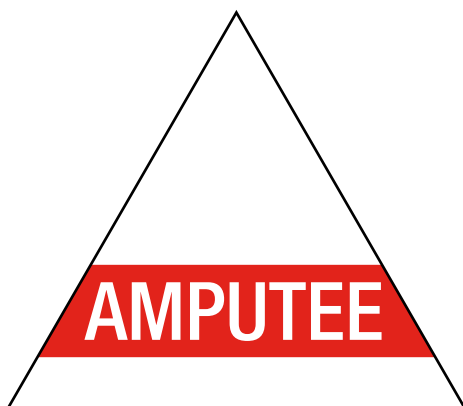


# ***PURPOSE***

**Journal of the  
Amputees Federation of New Zealand Incorporated**



**MARCH 2014**

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## MEET DWAYNE:

In 2008, he ran up all 1504 stairs of his first building – the Sydney Tower – in 23 min and 49 sec. He also was the first Double amputee to scale the 1576 steps of the Empire State Building Tower Run Up. Dwayne doesn't think of himself as the fastest or fittest, but believes that "life is worth living" and "you've got to do what you can with what you've got." Now he is doing it on Variflex XC feet by Össur.

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*The opinions expressed in this  
Journal are not necessarily those  
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# EDITORIAL

According to the latest Annual Report of the NZ Artificial Limb Service (available for you to read on their website [www.nzals.govt.nz](http://www.nzals.govt.nz)), “as at 30 June 2013 the service catered to 4,259 current patients registered with the NZALS throughout New Zealand”. *(I simply can't resist this opportunity to express my preference for the word “client” rather than “patient” - I'm sure the majority of you, like me, won't regard yourself as a “patient”!)*

However, I digress..... What is of more concern is the relatively small number of amputees who are members of an Amputee Society - at present just a little more than a thousand. The number has fluctuated over the years, with a relatively strong membership in the 1950's when the Federation was active in lobbying the Government of the day for free limbs - something it was successful in achieving in 1964. Maybe, in the present day when we have everything supplied *free gratis*, we need to have something for which to fight to counter apathy and boost our numbers? Of course if you're reading this the chances are that you ARE a member of a Society and I'm preaching to the converted. If, on the other hand, you are not a member and are reading this on our website, picked up a copy in the waiting room at a Limb Centre or in a hospital ward, how about getting in touch with your local Society? They would love to hear from you.....

I truly believe that the need continues for a strong group representing the interests of amputees - and as the only organisation to do so in NZ, that is us! We will continue to represent amputees, whether or not they are aware of us doing so, in matters of welfare and benefits, in providing support and encouragement, and in promoting independence. And if this helps newcomers to our ranks to take up the challenge and renew their participation in everyday life, then we will have gone some way to fulfilling the reason we were established 67 years ago.

As promised, included in this issue is an article on phantom pain. The subject is extensive (it could easily fill an entire issue!) and affects most of us in different ways - the lucky ones not at all. Those for whom the dreaded phantom is an ongoing problem will have their own way of dealing with it; if you would like to share this with readers in a Letter to the Editor it would be most welcome.

The next issue will bring a report on our Conference and the Give it a Go! youth weekend in Nelson 21-23 March. Watch this space!

Until next time, take care

*Lorraine Peacock*

## NEWS FROM OUR SOCIETIES

**Auckland & Northland** - There was a good attendance of amputees and supporters at the Annual General Meeting on Sunday 9 February. After all the reports were read (Presidents, Treasurers and Field Officers) and a few presentation made, a committee was elected. The Society Patron, Mr. Geoff Lamb, then presented a very speechless and stunned Secretary/Treasurer, Janis Bourne, with a Life Membership, and bunches of flowers. The afternoon concluded with a cuppa, coffee, cake, and lots of chat and laughter. *(A most deserving recipient!)*

**Waikato, Bay of Plenty & Districts** - A day on a Raglan Harbour Cruise boat in December sounded marvellous and too good to miss. A social function in Rotorua is planned for Saturday 12 April.

**Hawke's Bay/East Coast** - There's been plenty happening in the Bay, with a Christmas function at the Fishing Club in Napier and a car rally during February. Plans are under way for a project which will offer a gentle aqua exercise and fitness programme especially for amputees. It will involve two six week courses and it is hoped to have the services of a qualified instructor giving the assistance needed to ensure the safety and comfort of amputees participating.

**Taranaki** - For an update on latest news and planned activities, contact the Secretary (page 12).

**Manawatu** - The most recent function was the end of year luncheon with a Christmas theme held at the Hotel Coachman. The committee made phone contact and offered transport to those not replying to the newsletter invite. Twenty-two members attended - a special note of appreciation to those travelling from Wanganui. The AGM was to take place on Sunday 2nd March with a social time provided by the committee to follow.

