

ms.

Taranaki Multiple Sclerosis Society Inc.

mstaranaki.co.nz

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Issue 7 | Summer 2016

The New Plymouth Walkway.
Taken from the top of Centre City



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Thank you to our Taranaki sponsors and supporters

APEPSI Trust

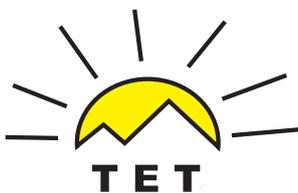


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New Plymouth Contract Bridge Club Inc.



Taranaki Racing Club



TSB Community Trust
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Contents

Thank You To Our Sponsors And Supporters.. 02

President's Annual Report For Feb 2016..... 03

Decisions Relating To Multiple Sclerosis Treatments 03

PHARMAC Consultation Document "Proposal Regarding Multiple Sclerosis Treatments" From The Multiple Sclerosis Society of New Zealand (Inc)..... 04

Patron and Auditor 05

Annual General Meeting Agenda..... 06

MSNZ Welcomes PHARMAC's Decision To Fund Two New First-Line Treatments For Relapsing-Remitting Forms Of Multiple Sclerosis..... 07

Sick Of Seeing Images Of New Plymouth? 08

Quiz Night..... 08

Make A Bequest To MS Taranaki..... 08

Field Worker's Report 09

www.kissgoodbyetoms.org 09

A Unique Perspective - A View From The Top . 10

Support Groups & Meet Ups 10

Mobility Problems? 11

Help Available In The Community..... 11

Can't Get Out? You Can Shop Online! 11

Need Health Supplements? 11

Join Our Facebook Page 11

The Voice..... 12

Having Transport Issues? 12

Your Image In This Newsletter 12

Useful Websites 12

Starting A Support Group..... 12

MS Robbed You Of Your Sight But You Would Still Love To Read? 12

Library 12

To Make a Donation 12

President's report

First of all I would like to wish all readers of this newsletter a safe 2016 and one with which you are content and as healthy as can be expected.

May **Peace, Joy, Love and Hope** be a major part of it.

Everyone will be receiving this newsletter in the mail which will include Nomination Forms for the Committee and Proxy voting forms.

The AGM will be held on Sunday March 20th at 1.30pm in our office at Onuku Taipiri Domain Hall.

I ask you to seriously consider attending this meeting to hear what we have achieved this year and our plans for the future. The committee work very hard to financially support your Field Worker by holding fundraising events and we need your support to give us the encouragement to continue.

Our Treasurer does an amazing job in applying for funds from the various organisations. Everything is becoming more complicated and all funding applications HAVE to be done on line and we need to prove to be not only

accountable for the money we receive but effective in the way that we spend it.

Fortunately our Treasurer who is also the Secretary is very computer literate.

I have said this before but I will say it again, Jeannette is worth far more than her weight in gold.

Our constitution states that members over the age of 65 years do not need to pay a subscription but are entitled to all the benefits. This has bothered me for some time as super-annuitants receive more from WINZ than those on a supported living benefit because of health and disability .

I therefore wish to propose a change at the AGM that everyone except those residing in rest homes pay an annual subscription. This will be presented as a Motion at the AGM.

The committee would like all members to pay a subscription which entitles them to the services of a Field Worker as well as contributing to our budget.

If you agree or disagree, come along to the AGM and voice your opinion.



We will be presenting an annual report at the AGM summarising the events which took place in 2015 and informing members of our plans for 2016.

You will be so welcome.

Warmest regards to you all.

