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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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'B3' - Unmasked

Brian Linehan – man of mystery! Well he is to us lot at MSFits. It would be a stretch to say Brian is a regular at the gym but he was regular enough to earn the Monica 'B3' – as the third Brian in our early days (we are down to two Brian's now but he remains B3). Man of mystery? Well we didn't know much about him. We knew he was a man of substance (he has that air about him – that 'been there, done that' demeanour). We knew he was a learned man (he used big words – and obviously knew what they meant). We knew he was a well-bred man (he had lovely manners, was polite and non-condescending – heck he even talked to Raewyn). We knew he was a kind man (you can't fake a smile like that). And yes, we knew he was a man of medicine ('B2' informed us of that – takes one to know one). So, when Liz said "Brian's been on a trip recently – ask him about it" – I thought this was a great chance to fill in some gaps.

Brian was diagnosed with MS in 1998 – he refers to it as the relapsing/remitting/progressive type. Apart from a few 'episodes' the disease hasn't had any undue effects on his life style although he does find certain outdoor activities "difficult".

Brian is a Pathologist by trade. He graduated from Otago University in 1961 and after doing his house surgeon years in Auckland, spent 3 years in Sydney before returning to New Zealand in 1971. He joined the partnership of Fitchet, Fairbrother and Symmans – a partnership that would set up the company 'Medlab' – a company which Brian would eventually be sole owner of. His sub-speciality was chemical pathology.

During this time Brian was involved with the New Zealand Army Medical Corps for 25 years and was Assistant Director of Medical Services (with a

rank of Colonel) when he left the service.

Brian 'retired' from medicine 10 years ago and is currently involved with the University of Waikato as the Pro Chancellor (that makes



Brian

him Deputy Chairman of Council. Jim Bolger the Chancellor is Chairman and Roy Crawford the Vice-Chancellor is the CEO) a position he was appointed to by the last Labour government (12 years ago) and since confirmed by the current National government. The position is apolitical and he is involved in the areas of governance of the University. Brian is also Chairman of the Finance Committee.

Outside of his career Brian and his wife Annette are travellers (explains his regular absences from the gym!) with their last trip to South America in September last year. Stupidly I ask why? "Because we hadn't been there" was, I suppose, the obvious answer. Brian was keen to experience 'the politics' of the places they visited and was a little surprised that his preconceptions of a place dominated by gangsters and drug smugglers with an anti-gringo mentality were way off the mark. "They were lovely people – open, friendly – and the younger people very polite." Brian says he felt safer wandering around places like Santiago, and Valparaiso than he did in Auckland.

Highlights of the trip included visiting the Galapagos Islands ("an amazing place – a virtual laboratory of evolution"); staying at a lodge in the Amazon jungle and taking treks each day out into the Jungle ("was a little disappointed not to see some of the

ms.

more famous local wild life such as Anacondas, but did see smaller poisonous snakes, the occasional tarantula spider as well as lots of spectacular birds”) and a trip to Machu Picchu (thought to have been the final Inca refuge of the Inca empire after the Spaniards came and famous for its imposing stone structures). “That place wasn’t exactly built for people with disabilities” Brian laughs. “There certainly aren’t any lifts or even hand rails and few flat paths”. Although Brian did observe a gentleman in a wheel chair at quite an elevated level – “He did have some rather strong looking supporters but it just goes to show you that having a severe disability doesn’t have to prevent you from visiting these sorts of places.”

Ian Maxwell



Brian at Machu Picchu, Peru

ME / CFS Update

Once again time has flown by, and another two busy months have passed. We had a good run of warm weather for a while, lulling us into thinking that winter might not be so hard on us this year, but the frosty mornings of late tell us a different story!

Reflexology was the topic at our April support group meeting. Linda Bell from Harmony Health gave a very interesting talk, and demonstrated on three lucky people, as she explained what reflexology is all about. Neeraj Duggan from the Boundary Road Homeopathy Clinic was guest speaker for May and gave a very interesting presentation about homeopathy.

During the month of May our focus has been on ME/CFS and Fibromyalgia awareness, with our awareness activities taking place during Awareness Week – May 12th - 18th. In the early 1990s Tom Hennessey founded an organisation to promote awareness for a spectrum of chronic immunological and neurological diseases, including ME/CFS, Fibromyalgia, Multiple Chemical Sensitivity and Gulf War Disease. He then set upon picking a day of the year to be designated awareness day for these conditions. Tom chose May 12th as ME/CFS Awareness Day to commemorate the life of the famous nurse, Florence Nightingale, who suffered from an ME/CFS-like illness from her early thirties. She was born on May 12th 1820, and after volunteering to nurse soldiers in the Crimean War, she became severely ill with ME/CFS-like symptoms, which may have been a result of Brucellosis. Because of the pioneering work of Florence Nightingale, we share this day with International Nurses Day.

