

Issue 77 – May 2023

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MS Waikato Trust supports people affected with Multiple Sclerosis and Huntington's Disease; 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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Bangers to Bluff

David Bowie, Fred Dagg and a Chief spotted in Te Kuiti, along with several Caesars, Cleopatra's and at least 1 Dolly Parton...

The "Bangers to Bluff" Rally is an annual charity event organised by the Rotary Club of Half Moon Bay. The challenge is to drive a vehicle registered and with a current WOF, costing less than \$2,000 from Auckland to Bluff and finish at Invercargill. The 2023 event ran from Tuesday 21st March to Saturday 1st April. The first day of the rally takes in the Raglan to Kawhia Rd and teams spend their first night in Te Kuiti.

MSNZ suggested members of the MS Waikato board might like to meet the teams for dinner as they were stopping in our patch, and Keith Small, Euan Reeve and I were delighted to accept on the board's behalf. It was only after we confirmed we were attending the dinner that anyone thought to raise the small matter of the fancy dress requirements for the event, on the theme of 'Leaders and Legends'. We had our AGM the week before the dinner and chatted about who we might become for the evening. Arriving home after the meeting, I glanced round the living room and saw the Aladdin Sane record sleeve leaning against the speaker and I had it - a musical leader and an undeniable legend, David Bowie. All I really needed to do was raid my daughter's face paint and I was away...

Bangers to Bluff is described as being '12 days of the road less travelled'. I can confirm that Keith and I took this motto to heart when we set out in the MS Waikato car to head down to Te Kuiti. Suffice to say that not all smartphone maps



Amber, Keith and Euan

were created equal, but the scenery was lovely as we drove in and out of rainbows through the late afternoon light. There is something to be said for taking the road less travelled, though we were only at it for an hour or so, these people had days and days of this ahead of them!

Who does that? Who arranges to spend 12 days in an old car on half-forgotten roads as the days get shorter and the temperature drops? According to my research, at least a dozen Fred Dagg's, a handful of Cleopatra's, a Dolly Parton, and a motley assortment of other notable characters from history, that's who! But beneath the costumes, the rally teams were all generous, adventurous, fun-loving people with a willingness to commit to some ambitious fundraising targets to help raise much needed funds for MS and Hopeworks. It was lovely to meet

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Bangers to Bluff

Continued from page 1

some of the teams and learn about what motivated them to get involved, their hopes for the trip and their highlights from previous endeavours.

I'm not sure Keith and I would make an ideal rally team in terms of navigation, but even spending this short drive together was a great opportunity to get to know one another better, to talk about what brought us to be volunteering for the MS Waikato board and what was exciting to us about our roles. It's easy to see how 12 days of Bangers to Bluff would create wonderful memories among the teams who take it on. Certainly the chorus of Fred Daggs (including our own Keith) belting out a rendition of the gumboot song seemed to be a very bonding experience! I am always proud to represent MS Waikato, but arriving in Te Kuiti on a wet Tuesday evening in full face paint and dressed as David Bowie was really a highlight.

Amber Hammill

Totara Springs

We were very fortunate to host another MS family camp at Totara Springs, the weather was fantastic and we had a lovely group of people with MS, and their family members.

We enjoyed the usual activities, Top Town team games, rock climbing wall, archery, hydroslide and giant slide, time by the river, kayaking, tubing, waterslide and the swimming hole, flying kiwi, archery tag, slug guns, mini golf, human foosball and go carts, not to mention a fun quiz night and the Burma trail.

We also appreciated having two of our MSWT board members taking time to come and join us. The afternoon by the riverside was greatly enhanced by the addition of Dave (board member) and his guitar, the lovely music in the background really added to the ambience and it was really nice having Keith (our chairperson) join us for dinner and the quiz.

Aside from the fun and laughter of taking part or watching the activities, there is always time for people to chat to each other about living with MS if they choose to. The ongoing friendships and informal support networks the camp provides are invaluable. MSWT run the camp every 2 years and we will let you know closer to the time the dates of the next camp. We are incredibly thankful to our funding partners Trinity Lands and WEL Energy Trust, whose generous donations have enabled us to keep the cost as low as possible.





Lego Masters

Every Monday and Wednesday morning a group of us afflicted under the MS Waikato umbrella, and a group of equally troubled folk with Parkinson's, gather to coerce our ill functioning bodies through a series of exercises and stretches at the Any Time Fitness Gym in Clarence St. It's an amiable group that has been going for many years in various establishments around Hamilton. Members have come and gone over the years but the vibe has always been the same with good natured ribbing between the groups along with genuine concern and support when required. Many friendships have been formed and maintained over the years.

I was intrigued however, on my infrequent trips to the gym to notice that a couple of the lads were often found on adjoining



Barry and John with a couple of their models.

machines speaking in hushed tones (dare I say conspiratorial) and occasionally referring to bits of paper. Being the nosey person that I am I wandered over and loitered in the near vicinity. It turns out the lads shared the same hobby – Lego Technic machines sometimes referred to as `Adult Lego`.

