

Image provided by  
Robyn Willis.



## Letter from editor in training



Hello Everyone. I am the new editor, albeit in training, so at the moment I am considering myself merely the gatherer of information.

My predecessor Liz has left some really big shoes to fill, so I hope that I am up to the challenge.

I am originally from Durban, South Africa. Where I met my then boyfriend. I met him just at the time that his MS was starting to show its painful side, and from one misdiagnoses to another. We came over to NZ in 2007. We ended up in Tauranga but always had a love for Taranaki, so when the opportunity came up for us to move here in July 2014 we couldn't pack the car fast enough. He is now my hubby, and I being the support/nurse/counsellor/mum/wife. I try my best but it's not so

easy when you have no idea of what is going on. You can read all about it, but it's not the same I guess. And thankfully he does better than most due to his very regimented lifestyle and eating habits.

But winter is coming and for most of you that means relief from the heat causing inflammation and pain and with one snow fall already on the beautiful Mount Taranaki (much to our excitement) maybe a trip to the Mountain cafe in full snow is in order.

We have decided to take up the momentous task of updating everyone's email addresses. If you would prefer the newsletter emailed to you, or your email has changed, or if you know someone who you think would like to read the emailed version of the newsletter please can you email me with the email addresses on cindsmith@yahoo.co.nz. Please put a heading of MS Newsletter so that I know you are not spam.

Kindest Regards *Cindy*

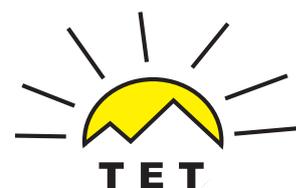
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Thank you to our sponsors and supporters



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Te Tahua Mā Ngā Whakahaere i Ngā Hapori

## President's annual report March 2015

This is the 35th Annual General Meeting of the Taranaki Multiple Sclerosis Society. I attended the first one in 1981 and many more since then.

Having undertaken a variety of roles as a member of the society during these 35 years, I somewhat reluctantly accepted nomination for the position of President at the last AGM as I felt I was past my 'use by date'. As you see, I am still here and ready to participate in a second year.



A brand new committee was formed at the last AGM and it took a while to get to know each other and the commitment each person was prepared to make.

Liz Wilkinson became the Secretary and also offered her creative writing skills to edit the quarterly newsletter. We have all seen the results of that. I have complimented Liz several times and the feedback from members has been excellent. Although Liz has been the editor of the newsletter, the actual format and presentation has been brilliantly done by Rachael Smith. A big thank you to both these ladies.

For a variety of reasons Liz has chosen to relinquish both the position of secretary and newsletter editor.

Words fail me when I try to describe the attributes of Jeannette Aldridge, Treasurer and Funding Applicant. Believe me, she is worth her weight in gold.

Jeannette spends many hours applying for funds to various organisations with successful outcomes.

The results are before you in the form of a healthy bank balance.

Our own fundraising achievements during Awareness Week at the beginning of September and from the Art Auction held at the end of October realised approximately \$3000.00. We also received an unsolicited donation of \$500.00 from the Lioness Club.

Another vote of thanks goes to Jill Smart who looks after our Website. Jill does a brilliant job under somewhat difficult circumstances. One of the circumstances is also a delightful bonus. Baby Alex, who is now 6 months old.

I must admit that website technology leaves me somewhat bewildered and I tend to refrain from using it.

I also thank very much, 3 committee members, Bev Walsh, Stewart Shaw and Des Brophy who have each brought their own particular skills to benefit the society during this past year.

I have regretfully accepted Bev's resignation due to increasing health problems.

Last but certainly not least is our Field Officer, Moira Paterson who deserves our utmost thanks and praise. Moira is only paid for 18 hours a week but goes above and beyond the call of duty. My aim is, with your help, to raise more funds so that Moira can work more paid hours.

We now have 82 client members living in Taranaki ranging from age 14 years – 80 plus. Quite a number live in more remote parts of South Taranaki resulting of course in higher transport costs.

Moira has arranged coffee mornings and lunches at various intervals through the year but these are not well supported. The

MS (*Moans and Sighs*) gatherings held at the Good Home Bar and Restaurant each month are also lacking numbers. A survey needs to be held this year to find out what members would like us to do for them in the way of socializing.