Our awareness activities this year included manning an all day stand for Fibromyalgia Awareness at Westfield

shopping centre in Chartwell, as well as having an ME/CFS stand at Bridge St Countdown. Despite the wind chill outside Countdown meaning an early finish for our volunteers, we had plenty of interest all round and quite a few enquiries for me to follow up. Fliers were widely distributed around the Waikato by Arthritis educator, Catherine Swift, who offered to help, and there was also a week long display in the Central library. I’m very grateful to all the volunteers who helped out – it couldn’t have been done without them.



Neeraj Duggan, Homeopath

Helen Maseyk
Client Services Coordinator ME / CFS



Amanda and Julia



Reflexologist, Linda Bell

MS Education Evening

The third MS education evening featuring Neurologist Jan Schepel took place in May.

Jan's reputation preceded him and we had a full house for his presentation on the symptoms of MS and possible ways of alleviating their effects. Question time at the end drew a good response from those attending as did a bit of politicking from rival party faithful's.

A new twist this year was a live demonstration of the effect MS has on balance. Carol volunteered to demonstrate a classic dive to the right with a half twist

(difficulty of 4.6) on the steps to start the evening. We weren't sure if this was prearranged with Jan or if it was a promotional exercise for the benefits of vitamin D. All ended well with no injury, a front row seat and a head start to the supper table – which was up to its usual high standard.

Thanks to the girls in the office for organising the talk and taking care of the refreshments.

Ian Maxwell



Janet, Liz, Jan and Tracey



Karen, Avril and Jan

The Waikato Wellbeing Show

In April we took part in the Wellbeing Waikato Show. Previously known as the Waikato Health and Disability Expo the show is now a part of the Waikato show. The show gives people the opportunity to find out about the amazing wealth of services and organisations in our region. Over the course of three days 12,000 people attended, so it was a busy few days!



Janet and Tracey



The MS Waikato Information Stand

Road Trip

As ideas go it wasn't bad. As ideas go coming from Bruce - it was mind boggling. 'Let's go visit Brendan (Murphy that is - ex MSfit now domiciled in Bethlehem, Tauranga).'

And so it came to pass on a hot, hot Monday in February the lads (Bruce, Brian and Ian) left on time in Bruce speak (1 hour late) to travel across the Kaimai ridge. The air-conditioning in Bruce's chosen mode of transport left a bit to be desired but that was rectified with the simple removal of the windscreen. Bruce's second mistake, (the first was asking me to go), was to ask if I had any music to play on the way over. A quick grab of the top six CD's on my pile revealed that only two cases actually had discs in them. The first - Meatloaf- seemed to meet with mutual acceptance but the second - Janis Joplin - left Bruce fumbling for his ear muffs and driving recklessly in an effort to get to our destination quickly.

Arriving at our destination after a record low two wrong turns, we were met by a sprightly Brendan and whisked off to a local tavern a few hundred yards down the road. We must have looked quite a sight - Brendan out front in his flash new electric wheel chair trying to negotiate kerbs, followed by Bruce talking animatedly to himself, followed by Brian guiding his Zimmer frame around the various footpath hazards and moi bringing up the rear rapidly melting in the hot sun and swinging wildly at pesky insects with my walking stick.

Safely inside we settled down with cool refreshments and pies to yarn the afternoon away - all the while keeping an eye on the Black Caps trying to save the Test match. Safely seeing Brendon and BJ through to their double century and century respectively (the enormity of which was totally lost on Bruce) we decided to head back before the rest home sent the dogs out looking for us. Once back there Bruce decided it would be nice to record the visit for posterity and hauled out the Watt family camera to record our fair image. It was at this point we realised Bruce had never been a Boy Scout and listened to Baden Powell's urgings to 'Be Prepared'. Alas the memory card was full

- the last remaining shot having been used earlier that morning to record yet another Bruce 'Trade Me' item. My suggestion to wipe the memory card and all those precious Watt family summer holiday photos was met with a look of desperation as Bruce conjured up a vision of Mrs Watt tearing his legs off. Warm handshakes, back slaps and it was off - no, not home but to the Mount!

Bruce has a tradition. Every time he goes to Tauranga he walks around Mt Maunganui. A quick look at the excited expressions on his travelling companions faces and he came to the conclusion he would be making the trek on his own. Brian and I settled ourselves in a breezy beach front café admiring the view and guessing from whence all the passing tourists (and local school girls) had hailed from. Bruce reappeared about an hour later and it was time for another tradition (one we were only too glad to partake in) - a Copenhagen ice cream and then we were off - home? Not quite. It was time to roam the suburban streets of Mt Maunganui to see if Bruce could spot any bargains. The only low for the day soon followed as we studied the pitiful sight of Bruce, crestfallen, standing by a free barbecue table and outdoor heater, and looking at the space left in the car (not the Ute) realising they weren't gonna fit (Debbie, you don't know how lucky you are!).

