



# KORU



## ME/CFS & FM Support

### ms.

Multiple Sclerosis  
Waikato

*Mahi tatau ki te whakawhiwhi he hapori rawe*  
Working Together to Provide a Service of Excellence

February 2019  
Issue 52

### **Kia ora and Welcome to 2019**

Happy new year to you all. I hope you all have had a great Christmas and happy holidays.

As I write this, we farewell January and welcome in February. Crikey! One month down already, I have a feeling this year is going to fly by as quick as the last.

I hope you are surviving this heat wave. The heat stops many people in their tracks and makes great difficulty in finding comfort, especially at night sleeping. I heard on the radio to put your sheets in the freezer. I tried this, much to my husband's dismay! Between making the bed and cleaning my teeth, the nice chill disappeared. I just hope the excessive heat doesn't stay around for too long, and in my wish for cooler weather, my heart goes to those suffering extreme snow storms in the northern hemisphere.

Looking to our year ahead... some change is abound! I have had many requests for a social group to be established and so have decided to alternate the Monthly Education Support Group Meetings with a social group meeting/coffee group, at a café. Please see the calendar enclosed to see what is happening when. I will also email out reminders the week before so keep an eye on your inbox. The first social group will be March 14<sup>th</sup> at Agora Café, Kent St Frankton 10.30am to 11.30am. A free car park is right across the road and it is close to a bus route.

The Education Support Group this year will also be seeing more focussed group discussions. The topic of February's meeting will be 'Stress' – what is it, how it impacts our body/health, and the sharing of stress management strategies and ideas.

So roll on 2019. I look forward to seeing you or speaking to you on the phone this year. Please remember that you can contact me if you have any questions or concerns regarding ME/CFS & FM, on 07 8344745, 0273855425 or at [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)

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Hei Koná Mai  
*Tracey Larsen*



**"Paddy, have you lived here all your life?"  
"No, not yet", he replied.**

**ANZMES Support Group  
Leaders' Conference  
August 2018**

I was very fortunate to travel to Auckland to attend the ANZMES Support Group Leaders' Conference last August 2018. The day had been organised as a combined networking and educational opportunity.



Other groups represented at the conference were: ANZMES; ME Information and Support Service (MEISS) Dunedin; Wellington Region ME/CFS Support Group (WellMe); Nelson Bays ME/CFS & FM Support Group; ME/CFS Auckland Support Group; MS Waikato Trust; East Coast ME Support (Gisborne); Millions Missing; Rest assured Respite Charitable Trust and Complex Chronic illness Support (CCIS) Tauranga.

Dr Nicola Swain, president of ANZMES, opened the meeting, welcoming attendees and acknowledging the groups represented. She said that research has shown that support groups can play a major role in helping people cope and live well with chronic illness.

The first speaker, health psychologist Dr Anna Friis, spoke about compassion as an antidote to chronic stress. She said that, working in our various roles, we would be familiar with responding in a compassionate way to others who are hurting. But what about compassion for

ourselves? 78% of us treat others better than we treat ourselves. Food for thought!

Erin Holland, physiotherapist, spoke on the topic: Is there a role for physiotherapy & exercise in ME/CFS? She said that, while components of traditional physiotherapy are applicable to ME/CFS, the physiotherapist needs to have a good understanding of the condition. She cited a 2016 study by Dr Peter Rowe on neuromuscular strain, which showed that there is neural irritability in ME

patients and that attempting to move/exercise already highly sensitized structures, leads to exacerbation. She recommended 'baby steps' with hands-on therapy, taking time to prepare the body for movement and desensitizing the neural structures – in effect retraining the nervous system. Baby steps can mean, as an example, starting with only a few shoulder rolls each day, as a starting point.

Other speakers were ANZMES executive committee member, George Connolly, who facilitated a discussion on managing difficult behaviour in the support group setting, and Dr Ros Vallings, who presented a report on the London Invest in ME Research conference she attended in June.

I enjoyed the opportunity to network and learn, put faces to names, and share ideas. Thank you ANZMES for organising this

*Article (slightly abridged), kindly provided by CCIS Tauranga.*

**The biggest lie I tell  
myself is  
"I don't need  
to write that down,  
I'll remember it."**

## November Support Group Kirstie Petch & Oliver Russell Osteopathic Approach to Health

Kirstie Petch and Oliver Russell spoke to our November group about osteopathy. Kirstie spoke of how she sought osteopathic treatment after an injury in 2010.



