

# KORU ME & FM Support

HAMILTON JUNE 2014 Issue 32



Hello everyone,

With our wintery weather lately – very chilly mornings, grey foggy skies, and some really heavy downpours, you’ll no doubt be on count down till the shortest day coming up later this month. Huddling up in a warm room with a good book and bowl of hot soup sounds like a good option to me!



The last couple of months have been very busy and a lot has been achieved. Our main focus of course was ME/CFS and FM awareness which you can read about on page 5. The main aim of May Awareness week is to educate those who don’t know about these conditions, because, as most of you will be aware, many people, including health professionals, are not well informed or completely oblivious to these illnesses! Even those who already think they know about them are likely to have misconceptions, believing that the illness is not that serious or that it’s psychological. They may hold those views because they don’t know any better; it’s what they were told, and no one has challenged those beliefs before. Together we are many and therefore more can be achieved in spreading the word. That’s why, like us, other ME/CFS and FM support groups throughout the country have been doing their bit to raise awareness, as has Anzmes, our national Society. It’s slow progress, but bit by bit we are making gains!

Some of you may be wondering what has happened about the follow up from the ME/CFS petition to parliament. The Ministry of Health offered an opportunity to discuss the report of the Health Select Committee, as there were questions about what changes could be expected in response to their findings. In March Dr Don Mackie and Dr David St George met with Dr Ros Vallings and Wendy Mathews for an hour and a half to discuss relevant issues. Anzmes has sent a report of the meeting to the Ministry of Health, and is now waiting to receive their report. Anzmes comments that: “It is hoped that this will be an opportunity to establish an ongoing relationship with them and that there will be more dialogue about issues affecting all of those with ME/CFS, leading to positive changes and initiatives. As you can imagine a lot was discussed in that time but suffice to say we shared on behalf of you all. Once we have their report we will be in a better position to see what impact the meeting has had and where we go from there.”

For the full report: [http://www.parliament.nz/ennz/pd/sc/documents/reports/50DBSCH\\_SCR5681\\_1/petition-201110-of-wendy-matthews-and-5454-others](http://www.parliament.nz/ennz/pd/sc/documents/reports/50DBSCH_SCR5681_1/petition-201110-of-wendy-matthews-and-5454-others) (Download on right panel at this link)

Our meeting topic this month is, ***‘Eating For Health and Energy,’*** and our July speaker will be discussing ***Sacro-Cranial Therapy.*** ***Check out details on page 4.*** A reminder – August 14<sup>th</sup> Dr Vallings will be with us. ***Meantime snuggle up and try to keep warm!***

*Helen*

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## Reflexology



Naturopath, Linda Bell, was our guest speaker in April, and spoke to us about reflexology. She explained that reflexology is an alternative health therapy which uses the application of pressure using finger and thumb techniques to the

feet, hands or ears, based on the principle that the entire body is reflected in these areas. Reflexes in the feet, hands and ears correspond to all the glands, organs, and parts of the body. Linda told us that reflexology is holistic and non-invasive, and works on a physical, mental, emotional and spiritual level. It is gentle and relaxing.



Reflexology dates back to ancient civilizations such as Egypt, India and China, but this therapy was only introduced to the West in the

early 20th Century by Ear Nose and Throat surgeon, Dr William Fitzgerald. He practiced in the USA and briefly in London and Vienna for 2 years. He was the founder of 'Zone Therapy,' an early form of reflexology. Reflexology was modified in the 1930s and 1940s by Eunice D. Ingham, a physiotherapist. Ingham claimed that the feet and hands were especially sensitive, and mapped the entire body into 'reflexes' on the feet renaming zone therapy to reflexology. Ingham's procedure and related practices developed by Laura Norman are used by modern reflexologists. Reflexology works on the reflex zones in the feet, hands and ears to stimulate the body's own healing response, and it assists the body to balance itself. It promotes gentle alignment of body, mind, and spirit to promote well-being, and may increase or re-vitalize energy levels. Reflexologists don't diagnose, prescribe, or treat specific illnesses; rather they treat the whole person.

Benefits of Reflexology include stress reduction, improved circulation, stimulated

nerve function, improved immune system and increased energy.

