

# MY NEWS

**ms.** Taranaki Multiple Sclerosis Society Inc.

FEBRUARY 2019 | ISSUE 18



**Healthy  
Eating**

*New Year  
New You  
2019*

**Donations over \$5.00 are Tax deductible.**

**TSB Account for donations:15-3953-0171101-00**

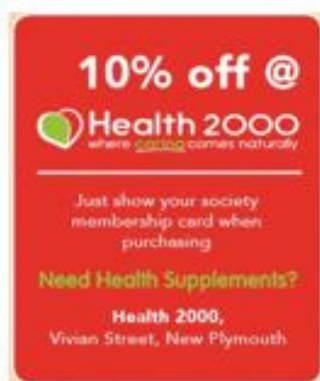
**Reg Charity CC25707 / IRD 48-603-671**

**P O Box 791, New Plymouth 4340 | Phone: (06) 751 2330**

## FRIENDS OF THE TARANAKI MS SOCIETY



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## THANK YOU TO OUR SUPPORTERS 2019



## MESSAGE FROM MARY, EDITOR

## EVENTS / MEETINGS

- \* MORNING TEA - WED 27TH FEB AT 11.00 AM
- \* AGM - SUN 24TH MARCH AT 14.00
- \* LUNCH SHAKEPEAR - THURS 21ST MARCH AT 11.30
- \* QUIZ NIGHT - MON 15TH APRIL AT 19.00

## IN THE NEWS

- \* NEW ZEALAND MOTOR NEURONE DISEASE REGISTRY
- \* BRAIN AWARENESS MONTH - 27TH MARCH AT 18.00

## SECRETARY / TREASURER, JEANNETTE'S REPORT FIELD WORKER'S REPORT





## MESSAGE FROM MARY, EDITOR

MORNING TEA  
WEDNESDAY 27TH FEBRUARY AT 11.00  
MS MEETING ROOM, 134-136  
NGAMOTU ROAD, ONUKU-TAIPARI  
DOMAIN HALL



Warm greetings to members and friends of MS Taranaki and welcome to the first newsletter for 2019.

You will be reading messages from Moira (Field Worker) Graham (President) and Jeannette (Secretary / Treasurer) and maybe a guest writer.

I am going to remind you of what is taking place during the next three months all of which will be detailed elsewhere in this Newsletter. The committee need YOUR support to help us through the year ahead especially when so much of our time is spent on fundraising.

1. **A morning tea will be held on Wednesday February 27th from 11am in our rooms.**
  2. MS Taranaki will be holding their Annual General Meeting on Sunday, March 24th at 2pm. This will be followed by afternoon tea. We look forward to your presence.
- Venue:** MS Meeting Room, 134-136 Ngamotu Road, Onuku-Taipari Domain Hall
3. **Fundraising Quiz Night will be held on Monday April 15th at The Good Home Bar and Restaurant. 7pm to 8.30 pm. We like to see 6 at a table. \$15.00 each.**

Please ask friends and family members to join us there. It is a lot of fun even if you are hopeless at quizzes as I am.

More information will be emailed nearer the time. Please let either Graham or I know two or three days in advance if you would like to participate.

Just a reminder that we have some excellent books in our library. Moira will be able to assist there.

I would like to wish you all a satisfying year and one which is as healthy as it is possible to be.

Give yourself a big hug.

*Mary Needs*

## Introduction to New Zealand MND Registry



Please allow me to introduce the New Zealand Motor Neurone Disease Registry. The Registry was established in 2017 with the aim of helping people in New Zealand with MND to participate in clinical trials and research about MND, if they would like to. The registry also aims to help researchers by assisting them to plan their research and helping to find people who may be interested in participating. Because MND is not common, and New Zealand is only small, finding enough participants for a study about MND can be difficult. Without a registry to gather details in one place, finding enough patients for a meaningful study can be a barrier to research.

Anyone who has been diagnosed with MND, or has a genetic form of motor neurone disease in their family, is eligible to register. Once you decide to participate, we will collect information about your clinical condition, any genetic testing result you may have and your contact and demographic information. I will then contact you if there is any research or study available that you would be eligible for. You can say yes or no to any of these opportunities as you wish, and I will never give out your contact details to any other party.

The information you give us, and your medical information is stored securely at Auckland DHB, where the registry is run from. Anonymised data is also stored in an online database maintained by the Australian Motor Neuron Disease Registry. This data will also be used to give us a picture of what MND looks like in New Zealand.

