

Spire is a service division of AQA Victoria



The power of peer support goes full circle

10



Open minds can bring new opportunities

COMMUNITY

8



You 'should be paid' to advise in research

SPIRE EVENTS

14



Cyathlon: Robotic Technology Olympics

SPIRE NEWS

15

AQA Victoria Ltd

ABN 90 006 691 185

Address

416 Heidelberg Road
Fairfield Victoria 3078

T 03 9489 0777

T 1800 999 128

F 03 9482 4371

E admin@aqavic.org.au

W aqavic.org.au

Postal Address

PO Box 219

Fairfield Victoria 3078

Board of Directors

Chairperson

Michelle O'Sullivan

Treasurer

Greg Schinck

Company Secretary

David Schreuder

Director

Dave Jacka

Director

Alexia Archbold

Director

Kylie Thitchener

Director

Joe Rose'Meyer

Spire NewsLink is the official newsletter of AQA Victoria Limited (AQA), and is published bimonthly.

Spire NewsLink seeks to publish material of interest to people experiencing issues in life arising from a spinal cord injury or other physical disability, their family and social networks, clinicians, professionals and other organisations with an interest in this community.

Spire NewsLink welcomes content for publication. Content will be published at the discretion of the Editor who retains the right to edit all submissions as they see fit.

Information in Spire NewsLink is furnished solely as a guide to the existence and availability of goods or services.

Any opinions expressed in Spire NewsLink are not necessarily those of AQA or the Editor. Original material in NewsLink can only be reproduced with permission from the editor. Donations towards production costs are greatly appreciated.

Copyright © Spire. All rights reserved.

CONTENTS

INFORMATION

4 Disabled Wintersport Australia

4 Accessibility Melbourne

HEALTH & WELLBEING

5 Feeling tired and sleepy during the day?

SPIRE EVENTS

6 SCI Community Network Groups Round-up

7 Upcoming Events

14 You 'should be paid' to advise on SCI research

COMMUNITY

8 Open minds can bring new opportunities

17 Lynda Dingley: Indigenous Aboriginal Artist

PEER SUPPORT

10 The power of peer support goes full circle: Peer Mentor / Mentor Peer Relationships

LEISURE

12 Yes, you can dance – and here's how

SPIRE NEWS

15 Cybathlon – the Robotic Technology Olympics

16 Spire Peer Health Coaching

COMMUNITY NETWORKS

16 Women with SCI Network

REGULAR FEATURES

ADVERTISEMENTS

4 Qualcare

18 Is your NDIS review coming up?

CLASSIFIEDS

19 Various items for sale and items for free

Volume 33: Number 04 / September 2019

FROM THE CEO

Congratulations to the organising committee of the Australian & New Zealand Spinal Cord Society (ANZSCoS) Conference held here in Melbourne in August. This is an annual conference that moves between host cities across Australian and New Zealand and brings together the SCI clinical and research communities and increasingly, people with lived experience. This year's theme was SCI – Working Together, Now and Tomorrow and the congratulations is that the conference engaged people with lived experience as organisers, delegates, presenters, speakers and partners in the conference.

One simple and pleasing optic to illustrate the point is that if you had entered one of the plenary sessions during the conference you would have seen the session being co-chaired by a clinician or researcher and a person with lived experience – including some of AQA's staff and volunteers.

The conference program itself included papers and posters presented by people with lived experience and one of the

international speakers was John Chernesky, Lead of Consumer Engagement at the Rick Hansen Institute, Toronto, himself a person with SCI. John gently challenged the SCI Research & Clinical communities and people with lived experience to up their game and embrace the obvious benefits of partnering in research and service development. He made the fundamental point that those affected by a decision have a right to be part of the decision-making process and that meaningful consumer engagement in research:

- Improves study design, protocols and choice of relevant outcome measures
- Aids in securing funding
- Increases study enrolment rates

His message to people with lived experience was to step up and better understand the research processes, to "be the change you want to see", acknowledge research abilities and limitations and be prepared to learn research skills.

Following the conference, AQA in partnership with Spinal Research



Peter Trethewey
Chief Executive Officer
peterretrethewey@aqavic.org.au

Institute was pleased to host what we called A Conversation with John Chernesky, where John led a more detailed discussion around meaningful engagement and partnering.

We look forward to contributing to future conferences and conversations with the outcomes and evaluations of peer led services and activities that will complement the powerful observations and personal narratives of the lived experience.

HIGHLIGHTS

Welcome to the September 2019 issue of NewsLink.

Our SCI Community Networks continue to power along. Please turn to page 6–7 for a recap and a list of future catch-up dates.

On pages 8–9, Emily Quattrocchi shares the trials and tribulations of her life post SCI, and highlights having a positive attitude has allowed her to return to the things she loved doing prior to her life-altering accident.

The power of peer support can be clearly seen in the Lenny Redrose

story. Lenny, who received peer support from Marcus Sanders, has now gone on to become a Spire peer support mentor himself. Marcus, in turn, received peer support back in 2012 from Wayne Bradshaw. Please turn to pages 10–11 to read this inspiring journey from mentee to mentor.

Rocca Salcedo had long grieved for her ability to express herself through social dancing. And then she saw an opportunity, and not only for herself. Please turn to pages 12–13 to read how she helped with setting up the 'Dance & Roll' program.

AQA Spire in partnership with the University of Melbourne and Fourier Intelligence are preparing an exoskeleton that will be entered into an international competition. Please turn to page 14 to read about this exciting news.

Finally, below are this year's contribution deadlines for the upcoming editions of NewsLink:

October	1 st October 2019
December	1 st December 2019

Disabled Wintersport Australia

Disabled Wintersport Australia (DWA) is a Not-for-Profit organisation that assist members to participate in snow sports at all Australian Alpine areas and not be financially disadvantaged.