“It was the one thing that helped me and since then it’s been a bit of a love affair”. As a result, Kirstie decided to train

at Unitech in Auckland, qualifying at the end of 2017. She returned to Hamilton and gained employment with a team of 9 osteopaths at The Osteopathic Clinic. Kirstie told us that to help people and to enhance their understanding of how their body works brings her a lot of joy because “what an amazing thing [our body] really is”.

Fellow Osteopath Oliver Russell accompanied Kirstie at our meeting. He trained at the University College of Osteopathy in London, qualifying in 1996. Scottish Oliver then moved to NZ in 1998 and is also a team member at the Osteopathic clinic.

Kirstie explained that the name osteopathy stems from the Latin ‘osteon’ for ‘structure’ (now mostly perceived as ‘bone’), and ‘pathos’ for ‘suffering or dysfunction of’. Osteopaths are often thought of as ‘bone doctors’, but their speciality is for the structure as a whole.

Dr Andrew Taylor Still founded the principles of osteopathy. Born 1828 in Missouri, USA to a preacher and country Doctor, Still was fascinated by health, human anatomy and machines throughout his life. His 4 principals were:

- Structure governs function – structural restriction leads to dysfunction and disease, and structure and function are reciprocally interrelated
- Rule of the artery – get good supply [of blood] to an area and drainage from it. If the supply and drainage are good, then the tissue will be healthy
- The body has its own medicine cabinet- one it prefers to access before introducing outside medications. The body is capable of self-regulation, self-healing and health maintenance

- The Body is a unit - the person represents a combination of body, mind and spirit.

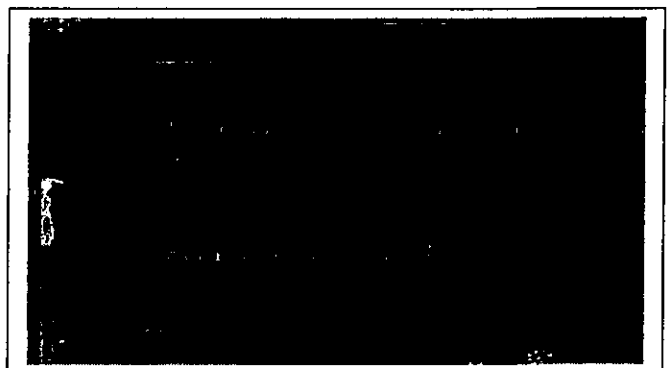
In osteopathy, although syndromes and pathology are acknowledged, they will avoid using those terms, instead choosing to talk about pathophysiology. When using the term pathophysiology, they are talking about a body that is doing the best it can under a set of altered circumstances. An osteopath’s job is to assess where this body is struggling, where it is able to express health, where it is best expressing health and where it is expressing dysfunction and then work to remove the dysfunction, so the body can continue to express health effectively.

Osteopaths do this work on a physical level, but also work with other professional to provide mental/physical/spiritual relief/treatment when needed. The treatment provided depends on many different factors (e.g. symptoms, other health conditions, history of interactions with health care providers, patient preference etc...) which means that no treatment will be the same and no osteopath will work in exactly the same way.

Osteopathy is the science and art of tissue diagnosis and tissue change; assessing and effecting. What is important is figuring out which tissues they want to change and influence, to achieve the necessary change. If no change is experienced, then they reassess and try something different.

Since 2003 Osteopathy have been regulated by the Osteopathic Council of New Zealand, established by the Health Practitioners Competence Assurance Act (2003). The title of "Osteopath" is protected by the Act, so that only osteopaths that are registered with the Osteopathic Council may use the title of osteopath and only osteopaths that hold a current practicing certificate may lawfully practice osteopathy in New Zealand.

