

Messenger

March 2021



A note from the Operations Coordinator

Welcome to another year.

2021 looks to be another year of uncertainty when it comes to Covid19. Things at Complex Chronic Illness Support are more certain. We are here and we are willing and able to support you. No matter what. We are looking forward to some new and innovative projects this year, which I'm hoping to confirm in the near future too.

CCIS Waikato It is with great pleasure that I can say that MS Waikato and CCI Support have come to an agreement. CCI Support will take over all of the support for CFS/ME & FM clients from the Waikato region. Effective immediately (transition time for clients to move across is till 1 April).

We now have a new Field Officer, Tracey Larsen, the current Waikato support worker (who has been there for almost 7 years) will continue in this role.

Why have we done it?

- MS Waikato were looking for other options for the service.
- They came to us to ask if we would be interested in taking it over.
- During Covid lockdown, I was on a zoom meeting with the Charities Service and it was their recommendation to pool resources etc.
- It will give us a bigger foothold for funding and a bigger voice, should we wish to make political waves.
- It just made sense to take up the mantle.

We were funded to look into the possibilities and make it happen. So we will now have:

- CCIS Western Bay of Plenty
- CCIS Eastern Bay of Plenty
- CCIS Lakes District
- CCIS Waikato

CCIS New Zealand, at this time we are only able to work with people in the Bay of Plenty and Waikato regions. This is due to funding being limited outside of these areas. Once we secure National funding (which we are actively working on), we will be able to provide services further afield.

Miranda Whitwell - Operations Coordinator.

53 FRASER ST, TAURANGA

Hours: Tuesday to Friday
operations@ccisupport.org.nz

9am till 2.30pm
07 281 1481 or 022 658 0251



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From Charlottes desk in the Western Bay of Plenty



Charlotte Kelp

Field Officer

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027 625 4449

Office Hours

Tuesday to Friday

8am till 1.30pm

WBOP@ccisupport.org.nz

I would like to begin by saying I do hope that everyone involved in our CCIS whanau have had the opportunity to enjoy their part of the beautiful country we call home. I would not be a true Brit if I didn't mention the weather and holey moley I have loved the sunny days and the rainy days! The temperature is just becoming comfortable and delightful like a subtle but tangible weight lifted.

This month we have been busy in the office with lots happening and many visitors. One included a special visit from local Labour Party MP, Angie Warren-Clarke. During our meeting we covered a lot of ground including the day-to-day challenges of our members, from gaining a diagnosis to the need for more community resources. We also discussed limiting ideological assumptions and stigma,

which are often perpetuated by the very systems that are designed to support and protect our cohort. It was great to be able to say that the dialogue is certainly changing with the current conversations around "long haul" Covid. We shared the exciting recent growth of our organisation and our resourceful capacity to support those with chronic illness. We were also realistic in discussing limitations around funding and resources. It was an upbeat and positive conversation and Angie was sympathetic to current circumstances, especially having personal connections to some of the conditions we support. The next step is to create a report on our data for office and keep the conversation open. Watch this space....

Charlotte Kelp WBOP FO

Lakes District—ROTORUA/TAUPO

Well, it has been an interesting start to the year. Rotorua had its first members meeting where we learnt a lot about knowing your rights and what help is available to us. It has been great to welcome some new members into CCIS Lakes district and hopefully we will see an increase of members at these meetings.

So, I have been pondering grieving this month. Not grieving for a person but grieving for the things that might have been and for the things I use to be able to do that I can no longer physically manage - I definitely do not miss being able to clean my bathroom, happy to hand that chore over. If you are also feeling this way, I just want to let you know that you are not alone and that these thoughts and feelings are quite

normal as we navigate life with a chronic illness. I have found discussing my feelings towards this has helped me. I have also realised that there is a lot I can still do and some new things I now do that I probably would not have taken up if my life remained chaotic and stressful. Yes, some days I miss the old me, but I am really enjoying getting to know the new me. The other useful tip is there are counsellors available who specialises in grief (of all types) and how to cope with it. It is okay to seek help when we are not coping.

