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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:

**Life Unlimited Building
20 Palmerston Street
PO Box 146, Hamilton 3240**

**Ph: 07 834 4740
mswaikato@mswaikato.org.nz**

**Liz - 07 834 4741
Karen - 07 834 4742
Tracey - 07 834 4745
Janet - 07 834 4740**

ManuScript is brought to you by:



Nicky Burne



Nicky's hunting crew



Nicky

Imagine you are snuggled up in a sleeping bag, sheltered by a grubby tarpaulin out in the pouring rain. No, this isn't an Auckland housing problem story – it is Nicky Burne's idea of having fun.

In April Nicky, her partner Nathan, his brother and father went bush at Whirinaki (between Rotorua and Taupo) hunting deer. For 20 years this was a bloke's only venture. But last year Nicky got invited along and obviously passed the test as she was invited along again. "I don't know why I'm the first woman" she says "I guess I'm the only one that has shown any interest". Thinking back to last year Nicky remembers her first trip as being quite stressful. "The bush is really rugged and I had to climb steep slopes, cross rivers and shuffle along narrow tracks with a sheer drop beside you. I initially found it all quite overwhelming and shed a few tears. But, I got through it and actually enjoyed the experience. So when the boys asked me if I wanted to go this year I was up for it".

Apart from 'being a mere girl' Nicky faced another challenge – she has

MS. "I was diagnosed with Relapsing/remitting MS in September 2015. It was all a bit of a shock" she recalls "I started crying as I had no idea what it was". Nicky had her first symptoms 11 years ago when she was 17. "I just went all numb and sort of lost all control of my body'. She was told by her doctor at the time that she had a pinched nerve. Over the next 10 years the same symptoms would come and go and Nicky assumed it was a pinched nerve each time and just rested up until the symptoms passed. Then last year she went to a physio to try and get some relief and was told 'a pinched nerve' didn't sound right. She went to see her doctor in Paeroa who sent her to Thames hospital for tests. Since being diagnosed Nicky hasn't really had any relapses apart from regularly feeling fatigued.

Anyway, back to the bush. "This trip was 9 days. The boys camp in the same place each year (about 5 km from the road) and have stuff buried there for when they might need it. Each day we would wake about 7, have breakfast, and Nathan and I



ms.

Nicky Burne (continued)

would head off in one direction and the others would go in another direction – meeting back at the campsite at the end of the day”. When I enquired how she handled the early starts she laughed. “I actually felt really good. I work in a bakery (Countdown Hamilton) which requires getting up at 2.30am. So getting to sleep from about 9.30 at night to 7.00 in the morning was a bit of a luxury – I felt like a normal person”. Nicky is also no ‘Greenhorn’. She is a self - confessed ‘outdoorsy’ person and does a lot of tramping in her spare time.

So... how did the hunting go. “Nah, not too good – we didn’t get anything. We saw a couple but couldn’t get a clear shot”. But I’m told that’s not really the point. It’s all about getting out in the fresh air and having a good time with friends. And...the hygiene aspect? “Well yeah...we



smelled a bit rank. We didn’t realise until we got back to civilization and got a whiff of ourselves” she laughs. May have to bury a hot top somewhere near for next year.

Ian Maxwell

The Eagle Huntress

In October we screened ‘The Eagle Huntress’ as a fundraiser at the Lido. This is the remarkable true story of a 13-year-old nomadic Mongolian girl who broke the gender barrier to follow her father training and hunting eagles in the remote Altai Mountains of North-western Mongolia.

We were blown away by the response to this screening and found ourselves booking a second theatre for the evening which we almost managed to sell out too!



The evening raised a total of \$1,986. Our thanks to the Lido, Flagstaff Pharmacy, Lone Star Hamilton and Life Unlimited for their support and donation of raffle prizes; also to Leanne and Karen for the catering.

Book Review

Life On Wheels by Graeme Sinclair

This book is essentially an autobiography by one of NZ’s best known recipients of MS.

If you want to read about someone suffering with the effects of MS and feeling sorry for themselves this is not a book for you. In fact if you want to find out anything about MS this is not the book for you.

MS is barely mentioned – only briefly discussing the fact the he has it and how he has had to adapt to accommodate it in his life. The one chapter entitled MS sees Sinclair championing alternative solutions and advising against going with mainstream medical procedures.

