

Inside:

The Biggest Loser	P1&2
Trustee Updates	P2
MS Education Evening	P3
World MS Day	P3
Invalids night out	P4
ME/CFS Updates	P4
HD News	P5
The Toilet Card	P5
MS Research	P6
Notice board & Sponsors	P7
Calendar	P8

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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The Biggest Loser

Paul Annis is a loser! In fact he is one of the biggest losers I know... and he is proud of it! In the 12 month period 8 May 2014 – 8 May 2015 Paul lost 41 kg from his bulky frame (144.5 kg – 103.5 kg and 30 cm off the waist) and underwent a life changing event.

The start of Paul's journey began early in 2013 when the MS exercise group moved from the Uni Rec to Anytime Fitness in the city. Us well meaning toadies had been hassling Paul for some time to join us at the gym and this new location was in the big man's 'can do' range and so in early March he duly made an appearance. With the guidance of Margaret (our instructor) he soon settled in nicely establishing the weights area as his 'hood'. It's not long before he convinces the gym manager to allow him to attend an extra day (Friday) but he struggles a little socially as us MS lot aren't in attendance. He eventually strikes up a conversation with Denise who is a part time cleaner/trainer at the gym and they share their back stories. Turns out that Denise is a bit of a legend at the gym having lost some 50 kg working out at the gym while also qualifying as a personal trainer! They strike up a rapport and Denise offers some technique advice on Paul's weight training programme.



Denise and Paul

A year on and Paul is struggling to attend the gym as he is recovering from a recent MS episode and also has depression. The gym manager, impressed with Paul's dedication over the previous year, offers him a free membership at the gym allowing him to attend whenever he is able. Denise also offers her services and takes him on as a client free of charge. She explains "Paul was my 'give back'. I used to be where Paul was at and people here helped me to get to where I am now." Photos are taken, measurements done and Denise gives Paul a gentle five day a week programme coupled with some nutritional advice. Paul takes to the exercise programme with gusto ... and parks the nutrition advice for now. "I figured seeing as I was working out five days a week I could afford to treat

myself to junk food a bit more often” says Paul.

After six weeks it’s time for Paul’s first weigh in. Feeling good and energetic Paul is dismayed to discover he has only lost 1.5 kg. Denise explains “You can’t lose weight by just working out in the gym – you have to look at your diet. It was a real reality check for Paul and changing his diet was the hardest thing he had to do. He changed his diet and bang – he lost five kg almost immediately”.

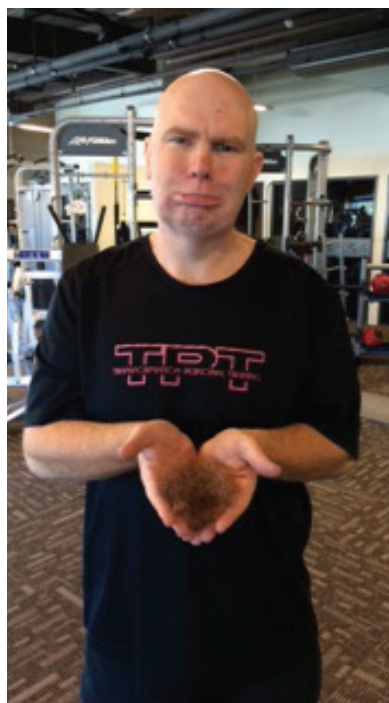
That was the ‘turn on the light’ moment for Paul. Denise continues “To do this you need motivation. My clients have to trust me – and once they see the results, they believe – that’s all the motivation they need.” But Denise says it’s not just about losing weight. “It’s letting them see what I see in them. It’s about giving them self-esteem – self-belief, getting them out mixing with others, changing their life style and their attitude.” Paul agrees “Sitting around home – I used to go to some pretty dark

places. But coming to the gym gives me somewhere to be – every day. There is a real social aspect to it and it is so much better for my mental health”.

Fast forward to 24 June 2015 and it’s time for another weight check with Denise. She reminds Paul about a bet he made with her in the early days of their association – “get down to 100 kg and I’ll shave the beard off.” Paul grimaces – “That seemed like a safe bet at the time.” The weigh in is done – 100kg on the dot. Out comes the chair, the scissors and the shaving cream... and enough witnesses to apply a suitable amount of peer pressure.

And so it comes to pass – the beard comes off to much fanfare, laughter and pointing. Cameras flash – history is recorded – the deed is done. Paul shrugs – it’ll grow back – but the weight wont!

