ms.
Multiple Sclerosis
Waikato

Issue 52 - February 2017

ManuScript

Working Together to Provide a Service of Excellence
Mahi tatau ki te whakawhiwhi he hapori rawe

Inside:

The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

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SPAN Trust

2016 Kawhia Cruise

Early November and it's 'Cruise' time again. As I make my way into the car park of the 'Jukebox Diner' I'm a little bit amazed that the car park is practically full of vehicles. On closer inspection I notice that most of the vehicles are motor homes whose owners appear to be having some sort of convention. I treat them with the disdain they are probably due and head for where the 'real' cars are parked. Looks like a pretty standard crowd for the event – around 100 cars and their passionate owners.

This is the fourth year the event has been held and as I wander into the diner I wonder to myself what I'm going to write about this year. As you know by now I am not a car person. Cars, to me, come in sizes – big, medium and small; most seem to be painted silver, white or black and generally cost the owner a lot to keep them on the road.

But the beauty of 'the Cruise' is that these cars of yester-year are all beautiful, generally large (and noisy) and painted in a greater range of hues – bright blues, reds, oranges, yellows... and yes, black ...but definitely not a silver car to be seen (unless you are looking at mine!!).

However, the owners may change each year but the cars are generally the same. So what more is there to say? I've said enough about Adam (the reason the Cruise exists); I've already covered my pubescent '1972 fantasies' cruising with my art teacher in her canary yellow and black MK 1 Mustang and the delightful Clare and her red and white 1961 Corvette aren't here this year for a catch-up.

Tell you what – how about stick to the basics – who, what, where, when etc. and let the pictures speak for themselves!

So, I walked in, bought my coffee and sat down for a chat with former MS Chairman Graham Haines and the 'hired help' Frankie and Phil Letford. After a bit of grovelling, and a certain amount of pleading, I manage to score a ride home from Kawhia and went off in search of whom I was going out with.

'My ride' is an old friend - Shelley's (Adam's wife who tragically died of cancer shortly after the first cruise) beautiful orange and white 1955

2016 Kawhia Cruise (continued)

Chevrolet. Poignantly my driver is going to be Shelley's dad Eric and we will be joined by her sister Katrina and husband Rob. We are underway as Adam heads out of the car park in his 1958 Apache Chevrolet ('Elmo') leading us to our first check-in point in Pirongia. A quick look at the sky and the clouds are looking a bit threatening – the couple in the topless red 'T' bird in front of us look nervously skyward as we join the queue heading south-west.

The cavalcade attracts quite a bit of attention as we negotiate the road works at Temple View and rumble on to Pirongia where the cars regroup and park up for another get together. The friendly local police cruise up and down the road checking us out before heading off to find someone to hassle. Adam decides it's time to move on and we rumble out leaving the good folk at Pirongia to their peace and quiet. If you have ever wondered about the benefits of power steering then this stretch of the road would sell you on the idea. Phil, my trusty driver, gets a real workout as he negotiates the many bends in the road and by the time we pull into the Oparau Road House he looks like he's done a good session at the gym. Graham, Frankie and Phil swing into action setting up the MS stand and selling raffle tickets. I get my priorities in order and go in search of food and coffee, then time for a wander me thinks and off I go to kick a few tyres, read number plates and chat. I notice a friend of a friend lounging on the bonnet of his car and wander over. "So ...Pete... I see you are giving the '31 Coupe (Ford) a spin today. This is the 5 window model isn't it?" Obviously impressed with my knowledge (it's amazing what you can learn from a number plate) he is about to launch into a technical discussion when I'm called away by Graham who is doing battle with a wind gust and trying to keep the stand earth bound. There's no auction this year so the Oparau stay is a little shorter and we are soon off on the last leg to Kawhia.

Kawhia proves to be quieter than Pirongia. But that is soon changed as the cars fill the local Reserve and regular band 'Shotgun' spring into action with their repertoire of 60's and 70's music. A sunny day, relaxing music and the eyelids get a bit heavy so I go for a stroll and check out the local coffee establishment.

Coincidently by the time I get back Frankie and co have done all the work and it's nearly time to depart. I dart off to thank my hosts on the way out and join the MS crew for the ride home. A nice relaxing day, good company, good cause – come and see for yourself next year. Thanks to Adam, Tristan and friends and all the sponsors for making the day possible.

Funds raised $2,084.00

Ian Maxwell

Apps to Keep Your Brain Engaged!

