



# Muscular Dystrophy Wellington Branch News

SEPTEMBER 2013

Charities Commission

Registration CC41097

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## From the Office

Our apologies to Freda Evans for incorrectly printing her name as Frieda Kearns (Pompe Network) in Dympna's dispatch in the May Newsletter.

We now have a volunteer assisting in the office on Wednesday mornings. Christine Keown has 34 years of administration and financial experience gained from working for the Ministry of Foreign Affairs. Fifteen of those years was as a Scholarship Officer for NZAID/MFAT. This role included assessing applications from overseas students for a scholarship to study in NZ, assessing their academic performance, liaising with International Student Officers at NZ universities and payment of invoices from the universities.

Christine lost her husband in March 2013 after 29 years together. As he was ill for some time she wanted to volunteer for a health body so she could give something back to the community. We have been the fortunate recipients of her time.

Christine enjoys reading, pottering in the garden, knitting and when the opportunity arises visiting family in Christchurch and Taranaki.

Dympna is away recuperating from an operation. She hopes to be back in the office by 23 September and on the road again by early November.

First Aid kits are selling well. We have our first order of ten completed. The thermometer is a digital one and the small carry bag and fold out compartments make it a pleasure to use. Keep those orders coming. Flyers available from the office.

## Presentation to Ulysses Bike Club



Ulysses Bike Club are our best supporters having been doing the Xmas Toy run for twenty years. The club purchase toys and spend several days taking them to our children in their schools and homes. They have come to know the children well over the years.

It was well overdue for the Branch to show their appreciation. Therefore Liz and I attended their last monthly meeting and presented them with a certificate

of appreciation. See photo.

We were warmly welcomed and Jim Furneaux, the club coordinator, reciprocated by presenting the club with a cheque for \$1,000. The meeting was very interesting and we now know more about the clothing that helps keep motorbike riders safer and warmer. After the meeting we were able to chat with the other members.

I now find myself eyeing up motorbike groups as they pass me on the road trying to see if they are Ulysses members - not that one can see any faces to help identify them.



# Dympna's Dispatch

I have been shaken up a bit with the recent earthquakes and I quickly realised how unprepared I was for an emergency after the first one hit on 21st July. Even in a state of emergency my indecision shone through as I dropped and covered under the desk; then decided the door frame would be safer but as I got to the door I realised the desk option was more practical!!! My family in Ireland couldn't understand why I got under a table. There is no risk of earthquakes in Ireland and it doesn't enter our minds of how you respond in this situation. It certainly has been an experience; thankfully no major damage has occurred or lives lost at this stage. It has given us all an early warning sign and woken us up to get prepared!! These notices on "getting prepared" are important. It can happen and may happen at any stage.

Since the first big earthquake on 21<sup>ST</sup> July I have been stocking up on water, food provisions, and getting my emergency kit together. I attended a seminar on getting prepared for an emergency and it has been on everyone's mind recently since the second big earthquake struck on Friday 16<sup>th</sup> August. This was felt throughout the Lower North Island and there are reports that it was felt in Auckland. Many of our members are scared and vulnerable in these situations. Drop, Cover, Hold is not possible for a lot of people and many are unable to get themselves out of an unsafe environment. This lack of control and inability to protect oneself creates a lot of anxiety and stress. I raised this matter at a recent seminar on "Getting Prepared". They acknowledged people with disabilities are vulnerable in these situations and the main thing to consider is getting your head covered. Getting under a door frame, ducking your head under some furniture or covering it with a pillow etc. if in bed.

**What can you do in an emergency?** Nobody knows when it will strike and you need to prepare yourself as much as possible, relevant to your situation and needs. **You** are in the best position to know your abilities and needs before, during and after a disaster. **Your plans must fit your own unique circumstances.** I have included some information on getting prepared and I strongly advise you to have an emergency kit if you don't have one already.