If you have a permanent disability and are heading to the alpine resorts, then becoming a member with DWA gives you access to concessions, equipment, pathways, programs and a number of other benefits including:

- Accessible accommodation in Falls Creek, VIC and at Jindabyne, NSW.
- Up to 50% concessional rates on regular full day lift tickets and
- Concessional rates on private snowsports lessons with an adaptive certified instructor.
- Access to DWA's adaptive equipment including sit-skis, outriggers, sno-wings and other adaptive equipment (subject to availability).
- Ability to participate in DWA members' camps run each season in Victoria and New South Wales and are open to all our registered members.

For membership enquiries please contact DSW;

T 1300 265 730

E membership@disabledwintersport.com.au

W www.disabledwintersport.com.au/membership/register-or-renew/



Qualcare is a division of AQA Victoria Limited and is an industry recognised provider of high quality personal care services. For over 20 years Qualcare has delivered personal care and support throughout the state of Victoria to people with a disability, injury or illness in their homes and communities.

T 03 9489 0777

E qualcare@aqavic.org.au

W www.qualcare.org.au

Accessibility Melbourne

Melbourne is a proudly accessible city and most of its attractions can be enjoyed by everyone.

Accessible amenities

Melbourne is a welcoming city with venues, services and facilities designed to make your trip into the city accessible, easy and enjoyable. Find out more about Melbourne's Accessible amenities at www.melbourne.vic.gov.au/community/health-support-services/accessing-melbourne/Pages/mobility-maps.aspx.

Travellers Aid

Travellers Aid has recently expanded its equipment hire with more manual wheelchairs and motorised scooters available from service centres at both Flinders Street and Southern Cross Stations.

Equipment can be booked directly through the Travellers Aid website at www.travellersaid.org.au/our-services/mobility-equipment-hire or by calling (03) 9068 8187. Equipment that is pre-booked 24 hours in advance can also be delivered to Federation Square carpark.

Car hire

Europcar Melbourne (www.europcar.com.au/products/wheelchair-accessible-car-rental), in partnership with Automobility, have wheelchair-accessible vehicles for rent, as do Wheelaway (www.wheelaway.com.au).

AQA Spinal Injury Info & Support

For news, information, photos and more...



Join us on
facebook

www.facebook.com/AQASpinalSupport

Feeling tired and sleepy during the day?

Researchers at the Institute for Breathing and Sleep (IBAS) have found that more than 80% of people with a T6 and above spinal cord injury (SCI) have sleep apnoea. It's having a big effect on their lives, but many don't know they have it, nor do they know it can be treated.

With support from the Transport Accident Commission (TAC), and in partnership with AQA, the researchers at IBAS have produced a series of videos featuring people with spinal cord injury (SCI) who have been diagnosed and treated for sleep apnoea.

"I was so fatigued that I would fall asleep even when I was driving my wheelchair," says Ben Gruter, who has T5 paraplegia and is a retired public servant. Today, his energy is restored and his grandchildren ride around the block with him.



"Our research found that 80% of people with a T6 and above SCI have sleep apnoea, which often causes problems with tiredness and fatigue," says Dr Marnie Graco who recently completed her PhD on the subject at the Institute for

Breathing and Sleep (IBAS). *"We found that most cases are undiagnosed, with people just assuming tiredness is just part of the burden of spinal cord injury. So, we reached out to people living with spinal cord injury and asked them to tell their story. We want to encourage everyone with daytime sleepiness or fatigue to talk to their doctor about sleep apnoea."*

Sleep apnoea is a kind of breathing disruption during sleep that has been linked to serious health problems including constant tiredness, poor concentration, heart attacks and depression. It affects up to 25% of the general population, but it is much more common among people with SCI.

"You might have sleep apnoea and not know it," says Professor David Berlowitz, a physiotherapist at The University of Melbourne and IBAS. *"If you snore, wake up tired, or you nod off during the day go and see your GP for a sleep study and, if needed, a treatment plan. Sticking to the treatment plan may be challenging but it can make a huge difference to your daily life."* A common treatment for sleep apnoea is the use of a Continuous Positive Airway Pressure (CPAP) machine during sleep.

"I love my CPAP machine" says Kate Herd, an author and designer who has C6/7 quadriplegia. *"Using CPAP means that I can wake up in the morning and feel like I've actually had a pretty good night's sleep, I can do all the things I want to do in a day. I'm glad that I use it and I wish I'd started using it sooner."*

If you or someone you know with a SCI has been experiencing symptoms of tiredness, IBAS and Austin Health advise that you talk with your GP for a sleep study and, if needed, a treatment plan.

You can watch the videos here: www.ibas.org.au/blog/read/77/do-you-have-spinal-cord-injury-tired-get-treated

HAVE YOU GOT A STORY TO TELL?

At Spire, we're always on the lookout for interesting, inspiring or unusual stories from our community. We are currently seeking volunteer contributors to share their lived experiences of SCI on our online community blog at www.spire.org.au/blog.

No blogging experience is necessary and if needed, one of Spire's skilled volunteers can help shape or edit your story.

For further information please contact Spire:

T 03 9489 0777

E info@spire.org.au

SCI Community Network Groups Round-up

There's always lots happening with our Community Networks. The groups provide an opportunity to connect with other people with an interest in spinal cord injury (SCI), share stories & ideas, network, socialise, and to get information on things like the latest equipment, policy developments, through to new developments in SCI management & research.

Shepparton Network

Shepparton Network

meets on the first Wednesday of each month. Recently, the group met with the Shire of Campaspe Council and discussed current and past inclusive projects in Echuca. In September, the group is looking forward to hear the results of the Deakin University research project that they contributed to last year.

Gippsland Network

The Gippsland Network meets on the second Tuesday of the month. The group alternate their monthly meetings between Warragul, Traralgon and Bairnsdale. At one of their recent meetings, they discussed the always popular topic of travel. The group shared tips and tricks on finding appropriate accommodation, bathroom adjustments, air travel and destinations.

Bendigo Network

The Bendigo Network meets on the second Thursday of the month. In the last few months, the group learned about Kinela and its meal delivery service, and learned how they can be more involved with Bendigo Council and its current and future inclusive projects.

