

Loud and Proud – Still

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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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ManuScript is brought to you by:



Six years ago I interviewed Mike Hogan regarding a job he had just acquired despite the fact he was in a wheelchair and vision impaired. Mike sung the praises of the firm where he was employed and the agency that helped him get that job. Mike held that job until November last year when he was made redundant but Mike being Mike was straight back on the phone to the agency and back into the job market. More about that later, but first ...

Mike and wife, Karleen, went on a little rail trip with a difference! The story starts last year when the couple were watching a 'Country Calendar' item on a new venture rail trail using a no longer used section of the main trunk line between Okahukura and Stratford. The company 'Forgotten World Adventures' were taking tourists along the 140 km route in adapted 'golf cart' like buggys.

The idea appealed to Mike and Karleen and when they saw the company had a stand at the Waikato Home show later in the year they went along to have a chat. The chap they spoke to was one of the owners of the company and he could see the benefits of having someone like Mike, with his physical disabilities, try out the trip and point out where things could be improved. "He said to us - 'You get yourself to the start and find accommodation and I will pay for the trip'." Mike didn't need any more encouragement and said "we'll see you there".

So in March this year Mike and Karleen headed off to Taumarunui (the closest town) for the night. "That was the first obstacle" says Karleen, "There were only two motels in the town that were remotely disability friendly". The couple were up early for the 8.00am start at Okahukura. The full trip is a two day affair but Mike and Karleen had decided to just do the first leg and finish at Whangamomona - "We paid someone to drive our car to Whangamomona and leave it there for us to return to Taumarunui" says Karleen.

Right, on with the trip! The first disability issue for Mike was what to do with his wheelchair. "They just folded it up and strapped it to the back of the cart - simple" says Mike! Karleen adds "Getting on and off the cart Mike definitely needed a hand so if you are going to do the trip you will need a support person".

The 'carts' themselves are petrol powered and the occupants propel them with the use of an accelerator. "There were about 20 carts all told - with company staff in the first and last cart" explains Mike. "Everyone is instructed in a variety of hand signals designed to let those behind you know what you are doing and avoid any accidents". "You also have to be prepared to help clear the track of any debris from slips etc". The trip itself was just beautiful. "The scenery is typical 'back country' New Zealand - rugged and untouched" says Karleen. "There is just so much history, (each cart has a booklet pointing out historical



Mike and Karleen

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sights and local points of interest) and you can sit back and take it all in". Mike adds "No cell phone coverage – just brilliant". "The best thing about this trip is that disabled people would not normally be able to access this area – it's just so remote". The only real problem they encountered was around toilets. "They have these really flash 'long drops' but they weren't really suitable for Mike".

Approximately 100 km and 21 tunnels later the convoy pulled into Whangamomona around 4.30pm. "It was a long day – but really worth it" says Mike. "The staff were great – couldn't do enough for us and nothing was a problem". "We were asked at the end what could be done to improve the experience for disabled people" adds Karleen.

Back to Mike and his job hunt. Mike, through disabled job agency Workbridge, has found employment with engineering firm GEA Farm Technologies who manufacture rotary milking sheds. Mike would not be able to do the job if it wasn't for his flash electric chair with a telescopic seat that enables him to adjust the height at which he is working. Mike is also grateful for the support of company Zoom Tec who supplied him with a portable screen which magnifies written material allowing Mike to be able to read work sheets. Mike is also supported by a job support fund which assists with his taxi fares to and from work. Mike completes a full day's work commencing at 7.30am working through till



Mike



Setting off

4.30pm. "For me it's a long day and I'm bugged when I get home – but I'll take that over being unemployed any day!" He adds that he's grateful for the support he has received from various agencies without which he would find it very difficult to get back into the workforce. "And that of course goes for GEA who were willing to give me a chance" he says.

Ian Maxwell

Since the interview was conducted, Mike has unfortunately had to give up this role due to problems with his eyesight. But Mike is still positive and now looking for other opportunities.

The Exercise Class

The exercise class at Anytime Fitness is still going strong. Run for us by our instructor Margaret Thomson the class caters for all clients. Remember, the right kind of exercise can significantly help with your health and wellbeing. The classes are also social, meeting others affected with the same condition. Classes are held twice weekly, a Monday and a Wednesday morning at 10.30 and last an hour at each session.

