

Inside:

MS Annual Neurology Education Evening	P1-4
Mastering Maungatautari	P4
Leanne Milligan	P5
Trustee Vacancies	P5
ME/CFS & Fibromyalgia	P5
MS Awareness Week	P6
HD News	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:

**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:



MS Annual Neurology Education Evening



Dr Matthew Phillips and Dr Jan Schepel

We had a large turnout for this year's event where we were very fortunate to have neurologists Jan Schepel and Matthew Phillips both presenting. Dr Schepel gave us a brief roundup of topics of interest including;

Biotin (Vit B7) which appears to have some promising potential. Studies are showing that high doses are considered good for the nervous system and may help the regeneration of nerve cells and myelin. Dr Schepel cautioned that if taking biotin he recommends stopping it 3 days prior to blood tests as it can alter blood results.

Ocrelizumab is showing some effect in primary progressive MS, particularly early in the disease, (2-3 years) where there is active disease. It is administered 6 monthly and while not yet available here the hope is that it may be available in NZ next year.

Stem cells, the risks remain high for this treatment and while it may have potential for the future, research and trials continue.

MS Base is a global data base which collects information about MS patients and treatments over long periods of time which can then be used for research. Waikato and Hamilton are involved in

conjunction with MS national. There will be more information about MS Base as it is rolled out.

Dr Schepel then handed over to his colleague Dr Phillips who has very kindly shared his slides. The information is below, if you would like a copy of the slides please email MSWT and we will send you the slides.

A Different Take On Multiple Sclerosis (MS) - Matthew Phillips, Neurologist

"The most common way people give up their power is by thinking they don't have any"

Alice Walker

Every person has the potential power to improve their MS.

However, this power must be **guided by the correct knowledge.**

Etiology of MS:

Genes Versus Environment Debate

Is MS primarily a genetic disease, or are genes a minor factor?

The "Primarily Genetic" View

- The genetic code is seen as **a script with an inevitable outcome** in which certain people have a genetic code that

MS Annual Neurology Education Evening (continued)

predisposes them to MS.

- For many reasons, this view is popular.
- It opens up the possibility of “tailored” **genetic therapy**, in which a person’s MS gene panel is analyzed and resequenced.¹
- **Genetic code is like a script**

The “Primarily Epigenetic” View

- The genetic code itself may **not be as important as the way it is translated** (altered using DNA methylation, histone modification, etc) meaning that environmental interactions primarily determine whether a person will get MS.
- For various reasons, the epigenetic view that the same gene sequence can be expressed differently, and this different expression is heritable, is **not popular**.
- However, it opens up the possibility that the person can alter their MS susceptibility.

Evidence?

- Much favours the **epigenetic view**:
- (1) Twin studies.²
- **Low concordance rate** in monozygotic twins for MS.
- (2) Increase in MS further from the equator.
 - Therefore **location** partly determines if a person gets MS.
- (3) World-wide, MS is probably increasing (even accounting for increased MRI scans and survival duration).³
 - From 1961-1996, MS prevalence increased by **300%** in Newcastle, Australia.
 - From 1990-2004, MS prevalence increased by **50%** and incidence by **400%** in Hokkaido, Japan.
 - From 1989-2005, MS incidence increased by **700%** in Tehran, Iran.

Pathogenesis of MS:

Outside-In Versus Inside-Out Model

Is MS primarily an immune-mediated inflammatory disease, or is something else driving it?

Outside-In Model

- Traditional model → sees MS as an **immune-mediated inflammatory** condition in which a “dysregulated” immune system attacks the nervous system.
- Hence, nearly all treatments are aimed at immunomodulation → if correct, modulating the immune system and halting inflammation **will** greatly slow or stop the MS.

Inside-Out Model

- Alternative model → sees MS as a **metabolic-degenerative** condition in which neuron and glial cell energy failure due to mitochondrial dysfunction

lead to cell degeneration, inviting an immune response.⁴

- We’re not treating this → if correct, modulating the immune system and halting inflammation **will not** greatly slow or stop the MS.