Mary Needs

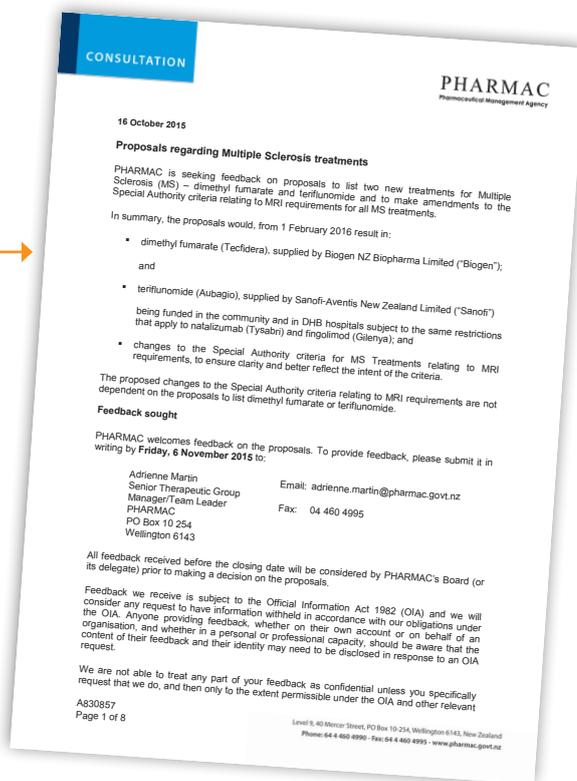
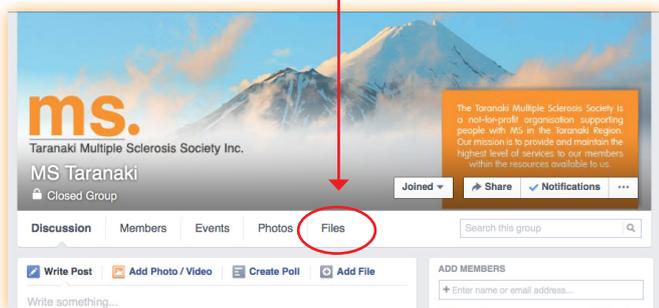
PRESIDENT

Decisions relating to Multiple Sclerosis treatments

PHARMAC is pleased to announce the approval of proposals to fund two new treatments for Multiple Sclerosis (MS) – dimethyl fumarate and teriflunomide – and to make amendments to the Special Authority criteria relating to MRI requirements for all MS treatments. This decision was the subject of a consultation letter dated 16 October 2015, available on PHARMAC's website.

The full copy of these 2 documents will be uploaded to the MS Taranaki facebook page under the files tab:

 <https://www.facebook.com/groups/MS.taranaki/>



PHARMAC Consultation Document “Proposal regarding Multiple Sclerosis Treatments” from The Multiple Sclerosis Society of New Zealand (Inc)

The Multiple Sclerosis Society of New Zealand (Inc) representing the MS Community has endeavored to liaise with the appropriate members of the MS Community for advice and feedback to formulate this submission. Consultation has been as much as has been possible in the time allowed.

We are very pleased that PHARMAC has agreed to consider funding these two new drugs, Tecfidera and Aubagio, under the terms proposed and making changes to those treatments currently funded.

As in our submission in 2014 nothing in these comments is intended to cause any delay in the implementation of PHARMAC’s decision in anyway. If the effect of considering any of these points was to cause a delay we would prefer to proceed on the basis proposed subject to our ability to have ongoing discussions with PHARMAC to make what we believe would be valuable improvements.

There are a number of elements in the proposal and on-going from the 2014 proposal for funding of treatments that we would like to address.

Decision based on cost

On Page 7 of the Proposal the PTAC recommendations are specified. Point no. 1 of the Summary is illogical. The recommendations that “Dimethyl fumarate be funded with a medium priority subject to the same access criteria as Natalizumab and Fingolimod, provided it was no more expensive than the beta-interferons or glatiramer acetate.” The reason these new treatments are being considered for funding is because they are more effective treatments and are very different to the older injectables. While the injectables are known to reduce relapse rates by 30%, recent data into the efficacy of Tecfidera (dimethyl fumarate) showed its:

“Robust Efficacy in Newly-Diagnosed Patients with Highly Active MS *TECFIDERA provided robust efficacy in newly-diagnosed patients who have highly active MS, as seen in a post-hoc analysis of two years of integrated data from the Phase 3 DEFINE and CONFIRM studies. Patients included in the analysis were diagnosed with RRMS within one year prior to enrolling in the DEFINE or CONFIRM studies, were either treatment-naïve or previously treated with corticosteroids alone, and met the criteria for highly active MS (two or more relapses within one year prior to enrolling in DEFINE or CONFIRM). Compared to placebo (n=77) at two years, TECFIDERA (n=84) significantly reduced annualized relapse rate (ARR) (56% reduction, p<0.0040), the proportion of patients who relapsed (56% reduction, p=0.0037) and time to sustained 12-week progression of disability (78% reduction, p=0.0067).”*¹

Therefore when Tecfidera’s reduction of relapse rate is 26% higher than the interferon-beta’s and glatiramer acetate why are they being compared financially when there are clear benefits to the patient and to the health system with less hospital admissions or health professional visits?