*The Osteopathic Clinic is situated at Bond St, Hamilton.  
For more information, phone: 853 9699*



## Page 4 Tips, Snippets, Contacts And Up & Coming Event

A gold coin koha is greatly appreciated thank you

ME/CFS & FM Education Support Group  
Melville Methodist Church, Bader Street  
Hamilton, - 10.30am – 11.30am

**11<sup>th</sup> April 2019** – Focussed group discussion – Sleep Difficulties

ME/CFS & FM Social Coffee Group at Agora Café, Kent St,  
Frankton, 10.30 to 11.30am  
**14<sup>th</sup> March and 9<sup>th</sup> May 2019**



### OTHER CONTACTS:

You may find it helpful to speak to others who also have ME/CFS and/or FM. Thanks to those offering such support. Please be aware that they will respond as they are able, according to how their own health is at the time:

CIANE (Sharn): 0211471933

LINDA: 8553934 or email [lindaderrick@yahoo.com](mailto:lindaderrick@yahoo.com)

BERNADETTE: 07 8686763 (Thames)

JANE: please email [aj158@gmail.com](mailto:aj158@gmail.com)



ANZMES

MS Waikato have  
Wheelchairs available to  
loan short term at no cost.  
Ph: 8344740 to enquire

## Notice of MS Waikato Trust Annual General Meeting

The AGM will be taking place on Thursday 21st March at 6.30 pm in the Life Unlimited Board Room. Financial members will be eligible to vote at the AGM. To reserve a seat or for more information please contact Janet on 07 834 4740 or email [janet@mswaikato.org.nz](mailto:janet@mswaikato.org.nz)

MS Waikato Trust held its Christmas lunch at the Hamilton Workingman's Club in December. We had a great turn out from each client group. Pictured here are some of the ME/CFS & FM clients who attended: Graham, Linda, Deborah, Andrea, (me) Michelle, Ann, Delwyn and Danae. A BIG thank you to a generous ME/CFS whanau who donated 10 free meals for the ME/CFS & FM group.

### HEALTH PASSPORTS

contain information about your health condition/s and how you want people to communicate and support you when seeking medical treatment.

For more information view  
[www.hdc.org.nz/about-us/disability/health-passport](http://www.hdc.org.nz/about-us/disability/health-passport)

**Tracey Larsen**  
**Client Service Coordinator**  
**ME/CFS & FM**

MS Waikato Trust

P.O. Box 146, Hamilton 3240

Phone: 07 8344745

Mobile: 027 3855425

Email: [tracey@mswaikato.org.nz](mailto:tracey@mswaikato.org.nz)

Website: [www.mswaikato.org.nz](http://www.mswaikato.org.nz)

**ANZMES**

PO Box 36 307

Northcote, North Shore, 0748  
Auckland

Ph 09 269 6374 [www.anzmes.org.nz](http://www.anzmes.org.nz)

**Medical Advisor**

**Dr Ros Vallings** Auckland

Phone: 09 534 3978 for clinic bookings  
or enquiries

MS Waikato would like to thank our sponsors and supporters.

SPAN Trust, WDFP Karamu Trust, Waipa District Council, COGS – Hamilton City, South Waikato and Waikato West, Anytime Fitness – Hamilton Central, Len Reynolds Trust, The Norah Howell Charitable Trust, Gallagher Charitable Trust, Page Trust, Ngahinapouri Golf Club, Waikato Lyceum Charitable Trust



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FOUNDATION

NZCT

the  
southern  
trust



Sir John Logan Campbell  
Residuary Estate



The Hamilton ME/CFS & FM Education Support Group operates under the umbrella of MS Waikato Trust. MS Waikato offers support, advice and advocacy to those with ME/CFS & FM in the Midland Health area, defined by the boundaries of Waikato DHB.

**Disclaimer:** Opinions expressed in Koru are those of the writer and speakers presenting to the monthly group and not necessarily those of the Hamilton ME/CFS & FM Support Group or MS Waikato Trust.

## ME/CFS & FM Education Support Group & Social Group 2019 Calendar.

● Support Group - Melville Methodist Church corner of Bader Street & Normandy Ave, Melville, Hamilton 10.30am to 11.30am. Please arrive by 10.20am for prompt start. A gold coin donation/koha is greatly appreciated.

● Social Group - Venue may change, will advise by email regarding Social Group venue a week prior.



