



Govett-Brewster Art Gallery  
/ Len Lye Centre  
Opening 20/07/15

## Letter from editor in training



Warm greetings to all. You would not think that we are half way through winter, it seems to be getting colder. For a chick from hot east coast South Africa, where frost is something you only hear about like, it's a myth, I was overly excited when I woke up on Saturday to frost outside. The neighbours must think I'm mad. The fabric on the deck chairs was white and so outside I pranced to take some snaps to load onto Facebook, when I started skating along the thin layer of ice on the deck surface. I think I squealed in delight. So bizarre what amuses some of us. But it was far too much excitement for Hubby, who preferred to remain inside and watch me through the glass door, shaking his head in utter disbelief at my antics.

But halfway through winter means half way through the year. It always seems like there is so much to do and not enough time to do it. Hopefully we can keep you posted and up to date with anything that is coming up. Please, if you are on Facebook, we have a local group where info, up coming events and discussions happen it is <https://www.facebook.com/groups/MS.taranaki>

Also I would like to invite anyone who has a story, an article, a question or just to have something to say (all MS related) to email me on [cindsmith@yahoo.co.nz](mailto:cindsmith@yahoo.co.nz).

Stay safe. Hugs

*Cindy*  
0212955202

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Thank you to our sponsors and supporters .....



The Grand Lodge IOOF NZ  
Friendly Society

Pacific Workers Sports Fund

## President's annual report March 2015 .....

Hi Everyone,

I am writing this on a VERY wet Saturday . Many parts of the country are suffering from the effects of either flooding or heavy snow falls.

Maybe by the time you read this we can begin to look forward to Spring.

The committee have been very busy on your behalf so please read the contents of this newsletter to find out what we have been doing and what is being planned.

Jeannette ( Secretary/Treasurer) and I drove to Palmerston North on June 3rd to attend a cluster meeting. Each region is expected to attend three cluster meetings a year.

The Central Region encompasses Wellington, Wanganui, Hawke Bay, Palmerston North, and Taranaki.

Each of these five societies were represented at this Cluster meeting and it was great to discuss and share concerns.

Two of the representatives are also on the MSNZ Board of Governance.

There are four regions in New Zealand each with four or five MS societies.

The MSNZ Annual General Meeting will be held in Auckland in October.

### WORLD MS DAY

was held on Wednesday May 27th.

An information table was set up in the library and remained until Saturday May 30th.

Volunteers 'manned' the table on Wednesday and we were able to respond to interested persons enquiries.

An excellent banner was made by 'Future Grafix' which is attached to the new table we had purchased.

### MS AWARENESS WEEK

will be held through out the country from Saturday August 29th - Saturday September 5th.

Four days has been booked at Centre City to sell raffle tickets and provide information. Pak n Save has provided us with a \$100.00 grocery voucher for our first raffle. A BIG thankyou to Pak n Save.

Saturday and Sunday August 29th and 30th the table will be at the bottom of

the escalator just inside the front door.

On Friday and Saturday September 4th and 5th, the table will be in the area of Muffin Break.

Please let Moira know if you are available to be on a roster during these four days.

The committee would appreciate help with fund raising during this week.

### RACE DAY

Last year Des Brophy arranged with The Taranaki Racing Club to sponsor the Taranaki Multiple Sclerosis Society on Saturday, September 26th 2015 which is the 'charity' day they have each year.

Des is no longer on the committee but Moira and I have been in touch with the race coordinator and the planned day will go ahead.

All we are expected to do is provide logos for the information sheet and the collection buckets. The Lions Club members go round with the collection buckets on our behalf.

I would really like to see members attend this race meeting wearing the orange shirts and handing out information cards.

Two more committee members are required to wear the Privacy and Health and Safety hats.

It is very unlikely that any issues will arise but its 'just in case'.

I am currently working on a survey form which I plan to send out with the Spring Newsletter in October. The committee need to know the 'how, what, where and why' of members.

### FUND RAISER

On June 30th the society held a Quiz Night at the Good Home Bar and Restaurant.

Graham Walker organised this and flyers were distributed as well as advertising the event in the Mid Week and on Face Book.

We aimed for 14 tables of 6 and ended up with 20 tables. WOW!