If you are a hunting and fishing kind of person you will probably love this book. If you run an enterprise that relies on sponsorship to get by you will find this book helpful.

If you know Graeme Sinclair from his TV weather days or from the “Gone Fishing” programme and want to find out more about the man you will enjoy this book. He had a tough start to life and has endured tragedy and has come through it all a better person. He lets nothing get in his way – especially MS – and he is happy to share his philosophy on life (and his political views). An inspiring read if you are an outdoorsy type of person with a disability.

Ian Maxwell



Walking NZ for MS



Recently I had the pleasure of meeting Nikki Ladd. Nikki is walking the 3,000km Te Araroa trail, to raise money for research into MS, her goal \$20,000!

In 2013 Nikki made the decision to combine some of the items on her to do list a) a big walk b) to fundraise for a charity that could create change for the people it supports, c) to honour those who have walked a harder path than herself.

Originally from Taupiri, where her parents share milked, she moved to Australia 10 years ago. Nikki had seen MS firstly impact on a close family friend then also on two work colleagues, and another who waited two years for a diagnosis. Nikki was also aware of the huge difference in funds made available for research into MS compared with many other conditions and wanted to do something to help. Although often involved assisting other organisations like Oxfam this is the first time she has been proactive in fundraising.

With a three year plan the idea of organising some alternative fundraising appealed to her. For the first couple of years this was through market stalls. With the help of friends, in the 1st year they asked people that when they gave items away, if they could to donate them and they sold these at the market days, in the second year the focus was food; the third year was to be the walk and directly asking for donations towards research.

Despite breaking her foot in January Nikki was determined to continue with her plans to walk the trail this year. Setting off from Cape Reinga on the 1st

September with her trusty backpack, nicknamed 'Nigel' which weighs in at around 18kg; the original plan was to walk the North Island in 70 days and the South Island in 86 days. Whilst the injury to her foot may have slowed Nikki down a little she has not lost any of her enthusiasm. Nikki is a bubbly, inspirational person passionate about helping fund research for a cure into MS and raising awareness. Hamilton is 800k into her journey, and taken her just over 6 weeks to reach us.

Her time in Hamilton is a bit of a rest break for a few days, but when we say rest break, it is a busy one! Last night she went to talk at one of the local scout groups – and went for a walk with them, she has taken a walk up the Hakamaratas, is going to meet some of our members at the exercise class tomorrow, has a wedding to go later in the week and perhaps a walk at Pirongia!

The highlights for Nikki so far are “getting to see New Zealand, everyday you see something amazing. The other day I saw a Kereru, it was like a watermelon. The reinstating of bush land, looking after New Zealand and how generous people are.” Nikki has enjoyed people walking with her and has been offered clothes, food and even lawns to camp on.

The lows she tells me would have to be the mud, not because it is dirty and gets everywhere, but because it's a weight that she doesn't need; and secondly not finding water when she needs it.

For the most of the walk Nikki will be walking alone but will have friends join her for some parts of it. Nikki tells me so far the track has excellent signage; with trail angels marked along the way on people's mailboxes too should she need extra directions. She has met some amazing people, many of whom are doing the walk for their own pleasure, some are tourists, one was walking it for his granddad as it had been on his bucket list but never achieved it.

This is effectively a double fundraiser, Nikki is raising funds for both research in New Zealand and Australia, to date the fundraising in Australia has raised almost \$12,000, in New Zealand this is currently just over \$3,000.

So what can you do to help Nikki? – Help raise awareness of her walk, tells others about what she is doing, they may wish to make a donation and every little helps.

To follow Nikki's progress go to www.facebook.com/walknzforms or www.walknzforms.com.au.

Janet Buckingham



To The Summit

On 15th September 2016 Nick Allen's first book 'To the Summit: Getting out of a wheelchair and to the Himalayas' was released.

To the Summit is the inspirational story of Nick Allen, who went from outdoorsman to wheelchair-bound with multiple sclerosis, then back to the life in the mountains he loves through sheer determination and grit. This remarkable story follows Nick's first faltering steps back into the outdoors and his most astounding adventure yet - tackling a Himalayan summit. The incredible photography in the book is all his own.