Not only were the lads - Barry Miners (Huntington's) & John Tart (Parkinson's) – both interested in Technic they were working on the same model – a HD Tow Truck. This model is comprised of over 1,600 pieces, and comes with a handy illustrated instruction manual of 500 pages. Now as someone who never got past `Meccano 2' and goes weak at the knees when `flat pack furniture' is mentioned I was immediately impressed. I don't possess the fine motor skills, problem solving ability or patience to even attempt such a project.

"It's not something you start and finish the same day" says Barry "Each section of the model comes in an individual packet and you just work on that piece and put it away till next time." Both Barry and John say they would normally work on the model for anything up to 2 hours at a time and that the ability to concentrate for long periods can



Barry with the box of their latest project – the HD Tow Truck.

be a factor in time spent.

John (a former pattern maker in the metal casting industry) has been a fan of Technic for longer. "I got interested when I helped my nephew back in England" – whereas Barry (a career Driver with over 40 years' experience with Huntly Mines and Porter Hire) only took up the hobby at Christmas. John has completed 10 models including a rather large miner's bucket wheel while Barry's current project is just his fourth.

When I referred to these as `boys and their toys', Barry was quite clear "They are scale models of the real thing and are quite intricate. The pictorial instructions are quite detailed but there is still a bit of problem solving involved in putting the model together. Good for the brain". As for the description of toys John says "These are models for looking at – not playing with. The completed models are displayed in places well out of reach of interested grandchildren. They can look, but not touch!"

I should note that when Barry and John brought a couple of their models for a photo some of the other `boys' in the group couldn't help themselves coming out for a look!

Ian Maxwell

AGM Updates

The MS Waikato AGM was held on the 16 March.

MS Waikato has a strong and robust board; this will continue to be led by Keith Small as Chairperson, and Dave Cordery as Deputy Chairperson. Although we lost Rebecca Watson when she moved overseas last year, we are fortunate to have Brenda Johnson now join the board. Our other Trustees are Mike Tuck, Bill Shaw, Euan Reeve and Amber Hammill.

Our Trustees all work in a voluntary capacity and we would like to express our sincere thanks and appreciation to them for the time they give and the knowledge they share.

The Michael Ford Memorial Golf Tournament

We recently held the Michael Ford Memorial Golf Tournament at Ngahinepouri Golf course. The tournament has been running for over 20 years and it is wonderful to see the support we have for the event, this year raising \$8,369.

After the unpredictable summer, we had a beautiful sunny day. With a full field of players, they had the opportunity to test their skills on the gambling hole as volunteer Sue took bets to see who could land a ball on the green, many were tempted to have a flutter, and there were prizes for nearest the pin and the longest drive too. The overall best stableford was awarded to Maurice Jarrett and it was lovely to have Joanne Ford join us again to assist with the prizegiving.

Thank you to our generous sponsors and to the players without which the tournament would not be possible. In particular, we would like to thank the Ngahinepouri golf club who donated the course to us for the day. Thank you also to Sue for giving up her time to assist on the day and Kay Gregory, our Master of Ceremony.

Our sponsors help in a variety of different ways, some making a monetary donation, others donating prizes or services for the day. They choose to do this to help make a difference; all funds raised remain in our region

to assist with the provision of support and education services for our clients and their families.



Please do remember our sponsors and support them too.

Gold Sponsors

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Chris Lynch – Midland Neurology

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Hoyts Te Awa

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Te Aroha Mineral Spas

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Whittakers

Living well with Huntington's Disease



You can continue to live your life with Huntington's disease (HD) if you focus on keeping your body and mind healthy. Research shows that people at risk, gene positive or diagnosed with HD can help reduce the impact of HD symptoms and delay progression by staying socially, physically and mentally active. Here some simple tips to manage the impact of HD.

1. Maintain your interests and social life

It is important to continue enjoying your hobbies, pursuing your interests and maintaining social interaction as this will increase positive thinking and provide a sense of fulfilment. This can be anything from reading, attending a fitness class, painting or having coffee with friends. Making time for yourself and engaging in activities that interest you are great ways of reducing stress and anxiety.

2. Stimulate your brain

Keeping the brain active is thought to build reserves of healthy brain cells which can reduce the severity and delay the progression of HD. Exercises to strengthen brain function should offer novelty and challenge, but more importantly, be of interest to you. For example, you can read aloud from books, play board games or puzzles, listen to the radio, test your recall by making lists of items, memorising them and see how many items you can recall from the list.

3. Stay physically active and eat well

Try to incorporate exercise and movement into the daily routine. This can be as simple as walking your dog, attending a yoga class or shopping. Make sure you choose an activity you enjoy. As long as you're moving and having fun, you are being physically active and taking control of the impact of HD. Additionally, eating regular, well-balanced meals is essential for your body and brain to function and is another simple way you can enhance your overall health and well-being.

