



Robyn & Tara Willis.
Volunteering for M.S. Awareness Week
Thank you Robyn for your photos

Contents

Thank You To Our Sponsors And Supporters ..	02
President's Annual Report For Oct 2015	03
Committee Members	03
MS Society Garage Sale.....	03
TPPA Implications For PHARMAC Raise Serious Concerns For People With MS	04
Make A Bequest To MS Taranaki.....	05
World MS Day 2016 - Employment Survey	05
Field Workers Report	06
AGM Report	07
Support Groups & Meet Ups	07
We Need Committee Members	07
How You Can Slow Down Your MS Progression	08
Support Groups & Meet Ups	09
Mobility Problems?	10
Help Available In The Community.....	10
Can't Get Out? You Can Shop Online!	10
Need Health Supplements?.....	10
Join Our Facebook Page	10
The Voice.....	11
Having Transport Issues?	11
Your Image In This Newsletter	11
Useful Websites	11
Starting A Support Group.....	11
MS Robbed You Of Your Sight But You Would Still Love To Read?	11
Library	11
To Make a Donation	11

Thank you to our sponsors and
supporters



The Grand Lodge IOOF NZ
Friendly Society

Pacific Workers Sports Fund

President's annual report October 2015

Hi Everyone,

Due to a variety of circumstances, this Spring Newsletter is late in being produced but I am sure it will be well worth reading. There is a lot of information in it.

Jeannette our wonderful secretary/treasurer and Graham our vice president attended the MSNZ AGM in Auckland on October 8th and have much to share from that meeting.

I was unable to attend this year as its only just over 3 weeks since I had my total hip replacement. After two postponements it was finally done on September 15th.

I am making good progress.

A big 'thank you' to all those who participated in Awareness Week at the beginning of September and the Race Day on September 26th.

Both events were successful and the public were very generous with their donations.

You will read an advert elsewhere in this newsletter informing members that we are holding a garage sale on December 12th. Please support this. We aim to make this a time of awareness, fund raising and fun. We have NPDC permission to place a marquee on the grass area outside our rooms in which we will have a barbecue for a sausage sizzle.

You will have read in the winter newsletter that the Good Home Quiz night held in June was very successful and a lot of fun too. We are hoping to organise another quiz soon.

Mary Needs PRESIDENT



Saturday, 12 December 2015 - 9 am
@ Onuku-Taipari Domain Hall, 139
Ngamotu Road, New Plymouth

Are there any good, unwanted items around your house that you are prepared to donate to the Taranaki Multiple Sclerosis Society's Garage Sale?

To arrange pick-up or delivery please contact:
Cheryll on 06 758 3210 or 021 141 6025

There will also be a cake stall care of
Mary (06) 751 1224

Committee members

AUDITOR

Mr O.A. Greensill

PATRON

Mrs Lynda Matthews

PRESIDENT

Mary Needs

VICE PRESIDENT

Graham Walker

Email: walkergj@gmail.com

Cell: 027 454 3423

SECRETARY/TREASURER

Jeannette Aldridge

Email:

treasurer@mstaranaki.co.nz

Ph: (06) 758 0507

Cell: 021 0229 9506

COMMITTEE

Stewart Shaw

• *Please see page 7 regarding committee members*

MS WEBSITE

Tamara Rimland

NEWSLETTER DESIGNER

Rachael Smith

FIELD WORKER

Moira Paterson

Cell: 021 985 285

Email: moitz56@yahoo.co.nz

TPPA implications for PHARMAC raise serious concerns for people with MS



The Multiple Sclerosis Society of New Zealand (MSNZ) is extremely concerned by the potential implications of the proposed Trans-Pacific Partnership Agreement for people with multiple sclerosis.

“The TPPA could undermine PHARMAC’s buying power and its right to choose the most appropriate and cost-effective drugs. It could also impede its ability to negotiate confidentially to gain the best price. This could have devastating consequences for people with MS and their families,” said Multiple Sclerosis New Zealand President Malcolm Rickerby.

“Many people with MS are from low income households or are beneficiaries, due to an inability to work caused by their MS symptoms. Many of their partners and family members are also on a low wage or are carers. This makes them extremely vulnerable to any increases in prescription charges, which we

see as a very likely consequence of the TPPA’s impact on PHARMAC.”

Mr Rickerby said that if New Zealand agrees to a situation where pharmaceutical patents are extended from five to eight years, as speculated by some commentators, this will have a serious knock-on effect and constrain PHARMAC from funding new drugs in the future.

“New Zealanders will pay higher costs for patented drugs for longer unless the Government increases PHARMAC’s budget to offset that change to patents. What we are seeking is a firm commitment from the Government that the extended patent protection resulting from participation in the TPPA will not limit or constrain access to the next generation of MS drugs.”