Evidence

- Much favours the **inside-out model**:
 - (1) Pathological.⁵
 - Brain white matter undergoing inflammation and demyelination shows mitochondrial dysfunction and neurodegeneration, but normal-appearing grey matter with no inflammation or demyelination **also shows mitochondrial dysfunction and neurodegeneration**.
 - (2) Clinical.⁴
 - Onset is 85% relapsing-remitting and 15% primary progressive, but the majority of relapsing-remitting MS enters a secondary progressive course suggesting **ongoing neurodegeneration**.
 - (3) Therapeutic.^{6,7}
 - Immunomodulatory therapies, including stem cell transplants, can profoundly suppress or eliminate inflammation but **neurodegeneration continues** regardless (still need more data on natalizumab).

What We’ve Got So Far...

- Much epidemiological evidence favours **epigenetics** over genetics in the etiology of MS.
- Much pathological, clinical, and therapeutic evidence favours a **metabolic-degenerative model** over an immune-mediated inflammatory model.
- The treatments in use, or being considered, are immunomodulatory and genetic, but if epigenetics and metabolically-mediated degeneration are the main problems, then we need a treatment that (1) **alters gene expression** and (2) **protects neuron and glial cell metabolism**.

The Role Of Diet In MS Is there one?

Does Diet Matter In MS?

- Generally, people with MS **suspect that it does**.⁸
 - A 2012 internet search using the terms “multiple sclerosis” and “diet” produced over 27 million links.
 - A 2008 German survey of 1573 people with MS showed a 41% lifetime use of dietary modification.
 - A 2009 Australian survey of 416 people with MS showed a 63% lifetime use of supplements and/or dietary modification.
- Major problem → there is an onslaught of recommendations out there about **consuming**

or avoiding certain foods; it’s hard to know who or what to believe.

The Real Diet Question

- Yet rather than talk about this or that food, perhaps we should talk about the three basic building blocks of food, **macronutrients**, and their ideal ratio.

(1) Carbohydrates (2) Proteins (3) Fats

What Is The Evidence?

- Unfortunately, the evidence supporting any particular diet in MS is **mediocre**.
- Let’s have a look anyhow → low-fat versus high-fat (ketogenic) diet.

Evidence For Low-Fat Diet

- In 1953-2003, US neurologist Roy Swank published findings on the **Swank Diet**.^{9,10}
- Very low in total fat (especially saturated fat), suggested significant reduction in MS progression.
- Major problem → his data was observational.
- In 2016, a one-year randomized controlled trial comparing the effects of a **plant-based diet** with a wait-list control group in people with MS was published.¹¹
 - No improvement in EDSS scores or MRI lesion load, but improved fatigue, BMI, and metabolic profile.
 - Major problems → probable placebo effect, fiber content not specified.

Evidence For Low-Fat Diet

- Up to 90% of the cells in the body are not human; they exist in the **gut microbiota**.
- There is a reciprocal interaction between gut microbiota and brain, the **gut-brain axis**.
- The gut microbiota **influences the brain** via:
 - (1) The **vagus nerve** (bacteria stimulate enteric neurons).
 - (2) The **immune system** (bacteria train immune cells).
 - (3) **Neurotransmitters** (bacteria synthesize these).

Evidence For Low-Fat Diet

- The gut microbiota is **moderately disturbed** in MS, with reductions in bacteria that produce metabolically beneficial short chain fatty acids.¹²
- These gut bacteria need to ferment **fiber** to produce short chain fatty acids, thus a high-fiber diet might augment bacterial growth, restoring the disturbed microbiota.
- Low-fat diet theory consistent with outside-in and inside-out MS pathogenesis models.

Evidence For Ketogenic Diet

- The high-fat, low-carbohydrate **ketogenic diet** has

been used for one century.¹³

- Reverses obesity and insulin resistance (type II diabetes) and medically refractory epilepsy.
- Major problem → seen as hard for people to follow, no data in MS.
- Simply mimics fasting; when glucose reserves are scarce, the liver must compensate by generating **ketones** to be used as an energy source by various organs, including brain.
- The “batteries” of nearly all cells, especially neurons, are **mitochondria**.
- Mitochondria can use either **glucose or ketones** for fuel.
- Ketones have **theoretical advantages** over glucose.^{4,13}
 - Generate more energy.
 - Produce **fewer reactive oxygen species**.
 - May **promote mitochondrial biogenesis**.
 - May **suppress inflammation**.
- Along with neurodegeneration, there is **mitochondria dysfunction** in both white and grey matter in MS.¹⁴
- Potentially, **ketones** could improve the energy metabolism in these mitochondria, thus a ketogenic diet might prevent energy failure in the neurons and glial cells, slowing or preventing neurodegeneration.
- Ketogenic diet theory mainly consistent with inside-out MS pathogenesis model.