Mornington Network

The Mornington Network meets at Steeples Restaurant in Mornington on the third Monday of each month. The group meets socially over lunch and discuss various activities they are involved with, share information, network, and support one another. It's always a fun and informal gathering.

Geelong Network

The Geelong Network meets on the third Wednesday of each month. In the last two months, they welcomed Solve Disability Solutions, an organization that builds new or customises existing equipment, and Geelong Adaptive Sports, which supports individuals to achieve their health goals at home or gym.

Ballarat Network

The Ballarat Network meets on the third Thursday of the month. In August, a couple of members took the V-line train for a Melbourne day trip. The group visited the volunteer-based organisation, Travellers Aid, and afterwards visited the National Art Gallery of Victoria. For one member in particular, it was a positive experience taking the train for the first time since his accident.

Ovens Murray Network

Earlier in the year Spire surveyed people living in the Ovens Murray area, near the Victoria –NSW, for the possibility of developing a new Network. Unfortunately, there was not enough interest. Spire will continue to monitor interest levels in the area.

Women with SCI Network

The Women with SCI Network meet every second month. At the last meeting, the group welcomed two clinical nurses specialists for a presentation on bladder and bowels. It was one of the biggest meeting turn outs, and everyone enjoyed the day and each other's company.

Professionals with SCI network

The SCIP network meets every three months, alternating between the office of Lonely Planet in the city and AQA Spire. The group supports people with SCI or similar physical complex disability in all aspects of career development. At the last meeting, the group tried out phone conferencing with other members for the first time, and discussed expectations, plans and topics for future meetings.

For up-to-date information on any of the SCI Community Network Groups, please visit www.spire.org.au/community/community-networks. If you're interested in getting involved, please contact us on 03 9489 0777 or info@spire.org.au.

Upcoming Events	Date	Time	Location
Traralgon Regional Network	10 th September 2019	11am – 3pm	TBA
Bendigo Regional Network	12 th September 2019	11am – 3pm	TBA
Ballarat Regional Network	15 th September 2019	11am – 3pm	TBA
Mornington Regional Network	19 th September 2019	11am – 3pm	TBA
Geelong Regional Network	28 th September 2019	11am – 3pm	TBA
Shepparton Regional Network	2 nd October 2019	11am – 3pm	TBA
Traralgon Regional Network	8 th October 2019	11am – 3pm	TBA
Bendigo Regional Network	10 th October 2019	11am – 3pm	TBA
Ballarat Regional Network	17 th October 2019	11am – 3pm	TBA
Mornington Regional Network	19 th October 2019	11am – 3pm	TBA
Geelong Regional Network	23 rd October 2019	11am – 3pm	TBA
Women with SCI Network	2 nd November 2019	2pm - 4pm	AQA Office 416 Heidelberg Rd, Fairfield
Shepparton Regional Network	6 th November 2019	11am – 3pm	TBA
Traralgon Regional Network	12 th November 2019	11am – 3pm	TBA
Bendigo Regional Network	14 th November 2019	11am – 3pm	TBA
Mornington Regional Network	18 th November 2019	11am – 3pm	TBA
Ballarat Regional Network	21 st November 2019	11am – 3pm	TBA
Geelong Regional Network	27 th November 2019	11am – 3pm	TBA
Spinal Cord Injury Network of Professionals (SCIP)	28 ^h November 2019	4pm – 6pm	Lonely Planet Offices 551 Swanston St, Carlton
Shepparton Regional Network	5 th December 2019	11am – 3pm	TBA
Traralgon Regional Network	10 th December 2019	11am – 3pm	TBA
What's Out There day (WOT)	12 th December 2019	11am – 4pm	Royal Talbot Rehabilitation Unit 1 Yarra Boulevard, Kew
Bendigo Regional Network	13 th December 2019	11am – 3pm	TBA
Mornington Regional Network	16 th December 2019	11am – 3pm	TBA
Ballarat Regional Network	19 th December 2019	11am – 3pm	TBA
Geelong Regional Network	23 rd December 2019	11am – 3pm	TBA

Open minds can bring new opportunities

Emily Quattrocchi sustained a T4 spinal cord injury at 24 years of age in a motor vehicle accident. In the following article, Emily shares the trials and tribulations of her life post SCI, and highlights how having a positive attitude has allowed her to return to the things she loved doing prior to her life-altering accident.

I am a very lucky woman with a fulfilling and rewarding life. That is something that many people know about me but don't know my personal struggle to believe. If I had been told in early July last year that my life would change forever by the end of the month, I too would have struggled to believe I would continue to love my life afterwards.

Last July on my way to work I had a car accident that changed my life forever. It has been a long road to recovery with many challenges but it has also included many great memories, which I will always cherish.

I suffered memory loss for a couple months after my accident due to a brain injury and I still have limited memories of my time at Austin hospital, but what I am left with is good memories. I have hazy recollections of only being able to talk for ten minutes at a time because of a tracheotomy



and then the amazing moment of when I had it taken out and I could talk the nurses ears off. I remember I spent my 25th birthday there and I loved it. I woke up to gloves blown up like balloons, nurses painting my nails red, nurses giving me presents and many of my friends and family celebrating with me. I remember that night I was laughing so much with my sister that nurses rushed in thinking I was dying.

I was then transferred to the Royal Talbot Rehab Centre. My brain injury was improving so I remember much more clearly all my good memories there. I remember my first social event at the Talbot which was a poker night. It was great fun and there were free pizza. At the time, I was PEG fed which meant I couldn't eat any pizza or any other food. Sitting at a table with everyone else eating sounds as if it might be difficult but everyone there was chatting to me and making jokes which made missing out on pizza not so bad.

I had worn a solid neck brace due to a C1 fracture for 3 months, and I remember how good it felt when it was removed. Not long after that I was allowed to eat food again. The unforgettable taste of my first meal, which was a bowl of

pasta and every good Italian's first choice, was amazing!

I remember playing pranks on nurses, including the time I filled a new catheter bag with apple juice and drank it in front of them. The significant moments when I realised I could still achieve my goals and ambitions, but just with a twist. I remember the many friends I have made since my injury and feel very lucky to know them.