About 25 members attended a barbecue held on a sunny Saturday afternoon in January in the garden area outside our rooms. This was enjoyed by everyone present. Thank you to Liz and Des for organising this event.

During the year ahead, I hope the committee will recognise World MS Day on Wednesday May 27th. Also focus on a full week of activity during Awareness week at the beginning of September.

Des Brophy has arranged a major fundraising event during a race meeting at the race course in September. This is certainly a fundraiser with a difference and should be a lot of fun. All volunteers welcome. Thank you Des for organising this.

Let us all continue to be dedicated to improving the daily lives of people with MS and ANC and their families.

*Mary Needs* President

WOULD YOU LIKE A  
**BIGGER**  
VERSION OF THIS  
**NEWSLETTER?**

Need a bigger font in your newsletter?

We can provide you with an A3 version for easy reading. Please let us know by contacting Cindy or Moira.



## Field worker's report



Hello to all you folk out there, I hope you are all keeping yourselves as well as you can be and a big welcome to all the new folk who have joined the society since our last newsletter.

Thank you to Cindy for picking up where Liz left off with editing the newsletter, sorry to see you go Liz and thank you Rachel for continuing to piece it all together. I know a

number of readers have remarked on the enjoyment they get from the newsletter and the information it holds.

The weather has turned and though it is still warm the rain is steady as I am writing this. I was assured by a farmer today that we do need it and I imagine we do though I can't say I enjoy driving in it. I do know a lot of folk were affected by the heat over summer so I am sure there are many who will be glad to see the back of summer.

Sadly we lost one of our 'Golden Girls' with the passing of Esther Rangitaawa. Our condolences go to her family and friends. She was my partner in crime when it came to garden centres and I will miss her terribly. A graceful lady who had a passion for her garden and a great sense of style and colour for her wardrobe, she had a very quiet peaceful way of looking at the world and a wicked sense of humour. I know her faith carried her through some hard times and I am sure she is in a happy place with her Piko.



**Esther Rangitaawa.**

*Moira Paterson* 027 4643940 | 0800 725 3767

## Toxin from tobacco smoke could increase pain in spinal cord injury and worsen MS

WEST LAFAYETTE, Ind. – A neurotoxin called acrolein found in tobacco smoke that is thought to increase pain in people with spinal cord injury has now been shown to accumulate in mice exposed to the equivalent of 12 cigarettes daily over a short time period.

One implication is that if acrolein is exacerbating pain its concentration in the body could be reduced using the drug hydralazine, which has been approved by the U.S. Food and Drug Administration for hypertension, said Riyi Shi (pronounced Ree Shee), a professor in Purdue University's Department of Basic Medical Sciences, College of Veterinary Medicine, and Weldon School of Biomedical Engineering.

The drug has been shown to be effective in reducing acrolein levels in research animals, and Shi is working to develop a low-dose version for that purpose in humans.

Mice were exposed to a level of acrolein equivalent to 12 cigarettes per day over three weeks. Previous research has focused on acrolein accumulation in the respiratory system but not in the bloodstream and spinal cord. It is known that acrolein is accumulated in urine in human smokers after years of smoking.

"This is the first animal study demonstrating that an acute short term of weeks of smoking could also cause acrolein to accumulate in urine and more importantly in spinal cord tissue, a part of central nervous system known to be vulnerable to acrolein, he said.

The researchers documented the concentration of biochemical markers for acrolein in the urine and spinal cord. Findings, appearing this week in the journal *Neuroscience Bulletin*, indicate the accumulation of the toxin was about 50 percent higher than normal, a level known to have pathological implications.

"The data indicated that acrolein is absorbed into the circulatory system and some enters the nervous system," Shi said. "It is expected that these findings may facilitate further studies to probe the pathological role of acrolein in the nervous system resulting from smoke and other external sources through long and short term, both active and passive exposure."



The research paper was authored by Melissa Tully, a graduate student at Purdue and the Indiana University School of Medicine; Purdue graduate students Lingxing Zheng, Glen Acosta, and Ran Tian; and Shi.

Acrolein is produced within the body after nerve cells are damaged. In spinal cord injury and in multiple sclerosis, the myelin insulation surrounding nerve cells is destroyed and the nerve fibers themselves are damaged by acrolein. The toxin acrolein also is found in air pollutants including tobacco smoke and auto exhaust.

