

MY NEWS

ms. Taranaki Multiple Sclerosis Society Inc.

FEBRUARY 2018 | ISSUE 14





THANK YOU TO
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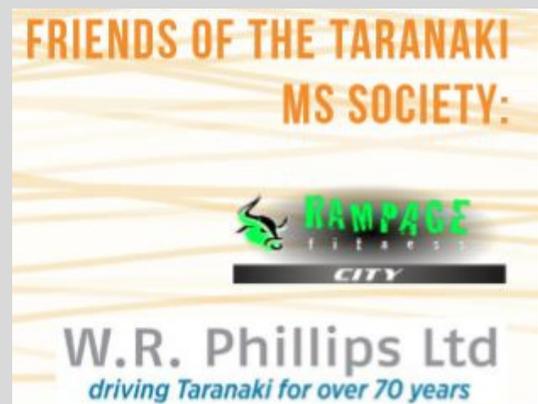
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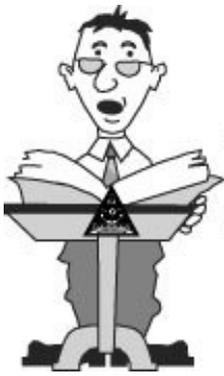
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FEBRUARY 2018



President's Report

Welcome to the first newsletter of 2018. A big thanks to Hilary our new Newsletter Producer. I do hope the heat we have experienced in January hasn't been too much of a concern to you all.

The first item to report on is our fundraiser 'Jazz in the Garden.' Everything seems to be on target for a successful afternoon of contemporary jazz with Hayden Chisham and friends at The Nice Hotel on Sunday February 11th.

Hayden was born and raised in New Plymouth and is a very successful saxophonist who now lives in Europe. Thank you to Linda Matthews, Grant Porteous and Terry Parkes for their organisation of this event. Tickets are being sold from The Nice Hotel.

Last month I was co-opted onto the committee of MSNZ. Over the last week that committee has been formulating a response to present to MP's regarding our position on medicinal cannabis. This was accelerated by the fact that the parliamentary first reading of two legalised cannabis bills, one for the Government and one for the Green's, was programmed for last week.

The basis for MSNZ's call on this issue, was the independent report they commissioned summarising current facts produced by Kerry. There is an executive summary of this report which will appear in this newsletter. The last paragraph of this report is MSNZ's support for medicinal cannabis as a therapy for pain and spasticity for pwMS. While the Green's bill was rejected at its first reading the Government's bill did pass its first reading. The debate that will follow will be very valuable as I am sure there is room for a heap of issues to be elucidated by those who understand medicinal cannabis and its potential as a therapy for pwMS. Currently, scientific research of MS related issues is advancing at an amazing rate. Some of the 'hot' topics at the moment are; the role of cholesterol in myelin repair, feedback from use of the new drug Ocrelizumab, resistance exercise therapy to slow progression and managing the mental and emotional impacts of MS. I am personally excited by all these advances.

Cheers,

Graham Walker



A message from the Editor

Greetings everyone and welcome to 2018 which I hope and pray will be satisfying and as healthy as it is possible to be.

It is common for people to be wished a happy and prosperous New Year. I do not like that word prosperous. It is no fun to be highly successful, earn lots of money if one does not enjoy good health.

Over the years, the society has offered helpful advice about diet and exercise. There are excellent books in our library, the contents of which have proved invaluable to a number of folk. Moira will be able to assist you here.

All financial members of MS Taranaki receive a membership card which attracts a 10% discount from Health 2000. Regular customers also receive a loyalty card. I know because I benefit from both.

I do hope you read Graham's PRESIDENTS REPORT in the November newsletter which informs us of all the work and research which is going on behind the scenes.

