



Christmas

Christmas is nearly upon us and we want to wish you a happy and safe Christmas. We will be closing from Friday December 20th and reopening on Tuesday 7th January.

Did you hear the news? CCIS has made a move.

In November we moved to [53 Fraser St, Tauranga](https://www.google.com/maps/place/53+Fraser+St,+Tauranga)
Office: 07 281 1481 or 022 658 0251
info@ccisupport.org.nz
www.ccisupport.org.nz



Summer has already decided to come and it started quite nicely with above average temperatures – we are all looking forward to the nicer season and getting out in the sun as we all know: WE NEED Vitamin D 😊. Many changes have happened recently, so let's start with the most important one. As you may have seen on facebook, we have shifted into our wonderful new building at [53 Fraser Street](https://www.google.com/maps/place/53+Fraser+Street) two weeks ago. We are happy to announce that the building has a ramp out the back by the disability park. Please let us know in advance if you will be using this, so we can open up the doors into the building. We are at the back of the building down the corridor.

What's New?

For starters, our MEssenger newsletter is getting a revamp. We are still looking at the members feedback, but for now... Instead of every 3 months, we will be doing a shorter more frequent update. It is preferable that this is sent via email, then you can click on the links for instant access to more information and contacting us. However, we will also have some sent out via mail for those paid members who request this.

Our Staff and Office Hours



Miranda Whitwell

Operations Coordinator.

Hours: Tuesday to Thursday

9am till 2.30pm

operations@ccisupport.org.nz

We've had a busy few months, with me finding my feet, employing new staff and finding, then moving to the new premises in Fraser St. But I'm loving working at CCIS and looking forward to what 2020 has in store for us.

New Western Bay of Plenty Field Officers

Waltraut and Charlotte Phone or Txt: 027 625 4449

Office Hours - Tuesday to Friday 9am till 2pm

waltraut@ccisupport.org.nz

or

charlotte@ccisupport.org.nz



From Waltrauts Desk:

Kia ora koutou

My name is Waltraut Speidel. As a passionate advocate for holistic health and wellbeing I enjoy working in the health sector. Working as a Health Care Assistant, I saw the need for improvements in this area and I wanted to have a greater impact on people suffering from various illnesses. This motivated me to go back to study. I hold a Bachelor degree in Community Health.

From my personal and professional background, I recognize the importance of holistic and individual support for people with complex chronic illnesses and feel passionate to be their advocate

in all respects. It is my vision to empower these people using a strength-based approach and hence to improve their quality of life. I believe in the innate potential of every human being and as such I am determined to improve the health and well-being of individuals as part of CCIS. Through my background in different administrative roles and as a teacher in a language school for children and adults, I feel well equipped for my new role as a Field Officer. During my entire life I have been supporting many people from all different walks of life and it is my heart's desire to make a real difference in peoples' lives. Gifted with a cheerful nature and being a hardworking person, I am excited to start my new adventure at CCIS.

He tangata, he tangata, he tangata – it is the people, it is the people, it is the people!

From Charlottes Desk:

Kia Ora, my name is Charlotte Kelp, I am a mother of four children and a health advocate here in the beautiful Western Bay of Plenty. After many years of struggling with my own health together with a passion for helping others, I was inspired to return to education and have recently completed a Bachelor in Community Health, majoring in Public Health. With my own diagnosis of ME/CFS, I have personal insight into the challenges of living with this disease. I am a firm believer that quality of life can be enhanced by utilising available supports around us, including family, friends and community organisations. I believe that with support and holistic management alongside an increased understanding of this illness, the burden can be lifted and our lives improved. This is why I am so excited to bring my knowledge, skills and compassion to share with you. I am determined to raise awareness of ME/CFS and passionate in supporting and empowering others on their personal journey with this illness. I feel very privileged to be working alongside you and I look forward to meeting you.