"It is already known that smoking can increase pain for people with spinal cord injury and worsen the condition of multiple sclerosis, but we don't know exactly why," Shi said. "I am saying that acrolein might be the key culprit here and that inhaled acrolein could intensify multiple sclerosis and increase pain sensation."

The research is ongoing and was funded by the Indiana State Department of Health, the National Institutes of Health, and an Indiana CTSI CBR/CTR Pilot Program Grant.

*Paper from Purdue University News*

2015

Support groups



NORTH TARANAKI

Coffee Mornings

Monday 11th May  
& Monday 13th July

@ The West Bar, Westown

NORTH

MS (Moan & Sigh)  
Wednesdays

After work drinks, 5.30pm,  
first Wednesday  
of the month.

@ The Good Home,  
Arikki Street.

SOUTH TARANAKI

Coffee Mornings

Thursday 7th May  
& Thursday 6th August

@ Sergeant Peppers cafe,  
Stratford

NORTH TARANAKI

Lunch Group

Friday 8th June

@ the Treehouse, 471  
Devon Street West  
New Plymouth

## 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



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

## Need Health Supplements?

Health 2000,  
Vivian Street, New Plymouth

**10% OFF**  
**Supplements**

Just show your society membership



## 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)

## 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**

## 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/>

# National Scholarships/Grants/Awards available to PwMS

MS National AKA The Multiple Sclerosis Society of New Zealand (Inc) - is a non-profit organisation formed to provide on-going support, education and advocacy for people with MS and their support networks. It also aims to educate the general public, employers and health professionals about MS and actively funds key research into the condition.  
<http://www.msnz.org.nz/>

**Maira can help apply for this stuff:**

## Outward Bound - Aspire Scholarships

This is a specially adapted low impact course for people aged 27+ who have a physical limitation – past participants for this course include people with MS, arthritis, joint replacements and back injuries.

It is an 8 day course where participants get to try all sorts of new, fun activities in a safe and supportive environment including: sailing, rock climbing, kayaking and high ropes.

The best news is that they are currently offering \$1890 scholarships for this course. People can apply for these scholarships through this link on the Outward Bound website: [www.outwardbound.co.nz/aspire](http://www.outwardbound.co.nz/aspire)

The full course fees are \$2390. The individual applying for the scholarship would need to raise the remainder of this.

<http://www.msnz.org.nz/Page.aspx?pid=460>

## Dorothy L Newman Scholarship

The Dorothy L Newman Scholarship assists people who have been diagnosed as having MS and as a result are unable to continue in their present employment, who need to change their employment and undergo a course of retraining in order to do so.

Applications are open solely to people with MS needing to retrain for paid employment.

Applicants will be required to explain in a statement in their application the reasons why they chose their course of study, how they intend to use their qualification on successful completion of their course and the likelihood of employment following the course.

Applications for the Dorothy Newman Scholarship fund for next year (2014 academic year) are now open. To receive a copy of the guidelines and application form email [info@msnz.org.nz](mailto:info@msnz.org.nz).

<http://www.msnz.org.nz/Page.aspx?pid=461>

## Esme Tombleson Awards

Esme Tombleson was the co-founder of the national Multiple Sclerosis Society in 1961 and from 1975 was President for many years. She was also founder and President for many years of the Gisborne branch and on the International Federation of the Multiple Sclerosis Society's executive. In 1987 she received the rarely awarded gold medal for distinguished services to Multiple Sclerosis.

In honour of her work, the MS Society of NZ offers the Esme Tombleson Award annually to people in New Zealand for the 'Person with MS of the Year' and 'Caregiver of the Year', which are presented at the MS Society AGM. The nominations for this award are organised through the Regional Societies and Co-ordinated through MSNZ every September.

<http://www.msnz.org.nz/Page.aspx?pid=354>

## Disability Grants

The Lottery Individuals with Disabilities Committee distributes funds to people with disabilities for the purchase of vehicles, scooters and other disability equipment to help them achieve independence and participate in the community.

