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EDITORIAL

We continue to move forward!

In September of this year, history was recorded when a Memorandum of Understanding was entered into between the Amputees Federation of NZ and the NZ Artificial Limb Service. This followed the Peer Support training session held in conjunction with the Federation's National Conference in April of this year and was motivated by the wish of AFNZ and NZALS to ensure that new and prospective amputees receive a professional, consistent and appropriate response to some of the many questions they may have about living with limb loss. It is hoped that the implementation of a national programme will enable trained Peer Support Volunteers to provide such a service to amputees, no matter where they reside in New Zealand. A Peer Support Business Case is currently being compiled which will set out the workings and funding details of the programme for an initial period of 3 years.

Notwithstanding this initiative, there remains a key role for Societies to provide an ongoing support network for both new and existing amputees. The advice, personal support and encouragement which Societies can offer to all amputees is the reason our organisation was founded more than 70 years ago. There will always be a place and need for such a service to be provided through our Society networks, as well as our Field Officers and Visitors.

The achievements of our youth amputees continue to dominate the news stories in this publication and this can only be good - they will play a key role in the future of this organisation. However, it would be great to have some stories of achievement from our "older" (in terms of age) readers. I'm sure there are a good number of you out there with plenty to share, so do get in touch.

Speaking about youth achievements, the recent announcement by the Prime Minister that Paralympians will in future receive performance enhancement grants of similar value to that of Olympians was great news and well overdue. One can certainly not disagree that "Our Para athletes are incredible role models that have inspired Kiwis to think differently about disability."

Season's greetings to you and yours from the **Home of the Ranfurly Shield**

Lorraine Peacock
National Coordinator

ROBOTICS HELP WITH THE CHALLENGE

Robotics helped one Southlander to get over the finish line of this year's Southland Festival of Running. Having lost her leg above the knee at a young age, Sandhiya (Sandy) Gilmete (36) has relied upon a prosthetic limb all her adult life. Last year a computerised prosthetic leg changed everything, from the way she walks, to feeling stable



in the ability of the limb's technology. The technology in the knee, which is rechargeable, uses a small computer to communicate and determine what movement her upper leg is doing and it adjusts what the limb will do in response to that movement. The limb, complete with a tattoo, is turned on by movement in her upper leg: with three clicks, she has a knee that allows her to walk on various terrains as the computer adapts to her movement. The new limb required Sandy to train herself to walk all over again, moving her hip in different ways to achieve a fluid motion. She said there were challenges in doing the 10km competition but having participated in the city's Surf to City, which was 6.5km, she was confident she could complete the 10km event. Sandy said she felt nervous about being able to finish when she competed in the event last year and this year's aim was to beat her previous time - mission accomplished!

(Excerpts & image courtesy of Stuff)

CONFERENCE & GIVE IT A GO!

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A GREAT CHOICE!



We were delighted to learn of the appointment of Kate Horan to the NZ Artificial Limb Service Board. Kate, who was born with a congenital leg deformity resulting in her lower left leg being amputated at the age of 5, has excelled in para athletics and cycling and continues to train towards representing New Zealand at the Tokyo 2020 Paralympics. In addition to her role on the NZALS Board. Kate works part-time for Parafed Wellington as Sport Coordinator, providing sport and recreation opportunities for young people with physical disabilities. Kate: "Working with young people with disabilities resonates with me personally having experienced a

similar journey myself. Being able to give back in a variety of ways, such as sitting on the Board, means I am able to make a difference to others lives. I see bringing my story to the Board role as providing a real context in the decision-making around this Service." (We look forward to the difference you will bring Kate)

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)

CAN YOU HELP?

I am an occupational therapist working within acute hospital services, and have a passion for working with people following lower limb amputation. I want to develop a guideline for occupational therapists to follow when supporting people during hospital admission and community services, with particular interest on ways to promote healthy body image following amputation. I would really appreciate help from Amputees Federation members. If interested in sharing your story and experiences, please contact me by telephone 021417277 or email taryn.kearney@waitematadhb.govt.nz Thank you.

JUMP JAM JOSH

(Reprinted with permission from the Newsletter of the Greater Wellington Region Society)



Josh Tia has been competing in Tauranga at the Anchor AIMS Games with his school, **Maidstone** Intermediate. Since its inception in 2004, grown from has competitors representing 17 schools and four sporting codes to this year's Anchor AIMS Games embracina 10,000+ competitors 320 schools throughout New Zealand, Tonga and the Cook Islands. The NZALS with the support of Parafed Wellington, Otto Bock, Ossur and the Amputees Federation piloted a Get Active Kids Activity Day in April this year. Josh

participated in this event and was able to trial an Activity Running Blade for the veryfirst time. Minutes later Josh was blazing up and down the Newtown Park track just like his hero Liam Malone. Josh is active in the many sporting codes and activities offered at his Intermediate. He really enjoys the mobility and agility his Activity Blade provides which allows him to participate competitively in all activities alongside his friends and peers. It seems safe to say that Josh

and his Blade are inseparable but wait... there's more to the sporting success of this young man. Swapping his basketball kit for swimming togs, Josh is temporarily separated from his Blade to compete in the pool. I am happy to report that Josh is coming home from the Anchor AIMS Games with a Gold Medal he won in the swimming pool. Tau kē! Josh you are amazing! Congratulations and well done. Check out Josh on OneNews by clicking on the link below.