Eastern BOP Field Officer

Elizabeth McGougan

Phone or Txt: 020 401 79092

elizabeth@ccisupport.org.nz

Office Hours – Tuesday, Wednesday and Thursday
9am -12:15pm



Greetings from the East

It has been a busy time here in the Eastern Bay as our members had our end of year function in November in order to beat the heat. We had a very lovely gathering at Winsome's home and it was a bonus to see her garden, she and Jim have amazing green thumbs.

Our coffee catch ups have been well attended and at each one I say I will take a photo then get carried away with the conversation and forget. We have one last monthly meeting on the 11th of December and we are going to look into the most recent research on ME/CFS & FM, then it's a well-deserved break for the year.

Looking back over the year it has been a really big one for me on the work front. I have had some sadness with the resignation of Kira and Tina and the restructuring of Joanne. I have seen some new staff and now am working with the wonderful team that is Miranda, Cherie, Waltraut and Charlotte. We are really enjoying working together to create a positive CCIS for everyone.

Next year we aim to streamline our content so everyone will be receiving the same content at each monthly meeting and that will spread across all forms of CCIS communication. We will kick February off with Reframing, it's such a great skill to be able to take a situation and reframe it in a positive light. More on that next year, but hopefully you will feel interested and engaged and able to attend the meetings you want.

As some of you know I went on a Meditation retreat in September and had a truly wonderful time. Yes, I was actually silent for 3.5 days and would have stayed silent longer if I could have. I have written about my experience for those interested and this will be the first of our Blogs on our website www.ccisupport.org.nz. Miranda is trying to drag our charity in the 2020's which is really exciting, we will still print information for members who don't have online access.

I just want to say a BIG THANK YOU to you, our members. Thank you for attending our monthly meetings, coffee groups and social gatherings, thank you for liking, commenting or sharing on Facebook, thank you for volunteering to help us, thank you for being a member of CCIS. We only exist because of you and may be one day we won't be needed, but for now we are here for you, to support you to living your **fullest** and **happiest life** while managing these complex and frankly s*\$^#y conditions.

Please drink lots of water over summer, keep as cool as possible and have as much fun as humanly possible. Because you deserve to be happy and you deserve all the joy this world has to offer you.

Merry Christmas and Happy New Year

Elizabeth, EBOP FO



Lakes Field Officer

Cherie Reinders Phone or Txt: 020 401 79091

cherie@ccisupport.org.nz

Office Hours – Please note I work 6 hours per week, primarily I work from home on Thursday each week for office based work, and I also work the occasional Friday and Wednesday especially for community visits/meetings and other out of the office outings.

Greetings from the Rotorua/Lakes District,

It is a pleasure to have the opportunity to contribute to our CCI Support newsletter MESSenger for the first time.

For those who haven't heard anything about the newest addition to the CCI Support BOP Team here is a little about me. My name is Cherie Reinders and I was thrilled to be appointed as the new Field Officer for Rotorua Lakes in October for 6 hours per week, which I mostly do Thursday's and/or Friday's, I am also making myself available on Wednesday's for member meetings/coffee groups. I am a mother of two young men, my eldest is 14 years of age, and my youngest son is 12. I have a background in social work and nursing (nursing albeit quite some years ago!). I myself have a health condition and some of the most disabling symptoms of my condition are fatigue, pain, and muscle weakness/cramps. Consequently, I have a strong empathy and understanding of the challenges of living with the impacts of impaired health and I am endeavouring to learn all I can about ME/CFS, Fibromyalgia and POTS. I am very keen to be educated and made more aware of these conditions (and others) from those with lived experience, so am looking forward to connecting with members in Rotorua Lakes region.

I am very motivated to provide whatever support, information, advocacy will assist individuals to achieve health/life goals and live well in the presence of their illness. I like to think of wellness as active awareness, continuous learning, active reflection, constant adaptations, choices, and adjustments in all aspects of life, in the pursuit of holistic health and wellbeing – and that process is a complex journey.

