



Multiple Sclerosis
Bay of Plenty

BOP Multiple Sclerosis Society (Inc.)

bopms.co.nz

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Newsletter – August & September 2017

2017 AGM



It was great seeing many of our members at this year's AGM, thank you very much to everyone who attended – especially to the Eastern Bay of Plenty members for making the trip over.

The meeting went well, all reports were read and the financials were discussed. Cliff was presented with a card and bunch of flowers as a thank you for the past three years as President, and the new committee members joining were welcomed (see their details below).



Thank you to the Tauranga RSA for allowing our group to use the private room off the Oak Tree Restaurant, and a special thanks to Farmers Tauranga for donating a Clarins beauty kit as a door prize – well done Josie for winning this beautiful kit!



We also wanted to thank our many volunteers for giving up their time to assist at our exercise classes. It was lovely to be able to present flowers to Liz (on behalf of herself and her husband Rick) who help out every Monday afternoon at aqua, storing the equipment at their home and assisting Rachelle at our major events (Tour of Tauranga and Golf Tournament). We appreciate all of our volunteers support.



A note from our new President

As this is my first contribution to the Newsletter I would like to start by saying thank you to all that attended the AGM in June. It was very pleasing to see such a good turnout. It has really set the tone for the direction I would like the BOPMS Society to take, i.e. more involvement from members and more interaction from the committee. It is vitally important that as a group everyone feels part of the Society and to this end I hope to get out and meet as many members as possible.

My first opportunity was the Meet and Greet that I attended on 29th June at The Raft organised by Cheryl. There was good conversation and nice surroundings that made for a very nice evening. There will be many more opportunities through the various fundraising events and social activities to further get acquainted with members.

Looking forward to the year ahead we are in a very strong position financially and will continue to look for avenues to fundraise so that we are able to support the current services and any future services that may be identified.

In closing I would encourage everyone to give the committee feedback about the services we provide and we are also happy to receive any new ideas. You are able to email me direct at president@bopms.co.nz or phone me on mobile 027 692 7736. In anticipation I would like to thank you for all your support and look forward to acting as your President over the coming year.



Best regards, Warren Scobie

BOP MS Committee

President: Warren Scobie

president@bopms.co.nz or 027 692 7736

Vice President: Patrick Kear

jeepey@mac.com or 021 482 643

Committee Members:

Averill Judd – averill.bub@gmail.com

Sonya Ferguson – jimsonya.ferguson@extra.co.nz

Rosalind Tayler – rosalindtayler@gmail.com

Dianne Boyle – diannz@kinect.co.nz

Fiona Clarke – fej98@yahoo.com

National Multiple Sclerosis Awareness Week : 28th August – 3rd September 2017

We are getting ready for the biggest awareness week of the year!

We are currently securing venues for our stands but expect them to be at Countdown Fraser Cove, New World Brookfield, Pak N Save Papamoa, Countdown Whakatane and hope to add Countdown Katikati and New World Mount Maunganui (depending on the amount of volunteers we get). We require two people on each two hour time slot (running from 9 am to 5 pm) **Friday 1st and Saturday 2nd September**. If you can assist please contact Rachele at your earliest convenience on 027 521 9977 or email admin@bopms.co.nz.



During this week we will also be spreading the awareness of Multiple Sclerosis, and our Society, at the following couple of events. If you can make it along to either of these evenings we'd love to see you there.

- ◆ **Wednesday 30th August: Quiz Night** – Cornerstone Pub (55 The Strand), 7.30 pm onwards
- ◆ **Thursday 31st August: Open Mic Night** – Mount Social Club (305 Maunganui Road), 9.00 pm onwards

WBOP Field Worker's Report

Hello everyone and welcome to our midyear newsletter.

There have been some interesting developments on the MS and HD research front so I thought I'd share some information with you about clinical trials and how they work so you can gain a better understanding of the processes involved before a treatment becomes available for public use.

What is a clinical trial?