Please feel free to contact me on email: [mndregistry@adhb.govt.nz](mailto:mndregistry@adhb.govt.nz) or ph: 0800 MND REG or 027 561 7332. I am happy to answer questions, or provide consent forms to participate. These forms can also be found at <https://mnd.org.nz/registry/>

Kerry Walker  
**NZ MND Registry Curator**

### What is MND?

Motor neurone disease (MND) describes a group of diseases that affect the nerves (motor neurones) in the brain and spinal cord that tell your muscles what to do. With MND, messages from these nerves gradually stop reaching the muscles, leading them to weaken, stiffen and waste.

MND can affect how you walk, talk, eat, drink and breathe. Some people also experience changes to their thinking and behaviour. However, MND affects everyone differently. Not all symptoms will affect everyone, or in the same order. Symptoms also progress at varying speeds, which makes the course of the disease difficult to predict.



## SECRETARY / TREASURER, JEANNETTE'S REPORT



The financial year finished on 31 December with a total income of just over \$42,000 and total outgoings of \$48,000 which is a nett reduction of almost \$6,000 due to a couple of funders deciding not to support MS Taranaki Inc. this year. We had been receiving \$5000 a year from TET Trust so our fieldworker can travel into the rural areas covered by TET but we didn't get this funding this year – of course we continued to provide the usual support to those who needed it throughout Taranaki.

The drop in funds would have been even greater had we not had such a positive response to our Street Appeal but of course if we continue to spend more than we make each year there will be an inevitable crunch-moment when some hard decisions will have to be made about the future of MS Taranaki Inc. and how people with MS and other neurological conditions are going to be supported. Due to our reserves, we will be okay for this year. We still have time to turn things around and we will be keen to hear from you at the AGM any ideas you have about this. We are also keen to have some new energy on the Committee. If you wish to receive a Nomination Form or a Proxy Form, please phone the Secretary on 06 758 0507 or email [secretary@mstaranaki.co.nz](mailto:secretary@mstaranaki.co.nz)

We will be moving to a bi-monthly meeting instead of monthly starting in April 2019.



Taranaki Multiple Sclerosis Society Inc.

PO Box 791  
New Plymouth 4340

[treasurer@mstaranaki.co.nz](mailto:treasurer@mstaranaki.co.nz)

### NOTICE OF 39<sup>th</sup> ANNUAL GENERAL MEETING

Sunday 24 March 2019 at 2:00pm

MS Meeting Room, Onuku-Taipari Domain Community Hall |  
134-136 Ngamotu Road, New Plymouth

**All members Welcome**

#### AGENDA

1. Welcome and Apologies
2. Acceptance of Proxies
3. Confirmation of Minutes of AGM 2018
4. Matters Arising from Minutes of AGM 2018
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
9. Proposed Remits
10. Subscriptions (Annual and Life)
11. General Business: The future of MS Taranaki Inc.

**AFTERNOON TEA WILL BE SERVED AFTER THE MEETING. PLEASE JOIN US.**

## Membership Subscriptions

While the subs only represent about 3% of our income, they are none-the-less very important. Not only do they provide essential funds for the publication of the newsletter, they are an indication to the Ministry of Health, the DHB, and other funders of the level of need and support for the work of this organisation. With the beginning of the new financial year being 1 January, the membership subs are now due for 2019. I will be sending out invoices but if you would like to pay your sub you can do so without the invoice by making your payment to our TSB account 15 3953 0171101 00 and make sure your name is included – please include your first and last name as we have members with the same last name. Sub \$20 a year or \$150 for life. Donations over \$5 are tax-deductible.



## FIELD WORKER'S REPORT

LUNCH INVITE  
IN STRATFORD

THURSDAY 21ST  
MARCH AT 11.30 AM

THE SHAKEE  
PEAR CAFE @  
THE PIONEER  
VILLAGE

Shakee  
Pear  
café @ the Village



I have just returned from leave with my family in Papamoa and Masterton. It was a good break away from Taranaki but as the heat was hitting Masterton so I was quite pleased to return back to a misty New Plymouth.

Before Christmas I purchased a cooling scarf from a clothing store called Oosh and it has been fantastic. We have some for the society and are selling them for \$10 each, if you wish to purchase one please contact me and I will get one to you.

A number of our members were unwell in the lead up to and around Christmas I hope you are all feeling much better.

We have a gathering on the 27th of February at the MS Meeting Room, Onuku Taipari Domain and it would be good to see you there. Those who do attend enjoy their time chatting and meeting other folk and of course the coffee and cake go down a treat as well. We also have a quiz night in April at the Good Home, all you have to do is gather a team of 6 and come along for a laugh and once again good food.