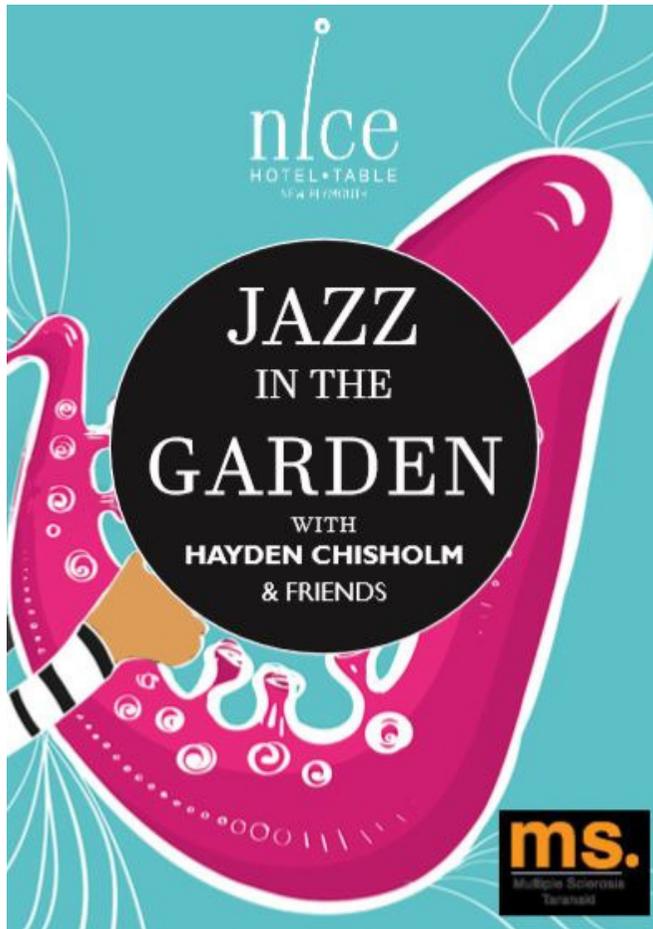
Analysis of big data has already shown that careful treatment choices can, and do, prevent many of the long term consequences of the diagnosis of MS.

There is an article in this newsletter about the drug 'ocrelizumab' which Graham is currently trialing.

The newsletter will look a little different this month as Hilary has offered to layout the newsletter for us. Rachael is taking time out as she is expecting her first baby very soon. She did a brilliant job for the society for 4 years as a designer for our newsletter and we thank her so much for her time and talent. Our grateful thanks to Hilary for offering to take on this task. Hilary is also our Web Administrator.

We will be having a morning tea on Wednesday, February 28th at 11am in our rooms as usual.

Mary Needs



FIELD WORKER'S REPORT

Hello again and, oh my gosh at the time of writing this, it is nearly the end of January. I hope everyone has had a great start to the new year and you are all finding ways to keep cool. I am loathe to complain about the fine weather but the heat has been a bit over the top. I find it hard to get to sleep at night and have the urge to nod off in the hottest part of the afternoon.

My son and his wife sold their home in New Plymouth and have moved to Papamoa, so I am feeling a bit sad as will not have my 2 granddaughters so close any more. Everyone says that it is only a 3 1/2-hour Trip and what a wonderful holiday destination but at the moment it feels like the other side of the world though I am sure I will get used to it in time

It is great news about Medsafe approving Ocrelizumab as treatment drugs for people

with Relapsing Remitting and Primary Progressive MS. I hope it doesn't take Pharmac too long to agree to fund it. It has been a long wait for people with PWms to have treatment available, so this could be their light at the end of the tunnel. As with all the treatment drugs it may not work for everyone, but it sure gives those folks a lot of hope.

I have been in touch with a few people lately who have been diagnosed with allied neurological conditions, some of them I have never heard of before. There appears to be more and more of these conditions and the sad fact is that so many of them do not have a society like ours to support them as they are quite rare. If you hear of anyone in this situation, please contact me and I am sure we can take them under our wing.

We are having another gathering at our room on the 28th February, so I am looking forward to catching up with everyone there.

Cheers,

Moira Paterson



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NOTICE OF 38th ANNUAL GENERAL MEETING

Sunday 18 March 2018 at 1:30pm

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 2017
4. Matters Arising from Minutes of AGM 2017
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. The Officers have all confirmed their willingness to serve for another year.
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
9. Proposed Remits:
Under the new rules of Charities Services, Taranaki Multiple Sclerosis Society Incorporated is no longer required to have its accounts audited. Therefore, wherever the word "Auditor" or the word "Audit" appears, this will be changed to "Reviewer" and "Review". Clause 9.1(g) and Clause 10.2(a).
Taranaki Multiple Sclerosis Society Incorporated has moved to using online banking and therefore Clause 10.2(d) be altered to include the words 'or by online transfer authorised by two signatories.'
10. Subscriptions (Annual and Life)
11. General Business: Discussion of name of organisation to include other neurological conditions.

