

Charities Commission

Registration CC41097

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From the Office

Thank you **Hyundai!** Hyundai NZ have donated four brand new, black, diesel Santa Fe vehicles to the branches to be used by the fieldworkers. Wellington branch picked up our new car from Brendan Foot Hyundai in Lower Hutt. The photo shows Garry Coulter, Service Manager, handing the keys over to our field worker, Dympna on 7 August. Dympna is especially appreciating the cruise control function on her longer trips.



We now have a **members corner** in our newsletter if you have something you want to sell, donate, need or want to share with us.

Are you thinking of **travelling** but think it would be beyond you. A site worth checking out is 'Disabled Travellers Guide to the World'. It gives useful tips, suitable travel locations, suitable cruise liners to use if one is disabled. It also has interesting travellers stories.

Price Waterhouse Cooper have offered to assist us for a day in October through the **Corporate Volunteer Scheme**. A team of them will spend an entire day with us learning more about muscular dystrophy and helping us brainstorm for fundraising / sponsorship / event ideas for 2013. They bring with them a wealth of experience and the old age that many heads are better than one will hopefully be proved.

The **Branch committee** recently attended a branch committee training session run by National Office at The Dowse, Lower Hutt. The workshop was on Working Together as a Family of Five and the Field-work Practice Framework.

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.

We appreciate that it is difficult to let everyone know when you change homes but please try to let the branch know if you have a change of address, phone number or email details. A quick phone call on our 0800 number will suffice. If no one is in at the time of your call please leave us a message with the changes. Our field worker has been having difficulties contacting members due to out of date details.



Dympna's Dispatch

It has been a busy three months since I started in this post as your field-worker. I have had the privilege of meeting a lot of wonderful people and have seen many parts of the country for the first time. Google map has become my best friend and worst enemy when I am trying to navigate from one area to another!

Over the last few months I have made contact with many members in Wellington, Hutt Valley, New Plymouth, Whanganui, Hawkes Bay and Gisborne. It was the first contact some members had with a field-worker and it was good to build your relationship with MDA. I acknowledge I haven't been in touch with everyone yet so please forgive me, I will be in contact in the coming months. If you would like to contact me before then I would be delighted to hear from you and will offer my assistance to the best of my ability. Alternatively if you want to meet and learn more about the service and put a face to a name I am only too happy to meet with you, your family / whanau.

You may have received a new publication from MDA entitled "Working with People with Neuromuscular Conditions".

This is aimed for health professionals to give them more information about some of the issues people with a neuromuscular condition may experience and the medical precautions and risks associated with conditions. I would advise you to show it to your health professionals and other agencies and individuals who work.

I have also been in touch with health professionals in each of the DHB's offering them an opportunity to meet and learn about our association and things to consider when working with people who have a neuromuscular condition. If you have any issues or experiences you want to raise regarding this subject please let me know. It is important health professionals are aware of these issues to help them better improve their future services for people with neuromuscular conditions.

One of the things mentioned recently is organising support groups or coffee groups, offering individuals the opportunity to get together in a non-formal way and meeting others who may be experiencing similar issues to themselves. I have noticed that many members are keen to network with others. It would be good to have a get together or social event at least once a year in each of the regions. I will be relying on you for ideas of events as it is geared for you (no idea is too small or too extravagant). Please let me know if

you are interested in meeting others in the association for a casual get together. I was hoping to arrange a coffee klatch in Hawkes Bay in October when I am in the area. I encourage members in this region to get in touch with me in the coming weeks if you would be interested in getting together in October and we can decide how best to proceed.

You will see a member's discussion board on this newsletter; these are issues raised during some of my visits. I encourage your responses. Please contact us if you have any information / questions / advice to include in the next newsletter.

I am attending the Neuromuscular conference "Riding the Wave" which is been held in Brisbane in October. It covers early intervention approaches to treatment and care and the latest life enhancing techniques, with a focus on both quantity and quality of life for those who are now living longer with neuromuscular conditions. This is a fantastic opportunity for me to learn about the latest advances in treatment, care and research that may be of benefit to our members and to share this knowledge with you.

Please let me know if you would like a visit when I am next in your region.