**There will be a lunch in Stratford at the Shakeepear on Thursday 21st March at 11.30am for all those South Taranaki folk.** Further information is in this newsletter.

Please do not forget the AGM on the 24th of March.

If anyone has something they would like to share with the other members please put pen to paper or fingers to keypad and send it in to us so we can add it to the newsletter.

Cheers

*Maisa  
Paterson*

THE NEUROLOGICAL FOUNDATION INVITES YOU TO

# BRAIN AWARENESS MONTH

## UNDERSTANDING RARE AND COMMON NEURODEGENERATIVE DISEASES

with Dr Andrew Munkacsi

Dr Andrew Munkacsi will be speaking about his latest research into the contribution of rare neurodegenerative diseases to understanding common neurodegenerative diseases. Light refreshments will be served after the event.



**WHEN:** 27 March  
**TIME:** 6.00 - 7.30 pm

**THE DEVON HOTEL**  
390 Devon Street East  
New Plymouth, Taranaki

*Registration is essential to attend.*

If you have any questions please email [RSVP@neurological.org.nz](mailto:RSVP@neurological.org.nz) or call Jackie at 0508 BRAINS (0508 272 467)

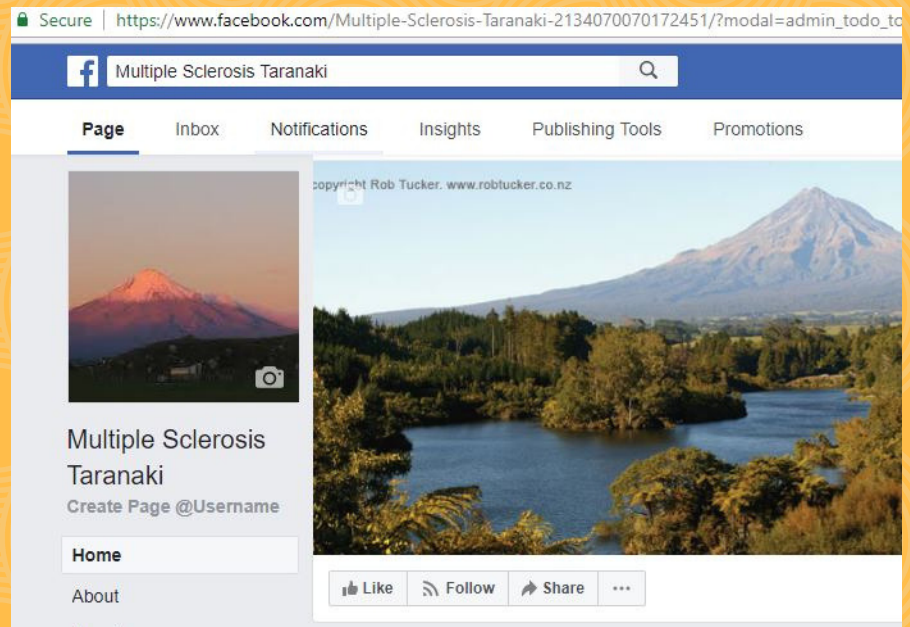
To register for the above event please go to Eventbrite link below :

<https://www.eventbrite.co.nz/e/brain-awareness-month-understanding-rare-and-common-neurodegenerative-diseases-tickets-55256198778>





An open public Facebook page has been created for general information please like and share the page.



[https://www.facebook.com/Multiple-Sclerosis-Taranaki-2134070070172451/?modal=admin\\_todo\\_tour](https://www.facebook.com/Multiple-Sclerosis-Taranaki-2134070070172451/?modal=admin_todo_tour)

## COMMITTEE MEMBERS

**PRESIDENT** Graham Walker **e:** walkergj@gmail.com **m:** 027 454 3423

**Vice President** Mary Needs **e:** needsmj@xtra.co.nz

**Secretary/Treasurer** Jeannette Aldridge **e:** treasurer@mstaranaki.co.nz **m:** 021 0229 9506

**Committee** Grant Porteous | Loren Walker | Ken Hazard

**Privacy Officer** Grant Porteous **m:** 027 760 7554

**Field Worker** Moira Paterson **e:** fieldworker@mstaranaki.co.nz **m:** 021 985 285

**Newsletter Editor** Mary Needs **e:** needsmj@xtra.co.nz

**Web Admin and Newsletter Layout** Hilary Cross **e:** hilyarcross6@gmail.com

**Patrons** Lynda Matthews

**Research Advisor** Kerry Walker

**Venue Address** 134-136 Ngamotu Road, Onuku-Taipari Domain Hall

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