

The Arthrogryposis Group of New Zealand

Newsletter 2009



January 2008 group photos



President: Jean Parsons
Secretary/Treasurer: Rebecca Butcher
Newsletter Editor: Patricia Devenoges

Kia Ora and Welcome

Nearly two years since our conference! Wow, how time flies. The planning for the 2010 gathering is underway. We look forward to seeing you all again. Thank you to Max, Ivan, Lani and Wendy (and Me), for contributing to this newsletter.

Best wishes,
TAG New Zealand

News from our Members

News from Max Butcher:



Hi everyone, Max here
Since the last conference I have been up to lots of things.
I went skiing in July.
Last Saturday we had our last soccer game, we nearly won, but it was 2 - 5.
And I became Player of the Day, because I played really hard and I tripped up a couple of times, but it didn't hurt.
After the conference in 2008, on March 22, I had a new little brother and we named him Oscar. He is good most of the time but he is still a little rascal.
I am doing really well at school. I can spell big words and write long stories with my laptop.
I am looking forward to seeing everyone at the Conference.
From Max



News of Ivan Parsons from his Mum:

Ivan competed in the National Disabled Ski Championships at Cardrona in July and won gold medals in the Slalom and Super G. He had a spectacular crash in the Giant Slalom when his ski links broke and although he was skiddooed down to base for a quick repair he didn't make it back in time for the second run and was disqualified. He was very disappointed and it was a harsh lesson on the inflexibility of international rules.

Ivan was captain of the under-seventeen soccer team this year. This year was the first year he didn't play as a dispensated player (which means 12 players are allowed on the field) and with his passion for the game, loud voice and accurate kicking skills he held his own admirably.

He plays soccer and table tennis, skis, swims, sings, fishes, catches the train into his city school and got 88% in his first Cambridge exam. He is a busy teenager.



News of Wendy Neilson

Wendy has been made a member to The New Zealand Order of Merit. She was presented with the award by the Governor-General of New Zealand, The Honourable Sir Anand Satyanand, GNZM, QSO.

Photo is of Wendy getting the award pinned on by the Governor General in April at Government House, Auckland.



Here is the full citation of the New Year Honour (Wendy says it was an overwhelming honour)

"Mrs Wendy Grace Neilson, M.N.Z.M., J.P.

For services to people with disabilities

Wendy Neilson has made a significant contribution to the disability sector through her work in disability support, advocacy, and education. She is the chair of the Disability Advisory Group for SPARC and President of the National Assembly of Disabled Persons. She has previously been treasurer and president of the Hamilton Branch of DPA and a special needs advisor to the Scout Association and Girl Guides Association over the years. She was also a member of the EEO Disabilities National Advisory Panel of the Department of Social Welfare. Wendy Neilson is a member and until earlier this year president of the Workbridge Council. She has been chair of the Gracelands Trust and was chair and trustee of the Hamilton Volunteer Centre, a trustee of the Queenwood Rehabilitation Trust, and a member of the Hillary Commission Strategic Working Party on Policy for People with Disability in 1989."

News from Patricia Devenoges

Holiday to Brisbane – Sept 2008

After 10 years of concentrating on study and beginning my first position as a teacher, I summoned up all my courage and went away on an overseas holiday. Not too far; Brisbane. An accessible city, plenty of cultural activities (does shopping count) and warm.

I decided that I wanted to go on my own, which meant it would only work if I could travel with my power chair. The internet was an excellent resource in finding accommodation. I stumbled across a lovely little B&B and after a number of emails it was decided that their interpretation of accessible and mine were the same. I therefore booked for 7 nights! (I thought this was going



to be the hardest part, and the airline would be easy, boy was I wrong!) Qantas had reasonable tickets, so I booked. I told them I would be travelling with a power chair. A day later I had a phone call asking for the weight, dimensions of the chair, and battery type. I obliged and still felt all was OK. A few days later I had another call to say that Qantas could not take me. What! It turns out that our belongings go into cubby holes (and depending on the size of the plane), and my chair was too tall. I then made contact with Air New Zealand and asked about their requirements. They were the opposite, my chair was fine, could not have been more helpful with making arrangements. I rebooked with Air New Zealand.