I hope your managing to keep warm and well.
Dympna, Field Worker

Visits for the coming months:

Hawkes Bay November (dates to be confirmed)

Kapiti Coast and Hutt Valley October

Taranaki Barbeque end November

Chairpersons Chinwag

Probably like most of you I am not sorry to say goodbye to winter and hoping this year we will get a decent summer!

The office has been busy; the middle of the year sees Margaret applying for all the COGS grants (Community Organisation Grants Scheme), which is a huge job and if successful will mean money for our Branch. Dymna has been making good progress but hasn't as yet being able to contact all of our 310 Wellington branch members. I have often heard members say 'we don't hear from or see our Field Worker'. If this is a concern/complaint of yours then please be pro-active and contact Dymna and either touch base with her or arrange a meeting. She doesn't bite and would be pleased to hear from you.

In the last few months Wellington Branch has had some really positive and supportive things happen for them....Firstly the brand new car, this is something really major for us and hugely exciting. We - the committee - are just amazed and thrilled by the generosity of this gift. I met the Chairman of the Hyundai NZ board at the beginning of August and thanked him on Wellington Branch's behalf.

We have a new treasurer on the committee. Brian Ko only came on board a couple of weeks ago. He has no ties to MDA but has a really sound accounting/finance background and it is important we have someone skilled keeping a close eye on our books. We recruited him through the Wellington Volunteer agency. Thank you so much to our previous treasurer who worked with us for a year. Fiona's skills and sensible advice definitely helped us through the last twelve months!

The 2013 bow tie campaign week is set for 16th to 24th March. This is going to be a crucial fundraising week for us and it HAS to be a bigger and better effort than last year.

Do you remember in 1988 Susan Devoy (now a Dame) walked the length of NZ, raising funds and awareness for MDA? She is one of the MDA Patrons. Next year is the 25th anniversary of this walk. Susan approached the Muscular Dystrophy Association. In Oct 2013 she wants to repeat the walk again for the Association - fundraising and raising awareness as she goes! time and did not become involved with Wellington Branch until 2007. A steering committee is being set up.

You will probably be wondering where my usual lecture is about money! I'd hate to disappoint so Here is some repeated history plus where we are at now..

In November 2009, a Field Worker Service and a branch office with two paid staff was set up. Money was set aside in the National Council budget for the purpose of setting up our office and running costs



This budget was \$90,000 till year end 2010. a very tight reign was kept on this money and we were accountable to and worked closely with the accountant at National Office.

Our yearly running costs (including salaries) have always been about \$110,000 and when we started in Nov 2009 our bank account was a healthy \$82,453 in term deposits and ready money.

2011 arrived, we managed to get through the year on successful grants, funds from bow tie week and other fundraising, member donations, a few subs and money from our bank account.

So far 2012 has been much the same except now we only have \$20,000 left in our bank account!!

Both National Office and National Council have been monitoring our financial situation for some months now via monthly financial reporting and knew we were struggling to raise enough funds to cover the costs of providing its fieldworker service and without support our future looked grim. At its June meeting the National Council agreed to cover the costs of the Wellington fieldworker's salary until the end of the year subject to production of a business plan showing how the branch would cover its own costs both this year and in the future. The National Council endorsed the plan that was presented to its June meeting. It comprises sections on cost management and income generation, with the latter comprising one, two and three year targets relating to MDA support, grants, telemarketing, member subscriptions, bow tie campaign, other branch fund raising events, and (eventually) government contracts.

This gives us some breathing space. The Wellington Branch Committee and office supports the proposed business plan, albeit that it was challenging, but Wellington Branch needs to be doing what it can to keep the fieldwork service running as it is vital to our members.

Our much older sister branches Canterbury and Northern manage to keep their heads above water and have been able to raise the funds for their fieldwork services for several years now without stress or having to be bailed out. Wellington Branch ought to be able to do likewise over time.

Because I have been chairperson for the last four years I can honestly say that without the 100% support of both National Council and national Office, I would not still be involved and the branch would not be functioning as it is today if they had not been there every step of the way.

News and Events

Taranaki Family Day and Barbeque

This popular annual event is coming up again fast. We are looking at holding it on either 24th November or 1st December 2012. Venue is to be advised.

If you are interested in providing the venue please let the office know. Dymna, the field worker, will be in attendance so it will be an opportunity for those of you who have not yet met her to do so.



