Purpose

Journal of the







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EDITORIAL

It is exciting to be able to record recent developments taking place within our amputee world and to know that they can only benefit the amputee of the future in this wonderful country of ours.

Whilst a skiing weekend for amputees (see page 4) would no doubt have had limited appeal for some, two other initiatives have the potential of being of benefit to those of us who have been around for some time, as well as those who will join our ranks in the future.

Firstly, the entering into a Memorandum of Understanding with CCS Disability Action marked a milestone of note. Advantages to the members of both organisations include sharing information relating to access and support issues and, at a national level in particular, coordinating representations and/or submissions to government or the media where there are issues affecting both organisations. It is now over to Regional Amputee Societies to follow through at grass roots level with local CCSDA branches to ensure the dissemination of information and resources of mutual benefit.

Secondly, we welcome the introduction of a Peer Support Training Programme which will take place alongside our National Conference in April next year. Many of our Societies already have either Field Officers and/or Volunteer Visitors who are available to provide support to members and new amputees in particular. This joint initiative by the Federation and the NZ Artificial Limb Service focuses on Peer Support Volunteers who will train and be specifically qualified to provide support to amputees attending a Limb Centre or Regional Clinic. The one-day training programme conducted by Melissa Noonan of Limbs4Life Australia will take place on Friday 20 April prior to our National Conference that weekend. For more information and to register your interest, follow the link in the article on page 7.

Once again, we will be offering a full weekend of information sharing and good company at our National Conference in Wellington on 20-22 April. Details of the programme and registration forms will be available on our website and through our Regional Societies early in December. We hope to see many of you there.

The blessings of the coming festive season be with you and yours.

Lorraine Peacock

AN HISTORICAL MOMENT

On 15 September of this year, Mark Bruce, President of the Amputees Federation of NZ, and Kim Willetts, President of CCS Disability Action, marked a new chapter in the history of the two organisations when they met in Christchurch to sign a Memorandum of Understanding. It is hoped that this MOU will facilitate co-operation to the mutual benefit of both organisations, whilst at the same time allowing for the retention of individuality and autonomy of both.

It is intended that the first step along this pathway is for relationships between AFNZ's nine Regional Societies and local branches of CCSDA to be established with a view to sharing resources and thus providing more effective support for the members of both organisations.

AMPUTEE SKI WEEKEND

Thanks to the initiative of Matthew Bryson and funding from Southern Trust, a group of seven amputees and supporters took part in a skiing weekend at Mt Ruapehu on 29/30 September. From the feedback received, everyone had an awesome time and there were many firsts: it was the first time a 58-year-old had skied; the first time an amputee had seen and felt snow; the first time someone had skied with a prosthetic leg. It was the first amputee snow trip! Wow, the challenges just keep on keeping on......



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INTRODUCING GAVIN WILSON



Dunedin sculptor Gavin Wilson lost his right hand in an industrial accident in 2012. He was initially aiven a standard prosthetic hand and hook, controlled by straps across the shoulders. Gavin's passion has always been art and carving/sculpting. particular help Initially. with the of an adapted enaineer. he various tools, including chisels and a mallet made from a car tow ball, to fit his prosthetic forearm. He then began looking on the internet to see what other options there were and became aware of the availability of much more sophisticated limbs. As he wore a prosthesis regularly, he became eliaible to aet fundina for an I-limb (a robotic hand) and

in 2015 he receive a phone call from his Case Manager to say he had successfully met the criteria to get an I-limb funded. He found this a very useful tool (Gavin prefers to call it an advanced tool rather than a hand as nothing can ever replace the function of a hand) but found it problematic as he could not use it for carving due to its fragile nature and inability to cope with the dust created from his carvings (he used to carve a lot of Oamaru stone). The I-limb was good for basic day to day activities but not handy enough for the workshop environment.

In 2016 he was contacted by Mark McDowall of the Dunedin Limb Centre asking if he would be interested in being a 'guinea pig' for Mathew Jury – a scientist, engineer and inventor based in Wellington who, after a three yearjourney, was in the final exciting stage of developing a New Zealand made robotic hand. Gavin was lucky enough to trial this hand and help Mathew and his team fine-tune a few design faults. Gavin has now been funded to have this Taska Prosthetics designed hand. "The sensors are activated by the muscle in my arm so if I tense them, it will do one thing: if I flex the muscles the hand will change position." The hi-tech hand is waterproof and more

durable than his previous hands. "I can do more domestic things like being able to hold a cup of coffee at the same time as opening a door." The battery powered robotic hand is equipped with blue tooth and can perform many gestures, with good and bad connotations, as well as shaking hands at various pressures. The rechargeable battery lasts about 10 hours. The technology attracts lots of attention, particularly from children. "They just love the idea of being a robot. It's good that they ask....there are a lot of people out there missing a limb and it's not something to shy away from."