Mauri Ora! I look forward to meeting you all,

Cherie, Rotorua Lakes FO

Articles of interest: In the emailed version of this newsletter, you can access these articles directly online. Today, I have attached one of them for your convenience. If you would prefer to receive this via email, please contact the office to arrange.

Elizabeth recommends this excellent research article by Cort Johnson. (attached)

The immune system in chronic fatigue syndrome (ME/CFS) has been kind of like a mirage in the desert. Given the way the disease starts and its symptom presentation – so close to the “sickness behavior” produced during an infection – it seems that the immune system must be a major player in this illness.

[Solid Ground at Last? Cytokines Make Good in Major ME/CFS Review](#)

The article Cherie (Field Officer Rotorua Lakes) recommends is a research article on perspectives of people living with CFS on the use of technology as a self management technique of CFS. Very interesting reading. Patient Perspectives on Self-Management Technologies for Chronic Fatigue Syndrome. You can find it here: <https://people.bath.ac.uk/cs3sj/papers/CHI2019-jones.pdf>

Latest research form Dr. Ros Vallings

In October Dr. Ros Vallings came to Hamilton providing the latest research which was very interesting. Currently many studies are being carried out worldwide, investigating the many bodily systems affected by CFS/ME. Researchers have shared their latest developments and many research papers are already out there. A power point presentation developed by Waltraut about this event is currently available, just txt or email us if you would like to receive a copy.

Networking activities

We as Field Officers attended a network meeting hosted by Western Bay Of Plenty Disability Support Trust and we made interesting contacts: *Enabling Love* and *Sailability Tauranga Charitable Trust*.

"Enabling Love" is a nonprofit organization which started at the beginning of 2018 with Joshua Perry as the CEO. Their purpose is to create a platform for people with disability to meet and share events, dating platforms and being active in socialising.

Website: www.enablinglove.nz

Facebook: <https://www.facebook.com/EnablingLovenz/>

"Sailability Tauranga Charitable Trust"

This trust offers sailing trips for people with disabilities – what a great opportunity and this service is free for the first sail. Later on, the members only pay a small yearly fee. Just contact them if you are interested

Website: www.sporty.co.nz/sailabilitytauranga

Facebook: <https://www.facebook.com/sailabilitytauranga/>



Members Survey

Have you received the members survey? This is an important part of CCIS. We need to know what you need from us and how we can better support you. If you haven't already, please fill this survey out and return via email or post. We can also send or post you another copy of the survey to you on request. Please contact [Waltraut](#) for this.

Calendar for 2020

MEMBERS MEETINGS

Topic for month	Tauranga	Whakatane	Rotorua
	2 nd Thurs of month	2 nd Wed of month	2 nd Wed of month
Reframing – language and thought	February 13 th	February 12 th	February 12 th
Pacing	March 12 th	March 11 th	March 11 th
Meditation / Mindfulness	April 9 th	April 08 th	April 08 th
Stress management	May 14 th	May 13 th	May 13 th
Systems of the body	June 11 th	June 10 th	June 10 th
Sleep support	July 9 th	July 08 th **	July 08 th
Restorative movement	August 13 th	August 12 th	August 12 th
Pain Strategies	September 10 th	September 09 th	September 09 th
Dysautonomia	October 15 th	October 14 th	October 14 th
Nutrition	November 12 th	November 11 th	November 11 th
Relationships	December 10 th	December 09 th	December 09 th

TAURANGA meetings

Monthly meetings are held at 53 Fraser St 1.00pm-3.00pm every second Thursday of the month. Light refreshments will be available. Please feel free to bring a plate to share.

Tauranga Coffee/Social Groups

These are casual meetings with no set subject or discussion points and are essentially volunteer/member run. We are looking at extending these social groups in 2020. If you'd like to help run one in your area, please get in touch with [Charlotte](mailto:charlotte@ccisupport.org.nz) on charlotte@ccisupport.org.nz or Phone or Txt: 027 625 4449

Mitre 10 Mega - Cameron Rd, Gate Pa - Wednesday 18th December 10.30am.
RSVP: Sharon on 07 578 1819 or via the Facebook group.