Nick's top tips to managing MS

1. Don't Give up Hope

When I was first diagnosed, I thought I had been handed a death sentence. For me, the resulting sense of hopelessness was just as debilitating as the actual disease. I didn't think there was any point in attempting to make changes that might improve my condition and was miserable.

MS changes everything and makes life tough, there is no doubt about it, but there is still every reason for hope. Life with MS can still be rich and full and I think it is important not to forget it. This is the belief — the hope — that carries me through those tough times and gives me a reason to keep on going.

2. Find Something to be Passionate About

In addition to hope, I need something to get me out of bed in the morning: something to be passionate about. Getting outdoors is one of the things that motivates me to keep on going. More than just an interest, finding a deep passion — even if it is for something completely crazy — is important because it will give you a reason to make changes and press on through the hard times.

3. Work Towards a Goal

Make an achievable goal that relates to your passion and work toward it. In the last few months, I have experienced a good deal of physical struggle and my balance has gone backwards, but I want to be able to do a bit of tramping and climbing in the summer. To get there, I need to work on my balance.

Right now, one of my goals is to be able to balance on one foot again for more than 10 seconds with my eyes closed. This will take some work, but it is achievable and once it's accomplished, I will try to balance for more than 15 seconds. Setting small, achievable goals like this makes it easy to measure progress, which I find hugely empowering.

4. Find Supportive Community

Pursuing a goal that you are passionate about is still a lot of hard work, particularly when the going gets tough. There are times when I have been discouraged and I have thought about giving up. That's when I need my supportive community to encourage and help me.

A supportive community is made up of people who are excited about seeing you achieve your goals and pursue your passion. They are also the people who understand you, won't judge you when you talk to them about your struggles, and will keep supporting you unconditionally. We all need people like this in our lives, especially if you have MS.

5. Communicate

I am not always very good at communicating how I feel — I hate admitting my struggles because it means acknowledging that MS is affecting me. However, your supportive community can't help you unless they know what's wrong! Talking honestly about how you feel is crucial when, in pursuit of your goals, you come to those obstacles that are insurmountable without the help of others. Communication enables you to find a way around these obstacles and overcome them.

6. Eat Right

Eating the right foods is pivotal to achieving my goals. I find that only particular types of food provide the energy I need. Every person will be slightly different, but I work off the Jelinek Diet, have made a few tweaks here and there, and now really notice the difference if I don't eat properly. Without the right foods, I would struggle to make it through a day, much less a gym session.

7. Exercise Often

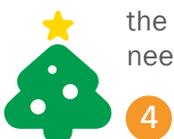
Gym is one of the key ways I keep on top of spasticity, pain, and issues such as balance. Progress is often slow — it has taken me six years of attending the gym three times a week to get to where I am now — but progress does happen. Again, having an achievable goal provides the motivation you need to keep moving and a way of measuring that progress. Exercise can be challenging with MS but no matter how limited your exercise may be, it will be worth it.

8. It's OK to Fail

To begin with, I was afraid of pushing to hard and crashing. A single, overly ambitious workout at the gym will knock me flat for a week. However, it is only in the process of getting knocked flat that I have learnt where my boundaries are, and figured out what not to do. Pushing the envelope in this way allows you to learn how to navigate the minefield that is MS and achieve your goals. I realise now that failure is often the way to achievement.

9. Say No to Stress

I am hopeless at saying no to people, which is silly because stress also knocks me flat. This is one of the areas I most need to address in my own life — I find it hard to



disappoint people. However, stress management is such an important part of living well with MS. As someone still trying to figure this out, I suspect that the secret may lie in consciously making my decisions in accordance with my passions and goals. If saying yes to something means that I won't have the energy to pursue my goal, I need to ask myself if it is worth the stress.

10. Be Thankful for the Little Things

Life is not one continuous mountain-top experience, nor can it ever be.

In between those mountain tops are the vast, monotonous valleys of everyday life. It is in the monotony that I find it easiest to lose sight of hope. However, one of the ways that I remind myself of the hope — of those mountain tops experiences — is by enjoying the faint glimmers of hope we see every day. Sometimes, it is simply in the way the afternoon light falls across a cobweb, the bead of morning dew on a bed of moss, the friendly smile of a person walking by, or the kind word spoken by a dear friend when you're feeling down. There is so much beauty

around us, so much for which to be thankful, so much to live for.