## Fieldworker service

I am writing this piece the day before my operation. By the time you receive this newsletter you may know I am off on extended sick leave until the 23<sup>rd</sup> September. If you have any questions or concerns in the coming weeks while I am off work you can contact the Branch Office or National Office. Opening hours follow. I hope to return to desk duties on 23<sup>rd</sup> September at which time I can be contacted via email and telephone. I plan to be back on the road at the start of November

and will be in contact to arrange visits in each region closer to the time. This leave of absence was unpredicted and therefore it has changed a lot of plans for the remainder of the year, including visits, events etc. Apologies for any inconvenience.

## Margaret is in the Branch Office:

- Monday 9am - 5pm
- Wednesday 9am - 5pm
- Thursday 9am - 2pm

Contact details: 0800 886 626

Email: office.mdawgt@xtra.co.nz

National Office is staffed Monday - Friday 9am - 5pm

Contact number 0800 800 337

I have called this section "Dympna's Dispatch" but I think it needs rebranding. I am open to other suggestions of what I can title my column. Let us know your ideas; they can be creative, original or alternative.

I look forward to seeing you towards the end of the year when I am back to full health.

Slán go fóill  
Dympna

*Note from Office. Dympna is recovering well*

## News & Events

### Palmerston North Lunch

Eleven members and their families met on Saturday 10<sup>th</sup> August in OE Café in Square Edge for lunch. This was an opportunity for people in Palmerston North to meet other people in MDA, share stories and network with others over a nice cuppa and some foodie delights.

The OE café describes itself as an Overseas Experience..... and it is intermingled with a community arts gallery, which provides a nice backdrop. Everyone interacted and got to know each other. This was the first time members in this area had the opportunity to meet and network with other people who had a neuromuscular condition. The feedback was positive and people expressed an interest for similar events in the future and opportunities to network and socialise with other members.

Thank you to everyone who attended. Unfortunately I forgot to take the camera out of my bag to capture the moment, but it's an excuse to get together again. In the last newsletter I spoke about the benefits of networking and socialising. If you are interested in organising or attending an event in your region please let us know.

## Membership Fees

Just a reminder that the Annual Membership Fees are now due. These fees go a long way towards funding our branch's activities including our much loved Fieldworker Service. \$15 for an individual or \$20 for a family membership is great value. Please pay promptly and let me know if for any reason you are unable to (as we appreciate it may not always be possible).

Westpac 03 1533 0006178 00 with your name and subs in reference or send a cheque to the MDA Wellington Branch Office. Thanks. Liz Mills

## Bow Tie 2014

The dates for the 2014 Bow Tie campaign will be 22 - 30 March.

As always, all money made in the branch area by our members during bow tie week, remains with our branch. It is not too early to start thinking about what you will do and the office will help you to get organised if needed.

We really need everyone to help to make this successful and we have a lot of big or small ways for you to be involved, this is a great opportunity to show your support to your branch and help us make some much needed funds. Ideas and support from the office to enable you to help out is only a phone call away. More information on this later!

From 2015 we expect that Bow Tie campaign will take place in June of each year with the planned, annual Muscle Miles



## **CARING CALLER**

### **Would you like a Caring Caller?**

If you are living alone, or you are housebound due to illness or disability, you can contact St John about getting a Caring Caller. They try to pair you up with a volunteer whose personality and interests match yours. Caring Callers might not yet be available in your area, but always ask St John - they love a challenge. Unlike some services for the elderly, Caring Caller is free of charge.

### **Do you know someone who needs a Caring Caller?**

People who are lonely do not always recognise that they need a friend, so it is up to others to get the ball rolling. St John welcome referrals from community-minded people who know of someone who could use a friend.

Enquire now on 0800 000 606.

## NOTICES

### **SEWER/DESIGNER NEEDED**

Do you know somebody who is creative and likes to think outside the box? We are looking for someone who is interested in making a customised neck collar for one of our young members.

They would have to work with the individual to discuss the type of device required and its design. If you know of anybody who might have these skills or is willing to share their time and advice please contact the branch.

### **CUPPA & CHAT**

Do you have a disability? Then come along to Moera Community House for a cuppa and chat, social interaction and meet new friends.

When: Weekly Every Friday  
Time: 10.30 am to 12.30 pm  
Where: Moera Community House Lounge,  
107 Randwick Crescent, Moera

FREE - ALL WELCOME

Contact: Lorraine - Coordinator - Ph: 568 9836

### **TARANAKI BARBEQUE**

Before we know it Christmas will be upon us.