4. Don't let change discourage you

We all experience change in our everyday lives. However, at times it can be unsettling, particularly when dealing with a diagnosis of HD. It is possible to cope with change and maintain a quality of life by doing the following:

- Stay informed of all possible options and difficulties you may face
- Knowing who you can talk to and have a support system you trust
- Plan ahead in relation to finances, legal matters (e.g. powers of attorney, will, etc.), accommodation, employment, how/when to speak to loved ones

<https://huntingtonsvic.org.au/wp-content/uploads/2021/01/3-Living-well-with-HD.pdf>



HD POCKET CARDS

MS Waikato have created a card which we hope some of you will find beneficial. The idea is that you can keep have one with you, and if needed it is an easy way to explain to a stranger if you are having difficulty with a task or activity. It also has a space on the back to personalise the card and to put an emergency contact if something happened and you were unable to communicate for yourself. If you would like any cards, please contact the office.



I have a medical condition called
HUNTINGTON'S DISEASE

- I may have difficulty walking
- I may take a little time in answering
- I may slur my words
- I am aware of what's going on
- Be patient and give me time to respond

NOTICE BOARD

Scooter Batteries

If you need to replace the batteries in your scooter we may be able to assist, please contact Liz on 07 834 4741 or email liz@mswaikato.org.nz

TravelScoot

We have a TravelScoot available for short term loan for a donation. For more information contact Liz or Karen.

Payments and Donations

If you wish to make any payments or donations directly to MS Waikato the account number is 02 0316 0488196 000.

Please remember to include your name and what the payment is for eg Subs.

Receipts are given for all donations, if you are not registered with us please email Janet with your contact details to enable us to forward a receipt – janet@mswaikato.org.nz.

Donations can also be made 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.

Entertainment Book

MS Waikato are selling the Entertainment books again this year. The books are now digital and contain thousands of dollars worth of vouchers. The books can be purchased as a single city, multi city or multi year. MS Waikato will receive 20% from each book sold. For more information and to view any current offers visit <https://nz.entdigital.net/orderbooks/1b54128> or contact janet@mswaikato.org.nz to receive this link.

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.

Alinkers

MS Waikato has an Alinker which is for client use. If you are interested in trialling this for about 6 weeks please contact Liz for further information.

Dogs in Homes

For the safety of our staff please ensure all dogs are secured when staff visit.

Library Books

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

Bequest

A bequest is a gift made through your will. A gift to MS Waikato is very easy to leave in your will and is a gift that makes a difference and lives on in memory. If you would like to include a gift to MS Waikato it will help future generations living with the effects of MS and HD.

A bequest to MS Waikato can be made through writing a will or making an amendment (Codicil) to your existing will. Please ensure your will states the donation is for MS Waikato, naming our organisation ensures the donation is received by MS Waikato and remains in our region. Making a will ensures that your estate is distributed according to your wishes. We recommend talking to your family to ensure they are aware of your wishes.

Wheelchairs

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

Subscriptions - Be in to win a free book

Please note 2023 subscriptions are now due.

The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed if subscriptions have not been received.

We have recently been gifted an electronic entertainment book, we would like to give this to one of our members and will do a draw for all those who have paid this year's subs. To be in to win, simply pay your subs by Sunday 11th June and you will be in the draw for the entertainment book, all those who have paid subs to date will be included in the draw.

Thanks to our Sponsors and Supporters



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MSWT EVENTS CALENDAR

June 2023

SUN	MON	TUE	WED	THU	FRI	SAT
				1 MS Support Group Hamilton Venue to be advised 10.30am	2	3 MS Walking Group 9am The Veranda Cafe Hamilton Lake
4	5 Kings Birthday	6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8	9	10 MS Walking Group 9am The Veranda Cafe Hamilton Lake
11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13 MS Support Group Churchill Café Te Awamutu 10.30am	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16	17 MS Walking Group 9am The Veranda Cafe Hamilton Lake
18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23	24 MS Walking Group 9am The Veranda Cafe Hamilton Lake
25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29 MS Support Group Mometewa Matamata 10.30am	30	

July 2023

SUN	MON	TUE	WED	THU	FRI	SAT
30	31 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton					1 MS Walking Group 9am The Veranda Cafe Hamilton Lake
2	3 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6 MS Support Group Hamilton Venue to be advised 10.30am	7	8 MS Walking Group 9am The Veranda Cafe Hamilton Lake
9	10 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	11	12 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	13	14 Matariki	15 MS Walking Group 9am The Veranda Cafe Hamilton Lake
16	17 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21	22 MS Walking Group 9am The Veranda Cafe Hamilton Lake
23	24 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27 MS Support Group Mometewa Te Aroha 10.30am	28	29 MS Walking Group 9am The Veranda Cafe Hamilton Lake

August 2023

SUN	MON	TUE	WED	THU	FRI	SAT
		1	2 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	3 MS Support Group Hamilton Venue to be advised 10.30am	4	5 MS Walking Group 9am The Veranda Cafe Hamilton Lake
6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	8 MS Support Group Churchill Café Te Awamutu 10.30am	9 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	10	11	12 MS Walking Group 9am The Veranda Cafe Hamilton Lake
13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15	16 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	17	18	19 MS Walking Group 9am The Veranda Cafe Hamilton Lake
20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22	23 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	24	25	26 MS Walking Group 9am The Veranda Cafe Hamilton Lake
27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	29	30 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	31 MS Support Group Mometewa Morrisville 10.30am		

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