Ian Maxwell



Ian, Paul and Denise



Updates to the Board of Trustees



Clare

Following our AGM earlier this year the Trustees have co-opted a new Trustee - Clare Simcock. Clare works for the Waikato DHB and has been a volunteer for many years taking the minutes of our board meetings. Our board of Trustees are now:

- Graham Haines – Chairperson
- Mark Etheridge – Deputy Chairperson
- Alan Garvin
- Graham Derrick
- Caroline Allbon
- Frankie Letford
- Clare Simcock

All of our Trustees are professional individuals and work in a voluntary capacity sharing their wealth of knowledge and experience with our organisation.

MS Education Evening



Mark, Jan and Karen

The Jan Schepel roadshow rolled into a hall near us in late May. The theme this time – new treatments for relapsing-remitting and progressive MS – attracted a good crowd (although I suspect a few, like me, may have been attracted by the promise of free food).

As usual Mark warmed up the audience with a few tried and true one-liners before bringing on the dancing girls – oops – I mean the MS field officers. Jan took the stage and stunned the audience with a near perfect start-up of the slide show (difficulties with this task had been previous evenings' highlights). Encouraged (or was that surprised) by this success Jan launched into a series of slides indicating types of MS, the effects of the

disease and the various time lines for a patient's health deterioration. Jan had obviously put a lot of effort into his slides which were colourful, clear – and easily read by the bad boys sitting in the back pew. I discovered I was the red line which went alarmingly up for effect and correspondingly down for health. Suitably depressed by this information I took to fiddling with my pencil and annoying people in the near vicinity (of which there were few as they were avoiding me – again!)

Jan proceeded to reel off all the new drugs coming onto the market or being trialled – most of which unfortunately were either unavailable to us or wouldn't be for a couple of years. Jan did appear to be rather excited by a medicine called Biotin however which is based on vitamin B7 and is accessible via various internet sites. Trials had been very encouraging to date and although not yet in the proven basket Jan's message appeared to be “if you can get it – give it a go”.

Jan's talk finished everyone assembled in a room (with the promised food) where Jan mingled and answered questions.

An informative night and thanks to Jan for again making himself available to share his knowledge with us.

Ian Maxwell

World MS Day

World MS Day is a global awareness day for Multiple Sclerosis. It is an opportunity to raise awareness and to bring people together. Taking place this year on the 27th May MS Waikato organised several stalls in Hamilton, Cambridge and Te Awamutu. The purpose of the stalls

is not just to raise funds but also to raise awareness and understanding of Multiple Sclerosis. The stalls raised a total of \$1,366, we would like to thank the many wonderful volunteers who gave up their time to assist us with this.



Paul and Dave



Amanda and Julia

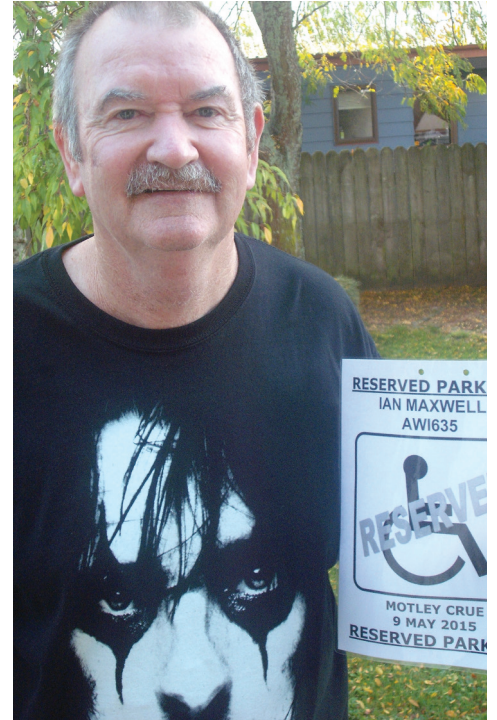
Invalids Night Out

If you are like me – a little unstable on your feet – you are probably not that keen at venturing out to functions or events. I recently celebrated a birthday and my lovely family shouted me to an Alice Cooper concert at Auckland's Vector Arena. Although very pleased at the prospect of seeing Alice again after an absence of some 40 years I was a tad concerned at how I would actually make it to the venue in a suitable condition to enjoy the event. On a good day I can shuffle/stumble for around 200m before collapsing in an embarrassing heap. So I looked up Vector to suss out where the nearest car parks were and noticed they advertised limited mobility parking spaces.

On enquiry I discovered they have 12 spaces in an alleyway about 100 metres from the Arena's front door. Booked a space and got up there to find a space with my name on it – talk about stress free parking. And it didn't stop there – they actually have a dedicated disability entrance and a lift to the upper level which they insist you take.

So, moral of the storey – don't be put off going places – ring and check out what special needs facilities some of these venues have. I have been told Mt Smart is also pretty accommodating when it comes to disability access as well.