What We Really Need

- So at the end of the day, the evidence supporting either diet in MS is mediocre.
- We desperately, vitally need **well-conducted randomized controlled trials** to provide definitive answers to our many questions!
- Otherwise, the role of diet in MS will **continue to be speculative**, with various people promoting unproven therapies (they may have merits, but they’re still unproven).

Conclusion

- (1) Much evidence favours epigenetics in the etiology of MS.
- (2) Much evidence favours the inside-out (metabolic-degenerative) model in the pathogenesis of MS.
- (3) If MS is primarily epigenetic and metabolic-degenerative, then in theory diet is potentially the ideal treatment.
- (4) Unfortunately the evidence for any diet in MS is mediocre; the most important thing to discover right now is the ideal fat to carbohydrate ratio, which is achievable, but we vitally need well-conducted randomized controlled trials to discover it.

MS Annual Neurology Education Evening (continued)

Every person has the potential power to improve their MS. We just need the correct knowledge to guide it - **that knowledge is attainable.**

References

- (1) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3760455/>.
- (2) <https://www.ncbi.nlm.nih.gov/pubmed/24652042>.
- (3) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3095836/>.
- (4) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4709725/>.
- (5) <https://www.ncbi.nlm.nih.gov/pubmed/18703006>.
- (6) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4517331/>.
- (7) <https://www.ncbi.nlm.nih.gov/pubmed/15026517>.
- (8) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5072637/>.
- (9) <https://www.ncbi.nlm.nih.gov/pubmed/12996138>.
- (10) <https://www.ncbi.nlm.nih.gov/pubmed/12591551>.
- (11) <https://www.ncbi.nlm.nih.gov/pubmed/27645350>.
- (12) <https://www.ncbi.nlm.nih.gov/pubmed/28696139>.
- (13) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3321471/>.
- (14) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3722885/>.

Mastering Maungatautari



Earlier in the year you may recall reading about Sue Dela Rue's challenge to traverse the Maungatautari Mountain. Sue received a grant from Mastering Mountains to support her as she prepared for this. The walk was not only a personal challenge but Sue also saw this as an opportunity to raise money completing this as a fundraiser for ourselves and the Maungatautari Ecological Island Trust. For those who are not familiar with it, Maungatautari is a mainland ecological island and wildlife sanctuary.

Sue's challenge inspired other MS clients and their families who joined her together with staff, friends

and neurologist Jan Schepel for the 11km walk over the mountain. The day of the walk, incidentally Sue's birthday, dawned calm and sunny, a welcome relief after all the recent rain!

The hike was along a new track and the group enjoyed getting to know each other as they walked the beautiful track with all successfully completing it. A wonderful achievement and Sue could not stop smiling!

We hope you like the photos below as much as we enjoyed the walk. Sue raised \$705 to share between the two organisations.



Leanne Milligan



There's a much used saying – "If you want a job done – get a busy person to do it".

Meet Leanne Milligan – a woman who personifies the word busy. Leanne is currently Chairman of the Board of Trustees for MS Waikato. She joined the nine member board in January 2016 and was appointed chairman just

two months later. One of the first things she did was set the date for her departure in March next year. "I've put in place a system to rotate the chairman every two years – this means we will have a constant flow of new ideas at the head of the board." Leanne also oversaw the drafting of a three year strategic plan to upgrade all the Board's systems and strategies. October will see the end of the first year of that plan and a review will be carried out to ensure they are on track.