Sacred Heart College Fundraiser

In June this year Sacred Heart College, Lower Hutt had a mufti day to raise funds for MDA. The school wore blue and really got in behind it. They had heaps of balloons, bowties, brochures and jellybeans. The ten school leaders wore MDA t-shirts and caps. As an awareness and fundraising day it was a huge success. The school role is 840 plus 40 staff and hopefully now 800 plus know

All the balloons got blown up and were taken to most classes in the school, even the principal put some in her office and wore a cap.

Many thanks to the girls in the SHC student council and the school. The college has been very supportive over the last five years and hopefully it will continue in the years to come. They raised \$700 and as you can see from the photo had a great deal of fun the photo had a lot of fun



Friedreich Ataxia

Friedreich Ataxia has a high incidence of diabetes. A parent lost their daughter due to not being aware of this fact and wants others to be aware of it.

Carol Wright

Roger Alexander Workshop

We are looking at asking Roger Alexander from Canterbury to do a support workshop for us on a Saturday, 10.30am - 2.30am.

There was an article about Roger in the Spring 2011 In Touch magazine. He is a councillor and trained teacher with three boys with Friedreich Ataxia

Medic Alert

A reminder that a 10% discount is still on offer to MDA members on the Medic Alert Enrolment Fee. This only applies to online enrolments, so unfortunately if you are not connected to the internet you will have to pay full price. If you have lost a bracelet you need to fill in a lost form. The replacement cost is \$80. For an Enrolment Form contact Medic Alert on 0800 840 111.

BUDGET HINT FROM SUPERGRANS

Instead of using expensive cleaners in a microwave oven, boil a cup of water with a few drops of vanilla or detergent in the oven. Let condensation form and then wipe away. Make a paste of bicarb soda and water for hard to shift dirt.

A big thank you to the staff and students of Sacred Heart College

Grand Opening of National Office New Building



Judy Bailey opened the new premises of the MDA National office on

Liz Mills, the branch Chairperson, represented us at the opening of National Office's new building at 419 Church Street East, Penrose, Auckland last month. The building is more disability friendly than the previous one and staff are finding it a more pleasant space to work in with the luxury of air conditioning. It is also closer to the airport for those of you who choose to visit them.



Mobility Dogs

In the Winter edition of the In Touch magazine information was given about applying for a mobility dog. The MDA have formed a partnership with Mobility dogs which means that MDA will pay \$1,500 towards the cost for any member successful in their application for a mobility dog.

[Mobility Dog Logo here](#)

Members Corner

For Sale

Teresa and Graeme Mason have a blue mobility scooter for sale. See photo. It is virtually new as it has only been used once. They paid \$3,500 for it and will sell for \$2,400. It has been plugged in on recharge all the time. No problems except they do not have need of it now.



Wanted

One of our members in the Hutt Valley is in need of a double bed (base and mattress). If you have one you no longer need could you please give the office a ring.

Mobile Phone Scams

A lady has now changed her habit of how she lists her names on her mobile phone after her handbag was stolen, which contained her mobile phone, credit card, wallet etc. Twenty minutes later she called her husband from a pay phone telling him what had happened. He said to her "I received your text message asking about our PIN number and I replied a little while ago." When they rushed down to the bank, the bank staff told them all the money was already withdrawn. The thief had used the stolen mobile phone to text 'hubby' in the contact list and got hold of the PIN number. Within 20 minutes, all the money from their bank account had been withdrawn.

Do not disclose the relationship between you and the people in our contact list. Avoid using names like Home, Honey, Hubby, Dad, Mum etc. And very important, when sensitive information is being asked through texts, CONFIRM by calling back.

Also when you receive a text message from friends or family to meet them, be sure to call back to confirm that the message is actually from them. If you do not reach them be very careful about going places to meet 'family and friends' who text you.

Doctors

Recently a member in Whanganui let us know about a very good GP, knowledgeable about muscular dystrophy, who was being transferred to Silverstream Medical Centre. It would be very useful if we could compose a list of such doctors. Is your GP very good? If so could you please let the office know who they are. A quick call or email would be appreciated.

Shoe Specialist

We are wanting to find a shoe specialist in the Kapiti/Wellington region who can advise on suitable shoes for our members. Could you let the office know if you can help.

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 our fundraising and other activities contact Margaret at the office on 0800 886 626

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

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