https://www.tvnz.co.nz/one-news/new-zealand/twelve-year-old-one-leg-impresses-aims-games?auto=5833320755001

AMPUTEE SNOW TRIP 2018

Following on from last year's trip to Mt Ruapehu, a slightly larger group of amputees and supporters took part in this year's trip to the Turoa skifield. Matt Bryson, who once again was responsible for organising the trip, features in an *Attitude* programme. Well done Matt - a great initiative!

https://www.facebook.com/61281423185/posts/10156535951603186/

LETTERS TO THE EDITOR and other contributions to *Purpose* are very welcome. We regularly feature the sporting achievements of our youth amputees and it would be great to hear from the more mature members of our group. Maybe you have achieved or are still "achieving" - do get in touch if you have anything which could be shared with other readers. Send your contribution to the Editor at 213a Bay View Road, St Clair, Dunedin 9012, or email to *coordinator@af.org.nz*

UR 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.

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

VIRTUAL REALITY:

A Promising Frontier in Phantom Pain Therapy

(Excerpts reprinted with acknowledgement to Amputee Journal) Individuals who experience phantom limb pain (PLP) may hope for a solution from this breakthrough in virtual reality technology (VR). Eight out of 10 people experience phantom pain, a feeling of discomfort in a hand, arm, or leg that's no longer there. With VR gaining traction beyond the realms of gaming and entertainment, the possibilities are endless.

What Causes Phantom Limb Pain (PLP)?

To this day, it's still quite a mystery as to what causes PLP. Several explanations range from PLP as a psychological problem, while other experts point to the spinal cord and brain as the culprits. Magnetic resonance imaging (MRI) or positron emission tomography (PET) scans indicate some parts of the brain - which used to be neurologically connected to the nerves of the amputated limb - produce activity as the patient experiences phantom pain. "The tactile representation of different body parts are arranged in the brain in a sort of map. If the brain no longer receives feedback from an area, it tries to reprogramme its signal reception map. That is the most common conception of how phantom limb pain occurs." Patients who have more luck recover from PLP with zero treatment over time. For others, this phenomenon can be quite challenging, because how can one treat pain from a limb that's no longer there?

Phantom Limb Pain Symptoms

Many amputees claim that their missing limb seems to be there, despite having undergone amputation surgery. Bear in mind that this is completely different from phantom limb sensation, which may manifest rarely in individuals who were naturally born without limbs. More common symptoms include:

- Occurrence within the first few days from amputation
- Pain can come and go at times, or be continuous for others
- Often occurs in the part of the limb that's farthest from the body
- Sensation can be shooting, stabbing, boring, squeezing, throbbing, or burning
- Patient can sometimes feel as if the phantom limb is placed in an uncomfortable position
- Pressure or emotional stress can trigger the pain in the remaining part of the limb

Two Treatment Options for PLP Therapy

Mirror Therapy

Mirror Therapy is a traditional treatment option introduced in the early 90s using a mirror box. The patient positions their "good" limb on one side and the remaining on the other. They are made to focus on the side with the functional limb and make "mirror symmetric" movements that are similar to how we clap our hands. Since the individual sees the reflection of the good limb in motion, it gives the phantom limb the illusion of movement as well.

Visual Image Therapy

Visual Image Therapy uses a process similar to Mirror Therapy which requires patients to imagine their missing limb without using a mirror box. The idea was that over time amputees would retrain their brain, with the treatment eventually easing the discomfort.

Both types of treatment have only had moderate success and have no formal trials. But what if we could use VR instead of a mirrored box? We could bring up a better representation of a missing limb, without having to rely on our imagination or a mirrored box.

How Virtual Reality Works in Phantom Limb Pain Therapy

Several researchers have tried VR as a form of therapy for PLP patients. Olf Blanke, a neuroscientist from Switzerland, gathered his team of scientists to show the effectiveness of virtual reality. "We managed to provoke an illusion: the illusion that the subject's legs were being lightly tapped, when in fact the subject was actually being tapped on the back above the spinal cord lesion, and when we did this the subjects also reported that their pain had diminished". Olaf explains that restoring an individual's sense of touch through VR may be the key for pain relief in patients. The patient wore VR goggles and saw the dummy legs from above, as if looking down on one's own legs. A camera filmed the legs, while the video fed into the goggles in real time. The scientist then tapped the patient's back with one rod and poked the dummy legs at the same time with another. This experimental set-up tricks the brain into thinking that the movement comes from the paralyzed limbs, which only goes to show the power of our minds, and the potential of how VR can help ease phantom limb pain.

