Purpose

Journal of the





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PURPOSE

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EDITORIAL

It would be a fair guess that none of us would have selected the loss of a limb or limbs as a life choice. And yet, here we are, all doing the best we can with what we have. As diverse as the people who make up the amputee community, are the skills, experience and knowledge possessed within the group.

Most, if not all, Societies in the country have an ongoing struggle to attract willing new faces to help with projects, social events or to serve on our committees. Sometimes it is even an uphill slog to encourage members to attend planned events.

While I understand and celebrate that being an amputee does not define us and we continue to be whoever we were before, we now have another set of stories and insights that are valuable when shared with others for whom gaining a piece of missing information from a fellow amputee is both enlightening and reassuring.

Please contribute by joining in. It doesn't need to be in a big, public way, but we are all experienced either as amputees or as someone involved with amputees and that experience is like gold. Discovering that someone else has been down the road you are currently on and not only survived but flourished, is some of the very best medicine. What I learned to my surprise is that there is a certain brand of humour that only another amputee "gets" and there is an unspoken understanding and compassion which exists only between one amputee and another. This is too valuable not to share.

Amputee Societies throughout New Zealand depend on the goodwill and participation of their members. Whether you are asked to agree to nomination for a "big job" such as a place on your Society's executive or committee, or something less time consuming, like having a chat with someone who is facing or recovering from an amputation similar to your own, please think about it before saying no. You would be providing an essential and very valuable service to your community and you may be surprised how much you enjoy gifting your personal insights to the amputee world.

Diane Walsh

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NEWS FROM THE REGIONS

Ackland & Northland - Hi, I'm Helen Hewitt, writing my first report for A/N as the new Secretary/Treasurer, having volunteered only a month or so ago. I am not an amputee myself, and desire to support those who are. My background is in finance and I work full time with Geneva Healthcare Ltd in Quay St Auckland. As part of the internal development within our Society, my goal is to establish better database structures and to be top notch with our administration, which will result in being able to reach out to our members in a real way. Recruitment for a part time field officer is underway, and we are already very well established in giving our members access to the Total Mobility Scheme initiated by Auckland Transport, (50% discounted taxi fares). I recently collected a stock of spare shoes from a shoe store in Onehunga and am in the process of taking photos of these and listing them online; anyone interested can email us on anamputeesociety@gmail.com

Hawke's Bay/East Coast - Our Society is ticking along nicely, we held a lunch get-together recently and have a couple more events planned prior to Christmas. We are working with the idea of a luncheon in the East Coast Region too. Our membership is stable in the upper nineties with a few members sadly passed on and new amputees joining us. Thanks to Geoff, our Field Officer, we have a great relationship developing with the staff at the hospital, who now regularly offer new amputees the opportunity to meet Geoff. (Diane Walsh, President)

Taranaki - Our Society continues to have good membership turnout for meetings. A book we purchased from Australia - "Little Miss Jessica Goes to School" by Jessica Smith (Paralympian swimmer) - makes a good read and sets a base for understanding life's challenges for the young ones, especially on their first day at school. We hosted three 3rd year Physiotherapy students from AUT out on placement for a day, showing them what we do as a Society, which was very enlightening for everyone. (Christine Windle, Secretary)

Manganui during July when Tim Crowe, senior emergency medical officer for the Wanganui District Council gave an account of the time needed to door knock and get residents evacuated in an emergency. Tim also talked about the value of having amputees volunteering to act as trauma victims in both civil defence and assorted emergency exercises. (John Maher, Secretary)

Freater Wellington Region - The committee has approved the Māori translation of our Society's name: Te Kāhui Mutumutu o Te Upoko o te Ika-a-Māui. We are looking forward to hosting a fun movie night coinciding with the release of the new James Bond film "Spectre" at the Petone Lighthouse movie theatre November 22nd. Another initiative is from committee members who are involved with the North City Country Music Club. They meet every 3rd Sunday of the month at the Porirua club and invite amputees and friends to come along and join in the fun. We are actively supporting our President, Kate Horan, in her endeavour to bring home cycling medals from Rio. (Ken Te Tau, Vice President)

Canterbury & Westland - A Christmas get-together will be held at the Hornby Club on November 29th and plans are well in hand for the hosting of next year's conference. (Eileen Popplewell, Secretary)

Cago & Southland - There was a good turnout of Otago and Southland members at the dinner in Balclutha. Annual events scheduled for November are the quadrant multisports, golf and barbecue, and Invercargill meeting and dinner. Visitors to the south are very welcome to join us. (Lorraine Peacock, Coordinator)

ewsletters 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!

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)

OUR THANKS to the Rehabilitation Welfare Trust for their donation towards the cost of the publication of *Purpose*.