I am looking forward to visiting Taupo next month and I will hopefully see some of you at the next Monthly Members meeting.

I hope you stay well and happy.



Tabitha Ramsay

Field Officer

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020 401 79091

Office Hours

Tuesday and Friday

9am till 2.30pm

lakes@ccisupport.org.nz

Greetings from the East.

So, it is a new year, a chance for a fresh start and to find some new growth in our lives. It has been wonderful to be contacted by members recently to inform me of the progress that they have made over the last year. Sharing in the joy of improvement is always heartening, I have also spoken to many members who are having a hard time now. I feel very privileged to learn about these tough days too. Many people assume that the pathway to recovery for our conditions is a straight line, but it is usually anything but direct! That is why it is so helpful to have the community of CCIS as a shoulder to lean on when it gets tough.

If you are wanting more CCIS community connection, then please attend one of the many monthly meetings. Each area has a physical in person meeting and we have the more accessible Young persons (12-20 yrs) and National meeting held online where any member of our CCIS whanau is welcome to attend these if they suit their needs better.

I am looking forward to a year of connection, fresh new dawns and scattering of hope for us all. I look forward to sharing this with you, my CCIS Whanau.

Ka kite ano au i a koutou, Elizabeth



Elizabeth McGougan
Field Officer

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9am - 2.30pm

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Tracey Larsen
Field Officer

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From the Waikato Desk

Hello Everyone

My name is Tracey Larsen and have been supporting the ME/CFS & FM community in the Waikato region for the past 7 years. I am very happy to be joining the CCIS team and look forward to expanding the Waikato service under CCIS guidance. Many of you may have already met my clients via Facebook, and in time, connect with some of them through online support meetings. If you have any family or friends in the Waikato region who require support, please feel free to pass on my details. Nga mihi.

Tracey

DR VALLINGS IS COMING TO SPEAK IN HAMILTON

Thursday 13th May

Time and Venue to be confirmed. Keep an eye on the Facebook page and emails from Tracey for further information about this.



National Members Report

Unfortunately, at this time we are only able to accept new referrals from people in the Bay of Plenty and Waikato regions. This is due to funding being limited outside of these areas. However, once we secure National funding (which we are actively working on), we hope to open up for National Members again



Towards Wellness HUB

It has been confirmed that we now have funding to create a 'Towards Wellness Hub' on our website. So we will be working on this and hope to have it up and running by the end of the year. Essentially, it means wherever you are and whenever you want access, the Towards Wellness programme will be available. It's still in the early stages of development, but I welcome any feedback as to what you'd like to have us include. Please feel free to email operations@ccisupport.org.nz any recommendations.

Towards Wellness Programme

Registrations are closed for Intake 1. Taking expressions of interest for Intake 2 now.

Cost \$200.00 for TWP1 ten two hour workshops held fortnightly, TWP2 is \$100. We also take part payments too if that is needed.

To register your interest email your field officer.

WELCOME TO OUR NEW STAFF!

It is official - Kelsi England is officially the Field Officer Assistant. She will be based in the Tauranga Office and will support the Field Officers in the production of publications and powerpoints, manuals and keep them organised. Welcome Aboard.

Kia Ora

Many of you will already know me, but for those that don't know, my name is Kelsi England. I have qualifications in Business Administration & Computing and Body Therapy.

My first experience with chronic illness began in January 2016. I went through the medical system for approximately 2.5 years, only to find myself with more questions and little to no explanations for what was happening in my own body. It was a really scary, unsettling time and I understand what it is like to go through that. I ended up finding my own path through alternative, holistic medicine. This was a massive turning point for my health and I slowly started to feel better. On the way, I've developed a passion for herbal medicine and spend a decent amount of my free time further educating myself on this.