Gavin's website for his art work is www.attitudedesignstudio.co.nz and the website for the taska hand is www.taskaprosthetics.com

ACC PARALYMPICS NZ OPEN DAYS

ACC and Paralympics New Zealand want to support and encourage New Zealanders with disabilities, their families and support people to get involved in Para sport and are holding five Open Days around the country between November 2017 and April 2018. Contact Keiran Wall kwall@paralympics.org.nz for dates and further information.

And for keen cyclists - a **Para Cycling Camp** is being held in Christchurch on 10-12 November which includes coaching and education opportunities for competitive riders. For more information contact Laura Thompson *Ithompson@paralympics.org.nz*

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PUBLICATIONS available (no cost) from the National Coordinator or Regional Society Secretaries

A New Challenge - Advice for New Amputees (a 32 page booklet) **An Ongoing Challenge** - A 60 page publication which covers a wide range of topics and includes personal profiles of 11 amputees.

A Challenge with Purpose - A History of the first 50 years of the Amputees Federation of NZ Incorporated (275 pages)
The Amputee Society of Otago & Southland Inc. -The first 60 years (146 pages)

Little Jellybean by Margot & Anton Wuts - for child amputees, their parents and families (24 pages)

PEER SUPPORT

by Sean Gray, CEO of the NZ Artificial Limb Service

Peer Support for vulnerable patients is important to help with life-changing events and their ongoing journey of rehabilitation. We also know from research and professional opinion that access to good Peer Support can enhance an amputee's quality of life and help them understand what can be expected from the changes they are going through. In recent times, we have worked with Field Officers from the Wellington and Hawke's Bay Amputee Societies to pilot Peer Support efforts with their presence in our Centre and regional clinics. Their participation in these clinics has provided amputees with a friendly voice, a translator of health jargon, someone to help with local coordination/connections to other health professionals and groups, and a champion to support their needs when they might not know what to say or how to say it. My personal observations have shown Peer Support to be a valuable service to amputees.

It is somewhat disappointing to me that Peer Support is not widely accessible with a national consistency. That's why it is exciting to announce that NZALS is working with the Amputees Federation of NZ to strengthen Peer Support for amputees by bringing Melissa Noonan from Limbs 4 Life in Australia to NZ in April 2018 to provide Peer Support training. For more information and to register for this training opportunity, go to

www.nzals.co.nz/noticeboard/peer-support-training-april-2018/

A person who might be interested in Peer Support generally has:

- a caring and supportive manner;
- well developed interpersonal skills and an ability to communicate confidently and effectively;
- high personal motivation and the ability to work efficiently without supervision;
- versatility and adaptability in responding to the needs of amputees;
- an ability to maintain confidentiality in relation to amputees and their families;
- cultural sensitivity and a commitment to multicultural issues.

NZALS acknowledges the value in amputees having access to a well-supported Peer Support programme, and the importance of providing support and resources to enable amputees to access services in order to enhance their quality of life, independence, and access to available resources. We also know that the more

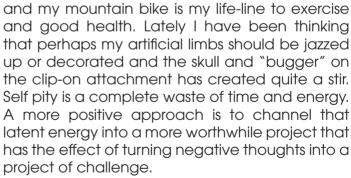
specific the Peer Support, the closer someone can associate with an amputee and the better the Peer Support, e.g. a parent with a child who had an amputation a number of years ago providing Peer Support to a parent whose child is about to have an amputation. As such, there is a variety of ways amputees can participate in Peer Support, including participation in the local Amputee Society through to being a volunteer Peer Support person for NZALS. The criteria to be a volunteer Peer Support person for NZALS is based on demand for the service, availability of roles, passing a police check, completing the online Privacy 101 course, NZALS training and the requirement of a current driver's licence.

For information on Limbs4Life, go to www.limbs4life.org.au, and for academic information on Peer Support, go to www.ncbi.nlm.nih.gov/pubmed/22522726

"MOTIVATED"

by Robert Porter

On 5 January 2005, riding a Kawasaki 1100 motor-bike I was given three seconds to take evasive action when a motor vehicle turned directly in front of me on a 100 km highway. My partner and I suffered life threatening injuries; however, we survived and the journey back to normality commenced. Disregarding all the injuries that eventually healed over several years, the amputation of my left leg below the knee was initially difficult to cope with but I had the overwhelming support of surgeons, hospital staff, and the Artificial Limb Service. Now at the age of 84 I can handle most activities except running



Sometimes it can be a rough road back to normal life but one thing I do know: don't take pleasure from misery, you can't change the past.

(If you would like to share your story with readers, get in touch with the Editor - contact details on page 2)

OUR THANKS to the Rehabilitation Welfare Trust for their donation towards the cost of the publication of *Purpose* and to the Lottery Grants Board for assistance towards administration expenses.

PROFILE: ROBBIE FRANCIS

"Living with Lucy"

from An Ongoing Challenge



Twenty-eight years ago I was born with a condition called Phocomelia, which meant the bones in the lower half of my legs didn't develop properly before birth. I learned to walk on a prosthesis, which became commonly known as 'Lucy Leg', and underwent further amputation and bone reconstruction surgery in my youth. Even so, my "good" leg continues to be a challenge and may also need to be amputated one day.