Can anyone help with a venue for the Taranaki Barbeque? It will probably be around 30 November 2013. It is always much nicer if we can hold it in someone's garden. The office buys the food etc. and will help set things up etc.

A list of suitable public venues would also be very useful for other events in Taranaki.

### **WANTED—EXPERIENCED DOCTORS**



It would be very useful if we could put together a list of doctors who understand muscular dystrophy and are communicative and supportive with those patients.

If you have a good GP we would love to hear from you.

## TRAVELLING OVERSEAS IN A WHEELCHAIR



Our family of four travelled from Perth to Wellington this July. Travelling by air is more complicated for us as our 19 year old son Jakob has Duchenne Muscular Dystrophy. Because of our son's disability our standard luggage includes a 150kg power wheelchair, a portable hoist, commode chair and other equipment such as wheelchair charger and six wooden blocks which can be used to raise up a very low bed. We used to take spare tyres and tubes as well, but now Jakob has puncture proof solid tyres. Below are some tips for travellers

### Air travel

It is important to confirm the airlines can transport the wheel chair and other equipment and is aware of any special needs the wheelchair user may have. The Boeing 37 we flew to Wellington in had a baggage hold with a low ceiling. This required us to lower the back of Jakob's chair from its upright height of 106 cm, down to a height of 84 cm to fit in the hold. Not all wheelchairs can be lowered. We usually travel with QANTAS because they provide a good service for people with disability. Qantas is the only Australian airline with an Eagle Lifter (see right). The Lifter allows a wheelchair user to drive up to the aircraft; the Lifter hoists the wheelchair user out of the wheelchair, into the aircraft and down the aisle to their seat. With other airlines Jakob loses his independence by being removed from his power chair soon after checking in, strapped onto a narrow undignified aisle chair, followed by a risky transfer to the aircraft chair. QANTAS has Eagle lifters at all Australian airports, and the good news is they are appearing overseas, including at Wellington airport. On



the aircraft Jakob gets fitted with a full harness to keep him sitting upright and secure for take offs and landing and especially in the case of turbulence.



### The internet & travel

Web sites such as *Trip Advisor* allow for a "wheelchair accessibility" filter to be applied to accommodation - but its critical to double check all access barriers with the hotel or apartment before booking. There are also some great blogs from travellers who use wheelchairs. By way of example, if you internet search 'Wheelchair Rome', up will come a series of personal and tourist oriented infor-

mation blogs and web sites. You will find out for instance, that wheelchair users can get into the Sistine Chapel in the Vatican using the exit.. what it doesn't

tell you, (as we found) is that the stair lifter at the Sistine Chapel can only handle a weight of 240kg, and may break down if used by a heavy power wheelchair. The tourist bureaus in many towns and cities now provide online information for wheelchair users - such as where you can locate wheelchair accessible public toilets. Also a good idea to locate contact details for agents for your brand of wheelchair, or people who can fix power wheelchairs in cities you are visiting. When Jakob's wheelchair broke down in Barcelona it took us half a day to find a mechanic who located an invisible break in a power cord.



### Accommodation

Our Wellington home was a two bedroom apartment in a converted 1930s art deco building near the restaurant precinct - our apartment is the 6 storey building behind Lynne (right) with the harbour on one side and Waitangi Park on the other. Ideal for wheelchair users. It is always best to double check accommodation to make absolutely sure there are no access barriers such as:- steps into the building or in areas the wheelchair has to travel; doorways and corridors too narrow for the wheelchair; bathroom and shower has a flat floor (i.e. no hobs, or steps); and that the shower entrance is wide enough for a shower chair. To illustrate what can go wrong - we booked an 'accessible apartment in Melbourne and found Jakob's shower chair would not fit through the entrance to the shower enclosure - luckily it did, but only after the glass shower door and hinges of the shower enclosure were removed. After we booked a fully accessible wheelchair room in San Sebastian, we emailed to confirm some details and were asked if "the 8 steps leading up to the hotel would be a problem?"

