

NEW FIELD WORKER - Dympna Mulroy

I am delighted to have this opportunity to introduce myself to the members of the Wellington Branch of the MDA. I have recently been appointed as fieldworker for the lower North Island. This is my first post within a volunteer organization and I am enthusiastic and honored to join your association.

I am a qualified Occupational Therapist (OT) from Ireland who moved to New Zealand in December 2010. Since then I have been working in Wellington Regional Hospital as an OT. I qualified in 2008 from Robert Gordon University in Aberdeen Scotland and worked in Ninewells Hospital Dundee for two years, before coming to New Zealand.

I chose Occupational Therapy because I have a passion to assist individuals achieve their functional potential while encouraging integration within their own communities. My experience to date is mainly working with individuals who have a variety of acute physical and neurological conditions. I am motivated to take on new challenges and learn from you the members, and other supporters of the association.

I am the youngest of a family of six who all reside in Ireland and I maintain a close relationship with them while abroad. I have an interest in skiing, walking, musical productions and dance. Since I arrived in New Zealand I started running and completed a 10k run last June.

I have been fortunate to have the opportunities to travel widely in Europe, which gave me the interest to experience other cultures and countries. Arriving in New Zealand has been like coming home - I have been warmly welcomed by the people I've encountered and Wellington weather is all too familiar to the West of Ireland! The landscape and wildlife are different to Ireland but I am enthralled by the countries unique and beautiful attributes. The inspiration I have received during my time here has encouraged me to make different lifestyle choices. This included a career change and embracing the new opportunities that challenge and motivate me, as does this work I am undertaking with you.

I look forward to meeting all of the MDA Wellington Members. Working together I am confident that I can make a valuable contribution towards your association, and be a strong advocate for the branch.



FROM THE OFFICE

If you have any idle equipment lying around that you no longer have a need for and would like to pass it on to someone who has a need, please give us a ring. It saves so much time to be able to just pass something on, whether it be a shower chair or an unused wheelchair etc.

From early March until the end of June each year, immunisation is free for New Zealanders aged 65 years and over and children and adults under 65 who have a neuromuscular condition. So if you haven't already had yours speak with your Doctor/nurse.

Please remember to let the branch know if you have a change of address, phone number or email details.



MDA GLIDING DAY

The Wellington MDA arranged a gliding day at the Taonui aerodrome near Feilding. It was a great opportunity for members from Taranaki, Hawkes Bay, Wairarapa and the Manawatu to get together for a family day on Saturday, 25 February 2012.

A great day was had by all. The weather was hot and dry for perfect flying conditions. The Gliding Club members were keen to get out the two gliders and the tow plane early, so our members could get into the sky and soar like a bird.

The first flight was taken by Stan Dickson from Masterton, who was a keen starter, happily being strapped into the front seat of a two seater glider with the pilot being in the seat behind. He led the way. There were numerous flights during the day and everyone was very enthusiastic to get into the sky. In particular, Joyce Scott just wanted a short 10 minute flight, but was up for over 30 minutes and reaching a height of 4000 feet. Various family members had flights as well.

Over lunch time a BBQ was provided and this gave the families an opportunity to get to know each other, give support and make new friends. All the boys got along and it was a great joy to see them together. A lot of fun was had.

I would like to thank the Manawatu Gliding Club for a marvelous flying day, BBQ helpers, the parents for travelling and giving your children a wonderful experience in gliding. A big thank you to Marty for helping arrange the day and for the support given to all members.

Louise Marchant

BOW TIE CAMPAIGN



Thanks to the help of a few members (welcome to the two new members who volunteered this year) and the Wellington Harriers Running club we raised the respectful total of \$3,199.60. The running club meant that we were able to collect at the Wellington Railway Station this year for two hours (7am - 9am).

Unfortunately we competed with the Cancer Society for over an hour of that time. It turned out that the Cancer Society had the wrong day so were asked to leave. The takings would have been much higher if that had not happened. It is certainly worth doing again and hopefully some members will be able to help us next year. The more people holding collection boxes at the station exits the better the takings. People were very generous considering they were rushing on to work. We chose a Friday hoping they would be feeling more generous before the weekend. The Harriers expressed surprise at how much they enjoyed themselves and at how many of the people getting off the trains they knew. I also found it an exhilarating experience.

Westpac Mall \$419.70, Pak n Save \$240.00, Railway Station \$630.00, Warehouse Petone \$90.00, New World Thorndon \$561.00, Pak n Save Upper Hutt \$57.00, Bow Tie (member collected at her work place) \$81.00, Gisborne Medical Centre \$98.80, Total Healthcare Palmerston North \$48, Other Bow Tie Donations \$974.10. Well done everyone!!!

CLEANING CURTAINS

To provide a service to elderly and infirm people Taylors Drycleaning on the High Street, Lower Hutt will come and take down your curtains, dryclean them and put them back up.

Nicola Bland

WAITANGI DAY GARDEN PARTY

MDAW was very honoured to be invited to attend the Waitangi Day Garden Party (Mon 6 Feb) at Government House, hosted by the Governor-General Sir Jerry Mateparae and his wife Lady Janine.



It was a fantastic couple of hours. The sun was out but the wind blew every now and then, so we were quite pleased we left our hats at home! It was formal day dress so was a nice opportunity for me to ditch my jeans and dress up. Jo Baldwin (committee member), Stu Mills (husband and 'pusher') attended with me.

Glasses of NZ wine, beer and OJ were flowing freely and the finger food was classy and very yummy.