**For funding purposes, an individual with a disability is defined as:**

*"a person who has a permanently reduced capacity to be transported, to be personally mobile or to communicate, as a result of a physical, sensory, psychiatric or intellectual disability."*

**Priority is given on the basis of:**

- the severity of the disability
- the contribution the vehicle or equipment would make to the quality of life of the person with a disability (the applicant)
- the financial circumstances of the applicant and their family
- the availability of alternative transport or assistance
- the family situation of the applicant
- the applicant's locality
- any lottery assistance received in the past

**What is funded?**

About 40-45% of applicants receive funding. The usual grant available for a mobility scooter is \$4,000 (+GST). The maximum grant for a car is \$10,000(+GST). If the need for a van can be justified, the maximum grant available is \$12,000(+GST). An additional grant of up to \$10,000(+GST) can be approved for a wheelchair hoist or vehicle modifications if required. There is no maximum amount for other mobility/disability equipment with applications generally being considered on their particular merits.

## Applications

To apply for a Individuals With Disabilities Lottery Grant download the application form, information sheet and application guide. Submit the application along with a letter of support from the MS Society, your fieldworker, therapist, doctor or person of standing within the community.

Applications may be made at any time. (There are no set meeting dates or closing dates for applications.) Decisions are made six to 16 weeks after applications have been lodged.

Lottery Individuals with Disabilities Information Sheet & Lottery Individuals with Disabilities Grant Application Form can be downloaded from the below link:

<http://www.msnz.org.nz/Page.aspx?pid=369>

## Scholarships/Grants/Awards available to people through MS National

MS National AKA The Multiple Sclerosis Society of New Zealand (Inc) - is a non-profit organisation formed to provide on-going support, education and advocacy for people with MS and their support networks. It also aims to educate the general public, employers and health professionals about MS and actively funds key research into the condition.

<http://www.msnz.org.nz/>

## 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](mailto:noz4r2@gmail.com).

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

A very big thank you to Robyn Willis who supplied the cover photo for this issue. It is of her friend's nails painted to support M.S.



## 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.

## 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.

## Health & Disability Advocacy

Advocates aim to assist consumers to achieve consumer-centred health and disability services and resolve complaints by:

providing advocacy services that focus on the resolution of consumers' concerns and any complaints about the quality of service;

promoting respectful relationships, whanaungatanga and communication;

empowering and supporting consumers/complainants to take their own action to improve health and disability services;

providing services that are responsive to the needs and aspirations of tangata whenua;

educating both providers and consumers on consumer rights.

There is no charge. Advocates are independent of health and disability service providers and funders and from government agencies. Advocates will keep your information confidential.

Phone 0800 555 050 to be connected to an advocate in your region.



## Starting a support group?

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



## Committee Members

**Auditor:** O.A. Greensill

**Patron:** Lynda Matthews

**President:** Mary Needs

**Vice President:** Graham Walker

**Secretary/Treasurer:** Jeannette Aldridge

**Committee Members:** Stewart Shaw

Jill Smart

Cindy Scott-Turner



To find out more about upcoming events see our Facebook page



Join our MS Taranaki facebook page where support and helpful information is always shared and available:

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

## Can't get out? You can shop online!

**Meals:**

[www.eatunlimited.co.nz](http://www.eatunlimited.co.nz)

**Supermarkets with online shopping/delivery (Countdown):**

<http://shop.countdown.co.nz/?banner=www>

**Vitamins and Supplements:**

[www.healthpost.co.nz](http://www.healthpost.co.nz)

## Presentation on Multiple Sclerosis and Exercise by Gilly Davy .....

On Thursday March 26th I drove to Auckland and attended a public presentation on Multiple Sclerosis and exercise by Gilly Davy. Gilly is a Sydney based, senior Neurological Physiotherapist and is an expert in the exciting new advances in the treatment approach to MS. The latest evidence is directing a significant change in the historical approach to MS and exercise. During a break in Gilly's presentation Graeme Sinclair, producer of the TV series "Gone Fishin'" and author of 'Life on Wheels' gave a motivational talk based on his own personal experiences with MS.

The notes that follow are salient points from the presentation as recorded by my daughter, Kerry on the night. I hope that they offer you inspiration and new ideas as they have for me.

### **26 March 2015 MS and Exercise Presentation Gilly Davy**

Many MS symptoms are improved by exercise including weakness, spasticity, sensory loss, decline in mobility, cognitive changes, pain fatigue etc.

78% of MS patients are inactive. Historically exercise was warned against due to fatigue and overheating. This is changing.

Exercising should be started as soon as diagnosed.

No link between relapse or worsening of condition and exercise.