### Wellington

We found Wellington to be a sophisticated and very pretty city located on the shores of a deep harbour, and lives up to its label as "the coolest little capital in the world". It's also one of the windiest places. On the day we arrived there were gusts of 120 km blowing in from the Antarctic.

## TRAVELLING OVERSEAS IN A WHEELCHAIR CONTINUED



**Access in public spaces:** The city is fairly good in terms of wheelchair access. There are lots of wide, flat walkways around the city and the harbour, and most public spaces and buildings such as the iconic Te Papa Museum of New Zealand and the Art Gallery are well ramped and have lift access. The excellent Westpac Rugby Stadium has really good access in and out, with a large number of well positioned wheelchair accessible spaces right around the ground. We found most shops and restaurants also wheelchair accessible. Classy restaurants like Logan Browns, situated in a stunning historic bank building has half a dozen steps out front, but caters to

wheelchairs through a side entrance.

**Curb ramps:** There are some issues with curb ramps, especially older cross overs at street corners. Jakob found these to be too steep and uneven, and he was often jolted out of position when using them. Wellington Council should consider adopting the design standards used in Australia and other countries (the best curb ramps are found in Barcelona).

**Wheelchair toilets:** Another significant design issue is Wellington's disabled toilets being too small for a wheelchair user who requires the help of a support worker. This was true in the Art gallery, the State Library, Te Papa, and many other public buildings. I would urge NZ planners to look to the disabled toilets design codes used in Australia.

**Steep paths:** Wellington has some beautiful walks, but some would not be suitable for the faint hearted.

The Zoo tried to convince Jakob to transfer to a manual wheelchair ("No thanks" he said), and would not allow us in until we agreed to avoid two areas with particularly steep paths. The zoo is worth a visit if you want to see a kiwi, or one of NZ's cute and hairy Maori pigs, the Kune Kune.



The ride up a steep hill to Carter's Observatory in a wheelchair friendly cable car is worth it for the spectacular view of the harbour and city. The meandering walk down to the city through the Botanic Gardens is a must, but some sections are fairly steep.

The Zealandia urban eco-sanctuary is a remarkable and tranquil place especially for bird and nature lovers. The sealed paths are very user friendly, but many of the little tracks take you up steep hills with pot holes and dangerous slippery gravel. Jakob was directed to an off road path which was dangerous. Zealandia should discourage power chairs from leaving the main paths.

### Transport

**Wheelchair taxi** - there were a few Toyota Hiace vans with wheelchair hoists, restraints, and staff trained in using the restraints. We were able to pre-book a taxi to pick us up from the airport after midnight.

**Buses:** Many buses claimed to be wheelchair accessible, with wheelchair ramps and dedicated spaces for a chair. The issue for Jakob was it was impossible to enter some buses because the corridor to the wheelchair space was too narrow, or obstructed by the ticket machine. Jakob's wheelchair is 64 cm wide, and fits down the corridor all wheelchair buses in our hometown of Perth. We would urge transport authorities in Wellington to consider the width of electric wheelchairs when purchasing new buses. Ideally the best wheelchair entry point is the centre of the bus as there are no restrictions on entry, and plenty of room to turn (see buses in Rome, Paris and Barcelona).



**Trains:** There is a good workable system on metro trains, with a wheelchair space in some carriages, and a manual ramp for accessing the carriage. Train staff were trained and relaxed in using these ramps.

**Ferry:** The ocean going ferries to the South Island are all wheelchair accessible. Regrettably none of the ferries operating in the Wellington harbour can accept a power wheelchair.

Hope our experiences assist your travels.

*Ranil Ratnayeke, September 2013*

## Oxygen Research

Oxygen may be given to patients with neuromuscular disease if they come to hospital. It is recognised that oxygen may increase the amount of carbon dioxide in the blood (carbon dioxide is a waste product that is removed from the body through the lungs). People with neuromuscular disease may be at higher risk of this, but the effect of oxygen on people with muscle weakness has not been well studied.