**Greater Wellington Region** - For an update on latest news and planned activities, contact the Secretary (page 12).

**Nelson & Marlborough** - All energy is focused on hosting the National Conference which promises to be a stimulating and interesting weekend.

**Canterbury & Westland** - A strong committee was elected at the AGM on Sunday February 16th, including new Secretary, Paul Jesson. Seven members will attend this year's conference in Nelson, with 3 first time attendees. Membership numbers have increased by 15 from last year, mainly due to a membership drive conducted with assistance from the Artificial Limb Service.

**Otago & Southland** - There was the usual bunch of enthusiastic supporters at the Southland meeting in Invercargill late last year and the AGM planned for early March promised to be interesting with the guest speaker, Professor Dirk De Ridder, head of Dunedin's neurosurgery research unit, talking on one of his areas of expertise - phantom pain.

**N**ewsletters of District Societies are available to readers on the Federation's website ([www.af.org.nz](http://www.af.org.nz)), along with plenty of other useful information.

**SUPPORT YOUR DISTRICT AMPUTEE SOCIETY  
IT SUPPORTS YOU!**



**“BLADE RUNNER”  
LIAM MALONE**

*(Excerpts reprinted from  
Nelson Mail)*

A young Wakefield athlete is well on the way towards becoming an elite amputee “blade runner” after receiving more than \$20,000 toward his Paralympic dream. Nineteen-year-old Liam Malone appeared on TV3’s 3rd Degree programme recently to speak about his goal of participating in the 2016 Paralympics in Rio. The former Nayland College student was born with a condition named fibular hemimelia, which meant both of his legs had to be amputated below the knee when he reached 2.

*(The little legs Liam is holding were his first ever prosthetics)*

Now studying commerce and psychology at the University of Canterbury, Liam is a keen sportsman who enjoys rugby, mountain biking, snowboarding and sprinting. In order to make it into his chosen discipline, he plans to buy a \$20,000 pair of carbon-fibre “blade” prosthetics that would sharply increase his speed and efficiency. He explained that when non-amputees ran, their leg muscles naturally returned “a large proportion” of energy expended, meaning they did not tire as quickly. His current prosthetics returned very little energy, but the J-shaped blades used by athletes such as South African sprinter Oscar Pistorius would work more naturally with his body. Oscar Pistorius has the same condition as Liam who said that he admired the older athlete’s sporting achievements despite his recent arrest



for the murder of his girlfriend. Further similarities between the two include their transition from rugby to sprinting, and both have lost their mothers. Liam's mother lived with cancer for six years before passing away last year. He said he expected the blades would change his running style, but he was unwilling to estimate how much faster he might end up. "I think a lot of it will come down to individual chance."

Following the TV show's screening, Liam received donations from all over New Zealand that more than covered the cost of his first set of blades. A trust has been set up to handle the overflow. "It's pretty remarkable actually, I didn't expect how many sponsors I got. It's been inspiring and overwhelming." He will be measured up for the blades by a technological team before ordering them through the New Zealand Artificial Limb Board in Christchurch. The process will be a new twist on a familiar theme for the teenager, who has destroyed "uncountable" prosthetic limbs during his athletic pursuits. He expects to receive the new blades within three to five months.

\*\*\*\*\*

## LETTER TO THE EDITOR

Hi Lorraine

I have just received and read *Purpose*. I am so looking forward to your article on phantom pain. A couple of things:

I continue to have phantom sensation and pain. When I start losing significant sleep I seek treatment. Over the past 10 years this has been acupuncture on the contralateral (other) limb where I feel the pain on my amputee side. I have only required it every few years. It has been effective. Recently I began having electrical jolts in my little leg which kept me awake all night. I found that a heated wheat bag over my little leg as I went to bed worked wonders, where touch, massage, tapping, pain relief did not work.

Treatment for Minor Skin Infections - Recently I had a superficial skin infection at the edge of my prosthesis. I went to a Pharmacist for assistance, as I was on holiday and wanted to continue wearing my prosthesis. I was given Crystaderm, a first aid treatment recently advertised on TV. Crystaderm is a mild form of hydrogen peroxide which the Pharmacist said is safe to be used on young children. It cleared the infection in a week leaving the skin clean and supple.