Ian Maxwell



ME/CFS News

Kia ora All

It has been an action packed few months since last writing. ME/CFS & Fibromyalgia International Awareness day on the 12th May went well with a stall at Chartwell. Lots of inquiry and interest was received from the public and \$100 donated. Thank you to the volunteers who helped out, it was greatly appreciated.

The support group meetings have been well received with interesting information shared. Coping strategies for daily living was the topic of an open group discussion in May. Many great suggestions were shared and a demonstration was given on pain management.

June saw guest speaker Donna Barraclough from Donna's Wellness Clinic sharing her knowledge regarding a holistic and natural approach to wellness. She stated that 84% of bowel health is determined by the health of your bowel and that bowel health in turn determines and supports immunity levels. She shared some great ideas on how to boost and support good bowel health and stated that finding and seeking wellness is a journey, not an overnight trip!

In July we had Craig Wills, WINZ advocate, speak to us about welfare benefits and how having an advocate

or support person greatly helps when dealing with WINZ. He spoke about the changes in benefits, and helped to answer questions regarding how to claim for supplements and alternative treatments.

Our next guest speaker is Dr Ros Vallings coming to share latest research findings on the 13th August. Please remember to contact me to register your intention to attend this talk, Ph 07 8344745 or email tracey@mswaikato.org.nz. I look forward to seeing you there.

Tracey Larsen



ME Awareness Day - Karen and Andrea



My goodness, it is August already. It has been a busy few months.

We, at last, had the opportunity to screen the much anticipated HD film, “The Inheritance” at The Lido Cinema in June as a fundraising event. We had a great turn out, almost filling the entire theatre. Feedback has been positive with many suggesting that although at times the hard reality of HD was difficult to watch, there was a graceful and dignified balance between the reality, medical knowledge, loving tender moments, humour and sadness. Above all it was seen as the courageous love story. The event raised \$1,800 and we would like to thank the MK Hiron Kowhai Family Trust for funding the screening.

A few weeks after the screening of The Inheritance, MS Waikato held the annual HD education evening with guest speaker Neurologist Chris Lynch sharing latest research and treatments. We had a good turnout despite the cold frosty night and the distance some had to travel. A good audience discussion was had afterward regarding Neurological services. Appreciation was voiced regarding the service that MS Waikato Trust and the Neurological team together provide to support our clients and families.



Karen Bird, Karen Thomas, Chris Lynch and Tracey Larsen

We have also recently organised another social event involving a morning tea at a residential care home where several HD clients reside. Some of our clients who live independently enjoyed socialising over coffee and cake with the residents. Some of them participate together at the gym class so to have the opportunity to interact in a social setting helped to strengthen friendships.

Tracey Larsen

The Toilet Card

Finding a toilet when out and about can be a challenge for people with bladder or bowel problems. It may even discourage some people from going out altogether.

With a Continence NZ Toilet card it states clearly that the holder has a medical condition and needs to use a toilet quickly. Most places you visit will be willing to help you. Even if you never need to use the card, it might bring peace of mind to have one in your wallet or purse.

To order a card, visit www.continence.org.nz/toiletcards or ring the helpline on 0800 650 659.



High doses of biotin in chronic progressive multiple sclerosis: A pilot study:

- Frédéric Sedel^{a, b},
- Caroline Papeix^a,
- Agnès Bellanger^c,
- Valérie Touitou^d,
- Christine Lebrun-Frenay^e,
- Damien Galanaud^f,
- Olivier Gout^g,
- Olivier Lyon-Caen^{1, a}
- Ayman Tourbah^h,

Highlights

- Biotin activates enzymes involved in energy production and myelin synthesis.
- 91.3% of SPMS or PPMS patients improved clinically with high doses of biotin.
- Improvement concerned chronic optic neuropathy, homonymous hemianopia or myelopathy.
- In all cases improvement was delayed from 2 to 8 months following treatments onset.
- Two multi-centric double-blind placebo-controlled trials are currently underway.

Abstract - Background

No drug has been found to have any impact on progressive multiple sclerosis (MS). Biotin is a vitamin acting as a coenzyme for carboxylases involved in key steps of energy metabolism and fatty acids synthesis. Among others, biotin activates acetylCoA carboxylase, a potentially rate-limiting enzyme in myelin synthesis.

Objectives

The aim of this pilot study is to assess the clinical efficacy and safety of high doses of biotin in patients suffering from progressive MS.

Study design

Uncontrolled, non-blinded proof of concept study

Methods

23 consecutive patients with primary and secondary progressive MS originated from three different French MS reference centers were treated with high doses of biotin (100–300 mg/day) from 2 to 36 months (mean=9.2 months). Judgement criteria varied according to clinical presentations and included quantitative and qualitative measures.