PHARMAC funding for the latest generation MS drugs is already seven years behind Australia due to Government funding constraints,

said Mr Rickerby. *“Only the latest MS drugs are shown to have clinical efficacy. In the case of MS treatment, there is no scope for substituting generics.”*

Since PHARMAC negotiated the best price for bringing two important new MS treatments to New Zealand last year there has been a strong demand for the new treatments, he said.

“The number of people applying for those treatments has already exceeded the number PHARMAC expected to be approved for treatment for the whole of 2015.”

Media release (30 July 2015)

Multiple Sclerosis Society of New Zealand Inc.

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

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.

World MS Day 2016 - Employment Survey

World MS Day 2016 will be focusing on Employment for PwMS. Please consider forwarding this survey to your members to assist the International Federation in gathering global information on this. They will be sharing the findings with us which we will share with you also.

PwMS and their caregivers are able to take part in this so please share on your website, facebook, newsletters and other networks. They are looking to have data from at least 50 people per country and have a global representation.

▶ **The Global MS Employment survey is now live!**
<https://www.surveymonkey.com/r/MSemployment>

The Survey will give MS organisations around the world an opportunity to tell governments and employers about changes and adjustments that can help people with MS to enter or stay in employment. They last ran the survey in 2010, so will be able to see what (if anything) has changed in the last five years and use the results to encourage decision makers and employers to make positive changes.

"Many people with MS would very much like to work, and are able to," said Peer Baneke, CEO of the MS International Federation. "The 2010 survey showed us how small changes like flexible working hours could have a positive impact on employment for people with MS. The new survey will give us a better view of what's happening around the world now, and also help to see if anything has changed. The more people who complete the survey the stronger our message will be, and the more useful the report will be in helping our members advocate for improvement in employment around the world. Help to strengthen the case by filling out the survey."

The survey will take about ten minutes to complete. We will also be looking at the results of other local and regional surveys when we write the report.

See more at: <http://www.msif.org/news/2015/09/17/take-part-in-the-global-ms-employment-survey/#sthash.t6FZZ0P5.dpuf>



Field worker's report

Collecting at Centre City during Awareness Week



Hello again, how time flies, the weeks seem to roll round faster and faster. I can't believe that we are already seeing Christmas stuff in the shops already. Eek! That time of the year again.

The past few months have been busy with Awareness Week and our collection at the Raceway. I would like to say a huge thank you to all those that helped with Awareness Week, your input helped the week to be as successful as it was. It was lovely to catch up with people I haven't seen for a while as we sat in Centre City. The public in general were interested in knowing about MS and many shared their stories of folk they know who have MS.

I was a bit worried when it came to collecting at the Raceway as we only had 5 collectors but it turned out that was all we needed. The highlight of the day was getting to watch the Jack Russell race, it was absolutely hilarious to say the least.

We now have a number of members taking the new treatment drugs and all appear to be doing well. It will be

interesting to see the results as time goes on.

I am also very interested to see how our members who are on the Terry Wahl diet do. As we all know there are no treatment drugs available for those with Primary Progressive MS so I now have 2 such members doing the diet and both are feeling the benefits of it.

THANK YOU!

To all the members of the Avant Garde Lodge I would like to express our sincere appreciation for your assistance in providing one of our members with a lap top computer. In particular I would like to acknowledge Graham Thompson and Colin Baker for their time they gave in making sure our lady had what she needed and spending time with her explaining what it was all about.

It is heartening to know that there are folk out there who are so willing to help others in need. The very fact

that you are so willing to listen and show such care for those who face challenges in their lives means so much.



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

AGM report

On Thursday 8th October I accompanied Jeannette, our Taranaki delegate, to Auckland as an observer to the AGM of M.S. New Zealand at the Jet Park Inn at Auckland Airport.

Here is a brief summation of the days business.

The morning session was taken up by four information presentations, cluster meetings of the various societies as grouped into five geographic areas across New Zealand and an award ceremony.

The first presentation was by Kevin McCaffrey and was devoted to changes the Government is about to make to the act covering Incorporated Societies. He explained that although the legislative changes will be tedious to work through the end result will be excellent and there will be a huge time frame allowed to implement those changes. The main thrust will be towards new financial performance reporting and development of new society constitutions; the goal being to better describe overviews of outcomes and outputs (who we are, why we exist and what we do), and improve transparency, describe best practice and better target effective governance.

Basically, the alignment of strategy to governance.