NOW PRINTING: PROSTHETIC LIMBS

(Reprinted from E News, Limbs 4 Life, September 2015)

Affordable open-source prosthetic limbs may be a step closer, thanks to the efforts of Queensland University Robotics Club students. The club is spending this semester creating a functioning prosthetic forearm with the intent of advancing open-source knowledge around the creation of 3D printed prosthetic limbs. Project manager and UQ Business student Lex Van Cooten (right in photo) said the team had spent six months working on prototypes before coming to its current model. "We used files from an open-source humanoid robot arm, and now we're working on how to get it to interface with the human body," he said. "It uses EMG (electromyography) – a very basic signal process that responds to connections on the muscles, that essentially opens and closes the hand. The next step is being able to grip things, which is where most commercial units are at."

The UQ Robotics Club is I working with amputees including Ben Tarbuck (centre), to test the unit. "The only thing we have available to us at the moment is cosmetic arms." prosthetic Mr Tarbuck said. "They kind of just hang there like a dead weight and are



good for nothing, or you can get a freaky-looking hook," he said. "Having an arm that's functional, and also accessible financially for people, would be a good move in the right direction." Mr Van Cooten said the students would use what they learned to contribute to other open-source files on building prosthetics. "It's a very active area," he said. "There are a lot of financial challenges for people seeking prosthetics. They can cost \$10,000 per component and there's no room for customisation. "We wanted to build something useful, to have fun but also add value. If we can bring something back to the open-source community and bring forward affordable limbs, that would be the ultimate goal." So far, the 3D printed limb costs around \$500 to make. The project has been funded through a UQ Sponsorship Grant, with robotics club member Fabian Vasuain (left) acting as head engineer. Visit http://uqrobotics.com/ for more information

OTHERS' NEGATIVITY PROVIDES MOTIVATION TO SUCCEED

(Reprinted from the Star Sports August 2015)

Dunedin athlete Jonathan Brownjohn (19) is a firm believer in having a positive attitude. Jonathan (or Jono as he is known by his peers) was born with Amniotic Band Syndrome — when he was in the womb he became entangled in the amniotic band which amputated his left leg at the knee. "Since I was born with it, it didn't affect me as much but still growing up I got bullied at school. It's whether you take it in a way that will drive you - it can push you harder or you can sit and feel sorry for yourself," he said. He used other people's negativity as motivation as he became involved in athletics — sprinting, high jump

and long jump — and at his first New Zealand Secondary Schools athletics competition, against other athletes with disabilities (AWD), he picked up five gold medals. He holds the New Zealand record for open AWD 100m sprint and high jump, and in March this year he won a gold medal in the 100m sprint at the IPC Grand Prix in Australia.

He was born in Papua New Guinea and moved to New Plymouth seven years ago before moving to Dunedin to take part in the Parafed Otago and High Performance Sport New Zealand programmes." I started athletics about five years ago. I started off with cross-country and, after sprinting out at the start of each race, my coach though I should be a sprinter. That's when he got me into athletics. "I was still competing with able-bodied athletes at that stage and two years later I got into the AWD side of things," he said. Whether competing against other AWD or able-bodied athletes, the most important thing for him was to concentrate on what he was doing and do his best. He



is not convinced he would have the same drive and motivation if he had been born without Amniotic Band Syndrome. "I've had that thought a lot. If I was born normally I would not have the same life I do now. My drive and motivation would be completely different, my sport goals would be different and I wouldn't have the support

and the friends I have now. I wouldn't be the man I am now so I'm grateful for it to be honest."

His ultimate dream is to compete at the 2016 Paralympics in Rio, Brazil. "I've always dreamt of competing internationally. Any sport I play I dream of competing at the highest level possible." He "definitely" felt like he had proved the bullies wrong. "They used to call me names and I'd separate myself from everyone else. I'd feel left out. I had to prove with sport that I can compete as well as them, if not better."

PATIENT FITTED WITH PROSTHETIC LEG THAT CAN FEEL

(Reprinted from Canterbury/Westland's newsletter, courtesy O & P Edge)

Austrian researchers have fitted a man with a sensory-enhanced prosthetic leg that can produce feeling, which they say increases safety and reduces phantom limb pain. "The re-established transfer of information also contributes to a more natural integration of the prosthesis into the body concept of the patient and, in this case, has led to the complete disappearance of previous long-lasting pains," announced the University of Applied Sciences Upper Austria (FH Upper Austria). The researchers, who are with the Research Group for Arm and Leg Prostheses Linz (ReALL), Department of Medical Technology at FH Upper Austria, provided a live demonstration of the prosthetic leg at a press conference in Vienna, Austria, on June 8. Prior to the fitting of the prosthetic device in laboratory conditions, the patient underwent targeted sensory re-innervation, a selective transfer of nerves from the residual limb, during which the sensorial nerve endings that once relayed communication from the sole of the natural foot were reactivated to serve as an indicator for pressure on the sole of the prosthetic foot. Six sensors were then attached to the foot sole of the prosthesis; the sensors are linked to stimulators inside the socket, allowing the patient to receive sensations from the prosthesis. The neural interface can then communicate feeling from the sole of the user's prosthetic foot, providing information about the type of ground that he or she is walking on and awareness of obstacles, which can reduce the risk of falls.

The initiator of the research project, Hubert Egger, PhD, a professor of prosthetics with the Department of Medical Engineering at FH Upper Austria, also headed the development of a prototype of a mind-controlled and sensory-enhanced prosthetic arm as the head of research and development of Ottobock, Duderstadt, Germany.