Tauranga Carers series 1

TWP Carers 12th March
General Members 9th April

Tauranga Towards Wellness Programme Tauranga 2020

TWP Series 1 workshops 10am-12pm on Tuesday commencing 4th Feb.
TWP Series 2 workshops 10am – 12pm on Tuesday commencing 9th June.

If you'd like further information on the Carers or Towards Wellness courses, please contact [Waltraut](#) or [Charlotte](#).

Free Counselling service in Tauranga 2020

We have the opportunity of having some 2nd year counselling students in 2020. We would like to offer this free counselling service to our clients. The counsellors are highly recommended by their coordinators and they will provide high quality service. This counselling will be offered for all ages and it will be provided in a strictly confidential environment. Please contact Waltraut on waltraut@ccisupport.org.nz or phone/txt: 027 625 4449 if you would like to participate in this.

WHAKATANE Meetings

Monthly meetings are held at the Whakatane Library 1.30pm-3.00pm approx. every second Wednesday of the month. Tea and coffee are available, and I encourage self-management of time, comfort and different modes of seating.

Coffee Catch-ups

Held on the fourth Tuesday of each Month at 10.30am at a local café with the aim of finding a suitable set café.

January 28 th	Roquette – 23 Quay St WHK
February 25 th	Julians Berry Farm – 12 Huna Rd WHK
March 24 th	Javaman – 214 The Strand WHK

ROTORUA Meetings

Rotorua Lakes Monthly Meetings are every 2nd Wednesday of the month 1pm-2.30pm at Rotorua Library meeting room. Social/Coffee groups are to be confirmed.

Please note: Some of our members are sensitive to chemicals. Please refrain from using perfumes/strong deodorants before the member meetings. Thank you for understanding. Suggested cafes can be changed by membership at any time. These are casual meetings with no set subject or discussion points and are essentially member run.



Facebook:

Just a reminder, for paid members, we have an online members [Facebook page](#). Keep up with the latest research, make friends and support each other.

Contact your Field Officer for more details.

Library

We have a great resource library packed with interesting and informative reads, including audio. Please feel free to contact one of our Field Officers and arrange a visit to borrow books from our library. RETURNS: If you do have any of our resources/library books and they are due back (borrowed prior to 6 October 19), please contact your field officer about having these returned. Thanks so much.



Donations, Subscriptions and Volunteering:

DONATIONS: We want to thank all those people who donate time and/or money to CCIS, on top of their annual subs. As a charitable organisation, we rely solely on donations, grants and subscriptions in order to provide the support for our clients. So every \$

counts. We are registered with IRD as being for charitable purposes, so donations are tax deductible. In April, you will receive a tax receipt for all donations made during the financial year. Thank you for supporting us.

SUBS: Thank you to all who have paid their 2019/2020 membership subscriptions. These are gratefully received. Membership cards: I have been asked about these, but unfortunately at this stage CCIS will not be issuing cards. This will be reassessed in 2020. I'm happy to talk to a volunteer about helping set this one up again.

Please note: that our bank no longer accepts cheques, but subscriptions and donations can be paid via cash or made at any time into our bank account.

Our bank details are: Kiwibank: Complex Chronic Illness Support Incorporated 38 9014 0140507 00. Please add your name as reference.

VOLUNTEERING: We now offer some of our clients and other volunteer agencies the opportunity to micro-volunteer at CCIS. For some, it is a bridging towards testing the waters about returning to the workforce, for others, it's just a feeling of contributing back. *Micro-volunteering* is when people complete small tasks to help run a larger project in a no pressure, stress free setting. If you are able to help out for an hour or two, even just for one day, your help would be greatly appreciated. Please contact Charlotte or the office if you are interested.

Phone: 07 281 1481 or 022 658 0251 Email: info@cciusupport.org.nz

Thank you for your support.

