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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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A Novel Romance

In the late 60s two young Kiwis (one born & bred – one adopted) left our fair shores to do their OE.

Maureen Malan was born in England and emigrated to South Africa, (her South African father was returning home following a stint playing professional football) with her parents when she was 9 years old. Four years later

when she was 13, they moved onto New Zealand. In 1969 Maureen left New Zealand after graduating as a staff nurse at Waikato Hospital and travelled to South Africa with a friend. After landing in Durban they travelled to Johannesburg where Maureen had family to stay with. She spent 20 months there working in private hospitals while squeezing in trips from Cape Town to Nairobi and Botswana to Rhodesia. Bill Goldsworthy (Shearer by trade) left New Zealand in 1966 to literally shear his way around the world, landing in South Africa in 1970. He toured the sheep farming districts on his beloved BSA Bushman 175 cc and demonstrated shearing equipment / procedures to the black labourers.

In 1970 their paths crossed in Johannesburg at an engagement party for mutual Australian friends. Their attraction was instant - the courtship brief - and they returned to New Zealand in 1971 to marry. They settled on a 300 acre farm in Bill's home town of Hoe-O-Tainui (out the back of



Maureen and Bill

Morrinsville) where they farmed dry stock (mainly sheep) and raised two children (Peta and Jim) over the next 17 years.

Maureen suffered the first symptoms of MS in 1976 "but over time they just disappeared" and she thought nothing more about them. She returned to nursing in 1987 working at Waikato Hospital. Bill and Maureen left the farm in 1988 and moved to Hamilton where Bill opened a second-hand book shop (a life-long passion for books) in Hamilton's main street which he opened three days a week. He eventually moved his business to the Arcadia Buildings in Worley Place where 'The Crow's Nest' (a nod to Bill's first collection – nautical books) operated six days a week and became a bit of an icon in the local book scene (known for the popular 'Quote of the Week' sandwich board on the pavement).

In 1999 Maureen started suffering from fatigue in her legs and eventually

ms.

decided to quit nursing and helped Bill in the shop. Maureen quickly became the 'face' of the shop on reception with Bill ('the brains') acknowledging "she was very good with the customers".

Maureen's fatigue issues steadily got worse and in 2003 she was diagnosed with secondary progressive MS. The couple decided to go for a trip back to South Africa while she was in reasonable health. This they did in 2004 stopping off in the USA, England, France and Italy and catching up with their children on their way back to New Zealand.

In 2010 Maureen was really struggling to get around and with the shop's lease up for renewal they decided to close the shop and move to an 'on-line' business operated from home. To reduce the stock on hand they had a couple of large sales and then donated everything else they didn't want to the Red Cross.

Bill now has a catalogue of very 'selective' books. He uses his 35 years of knowledge to scour book fairs picking up books that he knows will be of interest and value to someone. He occasionally keeps an eye out for specific titles requested by clients, who are mainly in New Zealand or Australia but can be anywhere in the world. One such occasion occurred recently following a conversation over coffee after a regular MS gym session. I casually mentioned to Bill that I had tracked down a book on military history that I was looking for my son's school history project. The book in question was

being sold at an auction for US\$200. I enquired as to why it would be quite so expensive and was told these books were originally commissioned by the Government and were only intended for the personnel in those units – hence they were quite rare. Unrequested Bill found another copy due to be auctioned in a couple of weeks' time and passed the information on to me. As coincidence would have it, Bill was wandering around a book fair in Hamilton a couple of days later and spotted the exact book I was after. Bill moved with uncommon speed, elbowed an old woman, who was also showing an interest in same book, out of the way and purchased it for the princely sum of \$3.00 and presented it to me with much ceremony at our next coffee session. (Father & son scored an excellence by the way!).

Maureen, who has been confined to a wheelchair for about four years, accompanies Bill when he makes excursions to book fairs around the North Island where they catch up with friends and pick up 'little gems' to add to the catalogue. I ask Bill if he is a collector or does he have a favourite type of book. The answer is direct "You can't be a collector – and a seller. I buy what I know there is a market for and what I will turn over relatively quickly with a reasonable profit."

One thing is for certain – you won't find any titles by E. L. James or Stephanie Meyer on the Goldsworthy's book shelves.

Ian Maxwell

Introducing ... Karen Bird



Another lamb has been thrown to the wolves ... well that's probably a bit dramatic. Karen Bird is the latest addition to the MS Waikato team. Karen started in March and will be working 12 hours a week assisting Liz and Tracey with support for the MS and Huntington groups.