It was a quiet, sombre Bruce as we cruised through Tauranga on the way home. It was now after 5.00pm and obvious we weren't going to make our ETA. Bruce pulls over to phone Mrs Bruce and realises his phone is missing. A quick trip back to the Mount reveals that yes, his phone had fallen done the side of his seat! Time for another drive-past of the barbecue table and its off home to mildly peeved spouses. A good day - and great to see Brendon in such good spirits! That is all (no picture included).

Ian Maxwell



Tysabri / Natalizumab

Biogen Idec made a submission to Pharmac over 2 years ago to include Tysabri on the schedule of funded medicines. We are still waiting on any decision. Since 1st July 2013 no new patients have been able to start treatment with no known reason. Currently there has still no criteria for access to funding been released. Numerous NPPA (Named Patient Pharmaceutical Assessment) Applications have been made to PHARMAC to try and gain access to Tysabri for patients. All of them have been declined. Currently there are around 2000 people receiving Tysabri in Australia and about 25 in NZ.

MSNZ is aware that there is considerable interest and frustration in the non availability of Government funded access to the drug Tysabri. MSNZ has written recently both to the Minister of Health and to PHARMAC. Copies of those correspondence are available on our website at www.msnz.org.nz. We are aware also that a number of individuals supported by their Neurologists have made their own submissions for funding to Pharmac without success.

To ensure that the very best case is put to the Government and Pharmac, Neil Woodhams, a member of the National committee and President of MS Auckland is coordinating a National response and establishing a Steering Group that will prepare suitable material for regions and individuals with in those regions to speak with their MPs and other parliamentary candidates in the run up to this year's elections.

To receive further information or to notify your interest in being a part of the Steering Group please email info@msnz.org.nz or call 0800 MS LINE (67 5463) with the following details:

- 1 The names, contact numbers and email addresses of those interested in being part of this process.
- 2 Copies of any correspondence that may have been written to Pharmac, the Minister or local politicians and their replies
- 3 Details of any verbal contact in respect of Tysabri that members have had with politicians Pharmac etc.

Submissions made by MSNZ in 2014

- 1) 13 February 2014 MSNZ wrote to the Minister of Health, Hon Tony Ryall requesting support in this matter. On the 14th March 2014 MSNZ received a reply from the Minister. As per the letter we encourage

you to keep an eye on the PHARMAC website www.pharmac.health.nz for any updates about Tysabri in the recent meetings.

- 2) 22nd April 2014 MSNZ submitted a response to the request by PHARMAC for feedback on the Named Patient Pharmaceutical Assessment Policy (NPPA).
- 3) 22nd April 2014 MSNZ submitted feedback to PHARMAC's proposed Decision Making Criteria.

MSNZ is committed to advocating for CHOICE for people living with Multiple Sclerosis

Tysabri Research Updates

Efficacy and safety of Natalizumab in multiple sclerosis: interim observational programme results

H Butzkueven et al. 14 Feb 2014 - JNNP Online

Background Clinical trials established the efficacy and safety of natalizumab. Data are needed over longer periods of time and in the clinical practice setting.

Objective To evaluate long-term safety of natalizumab and its impact on annualised relapse rate and Expanded Disability Status Scale (EDSS) progression in patients with relapsing-remitting multiple sclerosis (RRMS).

Methods The Tysabri (natalizumab) Observational Program (TOP) is an open-label, multinational, 10-year prospective study in clinical practice settings.

Results In this 5-year interim analysis, 4821 patients were enrolled. Follow-up for at least 4 years from natalizumab commencement in 468 patients and at least 2 years in 2496 patients revealed no new safety signals. There were 18 cases of progressive multifocal leukoencephalopathy reported, following 11-44 natalizumab infusions. Mean annualised relapse rate decreased from 1.99 in the 12 months prior to baseline to 0.31 on natalizumab therapy ($p < 0.0001$), remaining low at 5 years. Lower annualised relapse rates were observed in patients who used natalizumab as first MS therapy, in patients with lower baseline EDSS scores, and in patients with lower pre-natalizumab relapse rates. Mean EDSS scores remained unchanged up to 5 years.

Conclusions Interim TOP data confirm natalizumab's overall safety profile and the low relapse rate and stabilised disability levels in natalizumab-treated patients with RRMS in clinical practice.

Source: MSNZ MS Voice

HD Research

Space-Grown Crystals May Help Crack Huntington's Disease

Scientists hope space-grown crystals of the protein behind Huntington's disease could help them better understand the deadly neurodegenerative disorder. A novel experiment to study the so-called **Huntingtin protein arrived at its orbital laboratory** on the International Space Station on April 20 along with 5,000 lbs. (2,268 kilograms) of cargo delivered on board SpaceX's Dragon capsule.