Information provided by the MS Society of New Zealand.

'To the Summit' is published by Massey University Press the RRP is \$39.99, however prices may vary between suppliers. The book can be purchased from The Nile, Fishpond or directly from Massey Press - <http://www.masseypress.ac.nz/books/to-the-summit/>. A copy is also available in the MS Waikato library.

HD News



Barbara Walters, Ron Dick and Christine Higgins

MS Waikato recently hosted another successful education evening for our HD clients, families and caregivers. The focus of the evening was to offer practical information pertaining to local support services.

Barbara Walters from Disability Support Link (DSL) advised that anyone with a physical disability under the age of 65 can be referred to DSL for a needs assessment. If 65 or over the referral is passed on to the Health of Older Persons team. DSL's focus is to ascertain the support services required to enable the disabled person to continue living in their own home for as long as possible. Personal, household, social support and respite care for family members can be considered. When the disabled person is unable to stay at home, full funding is available for them to reside at a residential care facility. Once they turn 65 they can stay at the facility that has become home to them, but funding becomes means tested.

Christine Higgins from Community Occupational Therapy advised that an OT's focus is to provide equipment and advice to support safe and independent functioning in the home; to enhance a person's sense of wellbeing and ability to cope. Minimizing risk is key, whether it is providing equipment for lifting and transporting,

handrails, cushions to reduce risk of, or relieve pressure sores or offering advice regarding safety practices and techniques. Any equipment prescribed by a Community OT remains the property of Community OT. If the client later transfers into residential or rest home facilities they can take their specialised equipment, but it is the responsibility of the care facility to provide standard equipment such as beds and transferring chairs/hoists. Housing modifications can also be considered which can include ramps or external lifts and wet area showers. A strict criteria applies however as modifications can only occur once in a person's life.

Ron Dick, Neuropsychologist at Waikato DHB spoke of the genetic testing process, that is guided by international protocols which must be followed. It is a robust process that can take several months to complete which is often frustrating for the person being tested. The lengthy time frame is purposeful as much emotional processing often results for the client as awareness of the potential outcomes become more real for them.

A four stage process starts by consulting with a counsellor at Auckland Genetic Services. The second consultation can then be made with Ron to ascertain the reasons for testing (is it the wish of the client or that of others); as well as their psychiatric, psychological and emotional stability. Ron then reports back to Genetic Services on the client's suitability to undertake the test. Next the blood test is taken at Auckland Genetic Services and once the results are back from Australia, they are sent to the medical professional the client has nominated to disclose the results, which in many cases is Ron himself. Ron also offers follow up counselling if required.

Afterwards supper was provided giving everyone an opportunity to mingle and meet other families and talk personally with the speakers.

Tracey Larsen



ME/CFS News



Dr Ros Vallings visited the ME/CFS Education Support Group in August. This year she gave us a brief overview of the immune system and how it impacts ME/CFS, as well as sharing key points from the latest research presented at the 2016 'Invest in ME' London Conference.

She explained that the immune system is a protective mechanism that helps to keep bacteria and viruses in balance; an imbalance activates an immune response (as does an allergic reaction also). Immune cells located in the blood, gastrointestinal tract and brain produce immune modulating chemicals that circulate throughout the body. If these chemicals are being over produced,

tiredness, fevers, headaches, sore throats and swollen glands can result. In ME/CFS there is a lot of extra cell/chemical activity particular at times of relapse.

Researchers are continuing to study the link between microorganisms and bacteria, the immune system and the brain, and how this could be influencing the onset of ME/CFS. They are suggesting that auto-immunity (the immune response attacks and damages immune cells through producing excessive antibodies) maybe implicated in ME/CFS; stating that damage to the central nervous system can result in sluggish brain activity that could account for most, if not all, of the symptoms.

Some of the most exciting research is from the Gold Coast in Australia. They are very close to establishing a bio-marker, a simple blood test that can diagnose ME/CFS.

Upcoming Events

Kawhia Cruise

Join us for Adam Muirs Annual Fundraiser on Sunday 13th November
Starting with breakfast at 8.00am at the Classics Museums Jukebox Diner,
9.30 am leave the museum for Pirongia
10.00 am start at Pirongia for those wishing to join the rally
11.30 am arrive at Oparau Roadhouse for lunch
This will be followed by an auction and cruise onto Kawhia. 'Shotgun', the classic rock band will perform at Kawhia from 1.30pm.