Recently Leanne was in the news when she was appointed International President of Altrusa at the organisations 100th anniversary convention in Nashville, Tennessee. Altrusa is a non-profit organisation that strives to improve local communities through leadership, partnership and service. Leanne has served Altrusa from grass-roots level having helped form the Te Awamutu branch in 1994. She has served at every level of the organisation and has received numerous leadership awards. Prior to her appointment as International President Leanne had held the position of International Treasurer, International Service Development Chairperson, co-chaired the Governor's Council and served on the International Bylaws, Rules and Regulations committee. Leanne believes becoming an Altrusan was one of the best decisions she ever made having made great friends, enabled her to make a difference in her community and given her the opportunity to grow as a leader.

But wait there's more. Leanne is also a member of the board for the Assistance Dogs Trust and is a fellow of Chartered Accountants Australia New Zealand.

Oh, and by the way she has a job. She jokes it is the thing she does in her spare time. Leanne is the Chief Financial Officer of Waitomo Petroleum. At the time I visited there was the small matter of a hole in the pipe line from Marsden Point to Auckland on her mind. I dragged her away from a phone, sleeves rolled up, redirecting tanker drivers and endeavouring to allocate a much reduced supply of petrol to satisfy customers.

Whew! I don't know about you but I'm tired just writing this.

Ian Maxwell



Trustee Vacancies

A vacancy currently exists on the board of Trustees. This is a voluntary role and the board are seeking someone with previous board or director experience with skills/experience in one or more of the following area:

- Marketing and Communication**
- Fundraising**
- Health Sector**
- Counselling Services and Advocacy**
- Law**
- Finance**

For more information or to submit an application please contact Leanne Milligan (Chairperson) leanne@wpl.co.nz

ME/CFS and Fibromyalgia

MS Waikato also provides support services for people affected by ME/CFS and Fibromyalgia. We employ a qualified Field Worker and our services include the provision of information and education, advocacy and monthly support groups.

The ME/CFS and Fibromyalgia group have their own quarterly newsletter, Koru, which is written specifically to provide information and support to this client group.

If you would like to receive an electronic copy of this please notify Tracey by emailing tracey@mswaikato.org.nz.

MS Awareness Week

During MS Awareness week we had stalls in Hamilton – Chartwell and the BNZ in Frankton, Cambridge, Morrinsville and Te Awamutu, also a collector in the city centre. The stalls are invaluable in raising awareness and understanding of MS as well as the opportunity to fundraise. A huge thank you to all the volunteers who assisted with this, without your help this would not be possible. We raised a total of \$1,807.



HD News

Watch Their Dance by Theresa Crutcher-Marin

Would you marry the man you adored if you knew he had a chance of inheriting one of the cruellest diseases on earth?

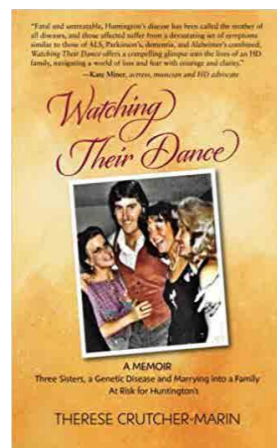
Therese Crutcher is not a risk taker. Through meticulous planning, she eliminates as much uncertainty from her life as she can. Yet during her senior year of college, blithely planning to marry her beloved John Marin, she is suddenly thrown into turmoil when John's sisters announce they finally know what killed their mother, institutionalized when her four children were all under ten. Phyllis had Huntington's disease, an inherited neurological disease with horrible odds: John and his three older sisters have a fifty-percent chance of inheriting this terrible wasting disease, which slowly kills the brain cells that affect movement and cognition. There is still no treatment or cure.

John says, "You never know what will happen in life," but his at-risk status shakes Therese to the core. How can she live with such uncertainty? Eventually, Therese decides to marry the man she loves. All four Marins choose to ignore what they cannot change; and in the early years, John

and his sisters—a big part of Therese's life—remain healthy, fun-loving, and as close as ever. Therese takes another big gamble and has a child, and then another.

When she observes symptoms in Lora, the oldest sister, Therese fears that Huntington's has found her. And when Marcia, the gentle middle sister, is diagnosed with the disease, Therese—with two small children, a career, and a husband now in the prime age range to show symptoms—struggles against the demons that feed her fear.