Entry Criteria

While we are extremely pleased to see the entry criteria remains at 0 for all treatments we are still concerned the overall entry and exit criteria is too tight. There needs to be some flexibility. New Zealand is the only country to have such stringent exit criteria under the EDSS Scale.

Some people diagnosed with Relapsing Remitting MS unfortunately experience a high number of relapses that produce disability in the long or medium term. In some instances a person may have attacks of the spinal cord which leaves them with permanent

disability in their movement. As per the EDSS scale this will put them over the 4/4.5 mark required to enter on treatment. However their poor recovery does not mean that they have a more progressive form of MS but are still considered Relapsing-Remitting. As Dr Wallace Brownlee argued in his 2014 submission “This situation is uncommon but about 5% of people with MS reach an EDSS of 6 or more as result of relapses rather than background progression. These patients are extremely important to treat because the early aggressive course tends to be maintained and they rapidly accumulate disability. No provision is made in the current entry criteria for this subgroup of patients.”²

¹: Biogen - 20 April 2015 - <http://media.biogen.com/press-release/neurology/tecfidera-dimethyl-fumarate-data-reinforce-strong-sustained-efficacy-newly-d>

²: Dr Wallace Brownlee – 27 August 2014 – [Submission on Multiple sclerosis treatments funding proposal](#)

The same situation stands and this should be addressed now. There needs to be scope in the entry criteria to treat those with Relapsing-Remitting MS who have experienced severe relapses to the point that their recovery does not go below the currently defined entry mark. These treatments may still have an extremely positive effect on other factors affecting the persons MS. Significant disability in one area should not clinically make someone ineligible. MSTAC should have the special authority to approve funding under these conditions should all other indications show the treatment will be effective.

These cases should also not be expected to improve beyond their current EDSS score as the treatments are not proven to improve disability but prevent a persons MS from getting worse.

Continued page 5

Exit Criteria

New Zealand is the only country with such stringent exit criteria based on the EDSS score. In comparable countries such as the UK and Australia

Neurologists are not restricted to take patients off treatment when they

reach a certain EDSS score but when there is clear long term evidence, often for a number of years, of the treatment not working or when they have been in remission for 10-15 years without any MRI activity, or in older patients (65+) who have a significantly reduced relapse rate, or those that are certainly progressing into Secondary Progressive MS stages.

MS is an active condition. Neurologists will commonly see patients whose EDSS score may rise from 1.0 – 3.0 during a relapse which may affect muscles, spinal cord or the eyes and have a limited recovery. The current exit criteria would therefore eliminate these patients from treatment. It is often noted that in the early stages of MS that the disease is more active and relapses are more common. These treatments are clearly understood to not stop relapses completely but lower the relapse rate. There needs to be more scope to enable people to stay on treatment and prevent more severe disability.

MSTAC Step

The process and number of stages that the neurologist and PwMS must go through to begin treatment as detailed in the consultation document is extremely lengthy and restrictive. We are not aware (although there may be) any other drug for neurological conditions where approval from a body like MSTAC is required.

A competent Neurologist should be able to prescribe treatments within the guidelines eliminating

the further delay imposed by the MSTAC approval step. Beginning treatment as soon as possible will prevent delays during a time of very high anxiety and stress. Research shows that these treatments must be given as soon as possible to be most effective. Extended waiting times have the potential to increase a person's chance of not fitting the criteria. It also consumes valuable Neurologist and MS Nurse time which would be better spent in face to face patient contact. Specialist MS Neurologist and MS Nurse resources are already severely stretched and their time would be better spent with their patients.

Guidelines for the prescribing and monitoring treatments should be sufficient for neurologists to adhere to with a proposed suggestion of an annual audit. MSTAC approval should only be required if neurologists are uncertain about the eligibility of the PwMS for treatment, they do not fully fit the criteria but there are valid clinical reasons, or there is doubt in the case.

