

**AMPUTEES FEDERATION OF
NEW ZEALAND INCORPORATED**

PURPOSE

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



MARCH 2011

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GUEST EDITORIAL

No. 92 – March 2011

As I conclude my time with the Artificial Limb Board my reflective thoughts fall naturally into two groups.

First of all, there is my recognition of amputees as, in general, a wonderful group of people all striving in their own way to maintain independence and live fruitful lives. I learned very early on what is frequently not appreciated at large, that every amputee is different and that generalisations do not help understanding. Every person is unique in terms of their physical condition and capabilities, the nature and extent of their limb loss, co-morbidities, personality traits and so on. But, in all I have come across whether it be at the young, fit and athletic end of the spectrum or at the other end where achievement is simply having sufficient independence to move around the home and get to the bathroom unaided at night, there is a determination to make the most of the situation. I applaud and admire that.

Secondly there is the nature of the Limb Service in New Zealand and its ability to make a difference in the lives of amputees.

The model which has been developed over the years of a single, stand alone, national service, government owned and funded and free to amputees, is just about unique in the world. It has given us a high profile internationally which has had its own rewards in terms of being in touch with best practice and latest developments. It has, however, carried with it an obligation to keep on top of the game which the Board has assiduously tried to do.

It all seems a good mix which has served New Zealand amputees well and which I hope will continue to develop steadily over years to come.

My good wishes to amputee friends and to the amputee population in general. I have so much enjoyed your company and the experience of sharing your rehabilitation service with you all.

Graeme Hall

(See page 4 - Ed.)

NEWS FROM THE REGIONS

Auckland & Northland - A successful Christmas BBQ took place in December, with 15 amputees and caregivers enjoying each other's company and good food. The AGM in February was also well attended; new committee members were appointed and a BBQ followed cooked by President Mali and Committee member Noeline.

Waikato, Bay of Plenty & Districts - Their annual Christmas function at Waihi Beach RSA was well attended, with 40 members joining in the fun. Sadly, Santa Claus was too busy this year to visit them! Congratulations to Edith Sealey who was presented with Life Membership at their recent AGM - a worthy recognition of the sterling service she has given for the last 25 years. And a warm welcome to their new Secretary, Janet McKnight.

Hawke's Bay/East Coast - A summer get-together was cancelled due to lack of interest - hopefully there will be more support for the AGM.

Taranaki - Their Christmas luncheon was held at Hawera and was very popular, with about 15 people attending. A pot luck lunch was to take place with this year's AGM.

Manawatu - They will be sorry to lose their Secretary, Christine, who is moving to Perth in June. Christine's efforts on behalf of amputees in the Manawatu have been appreciated and our good wishes go with her and Donald.

Wellington Regions & Wairarapa - We're not sure if no news is good news but we hope so!

Nelson & Marlborough - This small Society in the Top of the South is struggling to keep afloat; we encourage members to give it some much needed support.

Canterbury & Westland - Many locals had the privilege of helping at the recent IPC Games and found it an enriching experience, especially for those lucky enough to work in an area in close contact with the competitors.

Otago & Southland - At the annual get-together in Invercargill, Life Membership was presented to two Southland stalwarts - Maurice Elford of Invercargill and Lloyd Cavanagh of Gore - both very much deserved. Bob Smith, a past President of the Federation, retired from the position of President at the AGM, after six years of sterling leadership.

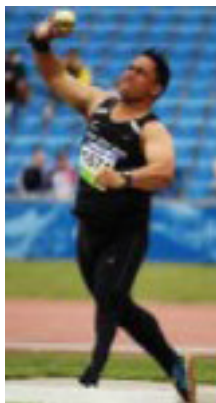
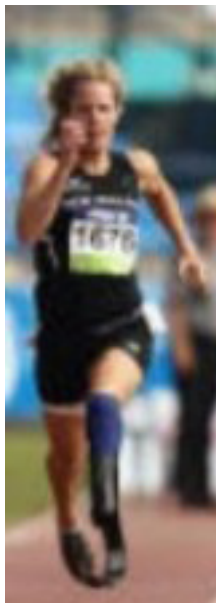
Newsletters of District Societies are displayed on the Federation's website (www.af.org.nz), along with plenty of other useful information.

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

WELL DONE TO OUR PARALYMPIANS!