I have countless good memories, but I also remember the moments that were not great. I cried when I found out that I had to do catheters during the night and I would never get to enjoy eight hours sleep again. I used to love playing netball and was devastated when I realised I would never play with my team again. I worked really hard in rehab with the physio for many weeks to be able to be signed off to transfer onto the toilet. When I finally got the okay to try, I realised my spasms would make it impossible for me to do a catheter on the toilet.



■ *continued on next page*

■ *continued from previous page*



I once tried to go to an entertainment venue and was told I wasn't allowed to participate because I was in a wheelchair, which made me really angry.

Before my injury, I had been a cheerleader for 5 years. I cried when I missed my first cheerleading national competition because I was in rehab.

I also cried when I had to say goodbye to everyone at rehab and enter the real world. I knew I was going to miss them and the safe environment the unit provided. In rehab we all have an injury and wheelchairs are the normal, unlike the real world.

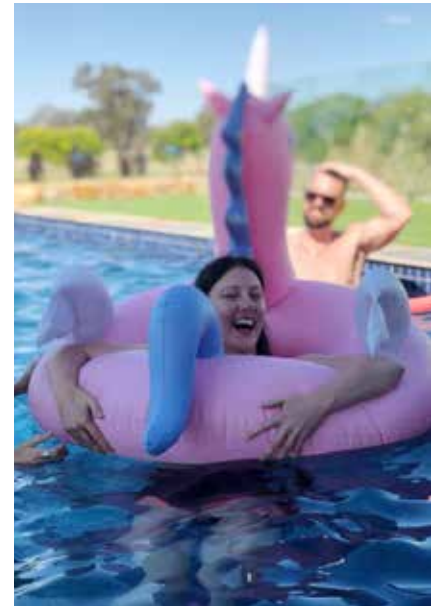
I have also felt anger with what having a spinal injury can bring. The day I left rehab, I got a pressure injury and had to spend 8 weeks in bed. I wanted to be up in my wheelchair and enjoying life.

It is my choice to focus on all the good things this injury

has brought me, and I truly believe I'm living my best life. I'm not ashamed to say I cried because being paraplegic is not easy and has its challenges but I can't deny that it has also brought me a whole lot more than I could ever imagine. All the supportive people I have met since the injury is something which I will always be so grateful for. The spinal community is wonderful and understanding, which we are all so lucky to have.

Since leaving rehab I have been able to get back to all the stuff I love. I now have the opportunity to bring something new to the sport I love in Australia. In July, I was the first para cheerleader who competed in Australia. I am starting the first para cheerleading team in Australia which will have the opportunity to compete in competitions in Australia and against other para cheerleading teams in America.

I finished my studies just before my accident and graduated university when I was in hospital but couldn't attend the ceremony. I was finally able to go to my graduation ceremony



in June, nearly a year after my injury.

I have a passion for filmmaking so I made a short documentary this year and it got into three film festivals - even one in America which was the Bafta and Academy Award qualifying festival. Getting into a film festival was a dream of mine even before my accident so it was an incredible feeling to see my film on the big screen. I have now started a YouTube vlog where I get to show everyone I have a fun and fulfilling life. I have started my own videography business called 'Empower Our Life' and I'm now starting to get clients.

I now have a new perspective on life and I'm not afraid to chase after my dreams. There's something about almost dying that gives one the determination to prevent anything holding one back. I'm genuinely so excited about my life and all the things I'm going to achieve.

The power of peer support goes full circle: Peer Mentor / Mentor Peer Relationships

The power of peer support can be clearly seen in Marcus Sanders story. Lenny Redrose received peer support from Marcus while in rehabilitation a few years back. Lenny has now gone on to become a Spire peer support mentor himself. Marcus, in turn, received peer support back in 2012 from Spire Peer Support Officer Wayne Bradshaw. Marcus shares his inspiring story of his journey from peer to mentor.

I met Lenny Redrose around 2.5 years ago through my volunteer peer support mentor duties. I went to see Lenny at the Caulfield Hospital in his acute phase of recovery. At 30 years of age Lenny had sustained a complete T4 spinal cord injury (SCI) as a result of surgery to remove a tumor on his spinal cord. All things considered Lenny was in reasonable spirits and was open and very positive to receiving and asking for advice, guidance and assistance in his new life living with a SCI.

Lenny and I instantly became friends as we had similar backgrounds. Lenny was ex-military, and had played a lot of sport (soccer) at high levels and I was an ex-policeman who had also played a lot of competitive sports at various levels over the years. At times I could see Lenny was struggling to adapt with navigating his way through life living with a SCI. We all know this feeling and the constant struggle to adapt to our new life and ever-changing and challenging environment. This is where, and why, I believe the Spire Peer Support Program is of great importance, not

only people who have recently sustained a SCI, but also their immediate family members who are also struggling to adjust to the changing conditions.

Over the course of Lenny's rehab and recovery we would talk and catch up regularly and no topics were off limits. I was just so happy being able to help and assist Lenny in any way possible, and I guess this is why many of us become peer support mentors as the work is very rewarding and extremely satisfying. We all need the help and support of others during such early tough times, but what we all really need is the lived experience of those who are, and have been, living a fulfilling positive life in the community with a SCI.

It's the occasional small positive things that are said and done that make the biggest changes and influences in someone's life. For example, I know that my life all changed for the better when I found team sport again in the form of Wheelchair AFL about 5 years ago playing at National level. It was such a positive influence in my life and brought me so much happiness, not to mention the

other benefits of improved health and fitness, mental health and social interaction and inclusion. Fast forward 5 years and the opportunities the sport has afforded me have been unbelievable to say the least. I'm in my second year as the Captain and Coach of the AFL St. Kilda Football Wheelchair Team in the VWFL, and am also employed by the club as their Community and Inclusion Ambassador. In early 2019 I was also fortunate enough to be head coach of the AFL Wheelchair State Team who recently won Silver over in S.A.