Closing Remarks

We thank PHARMAC for once again realising the importance of treatments and options for people with MS however we are keen to ensure funding is not unnecessarily restricted. This will not be achieved by restricting neurologists' abilities to prescribe treatments quickly, restricting entry and exit levels so tightly and making decisions based on cost comparisons with older treatments.

We thank you for the openness at which you have been willing to consult

with us on this document and hope we can work together to bring the best results to people with Multiple Sclerosis in New Zealand, bringing their opportunities for treatment closer to what is available in the rest of the western world.

Submission from MSNZ - PHARMAC
MS Treatments Consultation
Document released on 16 October
2015

Multiple Sclerosis Society of New
Zealand Inc.

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Freephone 0800 675 463
Website www.msnz.org.nz



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Multiple Sclerosis
Taranaki

Sunday 20 March, 2016
at 1:30pm

MS Meeting Room
Onuku-Taipari Domain
Community Hall
Ngamotu Road
New Plymouth

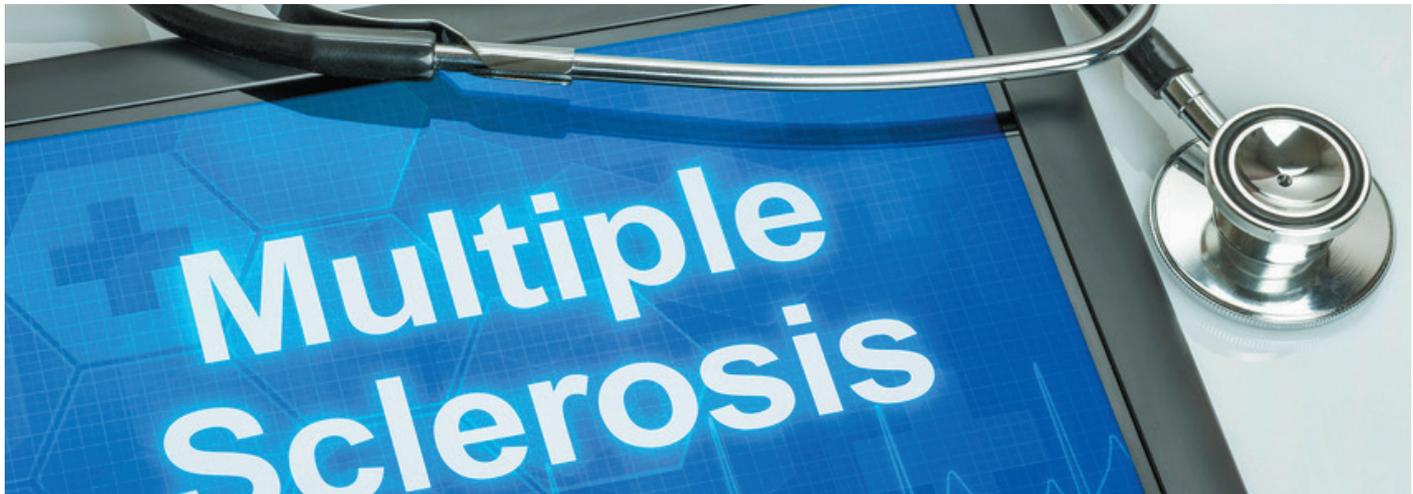
**NOTICE
OF ANNUAL
GENERAL
MEETING!**

**ALL
MEMBERS
WELCOME**

Annual General Meeting Agenda:

1. Welcome and Apologies
2. Acceptance of Proxies
3. Confirmation of Minutes of AGM 2015
4. Matters Arising from Minutes of AGM 2015
5. Adoption of the President's Report
6. Adoption of Treasurer's Report
7. Adoption of the Annual Statement of Accounts
8. Election of Patron, President, Vice-President, Secretary, Treasurer, up to 5 Committee members, Society Auditor and Privacy Officer.
9. Proposed Remit: Change to Clause 6.5 to remove client members who are 65+ years of age from the exemption of paying an annual subscription. **MOVED THAT** Clause 6.5 read "Life Members, Life Subscription Members, and client members who reside in a rest home are not required to pay a subscription but shall be eligible to stand for Committee and be entitled to be present, to speak and to vote at Annual and General Meetings of the Society." Moved: M Needs, Seconded: J Aldridge.
10. Subscriptions (Annual and Life)
11. General Business

MSNZ welcomes PHARMAC's decision to fund two new first-line treatments for relapsing- remitting forms of Multiple Sclerosis.