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## **BOOKS & RESOURCES AVAILABLE**

### **LIBRARY BOOKS**

If you are interested in  
loaning any of these books,  
please phone Tracey on  
07 8344745

- Adrenal Fatigue for Dummies**, A. Wiley  
**An introduction to the Lightning Process**, Phil Parker  
**But I Love You** Cherry G - True story on Psychological abuse  
**Chronic Fatigue/ME Support for Family & Friends** Elizabeth Turp  
**Chronic Fatigue Syndrome M.E.**, Dr Rosamund Vallings  
**Chronic Fatigue Syndrome**, Campling  
**Fibromyalgia and Myofascial Pain Syndrome** A practical guide to getting on with your life, Dr Chris Jenner  
**Fibromyalgia for Dummies**, R. Staud  
**Fibromyalgia- simple relief through movement**, Stacie L. Bigelow  
**FibroWHYalgia** S.Ingebretson  
**FM & Chronic Myofascial Pain** D. Starlynyl & M. Copeland.  
**Food Allergy Survival Guide**, Vesanto Melina Jo Stepaniak Dina Aronson  
**From Fatigue to Fantastic**, Jacob Teitelbaum  
**Healthier without Wheat**-A new understanding of wheat allergies, celiac disease and non-celiac gluten intolerance, Dr Stephen Wangden  
**Healthy Eating for IBS**, Sophie Braimbridge  
**Healthy Gut Cook Book** Gavin Pritchard & Maya Gangadharan - NEW  
**Hope & Help for Chronic Fatigue Syndrome & Fibromyalgia**, Alison Bested  
**Journey into Mindfulness** Patrizia Collard  
**Living With Fibromyalgia**, Christine Craggs-Hinton  
**Lost Voices from Hidden Illness**, Natalie Boutlon  
**Managing ME/CFS; A Guide for Young People**, Dr Ros Vallings NEW  
**Optimum Health the Paleo Way**, Claire Yates  
**Power of Vitamin D**, Safraz Zaldi  
**Recovery from CFS**, 50 personal stories, Alexander Barton  
**Reviving the Broken Marionette**-treatments for CFS ME and FM, Maija Havisto  
**Sacred Space ME/CFS Depression, Anxiety & Stres**, Elizabeth Bailey  
**Sophie's Story**-My 20 year battle with IBS, Sophie Lee  
**Stay Healthy** by supplying what's lacking in your diet, D. Coory  
**Taking Control of TMJ**, Robert Upgaard  
**The Anatomy of Hope**, Dr Jerome Groopman  
**The CFIDS / Fibromyalgia Toolkit-A practical self-help guide**, Bruce Campbell  
**The CFSID & Fibromyalgia Self-Help Book** A self Management Program for CFS and FM, B. Campbell  
**The Chronic Fatigue Healing Diet**, Christine Cragg-Hamilton  
**The Great Physician's Rx for Irritable Bowel Syndrome**, Jordan Rubin  
**The Irritable Bowel Syndrome Solution**, Dr Stephen Wangen  
**The New Zealand Gluten Free Cookbook**-food everyone can enjoy, Sophie Johnson  
**The New Zealand Gluten-Free Cookbook**, Jim Boswell  
**The Patient's Guide to CFS & Fibromyalgia**, Bruce Campbell  
**The Pocket Guide to CFS/ME; Key Facts & Tips for Improved Health**, Dr Vallings NEW  
**The Whole-Food Guide to Overcoming Irritable Bowel Syndrome**, Laura J. Knoff  
**Understanding Irritable Bowel Syndrome**, Dr Kieran Moriarty  
**What Your Doctor Doesn't Know about FM**, L. Veilink and P. Rhodes  
**Wherever You Go There You Are**, Jon Kabat-Zinn  
**Yoga for Fibromyalgia**, S. L. Crotzer  
**Your Symptoms are Real-What to do when your doctor says nothing is real**, B. Natelson

### **DVDS: AVAILABLE TO BORROW OR BUY FOR \$10.00**

- Dr Vallings – Vitamin B12 PLUS latest Invest in ME research 2018  
Dr Vallings – Orthostatic Intolerance and Salt PLUS latest invest in ME research 2017  
Dr Lapp's Feeling Better DVD – from his speaking tour in NZ April 2017 - NEW  
Dr Vallings's Key Research finding from Invest In ME Conference 2016, 2015, 2014, 2013, 2012, 2011,  
Dr Vallings - Pain Management 2011  
Dr Kathy Rowe, Paediatrician – Understanding ME/CFS in young people 2014  
Dr Nancy Klimas's Hamilton talk, 2010