80% of patients report fatigue; either central (brain has to send more messages along nerve due to damaged fibres) or neuromuscular (muscles have to work harder to perform same function). Neuromuscular fatigue is temporary, rest can regenerate strength.

Need a 'structured fatigue management plan'

Rise in body temperature equals rise in symptom presentation due to poor transition of nerve signals. - suggests drinking icy water and that hydrotherapy and cycling are the best options for exercise as they produce less body heat.

Inactivity causes complications to MS such as cardiovascular disease, diabetes, obesity, etc.

Evidence shows that exercise has a neuroprotective effect due to release of brain derived neurotrophic factors and nerve growth factors.

Exercise also promotes neuroplasticity and anti-inflammatory mechanisms.

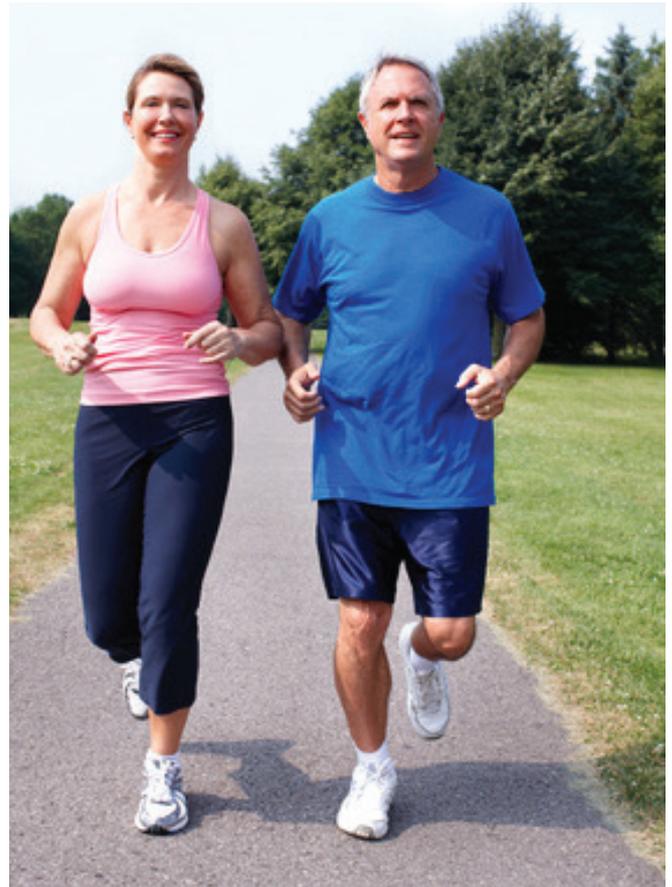
More activity = slower progression.

Note that you can not bank exercise, you must keep it up.

Strength training increases neural drive. Must be progressive strength training (getting harder with each session).

Stress, anxiety and depression are inflammatory and associated with symptom presentation. Exercise improves this as does meditation, mindfulness, etc.

Exercise must be high intensity. 70-80% of heart rate maximum (must be out of breath).



Boom and bust is to be avoided by ensuring that exercise is interval training 40-45 seconds of exertion then rest. Work : rest ratio of 1:1 – 1:3. Neurological physio can prescribe an exercise routine.

Specificity – as symptom presentation is individual, so must exercise routine and it should be goal specific i.e hand function, walking speed.

Must be a challenge or there will be no change. Feeling sore is OK. However, be mindful of what you have to do for the rest of the day. If exercise brings on symptoms that's OK as long as symptoms dissipate 30 minutes – 2 hours later.

Frequency of exercise should be 3-4 times a week, strength training 2 times a week.

Fun! Exercise must be fun or people wont stick to it. E.g. making it social.

Start small and build up intensity and length of exercise to build tolerance. Increase length and number of sets over 6 weeks.

MS get a head start program. 6 weeks of exercise training to give patients a start. (1 hour 2 times a week) promotes self management following programme completion.

Gilly is back in NZ in May 14th delivering a talk on neuroplasticity: what you need to cause change.

Cheers,

Graham Walker

# The Taranaki Multiple Sclerosis Society BBQ Saturday 24th January 2015

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Thank you to everyone that attended and was involved with the BBQ this year. Here are a few cell phone snaps of the day.



**ms.**

Taranaki Multiple Sclerosis Society Inc.