Forty-seven new World Records were set at the IPC Athletics World Championships held in Christchurch in January. Although not featuring on the medals table, New Zealand's amputee athletes can feel justifiably proud of taking part and achieving their best.

Having overcome a slight injury, Wellington's Kate Horan was "more than happy" with her 4th place in the T44 200m event. Kate's time of 29.17sec was just over a second behind winner, Maria Amelie Lefur, of France.



Auckland's Joe Flavell was another who was satisfied with his morning's work. Although not a medal winner, he did manage to record four personal best throws in the F42 shot put. He finished seventh in the competition won by Russia's Maxim Narozhnyy with a throw of 14.23m, just outside the world record.

Rory McSweeney of Dunedin made his international debut at the Paralympics and came 8th in his Javelin event with a Personal Best and was "very happy with that".



Also competing in the Javelin and Shotput events was 16 year old Holly Robinson.

Good Luck to you all for LONDON 2012!

Photos courtesy of Paralympics NZ

A RECORD OF SERVICE TO THE AMPUTEES OF NZ

On 16 February 2011 a special reception was held in the Beehive to honour Mr Graeme Hall, retiring Chairperson of the NZ Artificial Limb Board, for "his service to people with disabilities and the community". Graeme had been associated with the NZALB for over 22 years, having been appointed during the 1988-89 financial year. He became Chair of the Board in December 1996. His initial appointment was to provide the Board with his particular expertise - business skills - which he carried out with diligence and a high level of commitment. However, the amputees with whom he came in contact over his years of service soon came to know that he gave so much more than his "business skills". He became known to us as the "face" of the NZALB.



Graeme has always been totally approachable, no matter where and when the situation, and has had the ability to relate to all amputees at a level that has been easily understood. He has been readily accessible and always keen to take a personal interest when approached by individual amputees. After taking the position of Chairman of the Board, he was a regular attender at our National Conferences and had ready answers to all manner of questions relating to the Board's activities, both past and into the future. He never shied away from the hard questions (and there have been many put to him over the years!) and had a remarkable ability to calm troubled waters when appropriate.

Graeme's personal commitment to and concern for amputees has been of the highest order and we wish him well in his retirement.

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)

VISIT the Federation's website at www.af.org.nz It contains a wealth of useful information and "visitors" to the site number over 3,000 each month.

DISCOVERING A LINK TO THE PAST

by John Craig of Woodlands, 1 R D, Invercargill

I am the second child of Tom and Josie Craig. Tom Craig was the youngest child of James and Mary Craig, who arrived in Mokoreta in 1909. I was born on 27 September 1943 while my father was serving with the 38th Battalion in the Pacific. Our family farmed at Mokoreta until 1960, when we moved to Woodlands to have easier access to high schools and work opportunities for the family.

On 19 January 1959, while helping with the haymaking on our farm at Mokoreta, I was caught in a haybaler and lost part of my right leg. This was later reamputated at the hip in hospital. I had always assumed that my lower leg had been buried on the farm at Mokoreta, until I attended the Mokoreta-Redan District Reunion in February 2010. At this reunion, I was approached by Norman McRae and Fergie McEwan who said they had something to tell me about what had happened after I was taken out of the baler. It had been on their minds for 51 years.



After I was taken to hospital, they went back to the baler and removed my leg and put it in their vehicle. They drove down towards the bridge that crossed the Mokoreta River near the old hall. They didn't know what to do with it, so they decided to bury it. They dug a hole beside a concrete strainer post on the corner opposite the old bridge and buried it there.

I was really keen to find this post, so after the function finished on the Sunday, myself, my wife Alice and my cousin Lorraine McLennan decided to check it out and take photographs. When I got home that evening it dawned on me that part of my leg is buried on Craig Road which is named after my Grandfather and his family. It has given me great pleasure to know that part of me remains forever in Mokoreta and especially in an area named after the Craigs.

("John's Story" was written for a new booklet about the Mokoreta District. We are pleased he has shared it with us.)

PHANTOM PAIN *Reprinted with permission from Limbs 4 Life*

Phantom limb pains (PLPs) create a unique frustration for amputees. The idea that something which is no longer there can be so painful can be hard to accept. Many people feel they won't be taken seriously if they complain, or have an experience of being treated dismissively by doctors, so keep it to themselves. However recent research indicates that the dismissal "it's all in your head" has some truth. Phantom pain may indeed originate in the head, but that's why it must be taken seriously.