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

December 22, 2017 |
Advocacy, Treatments

Media Release –
22 December 2017



**OCRELIZUMAB
APPROVED BY MEDSAFE**

<https://www.msnz.org.nz/ocrelizumab-approved-medsafe-rms-ppms-awaiting-pharmac-review/>

The Multiple Sclerosis Society of New Zealand (MSNZ) is pleased that Medsafe[1] has approved the registration of ocrelizumab (Ocrevus®) for both Relapsing (RMS) and Primary Progressive (PPMS) multiple sclerosis (MS) in New Zealand.

Earlier this year MSNZ made two submissions to PHARMAC to request the inclusion of ocrelizumab on the Pharmaceutical Schedule for reimbursement. The Society awaits the outcome of the reviews expected to be held early in 2018.

“This is a great way to finish the year and a step in the right direction to slowing and potentially halting the progression of MS for many people who until now have had no access to treatments,” commented MSNZ Vice President Neil Woodhams. “This approval brings hope to many New Zealanders and we look forward to the outcome of PHARMAC’s meetings next year at which funding for ocrelizumab will be reviewed.”

MSNZ also hopes that PHARMAC will add ocrelizumab to the treatment options available for Relapsing MS. “There is a sub group of people with RMS who have fewer treatment options available due to being positive for the JC Virus which can cause a life-threatening brain disease. Ocrelizumab has been shown to be a good option for those who are JCV positive and we would welcome its inclusion,” says Woodhams.

“If PHARMAC approves funding for ocrelizumab we hope they will also approve proposals we have made regarding widening the access criteria which, at present, are restrictive and not in line with current research. MSNZ has a submission lodged with PHARMAC, requesting a widening of current criteria. Latest international research would justify such a move.” says Woodhams. As with all MS treatments currently available, ocrelizumab isn’t designed to be a cure but halts the progression of disability caused by the condition. “We hope PHARMAC will recognise the evidence of the long-term benefits for people with MS that this treatment can bring, keeping people active and engaged in their families, communities and the workforce.”

Graham Walker who was diagnosed with Primary Progressive MS five years ago is one of 20 New Zealanders receiving ocrelizumab as part of a compassionate programme for the past 2 months, “It’s incredible the improvements I have found to my daily life and mobility, particularly in ways I didn’t expect. I can now clap my hands palm to palm when previously my right palm clapped the back of my left hand, and I no longer drag my foot when I walk.” Walker is optimistic but also realistic about the treatment. “I hope ocrelizumab will continue to halt the progression of my condition and disability. I know it is not a cure but I hope it will enable me to stay active doing the things I love for longer like playing with my young grandchildren and cycling. I’m an optimistic person usually but this treatment has given me so much more hope for a bright future and will hopefully do the same for many more New Zealanders.”

[1] : <https://gazette.govt.nz/notice/id/2017-go6792> – notice number 2017-go6792 (consent for distribution of new medicines) – 21 Dec 2017

Heat Sensitivity and MS

Sadly a lady with MS passed away on Wednesday in Christchurch due to hyperthermia from overheating outside in the hot temperatures. This is a very sad event and we have assisted the Coroner's Office with the statement. Should any enquiries be received from media please pass these onto MSNZ to follow up.

On our website is some information for people with MS about how to keep cool in these extreme temperatures which can be found here: <https://www.msnz.org.nz/heat-sensitivity/>

<https://www.stuff.co.nz/national/100921402/christchurch-woman-with-multiple-sclerosis-dies-of-overheating?cid=facebook.post.100921402>



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DISCLAIMER: The views and opinions expressed in this newsletter are those of the authors and not necessarily those of the Taranaki Multiple Sclerosis Society. The Taranaki Multiple Sclerosis Society accepts no responsibility for accuracy of information contained within this newsletter.

The Taranaki Multiple Sclerosis Society 'My News' is strictly a newsletter about the disease. It does not provide medical advice, diagnosis, or treatment. This content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read.

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