I am very aware that I grew up in a world of privilege and opportunity. But things could have turned out very differently - a thought that hit home after I returned from working as a disability rights monitor in Mexico City. During my internship I had the opportunity to visit some of the most incredibly dark places on earth. Places where people like me, disabled people, are segregated, tortured and denied all human rights. In the words of Kiwi singer Brooke Fraser: "Now that I have seen, I am responsible." Having witnessed such horrific human rights abuses, there was no way I could continue with the status quo. Documenting the problem was simply not enough; I wanted to become an active part of the solution. So in 2014 The Lucy Foundation was born - yep, named after the one and only Lucy Leg. We're a social enterprise committed to empowering people with disabilities by working with local communities to promote education, employment and a culture of disability inclusiveness through environmentally, economically and ethically sustainable trade. Our first enterprise focuses on the production of specialty single-origin coffee and the economic and social inclusion of disabled people in both Mexico and New Zealand. The aim? To transform the coffee industry by showing how an entire

value chain of coffee can be good for the environment, economy and community, as well as being inclusive of disabled people - from seed to cup. With our team now on the ground in Mexico, working directly with local disabled people and coffee farmers, there's no telling where this road might lead and the impact it could have!

When I'm not running the Foundation I'm a PhD candidate at the University of Otago National Centre for Peace and Conflict Studies. My research is looking at the experiences of disabled people in places of war. I'm also on the Expert Reference Group advising the New Zealand Government on the new New Zealand Disability Strategy, amongst a variety of other part-time jobs that help me fund all these endeavours!

I love living with Lucy... and to think, this is just the beginning!

NEWS FROM THE REGIONS

auckland & Northland - As the Total Mobility Officer, Janis continues to visit recently amputated clients. These visits are worthwhile and enable clients to meet a fellow amputee, encouraging them to lead as normal and active lifestyle as possible. The committee is looking forward to some new input after the Annual General Meeting early in 2018.

Waikato, Bay of Plenty & Districts - A busy time is coming up, with a fishing trip planned for 18 November and a Christmas lunch on 9 December.

awke's Bay/East Coast - Little to report other than a need to fill the positions of Field Officer and Treasurer, both key roles within the Society.

reasonably well attended this time, which makes the clinics viable from the Artificial Limb Service's point of view. A very enjoyable afternoon car orienteering course was set up and organized by Bevan Joyce and was a great success for those that attended and who followed the instructions. We finished back at Bevan and Maia's place with a hangi and some very enjoyable socializing, where we were able to meet with new members. We will be meeting with some folk from the Waikato Society for another fishing expedition to Kawhia in November. (Wally Garrett, President)

Manawatu - With members living between Taihape in the north to Waikanae in the south and from Dannevirke in the east to

Wanganui in the west the committee has canvased members and for the AGM next year will give notice of motion to change our name to the "Amputee Society of Manawatu and Districts Inc." The committee also tries to better accommodate this spread of members in selecting member functions which share the need to travel. The next member function is a barbecue to be held on Saturday 11 November at 12 noon at the camping ground at Dudding's Lake in the Rangitikei. The hall and kitchen have been booked so hopefully weather will not be a problem and a great turnout of families will gather. The function to start 2018 will be a luncheon on Sunday 28 January at 12 noon at the Masonic Café in Levin. (John Maher, Secretary)

Greater Wellington Region - We are busy planning next year's National Conference at the Brentwood Hotel on 20-22 April. We are looking forward to hosting attendees for what will be an awesome weekend. (Ken Te Tau, Vice President)

Nelson & Marlborough - In Marlborough we are still enjoying our monthly lunches at The Clubs of Marlborough. Look out for your invites in the post and please come and join us. (Carla Taylor, Secretary)

Canterbury & Westland - Spring is most definitely here and we are all enjoying some much needed warmer temperatures after a cold, wet winter. Our Christmas function is to be held on Sunday, November 19th at the Hornby Club and we expect a great turnout once again. The Society held a sausage sizzle on October 1st and it turned out to be not only a successful fund-raiser but a great opportunity to raise our awareness in the community with our new teardrop flag on show for the first time. Many thanks go to ALL who helped out on the day but special congratulations must go to Chrissy, Alesha & Justine for their dedicated hard work in making this event such a wonderful success. (Mark Bruce, President)

tago & Southland - It's been a quiet couple of months but we are looking forward to our annual golf day/barbecue and Invercargill dinner in November. (Lorraine Peacock, Coordinator)

Newsletters of Regional Societies are available on the Federation's website (www.af.org.nz) along with other useful information.

SUPPORT YOUR REGIONAL AMPUTEE SOCIETY IT SUPPORTS YOU!

(If you are receiving this *Purpose* in printed form and would like an e-copy emailed to you, please let us know.)

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If you wish to do the same, you are more than half-way there - the remainder is as easy or as difficult as you make it.