The next topic presented concerned changes afoot to the way the Ministry of Health provides funds to the various regional M.S. Societies. I felt this was less clear and it seems we really have

to be alert to any changes and adopt a wait-and-see approach in the interim.

Next was a presentation of a new world-wide initiative that began in Australia called Kiss Goodbye To MS. The objective of this initiative is two fold; raise awareness and raise funds for research on both a national and international level. My interpretation of this concept and its marketing is that it is nothing short of inspirational. It is already up and running in Australia and several other countries and is planned to kick off in New Zealand in February/March 2016. Watch this space!

The fourth information presentation related to the launch of the N.Z. Multiple Sclerosis Research Trust as announced on the 2nd of July. The Research Trust was started with a \$900,000 investment portfolio, has a target of raising a minimum of \$5 million in the next five years and will use income generated from its investments to collaborate with partners to fund research that improves the lives of people with MS.

After lunch (which was worth going along for) discussion continued

around MS organisations newsletters and the MSNZ website.

Next was held a Special General Meeting where previously circulated remits amounting to constitutional changes were discussed, voted on and ratified.

The AGM itself was then held and

this followed usual protocol. After the obligatory welcomes and introductions previous minutes were presented, matters arising were discussed, annual reports were presented, President's, National Managers, Finance, and Field Workers' Representative, before officers were elected. Existing Officers were re-elected. The President is Cantabrian Malcolm Rickerby, the Vice President Aucklander Neil Woodhams and the National Manager is a very capable lady working out of the Christchurch Head Office, Amanda Keefe. I was interested to learn that the National body operates on a budget of about \$235,000 and last year were pleased to report a surplus of \$7,090. The meeting closed at 3.30pm, after which I appreciated the opportunity of meeting some of the key players and other delegates before grabbing a beer and heading to the airport to catch my plane home. I have a copy of the 2014-2015 Annual Report if anybody would like to peruse it.

Cheers, *Graham Walker.*

Footnote : One glaring point that I was able to take from my discussions with other regional MS Society representatives was that our local Taranaki Society really needs more representation at committee level. If you are able to help/contribute please hold your hand up. There are interesting and indeed exciting times ahead and we do need people who can contribute.



ms.

Taranaki Multiple Sclerosis Society Inc.

WE NEED COMMITTEE MEMBERS!

Please contact Moria or Mary if you are interested in becoming a committee member for the Taranaki Multiple Sclerosis Society.

How you can slow down your MS progression



How can I potentially slow down the progression of MS?

Exercise!! And regular exercise of 4 – 5 times a week can provide significant benefits not only for maintaining your muscle function and strength but also for reducing the inflammatory levels in your body and neurological protection. The most important element of your exercise though needs to be working hard enough that you actually get out of breath. It is when you get out of breath that vital hormones are released into the body and into the nervous system that increases the activity within the central nervous system, this helps to protect against degeneration.

What type of exercise would be best?

It does not matter what type of actual exercise you do, as long as it is something that raises your heart rate and gets you puffing. The important fact is that you do not need to be out of breath for long, 15-

30 seconds repeated a 2-3 times is all that is needed to start having a positive impact.

A great way to do this is on a static exercise bike, after a few minutes warming up, sprint as fast as you can for 20 seconds with no resistance on the bike. Then gently pedal the bike or completely stop for 40 seconds. Repeat the sprint and recovery time two to three more times, that is all that is needed.

Another excellent way to exercise if you have MS is hydrotherapy. The buoyancy of the water allows you to work your muscles hard without putting excess strain on other areas. Again use the principles mentioned about interval training.

But I have not exercised for a long time due to fatigue how do I start?

Fatigue is a major factor for the majority of people living with MS, and the last thing you often feel like is exercising. However the benefits of exercise completely outweigh the risks of not exercising. Regular

exercise will also provide you with more energy in the long run. However you need to start sensibly by initially only exercising for a very short interval 10 -15 seconds and resting for 30 – 60 seconds. Again repeat this three to four times most days of the week, trying to work hard enough to raise your heart rate. An easy way to do this at home is standing up and sitting down as fast as you can. Using a structured fatigue management program strongly recommended.

If you have not seen a neurological physiotherapist for a personalised rehabilitation program it is strongly recommended that you seek one out.

Written by Gilly Davy

Director and Senior Neurological Physiotherapist

Connect Neuro Physiotherapy



SUPPORT GROUPS & MEET UPS!

LUNCH GROUP

Monday November 9th at 12pm

@ Westside Grille
41 Tukapa St, Westown, New Plymouth

MS (MOAN & SIGH) WEDNESDAYS + COFFEE MORNINGS

These meet ups have been postponed
until early next year.

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)

ms.

Taranaki Multiple Sclerosis Society Inc.