



Charities Commission

Registration CC41097

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From The Office

The year has got off with a bang, hard to believe we are nearly into May already.

The Bow Tie Campaign has gone very well this year. Thank you to all those who volunteered their time to collect. This year we collected at Paraparaumu for the first time. A large group of volunteers made it possible to collect at several sites at the same time which meant they collected the impressive amount of \$836. Thank you to Kathleen White for coordinating this.

The results of other collection sites were:

New World Thorndon	\$354.40 (6 hours)
PaknSave Petone	\$407.30 (4 hours)
Westfield Mall	\$335.70 (4 hours)
Countdown Lower Hutt	\$256.20 (3 hours)
Wgtn Railway Station	\$1,187.40 (2 hours)

Great effort!!



Money from Bow tie boxes can be banked into our Westpac Account 031533 000617800 under Bow tie. Keep the boxes until next year and just get them replenished then.

We will be without Dympna until the end of July. Please do not hesitate to ring me if you require support with anything. If it is something tricky we have the support of the other branch Fieldworkers that we can call upon.

Hope your Easter went well.

Margaret

BRANCH AGM 27 APRIL 2014

Hope many of you can join us at our AGM on **Sunday, 27 April 2014**. Once again the Cossie club at 11 Logan Street, Upper Hutt have offered us one of their meeting rooms for free. There is plenty of parking available.

Lunch is available at the club for those who wish to eat beforehand. Suggest 12.30 for lunch. There is a good range of snacks or meals for you to buy at reasonable prices and the bar is open too. The meeting will commence at **2pm**.

We are very fortunate this year to have Miriam Rodrigues speaking to us about the Health Registry and next years Conference and Gemma Poke, clinical genetist for Genetic Health Service NZ to talk to you and answer your questions about genetic testing. This is your opportunity to ask those questions you have always meant to and never got around to!!!

Wellington Branch AGM – 2pm, 27 April 2014

Cosmopolitan club, 11 Logan Street, Upper Hutt

Dympna's Dispatch



Two Irishmen,
Pat and Murphy,
saw a sign saying

“Tree Fellers
wanted”.

Murphy said to
Pat

“If only Seamus
had been with us
we'd have got
that job.’



Most of you will be aware that I am going on extended leave this year. I am likely to be on holidays when you receive this newsletter. I am returning home to Ireland to spend some quality time with my family and friends. My last day is Friday 11th April. All going well I return to MDA on Monday 28th July. The Wellington Branch will be open for business as usual during my absence. Margaret will be in the office Monday to Thursday and I am sure you will keep her busy with your enquiries and questions. I encourage you to stay connected with MDA and don't hesitate to contact us if you have any concerns over the coming months.

It has been a busy start to 2014 for Wellington MDA, with social events in Hawkes Bay, Gisborne and our annual Bow Tie appeal and National AGM. These events were greatly received by our members and if anyone wants to assist in organising an event / social network opportunity in your region please contact the branch.

Margaret and I represented MDA for the launch of “The New Zealand Carers' Strategy Action Plan 2014-2018”. MDA are participants in the NZ Carers Alliance. The vision for the Carers' Strategy is that “New Zealand Aotearoa is a society that values individuals, families, whanau or aiga who support others who need help

with everyday living”. The Action Plan 2014-2018 reaffirms the Government's commitment to this vision.

Nearly half a million New Zealanders are carers and this is likely to grow as our population is aging and people are living longer and want to be involved in their communities and families. A lot of our members and their families are carers for a loved one and it is important you are supported and protected in these roles.

MDA is committed to providing support, information and advocacy to our members and their carers'. We recognise the impact a long-term condition has on all aspects of a person's life and their support networks. The Action plan can be downloaded online www.msd.govt.nz/carers-strategy

I apologise that I can not attend the Wellington AGM this year. Good luck to all the committee nominees for the coming year. I will be in contact when I am back in the country and I look forward to catching up with everyone on my return.

Dympna, Fieldworker

In Memory of Margaret Smith

Margaret Smith from Wellington (1946 - 2014) passed away in the loving arms of her husband John in March. Margaret had Facioscapulohumeral Dystrophy and has been a long time member of MDA. Margaret and her husband John travelled to various countries. John is a passionate fiddle player and musician and Margaret enjoyed hearing him play. They spent many a long evening watching cricket and other sports. John wanted to inform other MDA members of Margaret's death. MDA would like to thank everyone for their kind donations. We extend our deepest sympathies to Margaret's husband John Smith, their families and friends.

PALMERSTON NORTH YOUTH ONE STOP

Youth One Stop Shop (YOSS) provide Palmerston North's young people with a range of accessible, holistic and youth appropriate services. They aim to empower young people to make informed choices to enhance their positive well-being and self development. Youth One Stop Shop offers free information, support, advocacy, counselling, health services, preparation or life skills programmes and holiday programmes for young people aged between 10 and 24.

YOSS is an approved social service provider, supported by the Department of Child, Youth and Family, the Ministry of Health and Central PHO. You can contact them by phone 06 355 9506, or online www.yoss.org.nz

EVENTS

HAWKES BAY SAILING AND BBQ



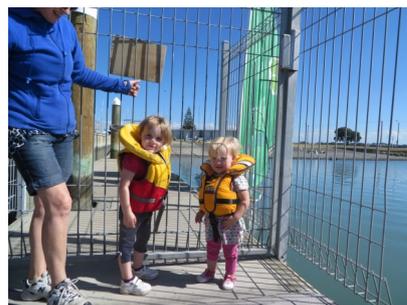
On 2nd March 18 MDA members, their family and friends attended a social gathering at Napier Sailing Club. Hawkes Bay weather lived up to its reputation as the sun shone and the sailing conditions were perfect. It was an opportunity for MDA members to network and meet new people in their community. All ages and levels of ability were catered for, which gave everyone the opportunity to be involved. Some people had been on sailing boats before and others tried it for the first time. Sailing is one of the few sports in which able-bodied sailors and disabled sailors can participate on equal terms. This was reported by one of the participants who for the first time felt confident and able to participate in a sport regardless of their disability. The sense of achievement and excitement has inspired him to continue with the sport.