After Lora dies, Therese feels unprepared to support her family should the unthinkable occur, so she earns a master's in healthcare administration and begins a new



career. When Marcia's symptoms worsen, John moves her nearby, and Therese lovingly oversees her care. Several years later, Cindy, the youngest, most athletic sister, also develops Huntington's, and Therese does the same, feeling that managing the care of these loved ones is a privilege and the greatest gift she can give them.

Thus unfolds a life filled with unpredictability, tough choices, and pain, and yet full of love, good times, and great joy. Therese comes to realize that the uncertainty she willingly took on has opened her heart to love more deeply; that acknowledging her world could change overnight has made her life richer. She has learned to overlook shortcomings and to compromise, to let go of anger when she can't control a situation, to find joy in the simple things. Life is just too precious to waste a moment on small stuff. And though John's sisters leave this world far too soon, the Marin siblings, she realizes, have taught her about embracing life, forgiveness, and unconditional love.

Sourced from Amazon.com.

We have this book in our library so if you would like to borrow it please phone Tracey 07 8344745

NOTICE BOARD

FACEBOOK

MS Waikato now has a Facebook page, do please like us on Facebook. Search for us as MS Waikato; alternatively visit our website www.mswaikato.org.nz and follow the link in library/resources.

LiveWiseMS

Live Wise MS is a new resource for those affected by Multiple Sclerosis. 'LiveWiseMS is not only sourced by trusted medical content but it is reviewed and approved by the International Organization of MS Nurses (IOMSN), a well-respected organization of nurses who focus solely on the care of those affected by multiple sclerosis.'

To access this go to: www.livewisems.org

PAYMENTS

If you wish to make any payments directly to the Trust bank account this is 02 0316 0488196 000 Please remember to include your name and what the payment is for eg Subs.

EXERCISE CLASSES

The last exercise class before Christmas will be on Wednesday 21st December, the classes will re-start on Monday 8th January.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@extra.co.nz

SUBSCRIPTIONS

Please note 2018 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.

HD Education Evening

MS Waikato will be hosting an education evening with two of New Zealand's leading HD researchers Dr Malvinder Singh-Bains and Dr Nasim Mehrabi. Topics of discussion include: Huntington's Disease Research The Brain Bank HDYO (HD Youth Organisation) Friday 10th November, 6.15pm (for a 6.30pm start) at The Link (corner of River Rd and Te Aroha Street). Register by Monday 6th November, email tracey@mswaikato.org.nz. A donation towards the evening would be appreciated; there will be collection pots at the venue.

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.

Christmas Closure

The office will close on Friday 22nd December and re-open on Monday 22 January.

Thanks to our Sponsors and Supporters



WDFW Karamu Trust • Waipa District Council • COGS- Hamilton City, Hauraki, South Waikato & Waikato West • Anytime Fitness - Hamilton Central • The Fine Homes Tour • Riverside Golf Club • The Sutherland Self Help Trust • The Gallagher Charitable Trust • Len Reynolds Trust • The Norah Howell Charitable Trust • Glenice and John Gallagher Foundation

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

MSWT EVENTS CALENDAR



DECEMBER 2017

SUN	MON	TUE	WED	THU	FRI	SAT
31					1	2
3	4 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	5	6 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	7	8	9
10	11 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	12	13 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	14 Christmas Lunch Hamilton Workingmen's Club From 12.00pm	15	16
17	18 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	19	20 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	21	22 MS Office Closes	23
24	25	26	27	28	29	30

JANUARY 2018

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

FEBRUARY 2018

SUN	MON	TUE	WED	THU	FRI	SAT
				1	2	3
4	5 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	6	7 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence 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 cnr Anglesea / Clarence St Hamilton	13	14 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	15 MS Support Group Mometewa Matamata 10am	16	17
18	19 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	20	21 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	22 MS Support Group Hamilton 10.30am Lola Cafe Dinsdale Roundabout	23	24
25	26 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton	27	28 MS Exercise Class 10.30am - 11.30am Anytime Fitness cnr Anglesea / Clarence St Hamilton			

Please cut here

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

Disclaimer: "MS Waikato accepts no responsibility for accuracy of information contained within this newsletter."