The classes are subsidised by MS Waikato through grants. The only thing we ask from you to attend is that you become a financial member (if you are not already) and make a donation of \$2 for each class that you attend.

If you have not been before and would like to give it a try please call Liz, Helen or Tracey and they will arrange an introductory visit.

Photos supplied by Ian Maxwell



The big and small of it. Marion and Paul proving there is a place for everyone



Photographic evidence that Mike Barton does exist



On ya bike girls! – Carole and Raewyn doing their thing



After class coffee regulars Brian, Maureen, Bill and Paul

Our New Rio's

MS Waikato are very fortunate to have been able to purchase two new vehicles, both silver Kia Rio's. This was only possible through the generosity of the Sutherland Self Help Trust and the help of Mike Tuck.

The Sutherland Trust provides grants to community organisations throughout New Zealand – we were presented with a cheque for \$35,000 by Mark Sutherland! The Sutherlands owned and managed New Zealand's first major chain of grocery stores – the Self Help Co-op – and it was their wish to create a trust fund to further community welfare in New Zealand. The family donated property to form a Trust and after 20 years the income from the capital was donated to causes judged worthy by a Board of Trustees. The Trust has now been making donations to community organisations for 52 years.

Mike Tuck (formerly of Mike Tuck Motors) has been a supporter of MS Waikato for a number of years. When Mike heard we needed new vehicles he offered to help, and actually did all the work for us! Mike promptly started researching our options for new vehicles and made recommendations. As soon as we were awarded

the grant he was back to work, negotiating the best possible prices for us, ordering the vehicles and organizing the sale of the other vehicles.

We would like to sincerely thank both the Sutherland Self Help group and Mike Tuck.



Mark Sutherland presenting the cheque to Janet

Our Support Services staff are providing services throughout the Waikato and Coromandel regions, so to be resourced with two safe and reliable vehicles is invaluable.

As a not for profit organisation MS Waikato is dependent on the generosity of funding organisations and fundraising to be able to provide our services to you.

Janet Buckingham



Tracey, Liz and Helen with the Rio's



Mike Tuck

Rod Milner Motors

For those of you who may want to consider purchasing a disability vehicle at some point please come and talk with us.

We have received a very generous offer from Rod Milner motors in Auckland. If any client purchases a vehicle from them they will donate \$500 to MS Waikato, it is important that they are informed though to ensure we receive this payment. They are long term supporters of the disability sector, having supported MS Auckland with these donations for a number of years and have now extended this offer to MS organisations throughout New Zealand.

Rod Milners are based in Greenlane Auckland they specialise in disability vehicles and stock a large range of disability and mobility vehicles of all types and offer free freight on mobility vehicles. Milners also have disability vehicles available to rent.

For more information on please ring Rod Milner on 09 5799632 or 0800 763645 or visit the website www.rodmilner.co.nz.

ME / CFS Update

Two more busy months have passed and only one more month to go until it's officially spring!

'Eating for Health and Energy' was the topic of our July Education Support Group meeting and our speaker, Helen Donnison, provided us with some very interesting nutritional information. Helen runs the Vibrant Health Centre in Hillcrest, and is a naturopath and medical herbalist. She has specialised in nutrition and metabolic health, and says that eating a wholesome diet and having a healthy relationship with food are vitally important aspects to creating good health. Sugars and processed food drain us of energy and nutrients, leading to energy fluctuations, fatigue, and impaired metabolism causing poor health and disease symptoms. Helen recommends cutting grains right back as they tend to cause inflammation and allergies, and she thinks they are the cause of many of today's illnesses. There was much more good advice and interactive discussion, and we all learnt a lot from the knowledge that Helen shared with us.

I invited Karen Whyte from The Hukanui Body Clinic in Chartwell, to speak about Cranio-Sacral Therapy at our July meeting. Cranio-Sacral Therapy is a gentle, hands-

on approach that releases tensions deep in the body to relieve pain and dysfunction. I was on leave at the time and missed the talk, which was a shame as it is an interesting topic, but fortunately Tracey Larsen was able to take over for me. This leads me on to tell you that the reason Tracey has been working closely with me is, because, after much thought, I have decided to retire at the end of the year. So Tracey will be stepping in to my shoes and taking over the reigns of the ME/CFS coordinator role. Tracey is very capable, committed and keen, and I'm sure she will do a wonderful job. Until then it's business as usual!