So this is just a snippet of how finding a sport and passion after a SCI has been able to change my life for the better. As my work continued with Lenny, I could see that he was a little withdrawn and isolated, and I thought that this was due to him not really having any other "wheelie mates" or being able to socially engage with others with SCI. Therefore, I thought of ways in which I could help



Marus with peer Lenny

■ *continued on next page*

■ *continued from previous page*

Lenny meet and engage with others alike.

Knowing and seeing Lenny's struggles only reminded me of my own journey and I knew that if I could get Lenny to come and try and engage in a new sport or activity that this may be just what he needed. One thing I did know and had learned about Lenny was that he was a very driven competitive individual and that he had loved team sport. This was my challenge... to get him down to one of our wheelchair AFL 'come and try' sessions. I knew that if I could get him down into a sports chair and on the court with the rest of us that I'd get him hooked! Well, all didn't go to plan at first as he failed to turn up for whatever reasons to the first couple of sessions. Anyway, I persisted with Lenny and after some strong words of encouragement he finally attended one of the sessions and was hooked and the spark and love of team sport was once yet ignited.

Lenny had picked up the sport very quickly and showed raw talent, he also had a very strong training and work ethic. He became once again a very disciplined hard worker and as a result I selected and drafted him to play for the St. Kilda Wheelchair AFL Team in 2018. Lenny has been a great solid contributor for the team and is constantly improving his fitness and game craft. Lenny has since gone on to achieve some amazing things, such as currently completing a Certificate 3 & 4 in Fitness as he wants to be a personal trainer (PT) for adaptive athletes. He also successfully completed the 2018 Spartan race and will be competing in the next Invictus



Marcus with mentor Wayne Bradshaw in 2015

Games. The list will continue to grow as Lenny has found his passion for sport, health and fitness.

Lenny himself now has also become a volunteer peer support mentor for Spire as he himself attests to it being a life-changing experience and wants to give back and help others. In his words Lenny explains *"Marcus has been one of the most important people in my life since my SCI. He has helped me make the transition to living with a SCI so much smoother. Earlier on I was struggling with lifestyle choices and was a little lost but Marcus was always there for me and to support me at times with some strong words of encouragement. As a result, I've been able to steer myself in the most positive direction and I have been achieving goals which I'd never thought possible. I now too have taken the steps to become a peer support mentor as I've experienced it first hand and love the benefits of it."*

So there you have it... the power of peer support really

works and can influence, enhance and change the lives of people living with SCI in a positive way! It's just such a rewarding experience to help others and give back.

I was inspired way back in 2012 by my peer support mentor Wayne Bradshaw to get involved in the program and now Lenny Redrose has been inspired by myself to become a Spire Peer Support Mentor! Hopefully this will continue on and I'm sure that Lenny will also inspire others to do the same - this is the true power and meaning of peer support and how it positively impacts people living with SCI. I really love and enjoy being a part of this program as you can really help, influence and impact positively on peoples' lives. Another one of the huge benefits are the fantastic friendships, bonds and close relationships that are formed as a part of the trust, empathy and understanding that is developed from being a peer support mentor.

Yes, you can dance – and here's how

Colombia-born Rocca Salcedo had long grieved for her ability to express herself through social dancing. And then she saw an opportunity to change that – and not only for herself. Below Rocca shares her journey.

As she tells the story, Rocca Salcedo had two motivations for setting up Dance & Roll, a dance club for people with physical disabilities that meets weekly in Kew.

On one hand, having previously set up a badminton club, and having also played tennis, she had been surprised by how few women with spinal cord injuries (SCI) played competitive sports.

She had thought that regular dance classes might attract more women to exercising in the company of others, in a structured way and on a regular schedule.

And on the other hand, having grown up in Colombia, on the northwest coast of the South American continent, where as she puts it, "everybody dances all the time", Rocca had recognised that dance was an element of her self-expression and social life that she had lost, and had grieved for.

"I found that I was missing that part in my identity," she says, still with an accent, and personifying Latin charm. "I wanted to dance, and I was missing that."

Rocca had come to Australia in 2001, aged in her mid-20s, on a two-year scholarship to pursue a Master of Laws degree. She had been struck by a car only months afterwards,

surviving with a C7 spinal cord injury, and after 18 months of rehabilitation here, she had stayed.

She had long accepted that even at Latin-themed gatherings, where almost everybody was dancing, she would find herself, mostly, looking on from her chair.

"Because I was in a wheelchair, I did not feel confident to join my friends on the dance floor," she explains.

"Many of the Latin dances are with partners, but people also dance together as individuals. I did not even feel comfortable dancing by myself – something that would have felt completely natural for me before I was injured."

It was when spectating at the Australian Dancesport Championship at Margaret Court Arena in December that Rocca saw a path to enhancing this part of her life. For the first time, the event included a ParaDance contest, featuring four couples from Western Australia. In addition, ParaDance world champions Julius Obrero and Rhea Marquez, from the Philippines, gave an evocative exhibition performance. Following is a link to their performance: www.youtu.be/VGIfmMpOPEg.

Rocca's first impulse was to join a ParaDance group in Melbourne, or a similar organisation for people with physical disabilities. But some research convinced her that no such group existed.

And so she determined that she would remedy that deficiency, for herself and for others.

Legal training and her experience with badminton helped her enlist a board and create Dance & Roll as a legal entity. She won enthusiastic support from the Royal Talbot Rehabilitation Centre, which made available its basketball court and lent wheelchairs for the group's inaugural event.

The 'Come and Try Day' on 21 February attracted more than 30 people – not only people with disabilities, but also partners and friends, and dance coaches. It was acclaimed by all involved, and Dance & Roll was on its way.

The group enjoys dancing in a big range of styles, from classical to modern. Sometimes it adopts ParaDance techniques undertaken with partners,



■ *continued on next page*

■ continued from previous page



The Dance and Roll group practising their moves

but more often it emphasises individual styles and group choreographies, taking inspiration from Los Angeles wheelchair dance troupe **The Rollettes**. Following is a link to the teams first competition at ICU Worlds: www.youtube.com/watch?v=-thAkMcV9Uk.