We are inviting patients with neuromuscular disease to take part in a study to gain more knowledge in this area. Participation involves one visit to the Medical Research Institute of New Zealand at Wellington Regional Hospital for around three and a half hours. Carbon dioxide levels will be compared while breathing room air for 30 minutes and breathing oxygen for 30 minutes. Carbon dioxide is measured using a small device clipped painlessly to the earlobe. We aim to have 24 patients take part in total. We hope the re-

sults of this study will help to improve the safety of oxygen treatment in patients with neuromuscular disease.

This study has ethics approval from the NZ Health and Disability Ethics Committee as well as support from the Research Advisory Group-Maori. With your permission the study will be discussed with your specialist doctor prior to enrolment.

If interested or you have any questions please contact :-

Dr Janine Pilcher, Principal investigator, Medical Research Fellow  
 Medical Research Institute of New Zealand,  
 Wellington Regional Hospital.  
 Ph: 04 8050 421  
 Email: Janine.pilcher@mrinz.ac.nz  
 Website: www.mrinz.ac.nz

## EQUIPMENT CORNER

### Speedy Bikes Dealership



#### Trikes New Zealand

have now obtained the New Zealand dealership for Speedy bikes and are bringing in a line of product, including the B26, Junior and the Rader clipon front wheels.

Pricing is expected to be around:

Rader clipon wheel unit	\$ 920
Speedy B26 clipon unit	\$5,800
Speedy Junior	\$4,999

Speedy handbikes are coupled in seconds without the help of any manually powered wheelchair - whether rigid frame or folding wheelchair. With a few simple steps, the clutch is mounted on the wheelchair. The functions of your wheelchair are not restricted in any way. For optimum driving comfort the patented lift system raises the front wheels of the wheelchair.

All hand bikes and wheelchair-pulling equipment from the Speedy program can use the speedy clutch system. For more information contact :-

Trikes New Zealand, 117-119 Oxford Street, Levin  
 5510 (06) 3678272

### Power Buddy

Never run out of power again! The Power Buddy's internally protected USB port is a safe and secure way to recharge any electronic device from your scooter or power wheelchair's battery. Simply plug the Power Buddy into your vehicle's XLR charging port and you can recharge any of your electronics while you ride!

The Power Buddy's premium design features two rows of powerful LED lights to help you see and be seen. The flexible swan neck design allows you to twist and move the Power Buddy so you can easily plug in your charging cord without having to fuss with it. The XLR plug can even be rotated 180 degrees to fit any position on virtually all scooters and power wheelchairs with off-board chargers. Some may be funded for those accessing work or school.

More information is on the Trade Me DME/ webstore. Price \$189 inclusive of freight and GST.

DME 0800 115 222 Email: sales@dme.co.nz



## VIC ON WHEELS



Wellington is often a perilous place for the physically disabled, its narrow streets snaking about the many hills, the crooked steps with inconsistent railings, and the notoriously bombastic bus service. Unfortunately the Kelburn Campus of Victoria University is like-

wise upon first glance a logistic fumble for those reliant on wheels. Thanks to the lobbying of the Cable Car Company a century ago, the campus is set halfway up a hill, its buildings are an array of styles, and many attempts to link them up to allow one to navigate from one end to the other without encountering a staircase have left their mark. If you are a prospective student considering Victoria, and you have a disability, read on.

As I have said, one can get across the campus in a wheelchair. The latest series of renovations have created a new hub where the old quad used to be, complete with two wheelchair elevators to negotiate the split level. If you want to be late to every class then by all means use them, they are painfully slow. In clear weather the ramp outside is much more convenient, and here is where I shall impart my first piece of wisdom: Wellingtonians are a helpful sort. Almost every time I've been pushing myself up a hill on campus I am offered help from random passersby. Some have even skipped the asking and simply pushed me to the top. When I fell out of my chair (due to being thoroughly stupid) a charming young woman ran to my aid. Wellingtonians are kind, so don't be afraid to ask for help as well.

Most people don't think about getting around on wheels, so they don't automatically realise that a heavy armchair in the middle of a narrow passageway in the library makes it impossible for us in wheelchairs to get to our books. Fortunately Victoria University's Disability Support Services (DSS) do, and they are the jewel of Student Services. Prompt reporting of an issue will mean a rapid resolution, whether it is elevator doors closing too fast (that ruined my morning, and my pride) obstacles in the library, even transport to University. They provide volunteer note-taking services, which I took until my circumstances warranted a personal note-taker to attend all my classes; at no cost to me. DSS smooth the road on campus, making it slick, easy riding.