Appreciation to our Funders for the 2019/2020 financial year



Board of Management:

Keith Appleton: President and Treasurer
Sarah Davey: Board Member

Matt Appleton: Vice President
David Harris: Board Member



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This Messenger Newsletter is made with help from our sponsors, if you would prefer to receive this via email please contact us on the above contacts and we will arrange it for the next edition. Thank you.



Simmaron Research

Scientifically Redefining ME/CFS

Solid Ground at Last? Cytokines Make Good in Major ME/CFS Review

Cort Johnson

November 25, 2019

cytokines, IL-2, TGF-B, TNF-a

25 Comments

The immune system in chronic fatigue syndrome (ME/CFS) has been kind of like a mirage in the desert. Given the way the disease starts and its symptom presentation – so close to the “sickness behavior” produced during an infection – it seems that the immune system must be a major player in this illness.



Powerful immune factors called cytokines seem like they must be involved in ME/CFS but inconsistent results have caused them, like a mirage in the desert, to slip away again and again (Image by TravelCoffeeBook from Pixabay)

Like a mirage in the desert, though, the powerful drivers of the immune system – the cytokines – seem to slip through our grasp again and again. Interesting findings pop only to be dashed by another study.

Thirty plus years of study have left us – according to several immune reviews – with precious little solid ground. A **recent review**, however, suggested that larger studies were finally producing more consistent results. Now we have the largest “study” of all – a meta-review of past cytokine (inflammatory protein) studies – that’s providing us a solid foundation, and from the unlikeliest of places, Kings College in the U.K., which has been better known as a bastion of cognitive behavioral therapy.

The senior author of the paper, the rather prolific Anthony Cleare, has focused for years on the HPA axis in ME/CFS. He and the lead author, Rebecca Strawbridge, have shared an interest in the role inflammation plays in HPA axis issues and depression. Strawbridge’s recent paper on the effectiveness of **anti-inflammatories in depression** clearly underscored how often inflammation instead of psychology is driving depression. Their new paper’s rather emphatic title “**Inflammatory proteins are altered in chronic fatigue syndrome-A systematic review and meta-analysis**” seemed to give notice that things had changed. ME/CFS is, at least in part, an inflammatory disease after all.

The review was broad: any diagnostic criteria was allowed and the main exclusionary criteria was that no stimulation of any kind was involved; i.e. this was an assessment of the immune system at rest. The 42 studies involved highlight just how hard researchers in this small field have searched for an immune cause of ME/CFS.

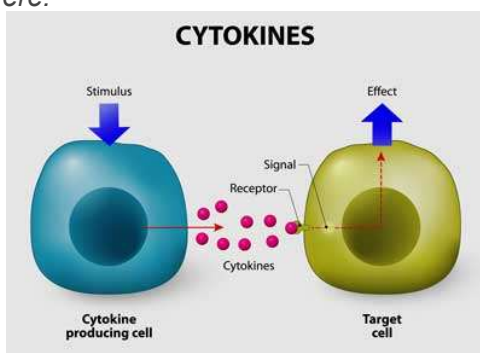
The authors of the present paper pointed out why the immune system has been such a draw for this field. “Phenomenologically” they noted, “ME/CFS is often described as a ‘flu-like illness’ and the diagnostic criteria to

some extent resemble the symptoms of sickness behaviour.” (Sickness behavior describes the symptoms produced by the brain during infection (fatigue, pain, cognitive problems, etc.) that serve to isolate an individual from the community – and thus help stop the spread of a pathogen).

The Review

The vast majority of studies used either the Fukuda or the 1994 criteria created by the CDC. Both criteria have been mostly discarded in favor of more recent criteria but it should be noted that most ME/CFS studies – including many with positive outcomes – used one or other of these definitions. (Only 8 of the 42 studies used the Canadian or International criteria – which may have issues of their own.)