"We hold classes every Thursday at the Royal Talbot," says Rocca. "And we have a choreographer who is a professional dancer." Following is a link to a Dance & Roll session at Royal Talbot: www.facebook.com/danceandroll/videos/363325357641586.

"Anybody is welcome – men and women – and people with any physical disability. It is important to stress that this is for people with physical disabilities. It is not just for people in wheelchairs. We have a lot of people who are amazed with the project and want to help. For example, we have support from VicHealth through its 'This Girl Can'

campaign, from Royal Talbot, and from spinal injury support organisation AQA Victoria."

Did participating in dance from a wheelchair connect Rocca painfully with what she had lost through her injury?

"Not at all," she reports. "It was the opposite! It was great thinking I could still do it. It made me feel more confident. For me it is amazing. I absolutely enjoy it. And it is very beautiful to see people who have never danced before in their wheelchairs having that experience and being happy."

Rocca, who completed her Master of Laws and who works in the legal field, also says she has been surprised by the extent to which dancing from a wheelchair provides a whole-body workout.

"I was very amazed, to be honest, that it was such a physical activity," she says.

"After that first session, I was feeling that I had done a lot

of exercise in areas of my body that we don't use. I was sweating, and I was feeling exhausted. I think this helps a lot to improve your balance and your upper body strength, as well as building self-confidence and your ability to engage in physical activities."

As for the question of inclusion at parties, Rocca is sure that her weekly training will help there also.

"Of course!" she exclaims. "I will feel more confident, and I will learn more steps to do by myself.

"You can show you are open to an approach in social situations by dancing by yourself. Because you have opened that window. I think this can be an opening of the mind, and not just for people in wheelchairs. I think it may help people in the wider community see that being in a wheelchair does not mean that do not want to dance. And it does not mean that you cannot dance."

Dance & Roll meets on Thursdays between 6pm–7pm at the Royal Talbot Rehabilitation Centre at 1 Yarra Blvd, Kew, Level 4. The first session is free. After that, membership is \$30 per year and there's a \$15 charge per session to cover costs for the coach and the venue.

For further information, please contact Rocca on 0408 523 742. The club has a Facebook page at www.facebook.com/danceandroll.

You 'should be paid' to advise on SCI research

John Chernesky, Consumer Engagement Lead with the Rick Hansen Institute in Canada, held an informal conversation session at the AQA Office with selected guests on how people with lived experience should insist on full participation in research projects.

People with lived experience should be paid to advise on all research into spinal cord injury, an international advocate told AQA guests late last month.

Payment should match sums paid to other expert advisers, John Chernesky told health professionals, researchers, research funders, Spire peer support volunteers, and other attendees at the AQA office in Fairfield.

John is Consumer Engagement Lead with the Rick Hansen Institute, a global spinal cord injury (SCI) network based in Vancouver, Canada.

The institute, an initiative of wheelchair marathon legend Rick Hansen, aims to accelerate work towards a cure for SCI-related paralysis.

In his 35-minute address, John summarised progress internationally in drawing the consumers of SCI research into the research process – not just as subjects to be poked and prodded, but as influential members of research teams.

By consumers he meant people whom the research aimed to help – people who had been injured, but also family, friends, carers, members of community organisations, even surgeons, depending on the aim of a particular study.

It had been shown that consumer participation in research could make the work more effective, he said.

And increasingly, funders of research were demanding that grant applicants showed how their projects would draw on consumer experience.

But the risk remained that consumers would be included only in a token manner – perhaps enlisted to lend their authority to a research proposal, and then ignored until they were invited to endorse the completed project as helpful.

John said one aim of his work was to influence researchers so that they could see the benefits of partnering fully with consumers in the creation of knowledge.

A full partner would help design and direct the research, and would be credited on published papers as a co-author.

A second aim was to encourage people with lived experience to take the most of their participation – by developing a good understanding of the research process, the problems faced by researchers, and the benefits that could flow to researchers from consumer involvement.

John was in Melbourne to present at the 2019 Annual Scientific Meeting of ANZSCoS, the Australian and New Zealand Spinal Cord Society. He kindly reprised his talk at the AQA office.

In answering a question from the floor, John cited a 2012 documentary, available on YouTube, titled *How to Survive a Plague*, which showed how at-risk people at the height of the AIDS epidemic had engaged with research organisations to accelerate progress on effective treatments.

"People don't die from AIDS any more," John said. "And the reason people don't die from AIDS is that people who were dying from AIDS got involved in the research."



Cyathlon – the Robotic Technology Olympics

AQA Spire in partnership with the University of Melbourne and Fourier Intelligence are preparing an exoskeleton that will be entered into an international competition. For those who don't know, exoskeleton is a lower limb device to assist individuals with limited mobility.

A group of University of Melbourne Masters students, specialising in mechanical and mechatronics systems, and who are undertaking their final year in their studies, formed the team 'ALEX'. ALEX is an acronym for **A**dvanced **L**ower-**E**xtremity **E**xoskeleton.

The team aims to develop the current user interface of the exoskeleton to be more robust to take on complex tasks such as walking on a cambered surface, walking up stairs, and walking up a ramp. The team also want to create this technology to be integrated and useful in everyday life in the future.

What is the next step of the project

The aim of the project is to push the boundaries of the existing design with the new software and a new interface



and participate in the Cyathlon 2020. Cyathlon is considered the "Robotic Technology Olympics" and will be held in Zurich Switzerland on 2–3 May 2020. We will enter as the first Australian team ever.

The Cyathlon is a unique championship in which people with physical disabilities compete against each other to complete everyday tasks using state-of-the-art technical assistance systems.

The tasks in the Powered Exoskeleton Race reflect everyday activities such as getting up from a sofa and overcoming obstacles such as stairs, ramps and/or slopes. Navigation in confined spaces such as doorways or between furniture are further challenges.