Karen has a nursing background and completed her training at Auckland's Middlemore Hospital before marrying a farmer and moving to Otorohanga. While there she spent her time as a district nurse in the Te

Kuiti area. The family moved to a farm in Gordonton and Karen carried on district nursing in the Huntly and Ngaruawahia areas. A change in direction saw her working as a teacher aide at the local Gordonton school for eight years.

Prior to joining MS Waikato Karen was working in volunteer roles for Hospice Waikato and Literacy Waikato. Why the change? "I just wanted to get back into working in the community again" she says. "I enjoy meeting people and I hope I can offer something to my clients."

Since starting at MS Waikato Karen has been on a steep learning curve getting to know the nuances of our lovely disease and I'm sure she will be happy to discuss any issues you may have. Away from the office Karen enjoys family time, patch working, hiking and rearing her lovely calves.

Ian Maxwell

Michael Ford Golf Tournament 2015



Waiting to tee-off!



David



Bruce and Ian

American statesman Benjamin Franklin once said "There are only two certainties in life – death and taxes". Well Ben let's add "... and Bruce will be late". Bruce is normally late on time by about 30 minutes so when it got to 45 minutes after the agreed picking up time I got a bit titchy. If there's one thing I hate (well there's several things I have a strong dislike for) – it's being late for an appointment and I was now later than I had said I would be. So, I sprinted (hobbled) to my car and headed off to Lochiel Golf Club – missing Bruce by a couple of minutes!

We arrived in time to tuck into the complementary cup of tea and biscuits and got introduced to the newbies – Kendal, Nicole and Stephanie – three volunteers from Volunteering Waikato. After we left the trio, Bruce and I loaded our goodies into our golf cart and headed for our possie beside the green. No. 3 volunteer Kendal had erected our gazebo, we moved in and began our normal formalities – "swap you a brownie for a banana and a biscuit, the grapes we will share and ... the pineapple lumps ... well, I'll look after those!"

Our bartering is interrupted by the thud of an incoming ball. Crickey a counter first ball – and in the circle! Bruce, always eager to please, leaps to his feet and delivers the agreed signal (although I don't think falling over and rolling down the hill was part of it). Three of the first foursome hit their target – we could be in for a busy day. Poor Bruce is already going red in the face and polishes off half of his water rations. A steady stream of golfers pass us by with a good percentage hitting the green from the tee but only two completing the hole in par figures. Boss Tracey wanders over and asks to borrow our buggy to go visit the newbies. Bruce offers to drive her there (no chivalry involved – Bruce is very possessive of our buggy and besides he's heard a rumour the sausages are ready).

While Bruce is away I face a barrage of over hit balls resulting in three lost and two retrieved. A lull in proceedings gives me the opportunity to dig out the crossword and sample the pineapple lumps. By the time Bruce reappears the rain has set in and everything is looking a bit bedraggled. Bruce hands over a soggy sausage and spies the pineapple lump packet. One left – oops. He looks at the crossword – 8 down; 7 letters

- 'breathing tube'. "snorkel" he says triumphantly, grabs the last piece of brownie and returns to the relative comfort of the buggy. I think I hear him mutter "evens".

It's about now we realise why gazebos are used predominately in the summer time. Large pools of water are gathering ominously on the roof and large drips are finding their way down my neck. A few judicious pokes with a golf club deals to the pools of water on the roof but the resulting waterfall turns our shortbread into a soggy mess. The gazebo is now listing dangerously at several different angles and we prepare to abandon ship. Me being an ex-scout had prepared for this turn of events by packing a rain jacket – Bruce being an ex-Aucklander hadn't!

The deterioration of the weather brings a similar downturn in the standard of the golf and the bunkers and rough patches surrounding the green become regular resting places for mis-directed balls. Words of encouragement and tips on club selection and putting technique offered up by us appear to go unheeded as the last foursomes slosh their way past and head for the comfort of the clubrooms.

Our gazebo obligingly collapses as we pack up and chuck everything into the buggy. Bruce, ever the boy-racer, manages a few wheel spins and some impressive off-road manoeuvres as we head back to a rapturous welcome – well Tracey seemed pleased to see us!

A quick drink, raffles, speeches, a debrief and an appraisal of the newbie volunteers and our day is done – excellent.

The best stableford and overall winner of the event was awarded to Simon Macaskill.



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Myles Needham
Glenview New World
Ron Flood

The tournament raised a total of \$5,168.

Big thanks to Janet for organising the event and to Tracey, Liz and ... Helen (making a guest appearance) for their efforts.