*Linda can be contacted at Harmony Health Clinic 32 Bernard St Chedworth, Hamilton Ph 021 2123048 She is offering a discount to members. Linda also teaches beginners yoga & does one on one yoga sessions.*

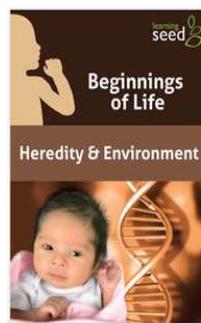
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## STRESSFUL RELATIONSHIPS

Relationship conflict and stress have been shown to have a clear negative impact on health, affecting blood pressure, contributing to heart disease, and correlating with other conditions. That's why

it's in your best interest to minimize or eliminate negative relationships in your life. Forming and maintaining relationships is hard for many people with ME/CFS and FM. Relationships can be hard work when energy is limited, and you're in pain and exhausted. Many people don't understand the illness, and this often includes family members. When you have ME/CFS or FM you have to make sure you minimize the things in your life that can make your symptoms worse. Sometimes, as painful as it can be, that means eliminating people. When a person makes you feel bad about yourself, runs you down, gives you a guilt trip about your illness, or otherwise drains your energy, you might have to consider whether it's worth having them in your life.

The silver lining of cutting negative people out of your life is that it means the people around you are those who really matter and care about you. It can relieve a lot of stress, and leave you feeling less drained, frustrated and exhausted.



**“Life consists not simply in what heredity and environment does to us, but in what we make out of what they do to us.”**

*Harry Emerson Fosdick*

## HOMEOPATHY

Homeopath, Neeraj Duggan is very passionate about his job. At our May meeting he told us that after four years in medical school and then a career as an accountant, he was keen to change to homeopathy after successfully being treated for a serious illness. He retrained and has been working for 15 years, and 'wouldn't dream of doing anything else!' Neeraj told us that Homeopathy is 200 years old and was founded by a German born physician and chemist, Dr. Samuel Hahnemann, who developed a system of medicine which treats 'like with like.' It means that a substance which in large doses causes the symptoms of an illness, can be used in minute doses to relieve those same symptoms. For example, the homeopathic remedy, Coffea, made from coffee, is used to treat an overactive nervous system and insomnia. Neeraj told us that Homeopathy is very safe and gentle, as the substances are very dilute and there are no side-effects. This means everyone from babies, pregnant women and the elderly can use them with no side effects. The only ill effects may arise if an unqualified practitioner prescribes a dose which is too high. This can happen when people do short courses and set themselves up without having enough knowledge. Neeraj is a classical Homeopath and did 4 years training and more study after that. He said people should ensure they find a registered practitioner. Some of the modern practitioners will mix the remedies but a classical practitioner won't, and, according to Neeraj, this is not such an effective and reliable method. It is most important to get a good history from the patient as personality is very important, so the initial consultation may be over an hour and will cover health issues, general characteristics, and personal and family history. This gives the Homeopath a holistic picture so that an individualised remedy can be prescribed. Neeraj told us that Homeopathy promotes well being, and helps in the health journey, but doesn't claim to be "a fix for everything."

*Neeraj can be contacted at: the Clinic of Homeopathy  
32 Boundary Rd. ph: 8548962. Also : Cambridge,  
Raglan, & Te Awamutu. Ask re his discount offer.*



## BOOK REVIEW:

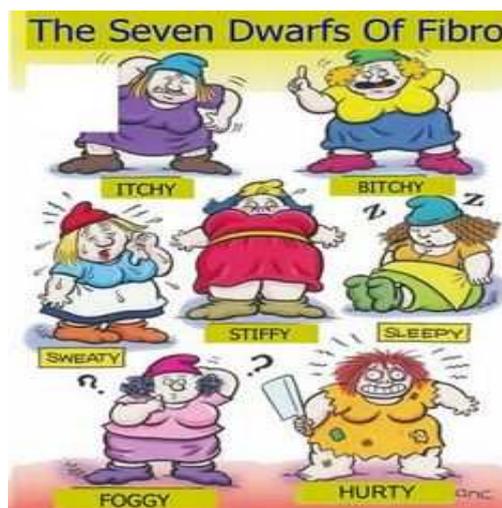
**TAKING CHARGE OF YOUR CHRONIC PAIN:**  
*The Latest Research, Cutting-Edge Tools, and Alternative Treatments for Feeling Better*