People are increasingly realising that exercising the mind is a really important part of a healthy daily routine. By using applications, or "apps", on phones, IPads and other technology you can maintain and improve your brain health and reduce the risk of dementia.

A number of apps – defined as self-contained programs or software designed for a particular purpose – are of particular interest to people with neurological conditions, their carers, families and health professionals.

We recommend that you search online for more information (we have listed below websites to visit to find out more). Typically you download the app through either the Google store (for android) or ITunes (Apple).

LUMOSITY (www.lumosity.com) Lumosity provides fun games that the website claims builds flexibility, attention, memory and problem solving among other neurological properties. Users identify capabilities they would like to build and Lumosity creates a personal programme for them with games to support their goals.

HAPPIFY (www.happify.com) Like the brain-training website, Lumosity, Happify aims to change the way you think through activities and games, this time with the goal of building a happier you. Start by choosing a happiness track – free options include "Conquer your Negative Thoughts", "Cope Better with Stress" and "Grow Your Inner Strengths" – then complete weekly activities that aim to hone happiness. The app also hosts articles and community features so you can connect with others who are working to maintain a more cheerful mind set.

DAILY YOGA (www.dailyyoga.com) With a database of more than 400 poses, this app offers guidance to beginners and advanced yogis alike. Yoga can be a great way to relax before bed, stretch tired muscles and get a good workout too. Like always, talk with your physician before starting a new exercise regime.

Source: ***wwwparkinsons.org.nz/The Parkinsonian***

Book Review

To the Summit *by Nick Allen*

Let me say at the outset that what Nick Allen achieves is pretty remarkable. He is an outdoorsman and has spent his life tramping the bush, forests and mountains of New Zealand. From a relatively young age (21) he starts feeling the effects (fatigue, weakness in limbs) of what would ultimately be diagnosed as MS. As with most of us that diagnoses is a slow process and he goes through a fair bit of heartache and soul searching. What is remarkable is that once he is diagnosed and is relying on a mobility scooter to get around he sets his heart on climbing mountains – firstly in New Zealand and ultimately in the Himalayas.

But I have a problem with Nick. At no stage does he accept that he has MS. He doesn't specifically say what type of MS he has (in fact he does his best not to mention MS at all) but I suspect from his gradual deterioration in physical condition that he has Primary Progressive – like me.

I always thought the best way to live with MS was to accept I had it and find the best ways to live with it. Although Nick accepts that he has to change his lifestyle (especially diet and specific exercise) he refuses to accept that he has MS and therefore there are limitations to what he can do. You may think 'Good on him' but I have a wee problem with that. He sees himself as a weakling - not a man and in the case of riding his mobility scooter "a laughing stock". He is always trying to prove he is as fit and healthy as other people – especially climbers.

To this end he tells no-one (other than family and a small group of close friends) that he has MS. That is fine it's his decision but when he is climbing on the mountains and everyone depends on each other doing their job he is actually putting their lives at risk. Point in case is when he is attempting to climb 'Stok Kangri' in India. He leaves his attempt a bit late in the season and has to make a climb with a 'stand in' guide who he does not know. He is critical of his guides unprofessionalism but he at no time tells him he suffers from MS and may have trouble with fatigue at some point on the climb. They ultimately fail to make the summit and with a bit of luck, and thankfully good decision making, they make their way down again.

It is to his credit that Nick then goes on to climb, and reach the summit of, 'Island Peak' a considerably higher mountain in the Himalayas. Thankfully his guide on that occasion was aware of his condition and they made allowances for it on the climb.

He gives two reasons for wanting to succeed in climbing this mountain – to change perception of MS as a disabilitating disease and – to raise money for the 'Mastering Mountains charitable trust' he set up to assist people with MS to achieve their goals. But I suspect it was a bit of personal challenges to prove he was still a man and be able to match it with his healthier counterparts.

Whatever! I may be judging him harshly as I'm bitter and twisted and wouldn't even consider climbing the stairs to the gym! Give it a read. You have to admire that he doesn't let the various setbacks he suffers get in his road. Oh, and by the way he is a bit of a photographer and there are some great photos liberally splashed throughout this book. Worth the read and the photos are amazing.

Multiple sclerosis: New blood test can identify types of MS and if treatments are working

Patients with multiple sclerosis will soon have access to a new test which can tell them exactly what type of MS they have and how well their medications are working.