We have a pilot

We will be entering the Powered Exoskeleton Race. In



this race, pilots with complete thoracic or lumbar spinal cord injury can complete using an exoskeleton. Only pilots with complete paralysis of the legs resulting from spinal cord injuries are eligible to participate. You're probably thinking the exoskeleton is able to fly seeing as the user is called the pilot... not quite yet unfortunately. The user is called the pilot because they actually command the device after heavy training. We have selected Lenny, who is also one of our mentors, to be the pilot. We will also have a backup pilot.

In addition to entering Cyathlon, the success of this research project will have positive implications in the development of exoskeleton devices as a whole to make this technology more accessible and enable potential users to live independently in a greater variety of areas and tasks.

We'll keep you updated with regular updates. Below are some social media links:

Website

www.alexexoskeleton.org

Instagram

www.instagram.com/alex.exoskeleton

Facebook

www.facebook.com/alex.exoskeleton

Cyathlon website

www.cyathlon.ethz.ch/cyathlon-2020.html

Cyathlon video

www.youtube.com/watch?v=xq8c_hgMOZ8

Spire Peer Health Coaching

Peer Health Coaching is a pilot health intervention service which combines up-to-date clinical information, together with the collective lived-experience and knowledge of spinal cord injury (SCI). It seeks to help people make informed decisions and explore options in making educated choices to achieve health and wellbeing outcomes which are important to them.

It can cover elements, including but not limited to;

- bladder and bowel health,
- skin and wound care,
- mental health and
- healthy lifestyles.

It is not a prescriptive health intervention, but an ongoing coaching service which supports and facilitates individuals to take control and ownership of their health outcomes and work towards them in a considered and informed manner.

The Peer Health Coaching service is principally a phone service but can be offered in other ways.

Please contact us on 03 9489 0777 or info@spire.org.au if you're interested in receiving support.

For further information on our Peer Coaching services please visit www.spire.org.au/resources/peer-coaching.

WOMEN WITH SCI NETWORK

Every woman living with a SCI has great knowledge, experiences and skills that could be shared to help form strong community and networking opportunities. At Spire, our aim is to facilitate the development and continuity of network groups that can eventually take ownership and coordinate themselves, while still being supported by Spire's people and resources. So in December 2017 Spire started a **Women with SCI Network** group.

The women's network is passionate and enthusiastic about providing a safe, honest and open space that is informed and led by women living with a spinal injury. The group meets the first Saturday every two months and participates in information sessions, practical classes and provides the opportunity to share their views, ideas and opinions.

If you would like to commit to this group but have other life commitments, or you are interested in just attending or contributing to specific events (e.g. workshops, seminars or information sessions), you can pick and choose to what suits you!

If you are a women living with a spinal injury and interested in joining the group, please get in touch with us at info@spire.org.au. We would love to have you involved, and have you help us continue to build and make this network successful.

SUPPORTING SERVICES TO PEOPLE WITH SPINAL CORD INJURY

Making a donation... (Donations of \$2 or more are tax deductible)

With community support Spire continues to make a difference in the lives of people with a spinal cord injury and their family that support them.

Spire uses the value of people with lived experience of SCI to provide peer-facilitated and peer-informed services & supports to others living with SCI to help them deal with the issues of life.

We invite you to consider making a donation to help maintain and grow Spire's resources and services. Whatever sum you donate will assist us to provide services to people with Spinal Cord Injury.

Online: www.spire.org.au/support-us/donate

By Phone: 03 9489 0777, please have your credit card available (Mastercard, Visa, American Express).

By Mail Please call us and we will post you a Donation Form.

Lynda Dingley: Indigenous Aboriginal Artist

After falling ill and being confined to a wheelchair, Geelong Regional Network member Lynda Dingley, discovered her true passion for creating art. As an indigenous person, Lynda finds the basis of her work comes from her heritage and the love of this country.

My name is Lynda Dingley. Throughout my life, art has always been a passion of mine. As I got older, art took a back seat to my career as a chef/teacher and raising my son.

However in 2007, I was faced with a new challenge. After falling ill, I had lost the use of my legs.

During the following year of rehabilitation, I decided to pick up a pencil and start drawing again. The pencil then turned into a paintbrush and I've been painting ever since.

I had finally found my true passion for creating art.

All my paintings are my own unique interpretation of landscapes and seascapes of Australia. These artworks

are created from my own experience of travelling around this beautiful country and evoking the style of my indigenous heritage.

All of my current work is created in my home, alone. In the past, I have been in art programs but I would love to build a community where we can share ideas, experiences and friendships with other artists.

My new goal is to create an accessible artist space here in my home of Geelong, where women with physical disabilities can explore their creativity. This space is for all artists, and all levels of skill are welcome, from beginner all the way to professional. Currently there isn't an artist

studio that is offering an open accessible artist studio, but I feel it is a much needed space for professionals and beginners to create new exciting art material.

I want this art studio to be successful for all women with physical disability who want to be creative and to share in creating art work in our own accessible artist studio.

After my spinal trauma, I found peace in art, a form of therapy. I would love to share this with more people where I live.

Please contact Spire on 03 9489 0777 or info@spire.org.au if you're interested in being a part of the Art Program in the future, or check out Lynda's Instagram to view or purchase her artwork at www.instagram.com/lyndadingley.





Is your NDIS review coming up?

Be sure to include Personal Development and Community Participation in your goals. We have the services that can assist you to achieve your goals.

Contact our NDIS team for further information on 03 9489 07777 or ndis@aqavic.org.au

03 9489 0777
ndis@aqavic.org.au
www.aqavic.org.au



FOR SALE

Quantum Q6 Edge 2.0 - Powered Wheelchair

Tilt & lift ilevel; 6 wheels & turns on spot, turning radius 20.5 inch; Bluetooth capable; Weight capacity 300lbs; Maximum speed 9.6km/h; J3 back; ATX suspension; Attendant controller added 12 months ago at a cost of \$1300; Purchased 2.5 years ago \$15,000.

Price: \$5,500

Phone 0411 953 637 (Sue) (06/19#a)

Ti-Lite - Manual Wheelchair

Titanium; Light weight; Fold up; Swing away/detachable footplates.