Phantom pain has been known about for centuries. The first medical description dates from the 16th century, 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: in phantom limb pain we mean pain which feels like it occurs in the absent body part. Phantom sensations are non-painful feelings in the absent part, while stump pain is pain occurring in the remaining part of the stump.

Who suffers from PLP? Well, almost all amputees do initially. For many this fades over time, but for the majority it may continue on for years. Many people experience frequent phantom sensations, but only intermittent pain. However when it occurs this pain can be severe enough as to be disabling. PLP's can occur from any amputation site and can even relate to internal organs that have been removed. They occur irrespective of age, gender or socioeconomic status.

There are some suggestions that traumatic amputations, or limbs that were painful before the amputation can lead to more persistent PLP's. It is also thought that children suffer less from PLP's, though they are by no means absent, and have been recorded in people with congenitally missing limbs.

So what causes phantom pain? Big question...

It was thought that irritation of the cut nerves in the stump caused the perception of pain in the body part those nerves had serviced. However treating these nerves with local anaesthetic or further surgery often has no effect on the phantom pains or sensations, so there must be more to it. Some people can get relief by rubbing their stump, or find the pain altered by how their prosthesis fits, which suggests 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 starts with the knowledge that the body is 'mapped' onto the brain, so all sensory input from a certain body part always goes to the same part of the brain.

After an amputation these brain areas stop receiving input from the missing part. Brain areas next to these, now understimulated areas, then start to take them over, and in doing so create phantom sensations. Evidence of this comes from the ability to create phantom sensations by stimulating body parts which have an adjacent brain map area. Thus 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 (for their brains have never received input from the missing part), or why the sensations should be painful.

All of these mechanisms seem to contribute something to PLP, but none seem to fully explain it. It has been suggested that all brains contains an imprint of the 'normal' or intact body, and that the loss of part of the body creates all sorts of difficulties in trying to form this image from what is essentially incomplete information. Some interesting experiments have been done which supports this. 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 is 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 not effective. In Australia the medications of choice are usually from the anti-convulsant group. These act to decrease nerve excitability. The trick is to decrease the unwanted activity without impairing normal, wanted activity. For this reason some people dislike these drugs, or find them ineffective. Other treatments include TENS (transcutaneous electrical nerve stimulation), acupuncture, acupressure, massage and warm or cold packs. These again work for some people but not for others, but have the benefit of usually having no side-effects. Always consult with your doctor before beginning a new treatment. It has also been suggested that decreasing pain in the time leading up to the amputation can lead to less PLP long term. Some studies support this, though not conclusively. In many cases it is also impractical as the surgery must be done urgently.

Geoff Hill, Bibliography. Wall and Melzack's Textbook of Pain. McMahon and Koltzenburg (ed). Elsevier 2006, 'The perception of phantom limbs'. VS Ramachandran & W. Hirstein, Brain 1998, 121, 1603-1630.

A MOTHER FIRST AND FOREMOST by Gillian Thomson of Christchurch



I have been an above elbow right arm amputee since I had a diving accident when I was 26. I also have severed nerve and tendon damage on my left hand and suffer from overuse in my left shoulder. I had always wanted to be a mother and three years after I got married I had my first daughter, followed by our second daughter three years later.

Matt, Libby, Gill & Grace Thomson

When the children were babies we got through by putting a list together of all the challenges that we would have ahead. We started by researching the internet and asking people a lot of questions, as well as calling on friends and family. The priority for us was obtaining the right equipment that we required, e.g. a lightweight pram that I could push with one hand, that had a swivel wheel for easy steering, and that could be collapsed and put in the car – all with using one hand. And that was just the pram! We learnt from experience to keep it simple and that things were not always going to be perfect and pretty but we could adapt.

At every stage of the children's life I face new challenges. My oldest daughter who is now five wants her hair done in plaits and pretty things before school. My husband has stepped up and learnt how to do this and my Mum helps when she stays one night a week. However, because I do the morning shift with the children my daughter has now had to learn to do her own hair at the age of five and helps immensely with the two year old. Luckily I have a very supportive husband who takes on some of the housework to stop the strain and overuse of my left shoulder and arm. My Mum and Dad help a lot looking after the kids which gives us both a rest! I think it's just about letting go and accepting that this is it, deal with it. For example I cannot take my two year old to swimming lessons as I cannot hold her for half an hour. However I work overtime making sure the kids don't miss out on anything because of my disability.