Key Points:

- It's the first test to accurately determine which kind of MS patients have
- Markers can also be used to see if medications are working
- Researchers have hailed it as a "stunning breakthrough" for Australian patients

At the moment, patients have to have an array of expensive tests to determine what kind of MS they have.

The study, published in Nature scientific reports, shows a blood test could greatly simplify and speed up this process, allowing doctors to adapt a patient's treatment more accurately and rapidly.

Neuroscience Professor Gilles Guillemin from Macquarie University said the discovery was the culmination of 12 years' hard work in the lab.

"We can tell you which sub-type of MS you have and if you respond to treatment," he said.

At the moment, patients have to wait weeks on a medication to see if it is effective.

"If you can have the blood test and see the marker not working, and this treatment doesn't work, the clinician will be able to realise very quickly change to another therapy," Professor Guillemin said.

MS is a debilitating disorder of the central nervous system that affects more than 23,000 Australians and 2.3 million people worldwide.

Professor Giles Guillemin says the test will help patients know if treatments are working. (ABC News: Meredith Griffiths)

What are the types of MS

- **Relapsing-remitting:** partial or total recovery after attacks or flares. This is the most common form of MS
- **Secondary progressive:** where patients have some recovery but later become steadily progressive
- **Primary-progressive MS:** Symptoms generally do not remit. 15 per cent of people with MS are diagnosed with this type

Source: MS Australia

MS patient Mike Hemingway believes the new test will make a "substantial difference". (ABC News: Meredith Griffiths)

Mike Hemingway was diagnosed with MS 15 years ago, but doctors could not tell him which form of the disease he had.

He was pleased to hear about the new test.

"It will make a substantial difference. For me, yes I would have liked to know 'this is what I have got'," he said.

Doctors hope if patients are put on the right drug earlier they will not be affected by MS as much as patients like Mr Hemingway have been.

"The earlier you can have those treatments the less damage there is going to be to your central nervous system and things like cognitive problems and walking problems vision problems hopefully will become over time things of the past," Mr Hemingway said.

Stunning breakthrough' for Australian Research

Matthew Miles, chief executive of MS Research Australia, said it was a "stunning breakthrough" for Australia and for Australian research.

"It's absolutely critical that we understand which type of MS, so people can be treated with the right therapy quicker, particularly when other therapies for progressive disease become available," Dr Miles said.

"There's the potential for being treated earlier, there's also the potential for being much more in control and peace of mind so you understand the disease."

The lead researcher of the study, Edwin Lim, who is currently based at Macquarie University, said the breakthrough was an important move towards personalised medicine for MS patients.

"The unique information that we will receive from the biomarker within an individual, means that it could also be possible develop biomarker guided personalised treatment for each patient," Dr Lim said.

Potential hope for other conditions: Researchers

The findings could have implications for other conditions such as Alzheimer's, Parkinson's, and motor neuron disease.

The test relies on detecting compounds in a pathway of the brain using a substance called tryptophan.

"By increasing our understanding of how our cells process tryptophan, we will be better able to identify its involvement in many neuro-degenerative diseases," Professor Guillemin said.

Source: ABC News medical reporter Sophie Scott and the National Reporting Team's Meredith Griffiths

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of the newsletter please notify Tracey by emailing tracey@mswaikato.org.nz.

Access4all

"Access4all" is an accommodation and activity guide intended for use by anyone with mild to major mobility difficulties, and an undiminished desire to travel. It has listings of motels, apartments, holiday parks and activities in most of the major NZ destinations. More are being added all the time. Every property listed includes an option of 1 or 2-bedroom accommodation for travellers with family members and/or caregivers

It is a graphic guide - its aim above all is to give impaired mobility vacationers confidence by showing what need to know places (especially bathrooms, entrance areas, bedrooms, surroundings) and activities are like. When people using the guide find what suits, bookings can be made directly from the site.

Have a look … **www.access4all.co.nz**

Health Passport

A Health Passport is a booklet that you can carry with you when attending hospital appointments or meeting with other providers of health and disability services. It contains information about how you want people to communicate with you and support you. The Health and Disability Commissioner (HDC) is working with District Health Boards (DHBs) throughout New Zealand to introduce the Health Passport into our hospitals.

Copies of the Health Passport are available from the Health and Disability Commissioner. They can be obtained by emailing healthpassport@hdc.org.nz. You can request either A4 (bigger) or A5 (smaller) sizes. The bigger size is also available with pictures.