The author, **Dr Peter Abaci**, is an anaesthetist and pain management specialist, and has suffered from chronic pain himself following an injury. He is director of the Bay Area Pain and Wellness Centre in California, and says that his mission is to help transform the way conventional medicine treats pain, and to restore hope for healing and long term health. Dr Abaci focuses on developing alternative solutions to treating chronic pain by 'drawing on neuroscience research, evidence based medicine, ancient healing remedies, stress management techniques, nutrition principles, exercise programs, art therapy, and real-life lessons'.



*This book is relatively new to our library, so thanks to Denise for reviewing it for me.*

She says that 'the book provided some interesting and helpful information. It appears that the best way to treat chronic pain is through a multidisciplinary approach/environment whereby all the medical specialists in their various disciplines are working together to help the person. This 'wholeness' approach/process provides alternatives to conventional medicine, using some of the Eastern approaches of Tai Chi, Yoga, Pilates, breathing techniques, as well as art therapy, an anti-inflammatory diet, and incorporating mind and body.'



## MINDFULNESS COURSE

A 3 hour mini retreat to learn and practise mindfulness skills in a friendly supportive environment. June 14<sup>th</sup> & July 12<sup>th</sup>. 1- 4pm.  
Venue: Hamilton Gardens - \$20.00 per session.  
Do one or both. *Contact jo-wall@outlook.com  
or phone 021 2665657*

## COPING WITH 'TWITCHES'

*I recently had an enquiry about this and thought it may be of interest to others. Ed.)*



Twitches, known as benign fasciculations, are common throughout the course of ME/CFS, although they tend to increase during exacerbations and relapses. Twitches can occur in any body part (legs, arms, torso, and face). They can occur continuously, sporadically, be widely distributed, or be confined to one area only. (Often eyelids and thumbs) Twitches increase with fatigue and decrease with rest. Research seems to indicate that twitches, like the loss of complex sequencing movements (as in speech), are due to a dysfunction of the basal ganglia. However, in as much as the nerve fibres that connect the basal ganglia to the cortex, pass through the hypothalamus; disruption of hypothalamic function could just as well cause fasciculations.

Twitches are primarily associated with the cholinergic system. Acetylcholine is the neuro transmitter involved in the motor system, which means it is responsible for the innervation of muscles. Excess acetylcholine in nerve synapses will cause twitches. Paradoxically people with ME/CFS have been found to have low, rather than high levels of acetylcholine. This results in an exaggerated response to acetylcholine.

In themselves, twitches are harmless and, although annoying, require no special treatment. Magnesium seems to reduce their frequency and extent, as does zinc. Benzodiazepines and other nervous system down regulators will also decrease twitches. Anticholinergics (antihistamines, tricyclic anti depressants) may cause twitches, as can exposure to pesticides. Caffeine consumption, stress, and smoking can worsen twitches. Eyelids twitches are often caused by dry eyes. Good quality eye drops can help lubricate the eyes and relieve twitches. General dehydration will lead to twitches in many parts of the body, particularly the legs, so adequate hydration is important.

## Useful Tips

The photo is of a shower brush which Janice, one of our members, got from a \$2.00 shop. Because she has thick hair, she uses it when she washes her hair. According to Janice it is great, in that it gets through thick hair quickly and easily – a bonus and an energy saver when you've got the extra effort of hair washing! Available from the Variety Shop near Wendy's, Chartwell, or through Helen



As well, Janice also recommends this sleek little stainless steel jug. It's only 15cm tall and holds 800 mls which is suitable for one or two cups. For those that have trouble lifting, it's much lighter than the normal jug, and only boils the amount of water needed, therefore saving on time and electricity bills. Cost: \$59.00. [www.innovations.co.nz/Kitchen](http://www.innovations.co.nz/Kitchen)