Those who were less inclined to navigate a yacht could sit back and relax while Katy, Paul or Mark took hold of the controls. We fuelled up with a gourmet BBQ and snacks. Thanks to our chefs Chris and Kevin who ensured the meat was cooked to perfection. A special thank you to Katy, Mark and Paul at Sailability Hawkes Bay, who provided their time, facilities and skills to ensure everyone was included and had a good time. They even got me in a yacht although I need more practice before I become a competent sailor. Thank you to all our members who attended to make the day a success. I hope everyone enjoyed themselves and we welcome more members to join us for future events. Pictures are on "MDA Wellington Branch" Facebook page. Please like our page and view the pictures.

Sailability is a non-profit, volunteer organisation which operates in numerous countries throughout the world. Sailability activities cover a broad spectrum, ranging from recreation, therapeutic and competitive activities, from grass-root, entry level through to elite World Championships and Paralympic training. Did you know Tim Dempsey who represented New Zealand at the London 2012 Paralympic Games has Becker's Muscular Dystrophy?

There are various sailing venues around New Zealand catering for Sailability including Hawkes Bay, Taranaki, Wellington, Auckland, Nelson/Marlborough. If you are interested in trying this sport contact your local CCS disability centre to find your closest sailing club or go online <http://www.sailability.org/nz/newzealand>

Dympna



GISBORNE MORNING TEA AND WORKSHOP



On Friday, 28th February members in Gisborne met at Pony Espresso Café. It was the first time MDA had organised a social gathering in the region. MJ Bloem from Life Unlimited explained and demonstrated a range of equipment they have available in their store. It was fantastic to see and hear about various aids that are available. Everyone had the opportunity to ask questions, try products and learn about available services and resources through Life Unlimited. Afterwards we shared stories over morning tea. Thank you to MJ for offering her time and to the staff at Pony Espresso.

Pictures from the morning are available on our facebook page “MDA Wellington Branch”.

BOCCIA

Luke from Boccia New Zealand attended the MDA inservice in February to inform us of this sport. I never heard of Boccia until I came to New Zealand and when Luke offered us the opportunity to “Give it a Go” I was the first to raise my hand!

Boccia is a cross between lawn bowls and petanque. It is a non-contact sport that is played indoors. It is an inclusive sport and can be played by all ages and abilities. Participants are required to sit when competing. It is a recognised game in the Paralympic that requires a significant amount of skill and strategy. Having never played lawn bowls or petanque I quickly picked up the rules for Boccia. It was interesting to spot the competition ones in our team when we started. We all got into it and I was excited to learn of a sport that can be enjoyed by many of our members. Boccia is still a relatively new sport which is expanding across the country. I strongly encourage anyone with the smallest interest in this activity to “Give it a Shot” and contact Boccia New Zealand. MDA are happy to support you in your goals should you want our assistance to connect with this organisation. Their contact details are:

Email: boccia@boccia.org.nz Web: www.boccia.org.nz Email: luke@boccia.org.nz Ph: 0800 503 603

YOUTH SPORT GROUP

There is an exciting opportunity and development for physically disabled young people in the Wellington region to participate in a sports group. Parafed Wellington in collaboration with the Halberg Disability Sport Foundation are establishing a Youth Sport Group.

This group will provide an opportunity for physically disabled young people, and their families to come together on a regular (monthly) basis to experience sport and recreation. Some of the objectives of the Youth Sport Group include;

- Increasing the sporting opportunities for physically disabled youth (5 -18 years)
- To provide pathways into sport
- To provide pathways into regional and national competition
- To provide a social network for families
- To improve disability awareness amongst sports within the region

Monthly sessions are set to include activities such as; Ten Pin Bowling, Sailing, Movies Session, Hurricanes/ Phoenix Game etc. The more the merrier, as numbers will determine sustainability and what they can do to move forward. If you're interested in attending these sessions or getting more information, please register your interest with Parafed Wellington Sport Development Officer Evan Gray: 021 2229 335 or parafed.wlgsdo@xtra.co.nz



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

Get involved

Tell us what you think....The branch If you have some spare time and would like to get involved with MDA Wellington, we can use your help, We are always welcome all members to visit the page, looking for volunteers to help with our make comments, submit photos and fundraising and other activities contact start conversations find us at MDA Margaret at the office on 0800 886 626. *Wellington Branch.*

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 By:

- The Lion Foundation
- COGS
- National Lottery Board
- The Pub Charity
- Hutt City Council Fund
- Infinity Foundation
- Jack Jeffs Charitable Trust
- Thomas Macarthy Trust
- Southern Trust
- First Sovereign Trust
- JBS Dudding Trust
- Eastern & Central Trust
- Hutt Mana Charitable Trust
- Endeavour Community Trust
- Winton & Margaret Bear Trust
- Trusts Community Foundation
- Whanganui Community Foundation
- Ulysses Bike Club Wellington
- Hyundai
- Onslow College
- Sacred Heart College

Contact us

Postal Address: PO Box 33037, Petone, Lower Hutt 5046
Phone: 04 589 6626 or freephone 0800 886 626

Office Manager: Margaret office.mdawgtn@xtra.oc.nz
Chair/Branch Rep: Liz liz.mdawgtn@xtra.co.nz