To ask about the Health Passport,
phone 0800 11 22 33 ext 5080 or email HealthPassport@hdc.org.nz

How to get the best out of your Health Passport

- Complete it as soon as you receive it (don't wait till you have to visit a hospital).
- Keep it safely with your other medical records (with your medical file or other paperwork that you may take to a hospital).
- Remember to take it with you every time you visit a hospital.
- Inform reception staff that you have a Health Passport when you go to a hospital.
- Keep your Health Passport close to your bed at all times when in the hospital.
- Remind all hospital staff who work with you to read the Passport.
- Remember to take your Passport with you when you return home.

Activity of Huntington's disease gene curbed for six months in mice

A single injection of a new treatment has reduced the activity of the gene responsible for Huntington's disease for several months in a trial in mice.

Huntington's disease is a genetic disorder that affects around 1 in every 10,000 people and damages nerve cells in the brain. This causes neurological symptoms affecting movement, cognition and behaviour.

Huntington's usually only begins to show symptoms in adulthood. There is currently no cure and no way to slow the progression of the disease. Symptoms typically progress over 10-25 years until the person eventually dies.

Now, the EU-funded FINGERS4CURE project team led by researchers at Imperial College London have engineered a therapeutic protein called a 'zinc finger'.

Huntington's disease is caused by a mutant form of a single gene called Huntingtin. The zinc finger protein works by targeting the mutant copies of the Huntingtin gene, repressing its ability to express and create harmful proteins.

In the new study involving mice, published in the journal Molecular Neurodegeneration, the injection of zinc finger repressed the mutant copies of the gene for at least six months.

In a previous study in mice, the team had curbed the mutant gene's activity for just a couple of weeks. By tweaking the ingredients of the zinc finger in the new study they were able to extend its effects to several months, repressing the disease gene over that period without seeing any harmful side effects. This involved making the zinc finger as invisible to the immune system as possible.

A lot of Promise

Project lead Dr Mark Isalan from the Department of Life Sciences at Imperial said: "We are extremely excited by our latest results, which show a lot of promise for treating Huntington's disease.

"However, while these encouraging results in mice mean that the zinc finger looks like a good candidate to take forward to human trials, we still need to do a lot of work first to answer important questions around the safety of the intervention, whether repeat treatments are effective, whether there might be longer-term side effects, and whether we can extend and increase the benefits beyond six months.

"In this study we weren't looking at how repressing the gene activity affected the symptoms of the disease and this is obviously a critical question as well. However, we have reason to be confident from our previous studies that repressing the gene does in fact significantly reduce symptoms.

"If all goes well and we have further positive results, we would aim to start clinical trials within five years to see whether the treatment could be safe and effective in humans. We are urgently looking for industry partners and funding to achieve this."

Cut off at the Source

The mutant Huntingtin gene is thought to cause toxic levels of protein to aggregate in the brain. Preventing the activity of this gene could theoretically halt the disease, but this has been difficult to achieve.

The gene is present in many different cell types in the brain, making it difficult to target, and every patient also has a non-mutant copy of the gene, which scientists need to avoid targeting with any intervention in order to prevent unwanted side effects.

The zinc finger protein sticks to the DNA of the mutant Huntingtin gene and turns off the gene's expression. "We don't know exactly how the mutant Huntingtin gene causes the disease, so the idea is that targeting the gene expression cuts off the problem at its source – preventing it from ever having the potential to act," said Dr Isalan.

By targeting the fundamental DNA of the gene, the zinc finger therapy also has the advantage over other potential Huntington's therapies of needing less frequent treatments.

Lengthening Effect

In the study, the researchers gave a single injection of zinc finger to 12 mice with Huntingdon's disease. They examined the brains of the mice at different intervals after the initial injection and found that on average, 77 per cent of the 'bad' gene expression was repressed in mouse brains three weeks after injection of the zinc finger, 61 percent repressed at six weeks, and 48 per cent repressed at 12 weeks.

By 24 weeks after the initial injections, there was still 23 per cent repression, which is thought to still be useful therapeutically. The team are now working on ways to lengthen the repression period even further.

The study was funded by a European Research Council Proof-of-Concept Award (ERC-2014-PoC 641232 FINGERS4CURE) and involved researchers from Imperial College London, Centre for Genomi Regulation (CRG) in Spain, and Universitat Pompeu Fabra in Spain.

Source: Imperial College London

NOTICE BOARD

The Michael Ford Golf Tournament

Our annual golf tournament is taking place on Friday 8th April. This will be held on the Lochiel course at the Riverside Golf Club.