A clinical trial is a type of research study that compares the effects of "health interventions" on people – most commonly new drugs or treatments. However, they may also examine the effects of other health interventions such as diagnostic methods, surgeries or procedures, technological devices and educational methods. Clinical trials are the most reliable way of showing whether a new intervention is safe, effective or better than what is already available.

If the pre-clinical laboratory based studies (typically involving human cells or animals) have shown promising results, the health intervention may go to trial stage. Trials have to progress through a set sequence of four "phases" to ensure the data collected is reliable and all those taking part are protected. Testing can be stopped at any time in any phase to ensure the safety of the participants.

Phase 1 (1 year+)

A phase 1 trial involves a small number of volunteers (20-80) that may or may not have MS. The aim is to see if a potential treatment is safe for people to use.

Phase 2 (1-3 years+)

Once researchers are satisfied that a treatment is likely to be safe in people, it can be taken into a phase 2 trial.

This involves a bigger group of people who have MS (100-300) and aims to measure safety and effectiveness. The drug is compared to a placebo (dummy drug) or one that's already available. Phase 2 trials are used to develop the best dosage, and this is taken forward to be studied in phase 3 trials.

Phase 3 (2-3 years+)

If phase 2 results show that a treatment is safe and has a positive effect in people with MS, it can be taken through to a phase 3 trial. The treatment now needs to be tested in an even bigger group of people with MS (1,000-3,000) to confirm its effectiveness, monitor side effects, and collect information that will allow the treatment to be used safely. The treatment is compared to a placebo or, if possible, an existing treatment. The trial can be carried out at multiple clinical sites across different countries.

Phase 4

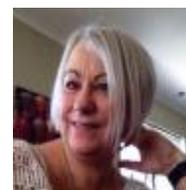
Phase 4 trials take place once new medicines have passed all the previous stages and have been given marketing licenses. A marketing license means the medicine can be made available on prescription. The safety, side effects and effectiveness of the treatment continue to be studied while it is being used in practice. *Source: MSIF website November 2016.*

I hope you found this helpful and informative in understanding the lengthy process involved in bringing new treatments to fruition.

If you have any questions don't hesitate to ask Max or I.

Stay cozy and warm, enjoy the warm rugs, hot drinks and children's rosy cheeks!!!

Warmest wishes from Cheryl
027 221 9977 / cheryl@bopms.co.nz



Wheelie Wicked Wheels



Introducing a collection of poems by one of our members, Janette Barclay!

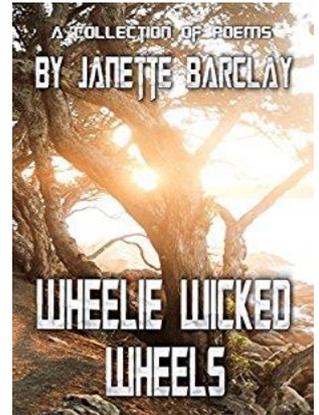
Born in the Shetland Islands off the northern coast of Scotland, Janette has enjoyed writing stories for as long as she can remember. After immigrating with her family to New Zealand at age 7, she learnt to speak English and has been fascinated with the written English language ever since.

Growing up surrounded by poetry-reciting and song-writing relatives, Janette discovered her own love of poetry in the 1980s and that her choice of words created gaiety and hilarity for her family.

When Janette was diagnosed with Multiple Sclerosis in 1993 she wrote poems for her own therapy, in getting used to MS and also using the wheelchair. She discovered children adapted better than adults, with

adults there was always the “I wonder what people are thinking” scenario. Her poems helped her get her head around everything happening, and to find the humour in life. She sees her book as encouragement for people to follow their dreams, apart from the MS.

Janette’s book “Wheelie Wicked Wheels” is available on paperback and as a Kindle version on Amazon. The timing of her book could not be better as the publication dates coincide with her upcoming 70th birthday. Thank you for sharing your book with us Janette and **HAPPY 70TH BIRTHDAY TO YOU!** We look forward to hearing about your celebrations.



EBOP Field Worker’s Report

Hi members, I hope winter is treating you well. Further to previous articles regarding tips to managing Multiple Sclerosis this time we discuss pain and sight challenges.

