCIA) Peer Support team organised the night out for SCIA members on Saturday 18 April. Before heading to the Comedy Store, we met for dinner at P.J. Gallagher’s Irish Pub, about one minute up the road from the Comedy Store. The pub was accessible and attended to all our needs, taking our orders from the table rather than expecting us to order at the bar. As it was the first time some of the members had met, everyone had a great time introducing themselves. Building new friendships and networks is what SCIA events are all about.

After dinner we made our way to the Comedy Store. The staff were fantastic, making sure we got to our seats before the show started. Although the building was accessible, there was only one lift, which could take just one chair at a time. But in the end we all made it to our seats. Everyone enjoyed the show, even if there was some crude humour. It was good to let loose for the night and have a laugh.

Taronga Zoo
Mosman, Sydney

Our independence was tested at Taronga Zoo. If you’re planning to go to the zoo, be prepared for lots of hills. The SCIA Peer Support team organised a day out at the zoo for SCIA members on Saturday 9 May. Despite the hills it was well worth the effort.

We met at the top entrance to the zoo near the car park. For those who didn’t drive, there was the public transport option. Some of us met at Circular Quay and caught the ferry to Taronga Zoo Wharf. Ferry staff were on hand to help those in power and manual chairs. After we disembarked, buses were available to take us to the top entrance. All the buses were wheelchair accessible, but because only two chairs can fit in a bus, we had to wait our turns. The Sky Safari cable car is also available to take you to the top entrance, if your chair is less than 61cm wide.

So that people could have their independence and trek around the zoo in their own groups wherever they wanted to go, we arranged to meet at the fish and chip shop for lunch at 1.30pm to catch up and chat about what we’d seen so far and where we were off to next. This approach gave people the opportunity to be independent and follow the zoo map wherever they chose.

As the zoo has lots of hills it’s wise to plan your day early with the access map on the zoo’s website. If you have a manual chair, an electric add-on like SmartDrive would also help.

The day went well with people feeling free to go their separate ways when they wanted to.

Since leaving hospital after a motorcycle accident in 2009 with complete T4 paraplegia, Heidz (pictured above) has learned to live a new life while keeping true to herself. She has travelled extensively overseas and goes out with mates to music gigs and festivals. She is now riding a modified trike, which enables her to get back to her roots. As an Education Officer at Spinal Cord Injuries Australia, she can show you how nothing can hold you back.
Following the huge success of the SCIA Independence Expo at Australian Technology Park in 2014, we’ll be returning over two days on Friday 15th and Saturday 16th April 2016.

Don’t miss your opportunity to be seen at Australia’s only disability expo specifically for people with physical disabilities. Register your organisation now to be part of this exciting event!