The Multiple Sclerosis Society of New Zealand (MSNZ) welcomes PHARMAC's decision to fund two new first-line treatments for relapsing-remitting forms of MS.

The new treatments: dimethyl fumarate (Tecfidera) supplied by Biogen NZ and teriflunomide (Aubagio) supplied by Sanofi-Aventis NZ will be funded in the community and in DHB hospitals, subject to the same restrictions that apply to natalizumab (Tysabri) and fingolimod (Gilenya).

"There are approximately 4,000 people with multiple sclerosis in New Zealand," says MSNZ spokesman Neil Woodhams. "This announcement is a really positive step forward for them."

Access to the two new treatments comes on the back of access to Tysabri and Gilenya last year and extended access to older injectable treatments.

"This time last year PHARMAC extended the access criteria for Tysabri and Gilenya and we are seeing how that change is making a difference in people's lives. We know from figures that PHARMAC has provided that 471 people with MS have been approved to receive Tysabri or Gilenya within the first 12 months of funding. We hope that the impact of access to Tecfidera and Aubagio will be just as positive."

MSNZ made several other requests as

part of its submission to PHARMAC in October, particularly regarding the overall entry and exit criteria for MS treatments.

"We are still concerned the overall entry and exit criteria are too tight," says Mr Woodhams. "There needs to be some flexibility. New Zealand is the only country to have such stringent exit criteria under the Expanded Disability Status Scale (EDSS)."

"Some people diagnosed with relapsing-remitting MS unfortunately experience a high number of relapses that produce disability in the long or medium term. In some instances a person may have attacks of the spinal cord that leave them with permanent disability in their movement. As per the EDSS scale this will put them over point that they can enter into treatment. However their poor recovery does not mean that they have a more progressive form of MS but are still considered relapsing-remitting."

Mr Woodhams says that there needs to be scope in the entry criteria to treat those with relapsing-remitting MS who have experienced severe relapses to the point that their recovery does not go below the currently defined entry mark.

"We remain concerned for patients who have had their first demyelinating episode (CIS) with proven MRI activity and demonstrable symptoms of MS

and who would benefit from early treatment still have to wait for a significant relapse. We understand from PHARMAC's feedback this would require a larger review in relation to budgets and risk/benefit analysis. Our concern is to ensure a person with MS does not have to experience disability from a relapse before they can access treatment. "These treatments may still have an extremely positive effect on other factors affecting the persons MS. Significant disability in one area should not clinically make someone ineligible."

In terms of eligibility, MSNZ is seeking reassurance from PHARMAC that these applications will still receive fair consideration.

"We would also value some clarification about whether applications would be accepted. PHARMAC have advised that applications can be made if circumstances are outside the criteria, however we would like more reassurance these will be fully considered."

Media release (8 December 2015)

Multiple Sclerosis Society of New Zealand Inc.

PO Box 32124, Christchurch 8147
Freephone 0800 675 463
Website www.msnz.org.nz

Sick of seeing images of New Plymouth?

Then please take a picture, draw a picture or send in something you would like to see of our newsletter covers.

I don't often leave New Plymouth but would love some covers of Hawera, Stratford, Inglewood or Eltham. So don't be shy! Send stuff in to Rachael at noz4r@gmail.com



Quiz Night!

Monday March 7th at 7pm
@ The Good Home

All interested persons to contact Graham:
(06) 7520 644
027 4543 423 or Mary
on (06) 751 1224

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Multiple Sclerosis
Taranaki

Make a bequest to MS Taranaki

A bequest is a gift made through your will, giving you the opportunity to acknowledge the worthwhile and ongoing work of the Taranaki Multiple Sclerosis Society Inc.

A bequest enables the gifting of property, an insurance policy, cash or other assets from your estate to the specified recipient.

It is so untrue that only the well off leave money to charities when they pass away. The reality is that without the gifts left in wills by people such as yourself, many of the charities would not survive or exist.