Helen Donnison

Helen Maseyk
Client Services Coordinator ME / CFS

World MS Day

Our annual appeal was held on Thursday 29th May to coincide with World MS Day. World MS Day is the only global awareness day for Multiple Sclerosis. With several stalls in Hamilton and stalls also in Cambridge, Te Awamutu and Taumarunui we raised a total of \$1,827. The purpose of the stalls is not just to raise funds but also awareness and understanding of Multiple Sclerosis. This wouldn't have been possible

without the support of the many wonderful volunteers who assisted on this day; we would like to thank all our volunteers for their help.

The lovely gift basket generously donated by Pak n Save Mill St was won by Life Unlimited's Barbara Tane. Those of you who have been assessed for mobility vouchers may know Barbara.



Barbara Tane



Louvaine and Jan

Emergency Preparedness for Wheelchair Users

Are you:

18 years or older?

A wheelchair user ½ or more of the time?

Living in the community somewhere in New Zealand?

If the answer is “yes” to these questions, then we need your help.

The Burwood Academy of Independent Living in conjunction with the University of Otago are conducting a survey of wheelchair users to explore issues about emergency planning and response for people with disabilities. The need for this study has arisen from the experiences of people with disabilities during the Canterbury earthquakes.

What's involved?

Participants are requested to complete a questionnaire, either online or by post. It takes about 10 minutes to complete the questionnaire.

What's the aim?

There are four outcomes we hope to achieve through this study:

1. To identify the level of support, from a group of disabled people, for the concept of a proposed Disabled Persons Emergency Response Register.
2. Provide a snapshot of the state of emergency preparedness amongst wheelchair users in NZ
3. Provide insights into the types of issues wheelchair users in NZ face getting ready for emergencies.
4. Establish what types of technology (eg: mobile phone, internet) that could sit alongside a register, are currently used by wheelchair users in NZ.

How do I get more information?

An information sheet and video can be viewed please email Janet@mswaikato.org.nz

Or contact Jason Nicholls on 021 0231 6451 to get a copy of the information sheet and questionnaire sent to you.

Ready to Roll Survey: Wheelchair users readiness for emergencies and opinions of a Disabled Persons Emergency Response Register (DPERR).

Jason Nicholls, Burwood Academy of Independent Living Research Fellow. Email nicja964@student.otago.ac.nz

Get Thru

Sadly from time to time we are faced with National disasters and emergency situations. While we always hope to not have to go through this it is important to be prepared just in case! The Get Thru government website is an excellent source of information, easy to find your way around and will help you prepare for this. The site can be found at www.getthru.govt.nz.

It contains information on:

- Disasters and how to keep safe
- How to create and practise a household emergency plan
- Assembling and maintaining emergency survival items
- Having a getaway kit

The site also contains a section for people with disabilities or special requirements with suggestions on how to best deal with situations you may face and getting the support you may need.

If you don't have access to a computer please remember many of our libraries do and they are free to use.

HD Education Evening

Huntington's Disease Education Evening

On Monday 30th June MS Waikato hosted an HD Information evening with guest speaker Neurologist Chris Lynch. Chris shared statistics outlining the number of people potentially inflicted with HD in the Waikato and how symptoms can be detected up to ten years pre-diagnosis. Such detection enables early intervention which supports higher-functioning, independent living for much longer. Chris also promoted the establishment of a close working relationship between the Neurological Services at Waikato Hospital and MS Waikato in order to provide a robust support service to those impacted by HD; a service that Tracey Larsen and Neurological Nurse Specialist Karen Thomas have started to establish. Such an idea was well received by the audience, of which a great turnout was seen despite the atrocious weather. Reports received by those who attended have been positive with the hope that this becomes



Tracey, Karen and Chris

an annual calendar fixture, which is the intention of the team at MS Waikato.