The most amazing thing is to watch and learn how the children adapt to my disability. We had to explain to the preschool that the children were not being naughty when they kicked open the door with their foot - it was just the way they learnt. We watch in wonder when the two year old pull her sleeve up and walks around with one arm

without even knowing that she's doing it. They use their teeth for opening up bottles etc. and they carry things under their arm and their chin but their hands are empty. We have to continuously remind them to use two hands.

I feel our children are enriched by having a Mum with a disability as they have developed a deeper understanding of difficulties and hardship, and have learnt to help with family chores and respect and understand responsibility. They seem to have a lot more empathy for people and are turning out to be very caring children.

My approach has always been that I'm a Mum before being a person with a disability. I actually forget that I have a disability until I get cornered by five year olds in the corner of the classroom and questioned. I try really hard to be part of the children's lives. As a family we laugh a lot about it all. To be honest though I do get tired really easy as it takes double the time to do something and sometimes very frustrating with ignorant people that make it a little more difficult for me because I have a disability. I do have a disability; and I do need help as I'm unable to physically do things. Simple really!

PACIFIC RIM CONFERENCE ON DISABILITIES

This 27th Annual Conference is being held at the Hawaii Convention Centre in Honolulu on 18-19 April 2011. Over 1,000 participants will join in this year's international theme "Humanity: Advancing Inclusion, Equality and Diversity". For further information, refer to their website at www.pacrim.hawaii.

TAKE TIME OUT FOR SOME HUMOUR

After a BA flight reached its cruising altitude, the Captain announced "Ladies and gentlemen, this is your Captain. Welcome to Flight 293 non-stop from Paris to Glasgow. The weather ahead is good, so we should have a smooth, uneventful flight. So sit back, relax and OH, MY GOD!" Silence followed.

Some moments later the Captain came back on the intercom. "Ladies and gentlemen, I'm sorry if I scared you. While I was talking to you, a flight attendant accidentally spilled a cup of hot coffee in my lap. You should see the front of my pants!" One Glaswegian yelled back, "You should see the back of mine!"

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 lorrystan@xtra.co.nz

COMPLAINTS PROCEDURES FOR AMPUTEES *A policy of the NZ Artificial Limb Board*

- If you have a complaint, do not be afraid to tell us. It is important that we know.
- All parties have the right to be heard.
- Amputees, caregivers, families/whanau who complain are assured that they will continue to receive services which meet all contractual requirements.
- A complaint can be made to your fitter or you may want to lodge a complaint to the manager. A complaints form may be taken away with you when you leave the LimbCentre and submitted in writing.
- You are entitled to have an advocate to support you during the term of the complaint and if you do not have one you will be advised of all possible sources to obtain one.
- Complaints will be handled at a level appropriate to the complexity or gravity of the complaint.
- Complaints will be handled sensitively and with due consideration of cultural and all other values.
- Any corrective action required following a complaint will be undertaken and all parties advised.
- The person handling the complaint will be impartial and act fairly.
- The NZALB will record all complaints and will regularly monitor trends identified to improve the service.

(October 2010)

Your Rights - As a person with a disability, you have rights to be treated fairly, to be free from discrimination on the grounds of your disability, and you also have the right to have your physical, emotional and social needs or desires respected. The Human Rights Act (1993) makes it illegal to discriminate against a person because of their disability. The rule applies at work or school, and when seeking accommodation. A Code of Health and Disability Services Consumers' Rights protects your rights to receive quality health and disability support services. A national, free advocacy service is available to assist where people with disabilities believe their rights have been breached. It is also important that you are aware that you have rights when visiting the Limb Centre. You can request an appointment with the surgeon at any time and you also have the right to request a private consultation with any person providing a service to you, e.g. the prosthetist or the surgeon.

THE AFTERMATH OF THE HAITI QUAKE

Excerpts from an article by Michael Matza of The Philadelphia Inquirer

SHE awoke before dawn in the one-room shack she shares with four family members, and began to dress. She straightened the bandage on the stump of her left arm and donned a denim skirt and white sleeveless blouse. She slipped on sandals and pink stud earrings. Then she walked half a mile up the dirt road to the village centre and squeezed into a taxi for the jarring ride to get a new left arm. "It's a big day for me", Sonia Donatien (32) said, anticipating the two-hour trip to the regional hospital where American prosthetists are mending victims of Haiti's earthquake. "I lost an arm. I am going to replace it."