Price Best Offer

Phone 5263 2150 (Kevin) (10/18#a)

Pride Quantum 6000Z - Electric Wheelchair

Purchased in 2010; very little use; fitted with a right hand side Q-Logic Controller; has a Tru-Balance Power Positioning system for power lift, tilt and recline; batteries are dead but prepared to purchase new once buyer has been found; original cost \$14,500.

Price \$2,500

Phone 0410 413 166 (Sue) (08/18#a)

Ramp - Portable

Folding; 3 Feet long; 28 Inches wide.

Price Best Offer

Phone 5263 2150 (Kevin) (08/19#a)

Trailer

6x7; Brand new; Registered until Oct 2019; Lockable

Price \$1,000

Phone 0402 204 992 (Colin) (07/19#a)

Easylift Liftboy II

Manufactured in Germany; Tested to all Australian specs and approvals; Used for 1 week only; Suitable for indoor and outdoor use; 240V plug in - no hard wiring or hydraulics required; max. lift height of 830mm, max lift weight of 300kg, fully mobile or permanent solution for the home or business; cost new \$12,000
Price: \$6,900

Phone: 0438 008 584 (Gerard) (06/19#a)

Twion Power Assist Wheels

Regenerative braking; Will fit most chairs folding or rigid; Great for off road & hills; Even better for steep downhill.

Price \$4,000

Mobile 0418 509 901 (Glenn) (05/19#a)

Vehicle Wheelchair Lift - Electric

Pride Silverstar Backpacker Plus; Installed in 2011; Very little usage; Remote controlled unit that comes out of the van and lowers to the ground; Easily fitted by auto electrician Original cost \$4,500. .

Price: \$800

Phone: 0410 413 166 (Sue) (07/18#a)

MORE CLASSIFIEDS

www.spire.org.au/community/classifieds

FOR SALE

1999 Ford Falcon GL Wagon

Reconditioned motor - only 10,000kms; Reg till Dec 2019; New tinted windows; New mags & tyres; Hoist roof rack; Hand-controls; All fitted out & ready to drive for a para or good quad; Have every receipt for all works completed on the vehicle.

Price \$3,000

Phone 0402 204 992 (Colin) (04/19#a)

2006 Holden Adventra SX6 VZ 4WD Wagon

4WD Auto; 152,568kms; 4 Air Bags; ABS Braking; 17" Alloy Wheels; Cruise Control; Power Door Windows & Mirrors; Multi function Steering Wheel; Remote Central Locking; Roof Rails; Garaged; https://carsales.com.au/_/details/SSE-AD-6274573

Price \$7,500 ono

Phone 0408 578 052 (Paul) (09/19#a)

Tyres (x13)

13 x 12" Wheels with new bearings; Never used. Sell as package. Pick up only from Strathfieldsaye.

Price \$20 Each

Mobile 0439 553 380 (Graeme) (09/19#a)

Olympian Wheelchair Hoist

Can lift up to 150kg power chair to car boots; Hardly used.

www.autochair.co.uk/products/scooter-wheelchair-lifts/smart-lifter

Price \$500 ono

Phone 9841 9255 (Michael) (10/18#a)

Roho Cushions

4 cushions sizes; 2 x 9x9 cells and 2 x 9x10 cells

Price \$100 Each

ITEMS FOR FREE

Quickie Electric Wheelchairs (x2)

Electric Wheelchairs - Quickie P-222SE & Quickie P-200; Neither chair been used for some time but complete so would expect with maintenance to be able to get going. Located at Gormandale Gippsland but could organise getting them to Traralgon for pickup.

Phone: 0438 093 430 (Sally) (07/19#a)

Catheters - Male

30 Boxes x 30 catheters in each; Self-Cath Soft Straight Tip Male - FR/CH 12-16Inch/40cms; Expires 20/08/2021; Picked up Sydenham.

Phone 9449 2524 (Michele) (09/19#a)

Wheels (x2)

No axles; Used; To be picked up - Strathfieldsaye.

Phone 0439 553 380 (Graeme) (09/19#a)

Tyres & Rims (x2)

26 Inch; Schwable tyres; No axles; Used; Pick up - Strathfieldsaye.

Phone 0439 553 380 (Graeme) (09/19#a)

SUPPORTING SERVICES TO PEOPLE WITH A SPINAL CORD INJURY

Making a bequest...

Bequests provide a legacy to an organisation you already support or want to support in the future. Making a bequest to AQA in your will is a meaningful way of supporting people with spinal cord injury. All bequests help strengthen the services provided by AQA that promote independence, quality of life and inclusion of people with disabilities in the community.

If you have included AQA in your will, or you are considering making a bequest to AQA we would love to hear from you so that we can acknowledge your support.

We would also like to include you on our list of supporters who receive our bi-annual supporters newsletter that provides an update of our services, the year's events and other activities that AQA is involved in that support people with spinal cord injury.

If you would like more information about making a bequest to AQA please contact Peter Trethewey CEO on 03 9489 0777.



Did you know AQA is registered not only to provide standard needs assistance with self-care activities and community participation but also high intensity?

Research: Intermittent Catheter Quality of life survey

Ethics Approval ETHLR.18.044

Do you use an intermittent catheter to empty your bladder?
Are you aged 18 or over?

Hollister Incorporated is conducting this global research project in order to gain a better understanding of the catheter user. This is a comprehensive survey; it includes attributes like; quality of life, social connectivity, UTI management, emotional aspects of life and other areas. Please help represent Australian I.C. users in this international research by completing the survey:

Link to survey:

<http://www.bit.ly/HollisterICSurvey>

(note: Survey closes June, 2020)

If you would like to know more, please contact Hollister Continence on freecall 1800 880 851 or Local Survey Investigator: Paris Prunell, Snr Mgr Global Clinical Education M: 0438 366 992 or email E: paris.purnell@hollister.com

Suite 3 / Ground Floor. 990 Whitehorse Rd.
Box Hill VIC 3128 Australia www.hollister.com

Continence Care
People First