To take part 'put a note in the bucket!' All funds raised to be donated to MS Waikato
For more information email Adam - info@kawhiacruise.com

Christmas Lunch

We would love to have you join us for Christmas lunch. This will be a 2 course buffet at the Hamilton Workingmen's Club. The lunch will be subsidised by the Trust for individuals who have paid their subs.

Date - Thursday 1st December

Time - Lunch will be served at 12.30pm, entry from 12.00pm

Cost \$10 for financial members

\$20 for non-financial members

Bookings essential by 28th November, phone 07 834 4740 or email janet@mswaikato.org.nz

The Michael Ford / MS Waikato Charity Golf Tournament

Our annual golf tournament is taking place in March (date to be confirmed), this will be played on the Lochiel course at the Riverside Golf Club.

Registration and morning tea 10.00am, shotgun start at 11.00am.

Early bird registration before the end of February \$35, after this date it will be \$40.

The tournament is a fun day out, includes morning tea, sausage sizzle and a drink during the game with great prizes to be won, it is open to players of all abilities.

If you are interested in playing, sponsoring, or volunteering at the tournament please contact Janet on 07 834 4740 or email janet@mswaikato.org.nz.

The Trustees and staff would like to wish you a safe and happy Christmas and a prosperous New Year



NOTICE BOARD

Subscriptions

Please note 2017 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. Thank you for your support.

Bank Account

Please note our bank account has now changed, our account number is now: 02 0316 0488196 000. If you pay your subscriptions directly and have previously saved our account details, you may wish to amend this now.

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.

Client Survey

Thank you to all of those who completed the recent client survey. The response rate was fantastic and we appreciate your feedback. The results from surveys do help us to tailor our services to best meet your needs.

Evening or Weekend Support group

If you are unable to attend the current day time support groups but would be interested in attending one either in the evening or at a weekend please contact Liz on 834 4741 or email liz@mswaikato.org.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.

Library Books

Please remember we maintain a library of books. With books to support MS, HD, ME/CFS and Fibromyalgia a list of titles is available on our website www.mswaikato.org.nz

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 to MS Waikato.

Please contact us if you would like to borrow a book.

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

Exercise Classes

The last exercise class before Christmas will be on Wednesday 21st December, the classes will re-start on Monday 9th January.

Christmas Closure

The office will close on Friday 23rd December and re-open on Monday 23 January.

Awareness video

The MS Society of New Zealand together with MS Auckland have recently completed an awareness video. To view this go to: www.youtube.com/watch?v=-6eraH6mIXI

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Rehabilitation Welfare Trust • The Norah Howell Charitable Trust





MSWT EVENTS CALENDAR

DECEMBER 2016

SUN	MON	TUE	WED	THU	FRI	SAT
				1 Christmas Lunch Hamilton Workingmen's Club from 12.00pm	2	3
4	5 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	6	7 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	8 ME/CFS Christmas Lunch Hamilton Workingmen's Club from 12.00pm	9	10
11	12 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	13 MS Support Group Te Awamutu Christmas Lunch Fahrenheit Restaurant 12.00pm	14 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	15	16	17
18	19 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	20	21 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	22	23	24
25 Christmas Day	26 Boxing Day	27 Christmas Day observed	28	29	30	31
** MS OFFICE CLOSED **						

JANUARY 2017

SUN	MON	TUE	WED	THU	FRI	SAT
1 New Year's Day	2 Day after New Year's Day	3 New Year's Day observed	4	5	6	7
** MS OFFICE CLOSED **						
8	9 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	10	11 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	12	13	14
** MS OFFICE CLOSED **						
15	16 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	17	18 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton	19	20	21
** MS OFFICE CLOSED **						
22	23 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS OFFICE RE-OPENS	24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27	28
29	30 Auckland Anniversary	31				

FEBRUARY 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 Waitangi Day	7 MS Support Group Te Awamutu 10am Dawn till Dusk	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 Matamata 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 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28				

MS Waikato Trust, Life Unlimited Building, 20 Palmerston Street, PO Box 146, Hamilton 3240

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

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