After all this complication, I was off on holiday!

Brisbane was wonderful, I had sunny days and warm temperatures, much appreciated after a Wellington winter. I cuddled a Koala, shopped, did walks along the river, rode the river ferry, met up with a friends' sister who lives and works in the city. She knew where the patchwork and craft shops were. She was so kind, she gave up her day off to take me on a tour. A quilter can never have too much fabric!

I had a great time away, travelling with my power chair was a really good option (once the airline was sorted) I was totally independent and felt like any other tourist!

News from the Te Whau Family

So what's being happening in the last two years? The girls (Lani, Keisha and Shantai), have now been at school for a year. They are in the same class. (Trust me - homework takes a lot of patience!) Our son, Shaymian, is off to high school next year. At the end of last year we had our bathroom modified, the girls' bedroom extended and ramp built. It's been fantastic and made such a big difference. This year has been our busiest and most stressful. (Well, other than the year the girls were born!) Lani had surgery on her feet and knees at Starship. Five months of traveling back and forth to Auckland. Lani has been an amazing, strong little girl. You all know the emotions and joy of seeing your children doing something for the first time. Now we have to wean her off her splints and see what she can do on her own. So basically, that's two years in a nut-shell. Hope all has been well with all of you. Look forward to seeing you all and catching up in Tauranga.

Regards the Te Whau Family



Top: Lani standing by herself for the first time (with splints on).

Below: One of the first photo standing with her sisters (Keisha/Lani/Shantai)

The girls in their school uniforms.



Internet Resources

If you Google AMC or Arthrogyrosis, a wealth of information appears before you. A number of other countries have very informative websites, people have setup blogs, chat rooms, face-book pages and the like.

The internet is also very good for researching particular procedures and possible outcomes. There is probably far too much information!

- Our New Zealand web page - <http://www.arthrogyrosis.org.nz/> has many of the links displayed.
- Arthrogyrosis - a text atlas, The book! Is now available as a pdf document. Free for downloading at the following address – http://www.global-help.org/publications/books/book_arthrogyrosis.html

2010 Conference News

The venue has been booked. All we need now is you!

The sunny resort town of Mt Maunganui will be the host to our biannual get-together. Over Wellington Anniversary weekend, 23-24 January 2010.

Families who have been coming together over the years get a chance to rekindle friendships and share progress stories from the previous two years. New families are warmly welcomed into the group.

The programme for the weekend is usually informal, final details will be issued upon registration.

The registration fee for 2010 has been set at \$30 per family.

There is a huge variety of accommodation available around Mt Maunganui, Tauranga and Papamoa. This will be the busy season so if you know now you are coming then book early.

The address of the venue is the church hall, St Mary's Anglican Church, Corner of Girven Road and Marlin Street, Mt Maunganui. Very near the Bayfair shopping centre and across the road from the Baywave pool complex and skate bowl.

Please return the registration form and fee as soon as possible to our Secretary / Treasurer.

TAG Conference 2010
c/o Rebecca Butcher
57 Helmore Street
Wanganui

Please note: If you are unable to attend and wish to continue your membership with TAG New Zealand, can you please fill in the lower part of the registration form and return. (We are endeavouring to keep an accurate membership list of contact details.) Thank you.

Registration Form – TAG Conference 2010

I / We wish to attend:

Family Name: _____

Adult Names: _____

Children's Names: _____

Name of the person with AMC: _____

Home address: _____

Phone number: _____

E-mail Address: _____

For catering purposes, are there any dietary requirements we need to know:

Please tick the box, if you do NOT want your contact details passed on to other families who are members of TAG New Zealand.



Confirmation of contact details for the Membership list

Sorry, I am / we are unable to attend, but wish to continue being a member.

Name: _____

Address: _____

Phone: _____

Email Address: _____

Name of the person with AMC: _____

Please tick the box, if you do NOT want your contact details passed on to other families who are members of TAG New Zealand

Sender:

TAG New Zealand
C/o Rebecca Butcher
57 Helmore Street
Wanganui

If no longer at this address PLEASE return to sender. Thank-you.