A fun evening and a very successful outcome.

120 people supporting MS

Hopefully we will be able to do it again next year.



Thankyou  
Graham and the great people  
working at the Good Home.

Warmest regards to you all .

*Mary Needs*

PRESIDENT

## Committee members .....

### AUDITOR

Mr O.A. Greensill

### PATRON

Mrs Lynda Matthews

### PRESIDENT

Mary Needs

### VICE PRESIDENT

Graham Walker

### SECRETARY/TREASURER

Jeannette Aldridge

### COMMITTEE

Cindy Scott- Turner

Cheryl Gadsby

Stewart Shaw

### MS WEBSITE

Tamara Rimland

### NEWSLETTER EDITOR

Cindy Scottturner

### NEWSLETTER DESIGNER

Rachael Smith

### FIELD WORKER

Moira Paterson

Phone: 021 985 285

Email: [moitz56@yahoo.co.nz](mailto:moitz56@yahoo.co.nz)

## Official launch of the New Zealand Multiple Sclerosis Research Trust



\$900,000 in grants kick starts Trust dedicated to New Zealand-based Multiple Sclerosis research

*From left to right, Peter Wood and Graham Wear, Trustees of the Auckland Region MS Trust present NZMS Research Trustees Neil Woodhams and Tim Preston a \$300,000 Investment Portfolio to establish funding for the Research Trust. Peter Wood is also a Trustee for NZMSRT.*

The New Zealand Multiple Sclerosis Research Trust (“NZMSRT”) today announces it has received a combined \$900,000 investment portfolio as founding capital for the Trust. A \$600,000 portfolio has been transferred from the Multiple Sclerosis Society of New Zealand and a \$300,000 portfolio from the Multiple Sclerosis Auckland Region Trust. The Research Trust has been established to stimulate, co-ordinate and support New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings.

NZMSRT Trustee Neil Woodhams said: “We are delighted to have secured this substantial initial funding. This is an important first step to securing much needed capital for the many New Zealand-based MS research projects that need our help. With the Trust now established, we will be looking at

*further opportunities to increase the capital base of the Trust.”*

The Trust has a target of raising a minimum of \$5 million in the next 5 years and will use income generated from its investments to collaborate with partners to fund research that improves the lives of people with MS.

With the rate of MS on the increase in New Zealand, there is a need to centralise the autonomous research being undertaken by numerous different organisations throughout the country.

*“A single point of focus is needed for funding MS research. In the past, in many cases research for MS has been one of only a number of research strands within organisations that deal with a wide range of neurological or other health conditions,”* Mr Woodhams said.

Because of its size, geographic

spread of population and the ability through the health system to accurately track individuals, New Zealand provides an ideal environment for MS research. Recent research has revealed that the incidence of MS for people living in Otago and Southland is four times that of people living in Auckland or Northland.

According to figures from the 2006 New Zealand National MS Prevalence Study, 2,917 people have been diagnosed with MS in New Zealand with the female to male ratio of illness at 3:1. The number of people with MS has continued to grow since then due to the number of new cases being diagnosed every year.

The Trust is registered under the Charitable Trusts Act.

*Acknowledgment to About New Zealand Multiple Sclerosis Research Trust media release.*

## 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.

## About New Zealand Multiple Sclerosis Research Trust .....

The New Zealand Multiple Sclerosis Research Trust was established for the purpose of stimulating, co-ordinating and supporting New Zealand-based research into the cause, prevention, treatment, alleviation and cure of Multiple Sclerosis (MS), and to obtain and disseminate research findings. Registered under the Charitable Trusts Act, the NZ MS Research Trust collaborates with partners to fund research that helps people with MS, informs people about research findings and uses fact-based research findings to improve the lives of people with MS. See: [www.msresearch.nz](http://www.msresearch.nz)

## Multiple Sclerosis Research Trust brochure .....

The New Zealand Multiple Sclerosis Research Trust brochure will be available to download from the Taranaki MS society facebook page:



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

in the files section. Alternatively you can email Rachael Smith to ask for a copy at [noz4r2@gmail.com](mailto:noz4r2@gmail.com).