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Orthopro welcomes this opportunity to introduce ourselves to the American T Orthopro welcomes this opportunity to introduce ourselves to the Amputees Federation and its wider community. Orthopro is a privately owned Wellington contablished in 2004.

provide both clinical and manufacturing/ We fabricating orthotic and prosthetic services. We are able to provide all types of upper and lower limb prostheses, including myoelectric prostheses. We have five conveniently located clinics situated in and around the Wellington region: Newtown, Lower Hutt, Kilbirnie, Porirua/ Kenepuru and Paraparaumu. Our Porirua/Kenepuru office has full clinical, fabrication and administration facilities. We currently service clients from in and around the Wellington region as well as other regions, including but not limited to Auckland, Thames, Tauranga and Hastings. Orthopro is currently able to provide services to ACC clients from all areas of New Zealand as well as Ministry of Health patients by special arrangement. Customers have expressed a strong satisfaction with the quality of service, delivery and patient care provided. This is built on Orthopro's commitment to providing experienced and qualified staff who strive to deliver quality/excellent services to meet the individual needs and requirements of their patients.

Our clinical and technical team currently consists of Des Nicholson and Greg Vos and we are pleased to have Lynda Allen re-joining the team after taking a break with her young family. In addition, we are supported by a dedicated administrative team of Bev Sullivan, Cheryl Nicholson and Cumarie Vos. Des aualified as an orthotist/prosthetist in South Africa in 1980, originally working in the Public sector. In 1994, he opened his own Private Orthotic and Prosthetic practice in South Africa. After immigrating with his family to New Zealand in 2002, he worked briefly for a Wellington company before deciding to establish Orthopro in 2004. Des has also previously worked at the Artificial Limb Centre in Wellington. He is a member of the NZOPA and ISPO. Greg qualified as a Medical Orthotist Prosthetist in South Africa in 2003. He ran a private practice in South Africa from 2005 to 2015 before immigrating to New Zealand with his wife and children. He is a member of NZOPA and ISPO. Over the past few years, Orthopro has also had the privilege of being able to employ four graduate German Orthotist Prosthetists (Johannes Green, Raphael Metz, Fabian Kastrup and Jamila Sardar) who chose Orthopro and New Zealand for their OE. Here they have been able to immerse themselves in New Zealand culture and gain a wide range of skills in orthotics and prosthetics,

in addition to contributing new ideas and plenty of enthusiasm to the work place. Furthermore, Jan Vaartjes is a 4th year Mechanical Engineering student specializing in Biomedical Engineering from Hanze University of Applied Sciences, Groningen, Netherlands has recently commenced his internship at Orthopro, where he will be working on an exciting new and innovative development in the prosthetic field, together with Des and the developer.

For further information visit our website www.orthopro.co.nz or e-mail info@orthopro.co.nz or phone 04-238 4500.

(For many amputees pain is a daily part of life; some overseas research esearch has shown that pain (phantom pain, residual pain or back/spine pain) affects 95% of all amputees. How to treat phantom pain continues to be high on the list of questions most asked by our readers and one of the most popular "hits" on our website. We do try and keep readers up to date of any new developments; excerpts from the following article in ACC's inMotion (September 2015) may provide some understanding when it comes to identifying and treating specific pain - Ed.)

AMPUTEE-SPECIFIC PAIN

There are many reasons an amputee experiences pain. Post amputation pain can be from post-operative pain, neuropathic pain such as phantom limb syndrome or neuromas and musculoskeletal pain from compensatory strategies that cause overuse syndrome or degenerative changes from osteoarthritis.

Factors Affecting Pain Control - The ability to cope with limb loss depends on many factors, and psychological setbacks can be frequent and often negatively impact one's ability to cope with pain. Losing independence and function often lead to depression and anxiety. These emotional responses to stress and a lack of sleep all heighten the perception of pain.

Assessment of Pain - Assessing the type and severity of pain is important in monitoring treatment effectiveness. Qualifying (describing the pain, e.g., "burning") and quantifying (using a scale to determine the level) through a pain journal is often helpful in identifying the right pain medication. Pain is subjective, and a treatment plan needs to be tailored for each patient.

Types of Treatment - Treating pain with oral medications can be an important part of pain management for many amputees.

Medications such as anti-seizure medications, antidepressants, antianxiety medications, sleep aids and opioid painkillers are some of the oral prescriptions that may be used to treat amputee-specific issues. If narcotics and other addictive medications are prescribed, these should be used with caution and monitored by a physician who is aware of the risks and looks at an amputee's pain from a holistic approach. Other options include non-pharmacologic treatments such as:

- Desensitization with massage, tapping or rubbing the limb
- Pressure with a shrinker, wrapping or the use of a prosthesis
- Healing of the residual limb
- Transcutaneous electrical nerve stimulation (TENS) or mirror therapy
- Interventional procedures such as acupuncture, nerve blocks, trigger points, Botox injections and ablation or excision of neuromas
- Psychology of limb loss with psychotherapy and counseling.



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