Despite the broad criteria (Oxford definition, CDC definitions included) used in most of the studies, this meta-review actually found evidence for an inflammatory state in ME/CFS. The authors hypothesized that pro-inflammatory cytokines and acute phase protein levels would be significantly higher in people with ME/CFS than controls, and low and behold, *they were*.



Cytokines and other inflammatory proteins turn on (or off) the immune system. High levels of pro-inflammatory cytokines produce inflammation.

Approximately 22 cytokines/immune factors were assessed in 42 studies dating from 1989 to 2016. The review suggested that about a quarter of the immune factors assessed in ME/CFS were elevated.

Elevations of two cytokines (tumor necrosis factor- α (TNF- α), c-reactive protein (CRP)), both of which have wide ranging effects, suggested that ME/CFS was similar to other “chronic immune conditions” which have a similar cytokine profile.

Synchronicity

A recent gene expression study highlighted both TNF- α and TGF- β as well. In fact, that study identified **precise** pathways associated with TNF- α which might potentially be targeted in ME/CFS. The fact that these cytokines are popping up in independent studies suggests we may finally be honing in on some key cytokines that are producing fatigue, pain and other symptoms in ME/CFS.

Cytokines involved in regulating inflammation ((IL-2, IL-4 and TGF β) appeared to be particularly affected. Three cytokines (IL-6, IL-1 and IL-12) involved in the early response to infection (perhaps suggesting viral reactivation was present) tended to be increased as well but were less consistently elevated. Interestingly, given the hypothesis that immune exhaustion occurs over time in ME/CFS, no trends in reduced cytokine levels were found.

Capturing Smoke in a Bottle

The authors noted that some similar (but different) findings have been found in fibromyalgia and depression, and that given the widespread co-occurrence of all three disorders teasing what is caused by what is tricky. Noting that fatigue is found in both ME/CFS and depression, and that inflammation can produce “disabling fatigue”, the authors suggested future studies more clearly delineate the extent of depression present. Activity levels and medication use – both of which can affect the HPA axis or immune system should be characterized. .

The review also noted, as did Van Elzaker's rather scathing recent review of **cytokine studies**, that measuring cytokines is a bit like capturing smoke in a bottle. Their levels fluctuate constantly and can be effected by activity levels, diet, medication use, weight, age, sex and "numerous other factors".

For instance, it's clear that activity levels, diet, medication use – all factors which could skew cytokine findings – will probably be different in ME/CFS patients. Therefore, they could by themselves account for the altered levels found. Plus a bunch of other factors (severity and duration of illness, illness triggers, illness history, sample collection, processing, storage) could all tweak cytokine levels.

Given that few ME/CFS studies accounted for most of these factors (and mostly used outdated criteria) it seems remarkable that the review found consistent results at all.

A Plea for A Cytokine Study (To End All Cytokine studies)

Once again, for the umpteenth time it seems, the authors left us with a plea for larger, more rigorously controlled studies. The authors, in fact, recommended what sounded like a cytokine study to end all cytokine studies. That study would subgroup patients, assess all confounding factors and then follow the patients over time (longitudinal study).



The authors "fervently" hoped a large, rigorous cytokine study could identify key cytokines that could be targeted with drugs.

A very large study using the best criteria available could tease out definitive immune biomarkers and pave the way for potential treatments. The increasing number of biologic drugs being developed to target specific cytokines make that drug arena a potentially very fruitful one for ME/CFS.

Dr. Klimas is certainly on board. Her Enbrel (plus mifepristone) trials in ME/CFS and GWI indicate she thinks she's already found a target. Enbrel, interestingly, targets TNF-a – one of the cytokines the review found elevated in ME/CFS.

Breaking their British reserve a bit at the very end of the paper, the authors stated they "fervently" await better studies so that they can conduct a more comprehensive meta-analysis- and better understand the role that inflammatory proteins play in ME/CFS.

One wonders if we could be just one or two very big, rigorous and comprehensive cytokine studies away from identifying an FDA-approved drug that could help many. This review will surely provide support for studies like that.