## UPCOMING SUPPORT MEETINGS

### JUNE 12th Education Meeting

10.30 -12md, Methodist Church, Crn Bader St & Normandy Ave, Melville

Speaker: *Helen Donnison, from The Vibrant Health Clinic in Hillcrest, Hamilton, will discuss Nutrition – Eating for health and energy*

### JUNE 24th Social Group

2pm Robert Harris Café, Chartwell mall

### JULY10<sup>th</sup> Education Meeting

10.30 -12md, Methodist Church, Crn Bader St & Normandy Ave, Melville

Speaker: *Karen White from Hukanui Body Therapies will discuss Cranio-Sacral therapy*

### JULY 22<sup>nd</sup> Social Group

2pm Robert Harris Café, Chartwell mall

**AUGUST 14<sup>th</sup>:** *Dr Vallings will be discussing the research findings from the recent 9<sup>th</sup> Invest in ME international conference in London.*

## ME/CFS & FM AWARENESS WEEK

**“Individually we are one drop  
Together we are an ocean”**

*Ryunosako Satoro*



As most of you know, International ME/CFS Awareness Day and Fibromyalgia Awareness Day are recognised on May 12th each year to commemorate the birth in 1820 of Florence Nightingale who inspired the founding of the

International Red Cross. Nightingale is believed to have contracted ME/CFS in her thirties. She spent the last fifty years of her life virtually bedridden. Events to publicise ME/CFS occur internationally throughout the year, but are more frequent during a week of awareness and fund raising activities that straddles May 12.



The Butterfly is one of the symbols of Awareness Week. A butterfly symbolises the new person emerging as they break free from life restricted by ME/CFS. Blue ribbons are

worn on May 12th to show support for those affected by ME/CFS, and purple ribbons for those affected by Fibromyalgia.

Our Awareness week started off on Monday the 12<sup>th</sup> May with a display on the large Community notice board at the Central Hamilton library. Prior to this, Arthritis Educator, Catherine Swift and I had liaised to discuss her offer to raise awareness of fibromyalgia throughout the Waikato, and, thanks to Catherine and her volunteer helper, fliers were distributed in Community centres, Winz offices, the university, Age Concern, the rheumatology clinic, and other places in the greater Waikato area.

Throughout Thursday the 15<sup>th</sup> May, a willing band of volunteers made their way to the Westfield shopping mall in Chartwell to assist on our Awareness stand with the aim of educating the public about fibromyalgia. Our bright purple balloons attracted attention and



*Amanda & Julia*

were given away to children of people stopping to look at our poster board. Thanks to Julia, Amanda, Maree, Pam, Sally, Ann, Emily and Graham for sparing some of your precious energy and time to devote to such a good cause.



*Andrea & Louise*

Because of a last minute hiccup with Pak & Save supermarket wanting to place us outside with no cover, we arranged to move to the Bridge St Countdown and set up our ME/CFS Awareness stand there. It was under cover but, although the day dawned bright and sunny there was a real nip in the air. So because the wind had whipped up a notch or two during the morning and the foyer was too



crowded to set up inside, we finished early. But huge thanks go to Andrea and Louise, Barry and Ellen, Colleen and Zsarina for braving the elements to help out.

*Graham & Emily*

## RESOURCES AVAILABLE

**DVDS - available to borrow  
(or buy for \$10.00)**

Dr Vallings August 2010 talk  
Dr Nancy Klimas's Hamilton talk  
Dr Vallings/Pain Management 2010  
Dr Vallings's IACFS/ME Conference  
Nov 2011  
Dr Vallings' Invest In ME conference  
June 2012 & May 2013