Results

In four patients with prominent visual impairment related to optic nerve injury, visual acuity improved significantly. Visual evoked potentials in two patients exhibited progressive reappearance of P100 waves, with normalization of latencies in one case. Proton magnetic resonance spectroscopy (H-MRS) in one case showed a progressive normalization of the Choline/Creatine ratio. One patient with left homonymous hemianopia kept on improving from 2 to 16 months following treatments onset. Sixteen patients out of 18 (89%) with prominent spinal cord involvement were considered as improved as confirmed by blinded review of videotaped clinical examination in 9 cases. In all cases improvement was delayed from 2 to 8 months following treatments onset.

Conclusions

These preliminary data suggest that high doses of biotin might have an impact on disability and progression in progressive MS. Two double-blind placebo-controlled trials are on going.

Reference *ScienceDirect*, available online at www.sciencedirect.com

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 \$1980 scholarships for this course. If you wish to apply for a scholarship this can be 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.

NOTICE BOARD

The Entertainment Book

The Entertainment book is still available through MS Waikato. The book contains over 2,000 offers for up to 50% off and 2-for-1 at the Waikato and Bay of Plenty's best restaurants, cafés, attractions, hotels, resorts, shopping and more that you can use whenever you like until 1 June 2016! A sample book is available to view in the office, books are \$60 each, available as a hard copy or digital. Call into the office to purchase one or order online at <http://www.entbook.co.nz/1b54128>.

Totara Springs

We are pleased to advise that we will have a camp at Totara Springs next year.

Date - 4 - 6 March 2016

Cost - \$60 per adult or \$40 per child (14 years and under), with a maximum of \$200 per family. The camp is subsidised by MS Waikato and places are limited, if you would like to reserve a place please contact Liz on 07 834 4741 or liz@mswaikato.org.nz

Kawhia Cruise

Join us for Adam Muirs Annual Fundraiser on Sunday 1st November

8.00am - Breakfast at Jukebox Diner

9.30am - Depart for Pirongia

10.30am - Depart Pirongia

11.30am - Arrive Oparau Store

12.00pm - Lunch/Charity Auction

1.00pm - Head to Kawhia

Prize giving at Kawhia & band playing from 1.30pm

To take part 'put a note in the bucket!'

For more information email Adam, Ray or Joanne kawhia.cruise@americanmuscle.co.nz

Subscriptions

Please note 2015 subscriptions are now due.

The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed. Thank you for your support.

Dr. Ros Vallings

NZ'S specialist in ME/CFS & FM

Thursday 13th August
10.30 - 12.00 at
The Methodist Church,
Bader St, Melville, Hamilton
Dr Vallings will be speaking about recent research and up to date knowledge on ME/CFS & FM. To book a place ring Tracey on 07 834 4745 or email tracey@mswaikato.org.nz

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

8076 B & B

Fancy getting away for a night or two? Jo and Sandy Sanderson's B&B in Hikutaia contains a two bedroom unit, it sleeps 4 to 5 people and is specifically designed to accommodate a wheelchair. Being only 200 metres from the Hauraki Rail Trail it is ideal to enjoy a walk (no hills) or you may like to borrow one of their bikes.

Mention MS Waikato when you book your break and Jo and Sandy will donate \$15 to us. If you are interested please view their website www.8076.co.nz To make a booking ring Jo on 078624943 or email Jo_bandb8076@yahoo.co.nz, and mention MS Waikato (don't use the online booking calendar as they won't know the booking is for MS people).

Launched - The Hamilton Disability Pride Film/Arts Festival

The festival has become a place to showcase and celebrate the many and rich talents within this community.

When - Thursday 24th September

Where - Performing Arts Centre,
Southwell School, Peachgrove Rd
Hamilton. For more information contact
Barbara Choat on 021 630 090 or
uschoats@ihug.co.nz

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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

MSWT EVENTS CALENDAR



SEPTEMBER 2015

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

OCTOBER 2015

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group TeAwamutu 10am, Dawn till Dusk	6 MS Support Group TeAwamutu 10am, Dawn till Dusk	7 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	8 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	9	10
11	12 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	13	14 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	15 MS Support Group Mometewa Morrisville 10am	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	26 <i>Labour Day</i>	27	28 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	29	30	31

NOVEMBER 2015

SUN	MON	TUE	WED	THU	FRI	SAT
1 Kawhia Cruise	2 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group TeAwamutu 10am, Dawn till Dusk	3 MS Support Group TeAwamutu 10am, Dawn till Dusk	4 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5	6	7
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 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	13	14
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 MS Support Group Mometewa Matamata 10am	20	21
22	23 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27	28
29	30 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton					

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