Registration and morning tea 10.00am followed by a shotgun start at 11.00am.

Early bird registration is $30 and is open until Thursday 30th March; registrations after this date will be $40. This is a stableford tournament and is open to players of all abilities.

All funds raised are used to assist with the provision of support services.

For more information on entering the event or sponsorship opportunities please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz

A day of fun at Hamilton Zoo

Dinsdale Lions in conjunction with Hamilton Zoo and Fiends of Hamilton Zoo will be holding their

21st annual zoo day on Sunday 19th March 2017 from 11.00 am – 3.00 pm.

Entry is free for people with disabilities and their immediate family/caregiver.

Bookings are not required. If you require further information contact Kay, email kaymax@xtra.co.nz

Library Books

Please remember we maintain a library of books. With books to support MS, HD, ME/CFS/ Fibromyalgia a list of titles is available on our website www.mswaikato.org.nz. Please contact us if you would like to borrow a book.

AGM

The AGM will be taking place on Wednesday 22nd March at 6.30 pm in the Life Unlimited Board Room.

Financial members will be eligible to vote at the AGM. To reserve a seat please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz

Board of Trustees

A vacancy currently exists on the board of Trustees. This is a voluntary role and the board are seeking someone with previous board or director experience with skills/ experience in one or more of the following areas:

- Marketing and Communication
- Fundraising
- Health Sector
- Counselling Services and Advocacy

For more information or to submit an application please contact Leanne Milligan (Chairperson) leanne@wpl.co.nz

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or are housebound due to an illness or disability. Volunteers phone clients regularly to check that everything is ok. The service is free, if you wish to enquire about receiving a regular call from a Caring Caller phone 0800 000 606.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz

Donations and Bequests

Donations to MS Waikato can be made at anytime through our website www.mswaikato.org.nz, please click the link 'Donate now' and it will take you to the Spark Foundations give a little website. Alternatively a direct link to this site is through www.givealittle.co.nz/org/MSWT.

A bequest is a gift to charity and is made through your will, please talk with a solicitor if you wish to make a bequest.

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WDFF Karamu Trust • Waipa District Council • COGS - Hamilton City, Hauraki, South Waikato & Waikato West
DV Bryant • Cambridge Lions • Anytime Fitness Tristram St • The Fine Homes Tour • Lochiel Golf Club • Pak n Save Clarence St
The Sutherland Self Help Trust • The Gallagher Charitable Trust • Rotary Club of Cambridge • Waikato Lyceum Charitable Trust
MediSun Ltd • Waikato Mobility Scooters • The Page Trust • Trillian Trust • Len Reynolds Trust
Rehabilitation Welfare Trust • The Norah Howell Charitable Trust

MSWT EVENTS CALENDAR

MARCH 2017

SUN	MON	TUE	WED	THU	FRI	SAT
			1 **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**2**	**3**	**4**
5	**6** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**7** **MS Support Group** Dawn till Dusk Cafe Te Awamutu 10am	**8** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**9** **ME/CFS Support Group** Methodist Church Bader St, Melville 10.30am	**10**	**11**
12	**13** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**14**	**15** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**16** **MS Support Group** Mometewa Te Aroha 10am	**17**	**18**
19	**20** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**21**	**22** **AGM – 6.30pm** **Life Unlimited Building** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	**23** **MS Support Group** Lola Cafe Dinsdale roundabout 10.30am	**24**	**25**
26	**27** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**28**	**29** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**30**	**31**	

APRIL 2017

SUN	MON	TUE	WED	THU	FRI	SAT
30						**1**
2	**3** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**4** **MS Support Group** Dawn till Dusk Cafe Te Awamutu 10am	**5** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**6**	**7** **The Michael Ford/** **MS Waikato Charity** **Golf Tournament**	**8**
9	**10** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**11**	**12** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**13** **ME/CFS Support Group** Methodist Church Bader St, Melville 10.30am	**14** **Good Friday**	**15**
16	**17** **Easter Monday**	**18**	**19** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**20** **MS Support Group** Mometewa Morrinsville 10am	**21**	**22**
23	**24** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**25** **ANZAC Day**	**26** **MS Exercise Class** 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	**27** **MS Support Group** Lola Cafe Dinsdale roundabout 10.30am	**28**	**29**

MAY 2017

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Please Cut Here

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Tel 07-834 4740, Email mswaikato@mswaikato.org.nz, Website www.mswaikato.org.nz