# The Taranaki Multiple Sclerosis Society quiz night

## Saturday 30th June 2015

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Taranaki Multiple Sclerosis Society arranged a fund raising quiz night to take place at a local bar and restaurant (*The Good Home Bar*) on Tuesday June 30th.

Never having done anything like this before, it was a good learning curve.

Lots of publicity with flyers, face book and word of mouth. The result being a very successful and fun filled evening.

There were six competitors at a table, each paying \$15.00. We hoped for fourteen tables but had twenty, that was a WOW!

One hundred and twenty people supporting MS. Not only a fund raiser but an awareness night too.

We hope to do one each six months.



# SUPPORT GROUPS & MEET UPS!

## ☛ NORTH TARANAKI

### COFFEE MORNINGS

Monday 10th August at 10am and  
Monday 12th October at 10am

@ West Bar  
41 Tukapa St, Westown, New Plymouth

## ☛ NORTH TARANAKI

### MS (MOAN & SIGH) WEDNESDAYS

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

@ The Good Home Bar  
21 Arikki Street, New Plymouth

## ☛ SOUTH TARANAKI

### COFFEE MORNINGS

Thursday November 5th at 10:30am

@ Sergeant Peppers Cafe  
Prospero Place, Stratford

## ☛ NORTH TARANAKI

### LUNCH GROUP

Monday September 14th at 12pm

@ The Good Home Bar  
21 Arikki Street, New Plymouth



## Teen With MS becomes running star



Kayla Montgomery



She has gone from being one of the slower runners on her high school team to one of the fastest distance runners in the nation, a rise fueled by an improbable motivation.

Three years ago, Kayla Montgomery, 18, was diagnosed with multiple sclerosis, an incurable yet treatable disease of the central nervous system.

While Kayla can run long distances without feeling pain in her legs, when she stops, her limbs give out and she collapses. As she crosses the finish line, her coach catches her to keep her from falling.

*“Probably a mile or so in, I start to lose feeling,” she said on TODAY Saturday. But she keeps going. “I don’t really focus on it. I just kind of ignore it and focus on finishing my race and everything else.”*

Kayla told TODAY’s Erica Hill and Lester Holt that she kept running after her diagnosis because she didn’t want people to think she was any different.

Kayla was also profiled in the New York Times, in a story that explained that her condition blocks nerve signals from her legs to her brain and describes how her legs gradually go numb as she races yet become uncontrollable when she stops.

At the time of her diagnosis, Kayla was among the slowest runners at

Mount Tabor High School in Winston-Salem, N.C. But she was determined to improve her times, despite her condition.

*“Instead of letting it stop me from running, I’ve used it to motivate me to break records,” she said last week on TODAY. “This past cross country season I was undefeated by any other North Carolina runner.”*

Now, she’s one of the nation’s fastest female distance runners, so good that she trains with the boy’s team, according to TODAY, and she receives no special treatment.

MS can cause muscle weakness, balance problems and in the most severe cases, paralysis. It’s not known how Kayla’s illness will progress, but she is making her running days count.

*“Since I know that my mobility is a gift right now, I guess I make every day that I run as best I can, so I don’t waste that gift,” she told TODAY’s Natalie Morales.*

When describing how it feels to run, she said “it kind of feels like I’m just kind of floating,” adding, “there’s nothing underneath me.”

While some may say that the inability to feel pain is a competitive advantage, Kayla’s doctor says the key to her success is her attitude, not her illness.

*“If any benefit is to be gained by her disease, it’s a mental edge, not a physical edge,” says her neurologist.*

Kayla’s parents, Keith and Alysia, were devastated when Kayla was found to have MS.

*“Finding out she had MS was gut-wrenching,” her dad said.*

*“I was thinking about, like all of the things that she maybe wouldn’t get to do,” said her mom.*

But they have been amazed by her accomplishments.

*“I don’t know how much faster she can get,” Keith Montgomery said. “I never thought she could get this fast, but at this point, I’ve quit doubting.”*

Kayla’s coach, Patrick Cromwell, has also marvelled at her progress.

*“Is she going to be an All-American or Olympian?” he said. “I don’t know. But I would have never thought she would improve eight minutes in four years either.”*

Later this month, Kayla is due to compete in the national indoor track championships in New York and she is headed to Lipscomb University in Tennessee in the fall.