For some people, making a bequest through their estate is the only way they will be able to make a significant contribution to an organisation they support.

If you would like to leave a lasting legacy to the Taranaki Multiple Sclerosis Society Inc., please include a bequest to the Society in your will. We strongly recommend you seek legal advice from your solicitor when adding a bequest to your will.

There are several types of bequests:

General Bequest: A gift of a specific dollar amount

Specific Bequest: A gift of a specific asset (land, property, shares)

Proportional Bequest: A gift of a specified percentage or share of the state

Residual Bequest: A gift that directs the society to receive all or portion of what remains in the estate after gifts have been provided to family/ friends and all debts/expenses have been paid.

Sample Bequest

I give \$..... or% of my estate to the Taranaki Multiple Sclerosis Society Inc. to be applied for its general purposes.

A receipt taken by my trustees as being given on my behalf of that beneficiary will be a complete discharge to my trustees for this legacy.

By remembering the Society in your will, you can secure the future services provided by the Society for people with multiple sclerosis in your community.

Field worker's report

Firstly I would like to thank Rachael the time she puts into putting this newsletter together and her patience and tolerance in the wait for my report.

I have had the last few weeks off work after injuring my back rather badly in the process of beautifying the garden. It has certainly been a learning curve about living with a disability and the pain and frustration that goes with it. I count myself very lucky that, albeit slowly, I am healing and will get over it and will certainly not be doing anything so foolish again in a hurry.

The weather has been exceedingly hot so I hope it isn't causing too many problems for you folk who are so badly affected by it. Air flow certainly helps to cool things down as do good fans and cold face clothes on the back of the neck or the forehead. There are other items of cooling clothing aids and I am sure you would be able to google them.

I would like to pass on the society condolences to Gail Stewart on the loss of her best mate, Arun, who passed away on the 30th December. Arun gave a lot of hours to the society on the committee, he was President for a time, and he was the van driver when we still had our van. He was happy to go all the way to Waitara return once a week to collect a client for exercise class. If ever I needed help he was always available to give his time and most recently donated \$200 through the sale of a PS3 game console. He will be missed especially his dry sense of humour and the lovely welcomes I got when I arrived to visit with Gail.

Our condolences also go to the family of Bernadette Salt who passed away on the 1st January. It was certainly not the best of starts to your year however much her passing was expected. She was a lovely lady and I always enjoyed my visits with her.

Gosh it is a bit of a dismal report for

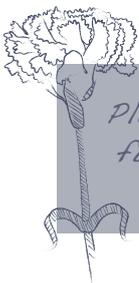


YOU CAN CONTACT MOIRA AT:
moitz56@yahoo.co.nz
Sclerosis
021 985 285

the beginning of the year but the words of the song 'things can only get better' keep floating around in my head.

Please take care and stay cool.

Moira



Please Remember: The Multiple Sclerosis Taranaki Society is a charity. To raise funds, we have to hold events. We need your support at our events so we can continue to support people with Multiple Sclerosis in our community.



WWW.KISSGOODBYETOMS.ORG

Make MS a thing of the past and **KISS MS GOODBYE.**

Kiss goodbye to MS is an initiative of MS Research Australia, Kiss Goodbye to MS calls on people with multiple sclerosis, their friends, family and colleagues to raise funds for vital research into the cause and cure of MS.

The events are being launched in May 2016 by the Australian fundraising campaign and it is going global.

MS Taranaki plan to be involved but we need ideas for a special fund raising event. If you have any **FUNDRAISING IDEAS** please let Mary or Moira know.

You will find information about Kiss MS Goodbye on their website: www.kissgoodbyetoMS.org

A unique perspective - A view from the top!



MS Taranaki has been given an exciting and unique fundraising opportunity by the Port Taranaki Authority. Six people will win the chance to ride the elevator inside the old power station chimney to the viewing platform on top. This experience will be raffled in the coming weeks. Tickets will be \$10 for the chance of three prizes each winning a ride for two people.

We are still working out the details with Port Taranaki relative to the exact date and time which we are hoping will be sometime early to mid-April.

If you are interested in helping sell tickets or wish to purchase tickets, please email Jeannette at treasurer@mstaranaki.co.nz or phone 06 758 0507 or txt 021 02299506, or email Graham at walkergj@gmail.com.