## LIBRARY BOOKS

**Recovery from CFS** -50 personal stories - Alexander Barton (2 copies)  
**Lost Voices**—families living with ME  
**Living With Fibromyalgia** – Christine Craggs- Hinton (3 copies)  
**Chronic Fatigue Syndrome** Campling  
**Managing Chronic Fatigue Syndrome & Fibromyalgia** - CD set by Bruce Campbell  
**From Fatigue to Fantastic-** Jacob Teitelbaum  
**Your Symptoms are Real- What to do when your doctor says nothing is real-** Benjamin H. Natelson  
**FibroWHYalgia** - Susan Ingebretson  
**The Chronic Fatigue Healing Diet** - Christine Craggs-Hinton  
**Verity Red's Diary** –A story of Surviving ME - Maria Mann  
**What Your Doctor Doesn't Know about FM** - L. Veilink and P. Rhodes  
**Reviving the Broken Marionette** - treatments for CFS ME and FM - Maija Havisto  
**Hope & Help for Chronic Fatigue Syndrome & Fibromyalgia-** Alison Bested  
**Taking Control of TMJ** - Robert Upgaard  
**The Patient's Guide to CFS & Fibromyalgia** - Bruce Campbell  
**Sacred Space ME/CFS Depression, Anxiety & Stress** - Elizabeth Bailey  
**The Introvert Advantage** - How to thrive in an Extrovert World -Marti Olsen Lani  
**Fibromyalgia and female sexuality** - Marline Emmal  
**Chronic Fatigue/ME - Support for family & friends** - Elizabeth Turp  
**Fibromyalgia for Dummies-** R. Staud  
**Yoga for Fibromyalgia** S. L. Crotzer  
**Sophie's Story** - My 20 year battle with IBS - Sophie Lee  
**Power of Vitamin D** - Safraz Zalidi  
**Wherever You Go There You Are** - Jon Kabat-Zinn  
**Diagnosing & Treating Chronic Syndrome** Dr Sarah Myhill  
**Chronic Fatigue Syndrome M.E.** Dr Rosamund Vallings (5 copies)

**Understanding Irritable Bowel Syndrome** Dr Kieran Moriarty  
**Taking Charge of your Chronic Pain** Peter Abaci  
**The New Zealand Gluten Free Cookbook** -food everyone can enjoy - Sophie Johnson  
**The New Zealand Gluten-Free Cookbook** - Jim Boswell  
**The Mindful Way through Anxiety** Susan M. Orsillo & Lizabeth Roemer  
**The Irritable Bowel Syndrome Solution** Dr Stephen Wangen  
**Fibromyalgia and Myofascial Pain Syndrome** A practical guide to getting on with your life. Dr Chris Jenner  
**Fibromyalgia- simple relief through movement** Stacie L. Bigelow  
**15 Natural Remedies for Migraines and Headaches** J.S. Cohen MD  
**The Great Physician's Rx for Irritable Bowel Syndrome** Jordan Rubin  
**Healthier without Wheat** – A new understanding of wheat allergies, celiac disease and non-celiac gluten intolerance Dr Stephen Wangden  
**The Whole-Food Guide to Overcoming Irritable Bowel Syndrome** Laura J. Knoff  
**Food Allergy Survival Guide** Vesanto Melina Jo Stepaniak Dina Aronson  
**Healthy Eating for IBS** Sophie Braimbridge  
**The CFSID & Fibromyalgia Self-Help Book** A self Management Program for CFS and FM by Bruce Campbell  
**The CFIDS / Fibromyalgia Toolkit** A practical self-help guide Bruce Campbell  
**An introduction to the Lightening Process** Phil Parker (3) 2 donated  
**Stay Healthy** by supplying what's lacking in your diet –D. Coory

## Wheelchair Availability



MS Waikato has wheelchairs available. No cost. Phone: 8344740 for enquiries.

## Contacts

### **Helen Maseyk**

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MS Waikato Trust  
phone : 8344742  
Mobile:027 7771344  
PO Box 146, Hamilton  
Email:helen@mswaikato.org.nz  
Website:www.mswaikato.org.nz

### **ANZMES**

PO Box 36 307  
Northcote, North Shore, 0748  
Auckland  
Ph 09 269 6374  
www.anzmes.org.nz

### Medical Advisor

### **Dr Ros Vallings** Auckland

Phone: 09 534 3978 for clinic booking.

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

Disclaimer : Opinions expressed in Koru are those of the writer and not necessarily those of the Hamilton ME Support Group or MS Waikato Trust.

## Contact others



You may find it helpful to communicate with others who also have ME/CFS or FM, especially if you're feeling a bit down, or you may want to know how others manage. Thanks to those offering support. Please be aware that they will respond as they are able, according to how their health is at the time.

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