She said on Saturday that she hopes to keep “running forever.”

*Lisa A. Flam is a news and lifestyles reporter in New York. Follow her on Twitter: @lisaflam*

# MD-PREV Aims to find out about genetic muscle disorders

## Genetic muscle disorders included

- Duchenne muscular dystrophy
- Becker muscular dystrophy
- Manifesting carriers of muscular dystrophy
- Congenital muscular dystrophy and myopathies
- Emery-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy
- Limb girdle muscular dystrophy
- Myotonic dystrophy
- Oculopharyngeal muscular dystrophy
- Distal muscular dystrophy
- Myotonia congenita
- Paramyotonia congenita
- Central core disease
- Pompe's disease
- Nemaline myopathy
- Myotubular myopathy
- GNE myopathy
- Periodic paralysis
- HyperCKemia

## MD-PREV aims to find out:

- How many people are affected by genetic muscle disorders in New Zealand.
- How these conditions impact on the person and those close to them.
- What support people receive and what else is needed.
- The overall aim is to improve the care and support provided for people living with a genetic muscle disorder and their family/whanau.

Genetic muscle disorders affect both males and females, of all ethnicities, from new-born babies to the elderly. Severity of symptoms vary across the different disorders but all involve skeletal muscle weakness and many include heart and lung problems.

By talking to every New Zealander living with a genetic muscle disorder and getting a better picture of how the condition affects them, we can help to improve health care services in New Zealand and deliver them to where they are needed.

If you, or anyone you know has one of the genetic muscle disorders listed to your left, or are being tested for one of these, we would love to hear from you.

Participation in this study will involve answering some questions about your condition and everyday life. You can nominate someone close

to you to take part too. A researcher can come and visit you at home or you can choose to complete the questions over the phone, or complete them yourself online.

## Please contact the MD-Prev Research Team:

Email: [mdprev@aut.ac.nz](mailto:mdprev@aut.ac.nz)  
 Phone: 0800 MDPREV (637738)  
 Text: 0212458597



# 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.**



## 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/>

## 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)

## 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](mailto: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)

## Field worker's report

Well here I am again, how times flies when one is busy and doing ones best to throw some fun into the mix. We have had our share of erratic weather lately with icy cold nights and mornings to persistent rain and flooding for some folk. I have to admit that when I found the lawn all icy with frost the other day I just could not resist going out and crunching in it like when I was a child. All that aside I hope everyone is managing to keep warm and dry.

I attended Field Worker training in May and although it was interesting there was no real exciting news to pass on to you. We heard about the new drugs Gilenya and Tysabri again but of course these are only available for those people with Relapsing Remitting MS. Should you wish to know more about these drug treatments please give me a ring.

There is a great programme that has been put together by Jessie Snowden called Minimise Fatigue, Maximise Life which sounds really good but unfortunately we do not have any facilitators in Taranaki trained to be able to run the course which is rather sad.

We have been offered a mobility scooter free of charge, so if there is anyone out there that requires one and is unable to afford to buy one please get in touch with me and we may be able to help.

We held our quiz night at the Good Home on the 30th June which turned out to be a roaring success, a full house and lots of humour. Some of the questions were pretty tough but we learned lots and I am looking forward to the next one. Thanks to all the people on my team Sharon, Ian, Nicky, Brian and Shaun. We didn't do too bad and averaged somewhere in the middle ratings. And of course huge thanks to Graham who got stuck in and organised the event and to his wife Julie for playing banker.

The committee is organising what is going to be happening for MS Awareness week and we will be running raffles so if anyone can help with this it would be much appreciated. We will be doing a street appeal and if anyone can help with this as well it would be great. A couple of us will be heading around the mountain and doing a round the main street walk in each town with our buckets so



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

your company and local faces could be of benefit to our cause. Beautiful bright orange MS Volunteer tee shirts will be provided.

That is about it for me but should you have any challenges or just need a grizzle please give me a call and leave a message if I am not available.

Kindest Regards

*Moira*



# WE NEED YOUR HELP!

**ms.**

Taranaki Multiple Sclerosis Society Inc.

Volunteers are needed to help fund-raise during national M.S. week. Your help can really make a difference and is much appreciated.

Details in Moira's and Mary's article.