VR gives the freedom to go beyond the confines of our bedrooms, desks, and homes. It allows us to create a world that's not really there, including hands, legs, or arms that used to be part of us. (*But in our lifetime? - Ed.*)

Visit our Website at www.af.org.nz

NEWS FROM THE REGIONS

Auckland & Northland - We are preparing for a Special General Meeting on Sunday 18 November at the Maungakiekie Golf Club, 5 Anita Avenue, Mt Roskill - starting at 11 am and followed by a Pay your Own Way lunch at the golf club. The reason for the meeting is to bring the rules of our Society in accordance with the Amputees Federation of NZ and other regions. (Janis Bourne, Secretary)

Waikato, Bay of Plenty & Districts - It's all go here! We've decided to pull apart everything we have and do, and take another look. Things are flying, so if you stand still for too long we offer training in the art of ducking! We're phoning our members, updating their details, asking what they want from us, listening to them - and along with getting valuable input, it is fabulous to connect with our community. I know they'll be reading this and nodding their heads "Yes, we have paid our annual membership fee!" We're also on Facebook, so check us out! On 25 November our End of Year celebration will see us kayaking on Lake Karapiro visiting places that, unless you are aboard a kayak, you just don't get to see. Lunch follows with some surprises of its own. We are looking forward to an exciting 2019 with more community connection, events, Conference, new Committee members on board and new initiatives. (Jill Moody, Secretary)

awke's Bay/East Coast - As we head to the latter part of 2018, our Society's Committee has reformed and re-jigged and has recently elected myself, Jacqui D'Ath, as the new President. Our previous President, Diane Walsh, has been welcomed back on board - this time as our Secretary. I am the daughter of Geraldine Kerley one of our amputees, who is on the committee as well. In September, we had a great function at the Duke of Gloucester with 38 attendees all enjoying a wonderful lunch and social catch up. Next stop is our Christmas function, which is always an exciting event for all who attend. (Jacqui D'Ath, President)

groups for the under 65's and over 65's and spoke to the assessors in the community about our service. This included Physiotherapists and Occupational Therapists. They also met the local CCSDA and flew the flag. It is 50 years since the Taranaki Society was first formed so a celebration was held in its honour. On Saturday 6 September a group travelled up to the Stratford Mountain House and had lunch. Peg Avery was asked to cut the cake in honour of our Patron for so many years - her late husband, Rash. (Wally Garrett, President)

Manawatu & Districts - No recent news from this region. We hope to once again see a good contingent of their members at next year's conference.

Greater Wellington Region - We were delighted by the announcement that our President, Kate Horan, was appointed as the new Board member for the NZALS. We know she will be an inspirational advocate and voice for amputees. We are actively supporting the NZALS in seeking funding to ensure that every child with limb loss can have access to an activity blade. This is an amazing initiative that needs our collective attention and support. (Ken Te Tau, Vice President)

Nelson & Marlborough - No recent news from this Society. However, word has it that a name change to *Top of the South* is proposed for this Society - watch this space!

anterbury & Westland - A very successful sausage sizzle was held at Mitre 10 on 14 October, with great support from the community and members which really added awareness to our Society. We are proud of a young member, Grace Johnstone, who portrayed herself very well on the Fanimals TV show with her lovebird "Smudge". She is looking forward to attending her first GIAG Youth event in Dunedin next April. (Eileen Popplewell, Secretary)

tago & Southland - A busy time lies ahead as we plan for next year's Conference combined with our 75th Jubilee. In the meantime, end-of-year dinners are planned for both Dunedin and Invercargill. (Lorraine Peacock, Coordinator)

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

A REQUEST FOR SPONSORS

If you know of anyone who would be prepared to advertise in Purpose and thus support a worthwhile cause, please ask them to contact the Coordinator at

coordinator@af.org.nz

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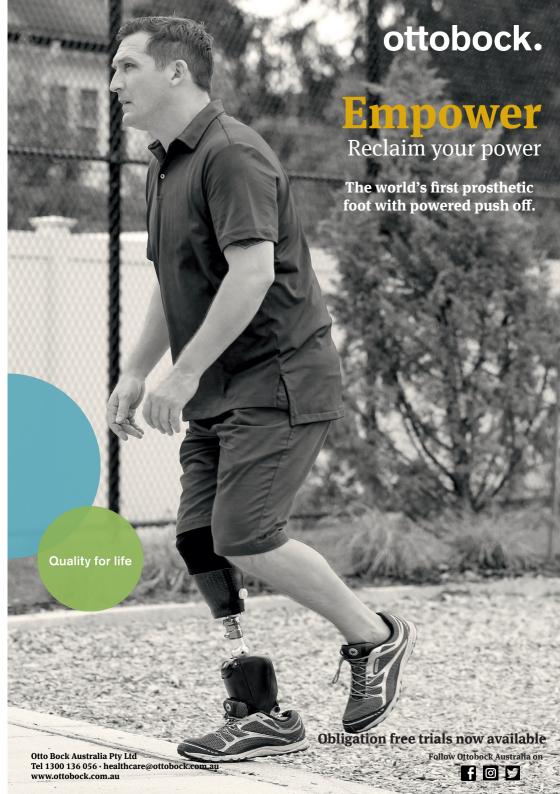
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Remember that you're not the first person to have lost a limb - many others have passed along the same route and achieved conspicuous success.

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.