National Huntington's Conference Perth Embracing Opportunities

Liz and I are very fortunate to have the opportunity to attend the next Huntington's Conference held in Perth WA. This is taking place 11 – 12 September at Perth's University of Western Australia, UWA Club.

It will bring together family members, researchers, allied health professionals, care workers and members and supporters of all Huntington's Disease Associations across Australia. This year is also the 40th anniversary of Huntington's WA

The program covers a wide range of topics such as, Strengthening Community Ties, Meeting the Clients Needs across the Care Continuum, Sharing Best Practice, Benefits for Supported Living from Individual Case Studies, and also our own Prof. Richard Faull is speaking on The Challenging and Exciting Journey of Research in Partnership with Scientists, Families and Communities. There is also a focus on the development of youth services and organisations, self help through mindfulness, fatigue and sleep management, new research and treatments for HD.

Day two presents' personal stories of Living to the Full and HD is Not a Life Sentence and ideas of Living Well with HD will be given, especially regarding effective communication and nutrition management. We will also witness a panel discussion regarding Embracing Opportunities in a Challenging Environment between leading figureheads.

It will be a crammed-packed two day event which we are both looking forward to, and accordingly would like to thank SPAN Trust for funding, allowing this opportunity to become a reality. For anyone that is interested in attending and would like to view the full programme please view online at www.huntingtonswa.org.au, or phone the MS Waikato Trust office on 07 834 4745.

Tracey Larsen



NOTICE BOARD

Kawhia Cruise - Fundraiser

The Kawhia Cruise will be on
Sunday 2nd November
and is being organised again by Adam Muir.

With breakfast at the Classics Museums
Jukebox Diner, the rally will travel onto the
Oparau Roadhouse and then Kawhia where
the classic rock band 'Shot Gun' will perform.
To take part 'put a note in the bucket'.

Wheelchairs

MS Waikato has wheelchairs
available for loan, for all enquiries
phone 07 834 4740.

Aspire Outward Bound Low Impact Course

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 you'll get to try all sorts of
new, fun activities in a safe and supportive
environment including: sailing, rock climbing,
kayaking and high ropes.

Aspire are currently offering \$1930
scholarships for this course.

If you wish to apply for a scholarship this
can done through a link on their website:
www.outwardbound.co.nz/aspire or for more
information contact

Simone Harris on DDI: 04 495 1767 or
Freephone: 0800 688 927.

The course will take place in September.
Applications close on the 22nd August.

Vitamin D

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

Easy Rider - 'Wheelie Friendly' Travel Club

Classic Flyers Tauranga
Thursday 21st August - \$75.00
Waipipi Bird Park - Thursday 16th October - \$70

For more information or to book a place contact
Hilary on 07 829 8925 / 027 273 6767
or email larry@easyrider.co.nz

Client Survey

A client survey is enclosed with your newsletter.
Regular surveys are essential to ensure that we
are meeting the needs of you, our clients, and if
any changes are required.

The survey is anonymous, if you could please
complete it and return it to us in the freepost
envelope provided by the 25th August.

Donations and Bequests

Donations to MS Waikato can be made at anytime
through our website
www.mswaikato.org.nz

please click the link 'to make a donation' and it
will take you to the Telecom Foundations give a
little website, there are no fees with the site so we
receive 100% of the donation you make.

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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COGS - Hamilton City, Hauraki, South Waikato & Waikato West • DV Bryant • Donny Trust • South Waikato District Council
The Lido • Anytime Fitness Tristram St • Lochiel Golf Club • Pak n Save Mill St • The Sutherland Self Help Trust



MSWT EVENTS CALENDAR

SEPTEMBER 2014

SUN	MON	TUE	WED	THU	FRI	SAT
	1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	2	3 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	4	5	6
	MS Support Group Te Awamutu 10am, Dusk Till Dawn	** MS AWARENESS WEEK **				
7	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	9	10 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	11 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	12	13
14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	16	17 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	18 MS Support Group Mometewa Matamata 10am	19	20
21	22 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	23 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	24 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	25	26	27
28	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30				

OCTOBER 2014

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 MS Support Group Te Awamutu 10am, Dusk Till Dawn	7	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 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	23	24	25
26	27 Labour Day	28 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30	31	

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