When mutated, the huntingtin protein causes Huntington's disease, a hereditary illness that impairs muscle control and cognition. There is no cure for the disorder, which is typically diagnosed in mid-adult life. For now, Huntington's disease is "essentially a death sentence," Gwen Owens, a Caltech graduate student who designed the experiment, said in a video. (**Weird Space Science on SpaceX's Dragon Ship (Infographic)**)

To understand how proteins function, scientists often use a technique called X-ray crystallography, which allows them to peer at the molecular structure of the protein when it's in a solid crystal form. So far, researchers haven't had much luck creating crystals of the huntingtin protein on the ground, but Owens

explained that crystals tend to grow more effectively in microgravity.

"On the ISS, we really hope to be able to finally get crystals that are big enough and perfect enough that we can solve the structure of the huntingtin protein," Owen said in the video.

If the experiment works, the huntingtin crystals will be brought back to Earth this fall to be studied in an X-ray crystallography lab.

SpaceX, a private company based in Hawthorne, Calif., launched the Dragon resupply ship toward the International Space Station on Friday (April 18) from Cape Canaveral Air Force Station in Florida using its own Falcon 9 rocket. The mission was **SpaceX's third of 12 cargo delivery missions** under a \$1.6 billion contract with NASA.

To watch a 3 minute video go to: <http://www.space.com/25575-space-crystals-huntingtons-disease.html>

Source: Space.com, authored by Megan Gannon, News editor.

Staff Update

Hello All. I have been in my role now for 10 weeks and I am settling in well. Educationally it has been huge, as I'm not learning about just one condition, but three; three that are vastly different but have many similarities. Learning at an intellectual level is one thing but where the most learning has come from for me is at the human level; learning about the impacts such conditions have

on individuals and family lives. Of those I have met thus far I have found their strength of spirit moving and inspiring. I am continuing to work towards and looking forward to meeting those I have not yet met.

Tracey Larsen
Client Services Coordinator

The Dorothy L Newman Scholarship

The Dorothy L Newman Scholarship assists people who have been diagnosed as having MS and as a result are unable to continue in their present employment, who need to change their employment and undergo a course of retraining in order to do so. Applications are open solely to people with MS needing to retrain for paid employment.

Applicants will be required to explain in a statement

in their application the reasons why they chose their course of study, how they intend to use their qualification on successful completion of their course and the likelihood of employment following the course.

Applications for the Dorothy Newman Scholarship fund are now open. To receive a copy of the guidelines and application form email info@msnz.org.nz. Applications close 30th June 2014.

NOTICE BOARD

Subscriptions

2014 subscriptions are now due; these are \$35 or \$17.50 if you hold a Community Services Card. A subscription form is enclosed for those who have not already paid.

Thank you for your ongoing support.

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

Raffle

Pak n Save Mill St have generously donated a large basket of groceries to assist with our fundraising for World MS Day, tickets are \$2 each.

If you would like to purchase a ticket please call into the office or contact Janet on 834 4740, email janet@mswaikato.org.nz. The raffle will be drawn 18th June.



Hamilton City Council Quality of Life Survey

A survey has been launched by Hamilton City Council's Community Development Unit and aims to inform the unit's work and ensure its resources are committed to the parts of the city where they are most needed.

The survey comprises 56 questions covering a range of topics – from services provided by Council, such as libraries and places for exercise, to connections with friends and family, household income and smoking.

If you would like to participate in the survey this can be accessed through the HCC website, at this link: <http://hamilton.govt.nz/qolsurvey>

The survey is open until 17 June. All respondents who complete the survey can choose to go in to a prize draw to win \$200 in grocery vouchers.

For more information contact Andy Mannering on 07 838 6465

Wheelchairs

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

HD Education Evening

A HD education evening with neurologist Chris Lynch will be held on Monday 30th June, 7.30 pm at The Link (corner of River Road and Te Aroha Street), this will be followed by a light supper.

To book a place please phone 834 4740 or email mswaikato@mswaikato.org.nz by Wednesday 25th June.

We do welcome any feedback you may have on the newsletter.

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The Lido • Anytime Fitness Tristram St • Lochiel Golf Club • Pak n Save Mill St



MSWT EVENTS CALENDAR

JULY 2014

SUN	MON	TUE	WED	THU	FRI	SAT
		1	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 Te Awamutu 10am, Dusk Till Dawn	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 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	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	31		

AUGUST 2014

SUN	MON	TUE	WED	THU	FRI	SAT
31					1	2
3	4 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dusk Till Dawn	5	6 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	7	8	9
10	11 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	14 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	15	16
17	18 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19	20 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	21 MS Support Group Mometewa Morrinsville 10am	22	23
24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26 ME (Chronic Fatigue) Social Group Meeting Contact Helen on 834 4742 for details Chartwell, 2pm	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28	29	30

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