I also have a reasonable amount of experience in mental health, mainly PTSD, anxiety and agoraphobia. I try my best to treat people with kindness and empathy, or at least not make their day worse! I am so grateful to be in this role and I look forward to meeting everyone.



NZ Covid Vaccine

We are in the process of putting together some information about the Covid vaccine. Please keep an eye on the Facebook private CCIS group or our website for further information.

Complex Chronic Illness Support Inc.

IT'S TIME TO RENEW YOUR MEMBERSHIP



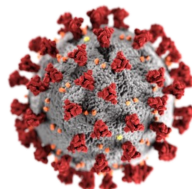
Contact us:
07 281 1481 or 022 658 0251
www.ccisupport.org.nz
info@ccisupport.org.nz

Once a year we ask our members to contribute to CCIS in a small way financially, it shows that they are committed to the cause and value us as an organisation. With a membership that is pro-active and engaged in the support services we provide, we show our funders and the community that CCIS is an integral part of support for not only the members, but their whanau/families, local health professionals and the community.

For \$40 annual subscription, you get access to:

- ☐ Qualified Field Officer support and advocacy.
- ☐ Newsletter - MESSenger
- ☐ Group support meetings - educational
- ☐ Special interest speakers and workshops
- ☐ Social groups
- ☐ Library - books & other resources are available for you to borrow
- ☐ Membership to our Private Facebook community.
- ☐ Access to our Towards Wellness and other Programme/s

Please see a membership form enclosed



Due to Covid:

Please use hand sanitiser provided upon entry to the building, scan the QR code and sign into the iPad on your left.

A staff member can help you with this.

Many thanks in advance for your cooperation with this



Complex Chronic Illness Support

Empowering People Towards Wellness

New Opportunities

Paid Roles

- Funding/Marketing officer
- Graphic Designer
- Filming Editor

Volunteer roles available:

- Newsletter writing/production
- Board Meeting minute taker
- Event Coordinator

We are looking for some special people to fill some vacant roles at CCIS. If you know anyone who would be interested in the roles, please let me know asap.

Thanks. Miranda - operations@ccisupport.org.nz



Supporter Workshop

Renaming of carers / loved ones workshop to "Supporter Workshop" – for HPs, family and friends or anyone wanting to know more about ME/CFS. Designed to inform and provide education of ME/CFS/FM including how to support those living with these complex conditions.

Workshop date Saturday 10th April 10am,

TAURANGA: 53 Fraser Street,

invites will be sent out this month.

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.*

Monthly Members Meetings.

April focus is **How to manage the fear of change**

May focus is **ME/CFS/FM Awareness Month**

June focus is **How to get good 'Rest'**

Tea and coffee are available and we encourage self-management of time, comfort and different modes of seating. Please refrain from wearing perfume, as some clients are chemically sensitive.

Tauranga

Second Thursday of the month 10.30 - 12pm

53 Fraser St

April 8th

May 13th

June 10th

Hamilton

Second Thursday of the month 10.30 – 11.30.

Melville Methodist Church Corner Bader Street & Normandy Ave, Melville, Hamilton

April 8th

May 13th

June 10th

Whakatane

Second Wednesday of the month at 1.30 pm

Whakatane Lyceum Club Rooms - 58 Domain Road Whakatane.

April 14th

May 12th

June 9th

Rotorua

Second Wednesday of the Month from April 11am – 12:30pm

The Arts Village – Herberts Room – 1240 Hinemaru Street, Rotorua

April 14th

May 12th

June 9th

Online Members Meeting

Is for all our members who want to attend a monthly meeting but do not have the extra energy to leave their homes. You must register with your Field Officer for this one.

Second Friday of the month on Zoom at 1.30 pm

April 16th

May 14th

June 11th

Young Persons ONLINE Group

Second Tuesday of each month at 1:00 pm – 2:30 pm.

It is on Zoom and run by a volunteer member who will cover CCIS monthly meeting content but will do it in a youth focused way.