This is a one-off opportunity kindly made available by Port Taranaki specifically to raise funds to support our work with people with Multiple Sclerosis in Taranaki.

"Six people will win the chance to ride the elevator inside the old power station chimney to the viewing platform on top."

Image supplied by Jeannette Aldridge



SUPPORT GROUPS
& MEET UPS WILL
RETURN SOON.

WATCH THIS SPACE...

Mobility problems?



Scooter shop offers a friendly service to all MS Society Members with a 10% discount on all sales and services including New mobility scooters, Pre-owned mobility scooters, Walkers,

Wheelchairs, Canes, crutches and walking sticks, Daily living aids, All service and repairs on mobility scooters and other equipment, Rentals on mobility scooters and Road side assistance via toll free number.

They will come to you or you can visit their store for a demonstration or a service at 14 Constance Street, New Plymouth, or at 51 McLean Street, Waitara.

Phone 757 8432 or 754 8432 or 0508 745543

See <http://www.scootershop.co.nz/> for more details and remember to tell Philip you are a member of the MS Society to receive your 10% discount.

Help available in the community

Saint John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or feel a bit lonely. Volunteers phone clients regularly to check that everything is o.k. To sign yourself up for this service and receive a regular call from a Caring Caller Phone 0800 780 780



St John

<http://www.stjohn.org.nz/What-we-do/Community-programmes/Caring-Caller/>

Can't get out? You can shop online!



Meals: www.eatunlimited.co.nz

Supermarkets with online shopping/delivery (Countdown):
<http://shop.countdown.co.nz/?banner=www>

Vitamins and Supplements: www.healthpost.co.nz

Need Health Supplements?

Health 2000,
Vivian Street, New Plymouth

10% OFF Supplements

Just show your society membership card when purchasing



Facebook

To find out more about upcoming events, Join our MS Taranaki facebook page where support and helpful information is always shared and available:

<https://www.facebook.com/groups/MS.taranaki/>

The Voice

Do you want to share your MS Story for publication in the National newsletter 'The Voice'

<http://www.msnz.org.nz/Page.aspx?pid=590>

Having transport issues?

The following transport systems are available to members, contact Moira for more details:-

Ironside Vehicle Society - Phone 06-753 6469

Total Mobility Scheme – Phone 0800 868 662

Access discounted bus fares – Phone 06-759 0019

Your image in this newsletter

Every issue of this newsletter a different image / photo will be used on our front cover. If you have any photos of you out and about in Taranaki you would like in our newsletter we would love to see them. Send your photos through to Rachael Smith via email at: noz4r2@gmail.com.

All other images used in the newsletters are purchased from <https://us.fotolia.com/>



Useful websites

Weka - New Zealand's weka website is for the use of disabled people, (their families, whanau, caregivers) and health professionals

<http://www.weka.net.nz/>

Do you know of any websites that would be useful to other members? Please let us know.

Starting a support group?

If you would like to start a support group (*with a focus and date that suites you*) please let Moira know.



MS robbed you of your sight but you would still love to read?

Audible maybe able to help you through Audio Books



"Audible Inc. is a seller

and producer of spoken audio entertainment, information, and educational programming on the Internet. Audible sells digital audiobooks, radio and TV programs, and audio versions of magazines and newspapers. Through its production arm, Audible Studios, Audible has also become the world's largest producer of downloadable audiobooks.

<http://www.audible.com/>

Library

Here the titles of some of the books we currently hold in our library:

- Exercises and MS
- Healing MS
- The Gift of Remission
- Finding Harmony
- Yoga and MS
- MS and having a baby
- Primary Progressive MS
- Curing MS
- When the Diagnosis is MS
- Overlooked causes and the prevention of MS
- Fly with me
- Facing the cognitive challenges of MS
- The Brain that changes itself
- Life on Wheels

Please contact Moira if you wish to borrow any of these books

To make a donation

If you would like to make a donation to the Taranaki MS

Society, just send us your donation by post with your name and address so we can send you're a receipt - all donations \$5 and over qualify for a tax rebate:

The Treasurer, Taranaki MS Society,
PO Box 791, New Plymouth 4340

The society is a registered charity under the Charities Act 2005 (No: CC25707)