Sore Muscles and Pain

Along with fatigue, it’s quite normal for MS patients to experience sore muscles and pain in their joints. To help you fight those uncomfortable achy moments, try these:

- A physical therapist can help, working with your body, and giving you tips on how to fight the pain, as well as recommend simple, easy physical exercises that fit your needs.
- You can also make an appointment with your physician and ask him/her to recommend over-the-counter pain medications that may help.

Sight and Vision

Having sight and vision problems is also on the list when it comes to MS symptoms. If you experience these, there are some things you can do:

- Try talking to your physician and see if he/she can prescribe some medication that could help you with your vision issues.
- If you’re an avid reader or just like to spend time online, limit your time with books and on your computer, and try not to wear out your eyes.
- Don’t forget that, just like any other part of your body, your eyes need to get some rest every once in a while, so give them a break.

I am receiving positive feedback regarding these MS symptom tips in that they do actually help which is great. Remember **knowledge is power** in keeping MS under control.

Our next support group lunch will be on Tuesday 8th August at the RSA starting at 12:00 pm.

All the best from Max

027 571 6898 / max@bopms.co.nz



Funding / Fundraising

A huge thank you to the WBOP Disability Support Trust for recently accepting our grant application.



Annual Donation Invoices

Thank you very much to those that paid their annual donations, and especially to those members that gave a bit extra to assist those that are unable to pay their fees. We will not be issuing receipts unless asked so please do contact us if you would like a receipt of payment. If you want to pay your annual donation however have misplaced your invoice please get in touch with Rachelle (admin@bopms.co.nz or 027 521 9977).

Thank you to the Western Bay of Plenty District Council!

Every year the staff at the Western Bay of Plenty District Council choose our Society to donate their May morning tea takings to. This year they donated \$586.00 and we are extremely grateful for their ongoing support!



“Drink, Dine, Donate” at RYE Kitchen on Tuesday 25th July

On the last Tuesday of every month Rye Kitchen donates 20% of all sales back to charity organisations. They have kindly chosen our Society for July so now we need to make sure this night is a success! Please consider dining or dropping in for a drink during this evening, and pass this information onto everyone you know.

To make a reservation phone 07 571 4138 or email bookings@ryekitchen.co.nz.

Tuesday 25th July at Rye Kitchen: 19 Wharf Street, Tauranga.



BNZ Closed for Good



On **Wednesday 23rd August** every BNZ branch will close their doors so their staff can assist various charities around New Zealand. We submitted applications to hold a sausage sizzle at Bunnings Warehouse Mount Maunganui and Mitre 10 Te Puke. It is a great opportunity for our Society to again raise the profile with handing out literature to those that visit the stand, as well as a small fundraiser. Our submissions have been approved however this will only go ahead if a BNZ staff member wishes to be on our stands. Fingers crossed we get a few people interested! Please keep checking our Facebook page for updates.

First Aid Kit Fundraiser



Be prepared for all kinds of accidents or emergencies with the first aid kits we are now selling as an extra fundraiser. For each kit we sell the Society will receive \$12.

The kit is a large, carry kit with transparent fold-out compartments that contains 77 items **including a digital thermometer!** It measures 240mm x 180mm x 85mm and follows OSH and consumer regulations. A complete list of the kits contents is available on our website (under the fundraising tab).

These kits often retail for well over \$60 however we are selling them for **just \$40**.

If you, or anyone you know are interested in purchasing a first aid kit from us please download the order form from our website or contact Rachelle on 027 521 9977 or admin@bopms.co.nz.

Thank you to our 2016 / 2017 supporters!

TECT • Pub Charity • The Lion Foundation • Bodmin Charitable Trust • North and South Trust • Bay Trust • WBOP DST • First Sovereign Trust • NZCT • Grassroots Trust • Infinity Foundation Limited • COGS • Dragon Community Trust • Lottery Grants Board • Amanda Sutcliffe and Co Ltd • Tauranga Citizens Club • Cohesion Online Ltd