Ian Maxwell



Stephanie, Tracey and Nicole



Simon and Dave



Back at the clubhouse



Graham and Mark



Our Volunteers

Waikato Wellbeing Show

The Waikato Wellbeing Show recently took place at Claudelands, MS Waikato was one of the many organisations to participate in this. The show is part of the Waikato show which has now replaced the Health and Disability Expo. The stall assisted in raising public awareness of the conditions that we support and the services that we are able to provide. We would like to extend our thanks and appreciation to the volunteers who assisted with this.



ME / CFS & Fibromyalgia Updates

Kia ora All

ME/CFS & Fibromyalgia International Awareness day is fast approaching on the 12 May, so circle your calendars. We have organised an information stall to be set up in Chartwell on this day. If you are interested in helping out on this day please contact me on 8344745. It appears that ME/CFS awareness is getting out there as more people are reaching out for help - I have gained over 12 new clients so far this year which has kept me very busy.

We have had some great speakers attend our Education Support Group in the last couple of months. Andrew Fraser of Zen Acupuncture Clinic spoke to us in March about the benefits of traditional Japanese acupuncture. He described treatment as gentle, painless and effective through its ability to free up the chi (energy) of the body by cleansing the body's blood and air. It is effective for musculo-skeletal problems, psychological wellbeing, digestive complaints, and respiratory problems. Andrew

has treated clients with ME/CFS and although there has been a process to navigate to obtain better health, they have found an improvement in their energy and overall sense of wellbeing.

In April Dr Sam Shay spoke to us about Adrenal health and the 10 point wellness system he has designed. He spoke of the hormone cortisol and its function and purpose; especially when we are faced with stress, highlighting how damaging stress can be to our bodies over a period of time. His 10 point wellness system is a holistic diagnostic tool encompassing physical, mental/emotional and biochemical components of our lifestyles and health. He recognises that it is a complex tool so he starts his treatment plan by working with the easiest and simplest things to change and prioritizing that which is most important for the client.

Tracey Larsen

HD Research

The use of sheep to investigate and research HD

Renee Handley from the Centre for Brain Research recently presented 'Investigating Huntington's Disease using a sheep model' at an AgResearch Staff Meeting at Ruakura in March. I was very fortunate to have been invited to this presentation.

The Transgenic Sheep Model is a collaborative investigation between The Centre for Brain Research in Auckland, South Australia Research and Development Institute, University of Cambridge and Massachusetts General Hospital, Harvard Medical School. While rodent models have provided much knowledge and understanding of HD, their usefulness is limited due to the size of the brain and their short life span. Meanwhile the brain structure of sheep is comparative to the human brain and the longer life span allows late onset symptoms to be investigated.

In 2005 the transgenic model began with the first microinjections administered to sheep. In 2006 six founders were born that expressed the full length human huntingtin gene with 73 CAG repeats. In Adelaide there are now 600 transgenic sheep spanning four generations and although they are not showing any gross phenotype (observable traits), what has been identified is an altered circadian rhythm with higher activity at night. However, once the sheep merge with other flocks such rhythms are not as detectable. (From a social science perspective I find this an interesting point, especially as research has shown that socialisation can slow the progression of symptoms.)

Hallmark features of HD have also been identified in brain tissue from the sheep, including the presence of protein aggregates and changes in gene and protein expression. As part of Renee's PhD she also found evidence of a



metabolic disturbance in the HD sheep, with increased levels of amino acids identified in the cerebellum (the part of the brain that controls voluntary movement and is situated at the back of the brain just above the spinal cord) and increased levels of fatty acids in the liver.

Changes in metabolism may suggest a cause for symptoms such as weight loss which is seen in HD. As part of ongoing work the Auckland team aim to find other markers of HD that can be measured in live sheep, such as a breath test to measure liver function (relating to metabolism). The ability to monitor the progression of cellular pathology in live subjects is critical for translating research to patients.

The transgenic sheep model has its limitations however, which has been noted in its lack of phenotype and also its genetic accuracy. Renee's current work is therefore focused on generating a new 'knock in' sheep model. In this model the sheep huntingtin gene will be replaced with an HD gene, as opposed to randomly adding an HD gene into the sheep genome (set of chromosomes) as was done for the transgenic sheep. The transgenic sheep is still an important model being used to study HD and for therapeutic trials. However the knock-in sheep will provide a more accurate model and hence improve the ability to investigate and understand the precise cellular mechanisms of HD.

We look forward to hearing about Renee's findings in the future.