There were over one thousand guests from many different fields and parts of the country - government, members of the Diplomatic Corps judiciary, business, sport, arts and culture, charities, religious groups, education and science.

In his speech, Sir Jerry said all New Zealanders are immigrants or descendants of immigrants, who had come to the land seeking a better life for themselves and their families. Earlier in the day, a special Waitangi Day citizenship ceremony took place, 24 people from nineteen countries were officially pronounced New Zealanders. In his speech he referred to the citizenship ceremony and paid tribute to the contribution of new New Zealanders to the nation. He then invited them to come up and receive a kōuka tree seedling to mark the occasion and as a welcome to our newest citizens of the New Zealand family. We finished by singing the National Anthem.

To the three of us, different highlights of the afternoon stood out - Jo liked how everyone sang 'God Defend New Zealand', Stu enjoyed the part where the new citizens were welcomed and received a native tree. I enjoyed being part of this whole outing it was a new, different and special experience for me.

Liz Mills, Chairperson

THANKS MARGARET

The last few months have been really busy at the MDAW office. We have an Office Manager who is employed 20 hours a week, but I don't know if our members actually realise that the day-to-day running of the branch (not talking about FWS side of things) has gone smoothly due mostly to Margaret and her unwavering dedication. During the last three months we have had bow tie campaign, Brain Day, Petone Fair - all of which she organised and attended on her days off because we did not have enough volunteers. She was at both the branch and the National AGMs. She worked extra days in the months we did not have a FW, she dealt with the basic enquiries, sorted out easy issues for members that were within her capabilities. She did not assume the role of the FW, she helped out where she could and she has also kept up with her own job. A lot of her extra work is done without her claiming the extra hours or taking time in lieu.

Margaret (along with the MDAW Treasurer) keeps a close eye on our finances. Without Margaret's watchful eye over the last couple of years, our branch would have been struggling financially a lot earlier! Margaret has understood from day one that she works for a not-for-profit organisation so she watches our pennies and nothing gets spent unnecessarily.

Just recently I took six weeks leave and from 12 June for 6-8 weeks I will be out of action due to orthopaedic surgery. I have no qualms about leaving the MDAW office in Margaret's hands.

So thanks Margaret for the work you do as our Office Manager and all the extras you undertake on behalf of the branch. Your willing, generous, caring and obliging nature has helped us out and is appreciated.

Liz Mills, Chairperson

NEW MDA WEBSITE

After many months of work the new version of the MDA website is now live. The website is still at the same web address www.mda.org.nz.

The website has a new look and feel and is easier to navigate; there are additional features such as videos and more downloadable information (MDA brochures, etc). Please note there will be more features added to the site going forward - this is phase one.

KOZI TOES POSSUM FUR INSOLES FUNDRAISER

This is a new initiative that the Branch will trial as a form of fundraising. A flier is attached and it would be a great help if you could pin it up at your work, on your local library noticeboard, tell your friends and ask them to spread the word and /or email it on to other contacts you may know. These insoles are just the thing for these cold days. The price is good and you will be helping the branch at the same time. To order ring the office on 0800 886 626 or email office.mdawgtn@xtra.co.nz.

NEW MEASUREMENT TOOL FOR CLINICAL TRIALS TO HELP CHILDREN WITH CHARCOT-MARIE-TOOTH DISEASE

An international study led by the University of Sydney and published in the *Annals of Neurology* has the potential to improve the design of clinical trials for the treatment of Charcot-Marie-Tooth disease, a disorder which affects the peripheral nervous system.

Charcot-Marie Tooth disease (CMT) is among the most common inherited neurological disorders, affecting one in 2500 people. Symptoms such as leg weakness, foot pain, trips and falls develop in the first two decades of life, with some patients wheelchair bound by 21 years. Currently there is no treatment for any form of this disease, but clinical trials are increasingly occurring.

“While it is very positive that clinical trials are taking place in this area, it is vital that trials are based on appropriately selected patients and carefully chosen outcome measures,” says Associate Professor Joshua Burns, Chief Investigator from the University of Sydney and The Children’s Hospital at Westmead. “This relies on being able to measure disease severity accurately, and in turn the patient’s response to treatment, which we were previously unable to do in children.”

In response, Associate Professor Burns and colleagues from the USA, UK and Italy designed the CMT Pediatric Scale (CMTPedS), a patient-centred multi-item rating scale of disability for children with CMT.

“Rating scales used for adult patients are inappropriate for children and since most forms of CMT affect children there was an obvious need for a new clinical tool.”

“Furthermore, it is during childhood that we anticipate that treatments for CMT may be most effective - before the disease progresses and makes repair more difficult.”

During a 14-month test period the CMTPedS was administered to more than 170 children aged three to 20 with varying types of CMT in Australia and internationally via the Inherited Neuropathies Consortium. Analysis of these data supported the viability of CMTPedS as a reliable, valid and sensitive global measure of disability for children with CMT from the age of three years.

The CMTPedS can be completed in 25 minutes and will have broad application in clinical trials of rehabilitative, pharmacological and surgical interventions. “There is growing international support for the rating scale to be implemented as the primary outcome measure in studies of children with CMT because the quality of the measure has the potential to influence the outcome of clinical trials and patient care,” says Associate Professor Burns.

This research was supported by grants from the National Health and Medical Research Council of Australia, the National Institutes of Neurological Disorders and Stroke's Office of Rare Diseases, the Charcot Marie Tooth Association, the Muscular Dystrophy Association and the CMT Association of Australia.

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