Three months ago, Donatien's crushed arm was removed in a delicate operation by University of Pennsylvania Health System surgeons on a relief mission. Now, in a matter of hours, she would get the first prosthetic arm delivered in Haiti since the quake. The January 13 cataclysm devastated much of the country. It killed more than 230,000 people and left thousands of victims whose crushed or severed limbs had to be surgically removed.

Handicap International, the French medical group working with the World Health Organisation and the Haitian Government to co-ordinate amputee care, puts the number of amputees, including people who lost fingers or toes, at 2,000 to 4,000; other aid groups say the total is at least 6,000. Even before the quake, Haiti had an amputee population of about 80,000, almost none of whom had prosthetics. In a shattered country where even able-bodied people have trouble carrying buckets of water or squeezing through the stalls of jammed outdoor markets, amputees are especially vulnerable. The earthquake destroyed the country's only two prosthetics workshops. The quake has produced a broad effort by foreign volunteers, using donated materials and expert staff from overseas companies, to introduce developed-world prosthetics, physical therapy and different attitudes about public health. These people are rebuilding women and men torn apart by the quake's violence and ravaged by subsequent infections. But the long-term goal is to train local technicians and physical therapists to create a prosthetics industry that can be self-sustaining in Haiti, because patients who get prostheses now will need refitting throughout their lives. Relief workers say it is too early for a precise tally of the injuries, although preliminary surveys indicate lost legs exceed lost arms nearly by 6:1. Legs were particularly vulnerable because the tremors that knocked people to the ground left them prone and defenceless against falling debris. Many lower-extremity amputees have already been fitted with temporary legs by the foreign volunteers and are learning to walk. The top priority is to make them ambulatory.

The Hanger Orthopaedic Group, a publicly traded manufacturer of orthotics and artificial limbs with 690 patient-care centres across the US was one of the volunteer companies which provided prostheses to the amputees of Haiti and donated Donatien's \$US8,000 arm as part of a million-dollar relief contribution.

Following the January 2010 quake, Donatien had been buried for two days in the rubble between the second and third floors of the Port-au-Prince house where she worked as a housekeeper, her left forearm and hand crushed between concrete blocks. After being dragged out over crumbled concrete and afraid to sleep indoors, she spent uncomfortable



nights in the courtyard of an undamaged house and by day sought treatment at emergency clinics for her hand which had turned black and had no feeling. Eventually, friends gave Donatien \$US45 for a taxi fare to get to the respected 105-bed hospital in Cange where a surgeon explained that the gangrene in her lower arm and hand could spread to her vital organs. Donatien faced a stark choice: lose the limb, or very likely lose her life. Fearing disability and disfigurement, Donatien hesitated but a day later she chose amputation.

Sonia Donatien and her daughter, Soleikah

A month later, Hanger's lead prosthetist in Haiti, John Tew, took measurements of her stump and of her sound arm. The next day, Tew shipped the measurements and a plaster cast of Donatien's stump on a regular flight to the US and it wasn't long before the finished product was returned to Haiti. For its introduction to Donatien, the brown limb was dressed in a sleeve of white gauze. All eyes turned towards the arm. Suspense filled the air, as when an artwork is unveiled. As Tew peeled back the gauze, Donatien cast a sidelong glance at the arm, averted her eyes, looked back at it, and then glanced briefly at her stump, sizing up how it would fit. After three attempts and adjustments, Donatien's stump was properly seated into the socket. Tew then helped Donatien put on her light, long-sleeved jacket. With only her prosthetic hand showing at the end of the sleeve, she looked balanced and whole again. For a start, Tew just wanted Donatien to get used to wearing it so he did not connect the thin cable that would control the opening and closing of the hand. Through the hospital in Cange, a therapist would teach her to make the most of the arm's functionality.

Unemployed now in a chronically poor and shattered country, Donatien doesn't know where her life will take her. Her first meeting with her new arm was just the start of a relationship. It will be months before their ultimate compatibility is known. She is impatient to have the cable hooked up so she can make the arm move. But she is grateful to have come this far and is beginning to feel whole again in a land where amputees don't usually get that chance.

AFFILIATED DISTRICT SOCIETIES

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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.**