Tracey Larsen

Preparing For Your Specialist

Something strange happens when many of us arrive for an appointment with a medical specialist—we seem to forget the symptoms that have appeared since our last visit.

As neurologist Professor Tim Anderson, Clinical Director of the New Zealand Brain Research Institute, pointed out at the Multiple Sclerosis and Parkinson's Society of Canterbury's Education Day Talk, this is a common occurrence for many patients which limits the usefulness of a consultation.

No matter their level of accomplishment, specialists simply aren't able to guess an individual client's specific experience of their condition since their previous visit, the symptoms that have appeared—or disappeared—and any favourable or unfavourable response to the medication they're on.

Given the importance of these visits in the effective management of MS, applying simple strategies to be better prepared for visits allows us not only to help our doctors to help us but also to be more strategic about our health care.

So, what are the things you can do before, during, and after you see your specialist to get the greatest benefit from the visit?

A good first step is to approach an appointment with the same strategic intent as you would an important business meeting—be well prepared.

What is helpful when seeing your specialist:

- Updated medication list
- The things that bother you most
- What things you would like to be better
- Any other new medical problems
- A “significant other” to accompany you
- Written notes if your memory is a problem

Unlike a business meeting, you're not entering a negotiation to persuade a good deal out of a reluctant supplier or client, but just like a business meeting you are trying to get the most out of the situation and this requires some planning.

Being able to report your symptoms and concerns accurately helps specialists get a better handle on your situation more quickly and will most likely lessen any anxiety you might usually experience as your appointment date approaches.

The article is based on a talk Prof. T Anderson gave at the MSPD Education Day in 2014 and as printed in MS New Zealand Voice.

Fundraising

We have some great fundraisers being planned for this year but we do need your help to help ensure their success.

The Entertainment Book

MS Waikato are selling the Waikato/ Bay of Plenty Entertainment books this year. For only \$60 you receive thousands of dollars worth of vouchers in our region with many 2 for 1 offers. MS Waikato will receive \$12 from each book sold. The book is now available to view in the office and can be purchased as either a book or digital membership. The more books we sell the more we will raise so please let your family and friends know too.

To purchase visit <http://www.entbook.co.nz/1b54128> or call into our offices.

World MS Day Our annual appeal will take place on **Thursday 28th May**

Kawhia Cruise The Kawhia Cruise will take place on **Sunday 1st November**

NOTICE BOARD

** World MS Day **

Thursday 28th May

World MS Day is the internationally recognised day for MS Awareness.

MS Waikato will be having stalls around the Waikato, if you would like to volunteer to assist please ring Janet on 07 834 4740



Education Evening

An MS education evening with neurologist Jan Schepel will be held on Friday 22nd May, 6.00 pm at The Link (corner of River Road and Te Aroha Street), this will be followed by a light supper.

If you would like to attend could you please advise us by Monday 18th May, phone 834 4740 or email mswaikato@mswaikato.org.nz.

Choral Therapy Group

For people with neurological conditions ... to improve voice, speech and respiration!

When: The 2nd and 4th Tuesday of every month from 10 - 12 pm

At: St John's Methodist Church, 20 Wellington Street, Hamilton East

Please take a gold coin donation to cover costs

Tea and Coffee will be provided

For more information contact
Janine 027 2555 123 or
Maryanne 027 2444 123

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.



A must see
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. Circle your calendars today

St John's Caring Caller

Caring Caller is a service that St John provides for people who live alone or feel a bit lonely. Volunteers phone clients regularly to check that everything is ok. If you wish to sign yourself up for this service and receive a regular call from a Caring Caller phone 0800 780 780.

Easy Rider - 'Wheelie Friendly' Travel Club

Roselands Restaurant - Thursday 11th June
\$70.00 (Bus / Lunch)

Mystery Trip - Thursday 30th July
\$70.00 (Bus / Lunch / Tour)

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

Please remember International Awareness Day Tuesday 12th May

Awareness stalls will be in Hamilton, if you would like to assist please ring Tracey on 07 834 4745.



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

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Lochiel Golf Club • Pak n Save Clarence St • The Sutherland Self Help Trust • The Gallagher Charitable Trust



MSWT EVENTS CALENDAR

JUNE 2015

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

JULY 2015

SUN	MON	TUE	WED	THU	FRI	SAT
			1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	2	3	4
5	6 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dawn till Dusk	7	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	9 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	10	11
12	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	16 MS Support Group Mometewa Morrisville 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	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30	31	

AUGUST 2015

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

Please Cut Here

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