The group is open to all members aged between 12 - 25 yearsil elizabeth@ccisupport.org.nz to be added to the list.

April 13th

May 11th

June 8th

Social Groups.

These are casual meetings with no set subject or discussion points and are essentially member run. The Kaupapa of the groups are to empower connections with each other, learning helpful information for management, sharing, laughing and appropriate friendships. Finding friends who experience what you experience is so very important. It is difficult to keep your friends when you live with a condition that means you can't go to social events when you want to. So, finding a person who understands and "gets it" can be so empowering and helpful.

Greerton Coffee Group

Venue: Greerton Mitre 10 Mega (3rd Wed of each month) 10.30am

April 21st

May 19th

June 16th

Papamoa Coffee Group

Please call Sonya if you have any more questions or would like more information about the group 027 753 2973

Venue: Double Teaspoons (outside foodcourt), Papamoa Plaza, 10.30am

April 7th

May 5th

June 2nd

Tauranga Social Group

Venue: Grindz cafe, 50, 1st Ave, Tauranga
(Last Friday of each month) **10.30pm**

April 30th

May 28th

June 25th

Young at Hearts Social Group

Venue: CCIS Offices, 53 Frasers Street, Tauranga
(1pm - 2.30pm 4th Tuesday of each month)

April 27th

May 25th

June 29th

Waikato Social Group

Venue may change, you will be advised of location by email a week prior. 10.30 – 11.30am

April 20th

May 25th

June 22nd

EBOP Coffee Catchup

4th Tuesday of the month at 10.30am

April 27th - Robert Harris – Cnr Strand & Richardson WHK

May 25th - Javaman – 214 The Strand WHK

June 22nd - Red Barn – 237 Thornton Road Thornton

New Social Groups starting soon

in Rotorua, Katikati, and Bethlehem

Please let your Field Officer know if this is something you are interested in attending.



SIMPLY LIVING

I have been reading and thinking about slower living and how I can live a simpler lifestyle. I have been pondering on how to simplify routines and live a more peaceful existence. My first baby step is to stop writing to do lists, this seems so counterintuitive to me but I have recently become familiar with term creative thinking and I like this way of recording things in my diary much better. My next plan is breathing (my way), followed by sitting, becoming lost nature, and then taking slow walks barefoot, followed by who knows what yet.

A thing I have always been fastidious about is donating items that are surplus to requirement, but now I am looking around and questioning “do we really need all this stuff”? I remember the very day I arrived in New Zealand with only a couple of suitcases and a big sense of wonder, and it felt amazing. Of course it doesn't take long to accumulate items, so 14 years later, here I am bogged down again with too many things and not enough homes. I have always loved reading about the concept of minimalism, “intentionally living with only the things that I need” and obviously this is open to interpretation! But, I have always been resigned to thinking, well I have a large family, this type of living could never be a reality for us. But that is just perpetuating the exact type of thinking I am trying to release myself from. Minimalism does not have to be an absolute adjective, I've figured it can also be a verb as in doing or practicing. Here a little reframing will go a long way to make this fun and manageable.

This will not be my perfect project but one that begins with gentle decluttering and thinking twice before heading to the mall. Living in a busy household, I find myself dashing to the shops for one thing or another but am now experimenting with improvisation. OK, so swapping the empty tube of tomato paste out for tomato ketchup in a bolognaise isn't exactly the most creative thing I have ever done, but it feels good all the same! I do have visions of upskilling in simple living and it certainly seems something worth celebrating just for the shift in thinking. This season, for me, is about noticing habitual unquestioned behavioural patterns and redefining what has a place in my day to day living. My intention is to live a less consumer driven existence (including social media) and a more wholehearted life. I am still figuring out what this means and what changes I will encounter. Just for now though, its feeling like a breath of fresh air knowing that I have an option to make these changes no matter how small they might seem.