Most of the older lecture theatres have been adapted to provide accessibility for wheelchairs, and the newer theatres feature a special sound system to enable the hearing impaired to listen more acutely through an FM system. There are many disabled students, of varying severity studying successfully and happily at Kelburn Campus. I will not say that no stone has been left unturned, but a great effort over the last decade has gone into addressing accessibility at Victoria.

My point, I hope is clear, if you are a prospective Victoria student with a permanent or even temporary disability, there is no reason to pass it over on account of disability.

For further information on accessibility, please contact DSS on +64-4-463 6070, or visit the website: [http://www.victoria.ac.nz/st\\_services/disability/](http://www.victoria.ac.nz/st_services/disability/)

*Joseph Boon*

## Pricing Program for Disability Support Services

Disability Support Services, within the Ministry of Health, have recently engaged KPMG to establish a set of nationally consistent prices for providers of the following services:

- Home and Community Support,
- Respite Care,
- Carer Support,
- Child Development,
- AT&R,
- Supported Independent Living, and
- Community Residential Living (includes high and complex needs).

KPMG is seeking the active participation of the disability community over the second half of 2013, around the three key phases of the programme.

1. Establishing pricing principles to guide KPMG in the development of the pricing models and the Ministry of Health when funding the sector.
2. The confidential collection by KPMG of relevant cost and activity data from providers in the disability sector.
3. The development and testing of evidence based pricing models which reflect both the pricing principles and ensure like pricing for like services across the sector.

## IMPORTANCE OF LAUGHTER

The physical benefits of laughter are phenomenal. It stimulates the brain, the nervous system the respiratory system, the hormonal system, and the body's muscles. In addition, it lowers blood pressure, lightens depression, strengthens the immune system and reduces stress. It is a pain reliever, as it triggers the release of endorphins, the body's natural pain killers, which provide a temporary distraction from the pain.

For us to stay healthy, we need to release built-up tensions. Medical professionals have recognized the powers of laughter and are starting to use humour and laughter in the treatment of patients.

Laughing is totally natural. It is organic, naturally sweet, has no chemicals, no preservatives, no artificial additives; you do not require batteries; it is low in energy gain, non fattening, non-polluting, free of cholesterol, trans-fat and saturated fat. You do not have to join an expensive health club nor wear ridiculous spandex outfits. You can practice it 24 hours a day and there is absolutely no cost. Do a google search on "Laughing Yoga" and give it a go.

## Get involved

Tell us what you think.....The branch facebook page for 'MDA Wellington Branch' is becoming more active. We welcome all members to visit the page, make comments, submit photos and start conversations find us at *MDA Wellington Branch*.

If you have some spare time and would like to get involved with MDA Wellington, we can use your help. We are always looking for volunteers to help with event management etc. Contact Margaret at the office on 0800 886 626 to volunteer.

## About us

Muscular Dystrophy Association Wellington provides a Fieldworker Service that aims to do the following:

- Home based visits
- Support for new diagnoses
- Referrals to appropriate agencies
- Advocacy and support
- Liaising with other services to coordinate clients needs
- Information and knowledge on Neuromuscular Conditions
- Facilitating social contact with others
- Attendance at multi-disciplinary clinic

### Proudly Sponsored and Supported By:

- Ulysses Bike Club Wellington
- The Lion Foundation
- COGS
- The Pub Charity
- National Lottery Board
- Hutt City Council
- Infinity Foundation
- Jack Jeffs Charitable Trust
- Thomas Macarthy Trust
- First Sovereign Trust
- The Southern Trust
- BA Lewis Charitable Trust
- Eastern Central Community Trust
- The Warehouse Petone
- Sacred Heart College
- Onslow College
- Samuel Marsden Collegiate School



**MUSCULAR  
DYSTROPHY**  
Association of New Zealand Inc.  
*Te Ropu Mate Horakiwa o Aotearoa*

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