*(All good advice, thanks Liz)*

**LETTERS TO THE EDITOR** and any other contributions to *Purpose* are very welcome. If you have anything to share with readers, please send it to the Editor at 213a Bay View Road, St Clair, Dunedin, fax to (03) 455-9547, or email to [info@af.org.nz](mailto:info@af.org.nz)



## PHANTOM LIMB PAIN

*(by Geoff Hill, With acknowledgement to Limbs 4 Life)*

Phantom Limb Pain (PLP) creates a unique frustration for amputees. It can be hard to accept the idea that something which is no longer there can cause such pain. Many people feel they won't be taken seriously if they complain, or they have an experience of being treated dismissively by doctors, and so keep it to themselves. Recent research indicates that there is some truth in the common dismissal, 'it's all in your head'. Phantom pain may indeed originate in the head, but that is why it must be taken seriously.

Phantom pain has been known of for centuries. The first medical description dates from the 16th century, and the term itself was coined during the American Civil War. The famous British admiral, Lord Nelson, was known to have suffered from PLP. Let's clarify: by phantom limb pain we mean pain experienced in relation to a limb that is not physically part of the body. Phantom sensations are non-painful feelings in an absent part, while stump pain occurs in the remaining part of a stump. Who suffers from PLP? Almost all amputees do initially. For some this may fade over time, but for the majority it may continue for years. Many people experience frequent phantom sensations, but only intermittent pain. When this pain does occur, however, it can be severe enough to be disabling. PLPs can occur from any amputation site and can even relate to internal organs that have been removed. They may occur irrespective of age, gender or reason for amputation. Some suggest that traumatic amputations - or limbs that were painful prior to amputation - can lead to more persistent PLPs. It is also thought that children suffer less from PLPs, although they are by no means absent. PLPs have also been experienced by people with congenitally absent limbs.

So what causes phantom pain? It was thought that irritation of severed stump nerves caused pain perception in the part of the body previously serviced by those nerves. However, treatment of the nerves with local anaesthetic or further surgery has often had no effect on the phantom pains or sensations, so there must be more to it. Some people achieve relief by rubbing their stump, or find that the pain is influenced by the way in which their prosthesis fits. This suggests that these nerves do have some role in phantom pain. Any nerve injury can increase activity in the spinal cord. This may take the



form of increased sensitivity or abnormal spontaneous nerve activity, which might register as PLP. It has also been shown that, following these injuries, areas near the injured site can refer pain to the phantom part when stimulated. Another theory is that of cortical remapping. This is derived from the process of cortical mapping that shows where sensations from different parts of the body are normally processed in the brain. The part of the brain that receives messages from a normal limb may begin to receive messages from other areas after a limb has been amputated (cortical remapping). Evidence of this comes from the ability to create phantom sensations by stimulating body parts which have an adjacent brain map area. For upper limb amputees, touching certain parts of the face can cause phantom sensations, while for lower limb amputees, the adjacent brain area is the genitals. This has been confirmed with brain scanning techniques. However, this does not explain why phantom limbs can feel like they are moving, why congenital amputees sometimes have phantom pain (as their brains have never received input from the missing part), or why the sensations can be painful. All of these mechanisms seem to contribute something to PLP, but none fully explain it. It has been suggested that all brains contain an imprint of the 'normal' or intact body, and that the loss of part of the body creates various difficulties in trying to form this image from what is essentially incomplete information. Some interesting experiments have been performed which support this. One example is where upper limb amputees place their intact arm in a box. The box contains a mirror arranged to create an image of their arm where their amputated arm should be. Some people then felt an almost instant effect, with their phantoms moving, relaxing and their pain decreasing. The theory is that the visual feedback of seeing two intact arms 'tricks' the body into feeling whole again. So obviously, phantom pain is a complicated syndrome. Stump, spinal cord and brain may all be involved, probably in different combinations for each person. The question now becomes, 'what do we do about it?'

It has been suggested that decreasing pain in the time leading up to amputation can lead to less PLP in the long term. Some studies support this, although not conclusively. In many cases, it is impractical as surgery must be performed urgently. In terms of PLP management, it is perhaps better to consult a doctor with experience in PLP, rather than a GP who may not appreciate its subtleties. Because of the complex nature of PLP, conventional painkillers are usually ineffective. The medications of choice are usually from the anticonvulsant group. These act to decrease nerve excitability. The trick is to decrease the unwanted activity without impairing normal activity. For this reason, some people dislike these drugs or find them ineffective. Other treatments include TENS (Transcutaneous Electrical Nerve Stimulation), acupuncture, massage, acupressure and warm or cold packs. Again, these work for some people and not others, but their advantage is that they usually produce no side-effects. It is recommended to always consult with your health care provider before beginning any new treatment.

## PROFILE - MISS BEA WUTS

*(by Diane Walsh, President of the Hawke's Bay/East Coast Society)*



Bea Wuts is a busy, gorgeous 6 year old, who is learning to dance. Bea was born with a rare condition called arthrogryposis which is defined as congenital contractures resulting from stiffened joints, shortened ligaments and muscle weakness. Bea's problems were detected at Mum Margot's early pregnancy scan. At first there was a suggestion that Margot's unborn baby had severe talipes as well as abnormal positioning of her hands. Margot and Anton Wuts set about finding out all they could, but because there was little definite information available they were given a progressively bleak picture of their little baby's future condition. Margot felt that during her pregnancy doctors would offer alarming speculation rather than admit

that they simply didn't know the extent of the baby's abnormalities. When Bea was born in March of 2007, her parents were delighted to find that she was a beautiful baby girl, normal in every way apart from problems with her feet which had contracted and stiffened into abnormal positions. Margot comments that Bea had the most beautiful hands, with long fingers and smooth skin, only mildly affected by arthrogryposis.

At seven days of age, Bea's feet were put into casts; this was later followed by surgery and boots which Bea had to wear 23 hours a day. As time went by, due to her stiffened ankles and feet, Bea began walking on her tippy toes with her feet rotated, a gait that lead to severe pain in her feet and hips, also causing the risk of permanent damage to Bea's posture and skeletal development. At two and a half, Bea underwent extensive and major reconstructive surgery on her feet and ankles, followed by three grueling months in plaster casts which held her feet in an aligned position. Margot and Anton endured weeks of little sleep; Bea's pain and distress were too much for one parent to manage overnight as Bea screamed non stop, sleeping only from exhaustion. After three traumatic months when the casts were removed, Bea's tender feet had to be forced into orthotic boots, despite the pain. At first, Bea's feet sat flat on the floor, but within three weeks they had rotated back to the same malposition and Bea's parents had to face the disappointment that the surgery had not worked. Further plans for surgery were suggested and it

became clear that the surgery would need to be repeated regularly until Bea stopped growing at about sixteen years of age. Margot says it was then that she realized that if Bea was exposed to such relentless surgery, not only would she lose the chance of a normal, peaceful childhood, but the damage to her hips and other joints from inactivity and abnormal gait may ultimately lead to a wheelchair for Bea. Margot says that she felt respected and listened to by the medical and associated professionals who she and her family encountered. Bea however, reacted with terror when meeting her local surgeon after several painful experiences.

Eventually, Margot and Anton began considering amputation of Bea's feet as a way to give her the best chance of a normal life. After discussing the idea with an Auckland surgeon, the Wellington Limb Service prosthetists, and talking it over with Bea, the difficult decision was made. Margot is grateful that as a parent her ideas were seriously considered as valid in determining the future treatment of her child. Bea was a kindy girl, aged four, when she went off to Auckland for the amputations which started the exciting journey to new feet. A lot of creative planning and preparation went into ensuring that Bea understood the reality of having her feet removed. Following the amputation, the surgeon reported that Bea's ankles were irreparably damaged, a powerful affirmation that Margot and Anton had reached the correct decision. Margot was nervous about Bea's reaction to seeing her stumps after the amputation, but when Bea first looked under the blankets, she joyfully said with a gasp of relief, "Mum, I've got no feet!"

These days Bea has her new feet and experiences the happiness of pretty new shoes. Bea manages her prosthetic feet very well; she runs and jumps and dances, she's a whiz on the trampoline and enjoys a ride on her scooter. At home, Bea enjoys the freedom of walking on her stumps which have the sole skin of her original feet on them. She is pain free and loves to play with her big sister Maddy and little brother Arlo, as well as her friends. She's off to school now and enjoying the exciting childhood that a little girl deserves .

**PUBLICATIONS** available (no cost) from the National Coordinator or District 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 10 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)

**AIR NZ AIRPORT HANDLING NOTICE -  
Wheelchairs and Boarding (Domestic)**  
(Effective from November 2013)

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Any customer with reduced mobility who requires assistance from airport/ground handling staff from the check-in area to the boarding gate will be advised to report back to a specific area at no less than 40 minutes prior to departure. Airports are required to ensure that all customers requiring assistance to board must be at the boarding gate 10 minutes prior to boarding commencing. Those customers with caregivers who are taking these customers to the boarding gate themselves must report to the boarding gate 10 minutes prior to the boarding time printed on their boarding pass or shown on the airport monitors.

**OUR THANKS** to the NZ Lottery Grants Board, Pub Charity, the Lion Foundation and the NZ Community Trust for their recent grants; we very much appreciate this support.

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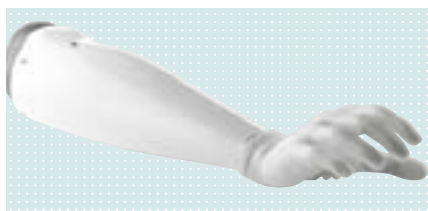
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