For information on minimalism check out:

<https://www.theminimalists.com/minimalism/> – “Joshua Fields Millburn & Ryan Nicodemus help over 20 million people live meaningful lives with less through their website, books, podcast, and Netflix films”

The Art of Letting Go with Joshua Fields Millburn and Ryan Nicodemus – TEDx Talks <https://youtu.be/w7rewjFNiys>

Charlotte—WBOP Field Officer

ME/CFS new information for General Practitioners.



There has been a flurry of activity in the media recently with Prof. Warren Tate, Dr Rosamund Vallings and others speaking with the media about new research in ME/CFS. The interest of the media has been piqued by Long Covid Syndrome which Dr Vallings suggests maybe Post Viral Syndrome (Radio New Zealand, 03.02.2021).

This new media exposure is very heartening for the ME/CFS community and it is even more encouraging to see that the NZ Doctor magazine has republished in their February edition excellent article on "How to treat ME/CFS" written by Dr Cathy Stephenson and Psychologist Rose Silvester. This will land in many medical practices all over the country which will enable many more medical professionals to learn more about the condition.

Additionally, the Goodfellow Unit which provides continuing education for General Practitioners has created a Medcase for ME/CFS written by Dr Vicki Mount, General Practitioner, with expert review by Dr Rosamund Vallings. This document is written specifically for General practitioners around diagnosis and treatment of the condition.

This increased media exposure is long awaited, and it may signal an increased awareness from the wider community in the condition. The hope is that this will not be another flash in the pan but a sustained increase in awareness raising.

Members can also do their own awareness raising, by forwarding the recording links, magazine articles, and article links on to friends, family, and medical professionals.

Elizabeth.
Eastern Bay of Plenty CCIS Field Officer

Reference:

RNZ – Nine to Noon – Kathryn Ryan interviews:

Radio New Zealand. (03.02.2021) Dr Rosamund Vallings on Covid long-haulers and CFS-ME

<https://www.rnz.co.nz/national/programmes/ninetoonoon/audio/2018782096/dr-rosamund-vallings-on-covid-long-haulers-and-cfs-me>

Radio New Zealand. (10.02.2021) Understanding long haul Covid-19

<https://www.rnz.co.nz/national/programmes/ninetoonoon/audio/2018782946/understanding-long-haul-covid19>

Stephenson, C. Silvester, R. (2021, February 3rd) How to treat ME/CFS, New Zealand Doctor.

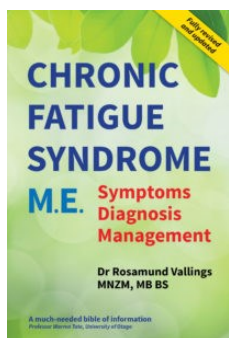
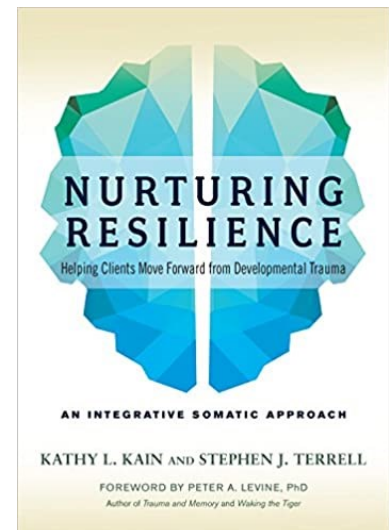
Mount, V. Vallings, R. Chronic fatigue syndrome/Myalgic encephalomyelitis. Managing CFS/ME in general practice: new ideas. Medcases. The Goodfellow Unit. <https://www.goodfellowunit.org/medcases/chronic-fatigue-syndromemyalgic-encephalomyelitis>



Nurturing resilience

by Kathy L. Kain, PhD
and Stephen J. Terrell, PsyD

This is a fantastic read if you are interested in how trauma can effect our psychology and physiology. The authors detail how early childhood trauma can be stored in the body and create chronic illness. A broad scope is covered from early childhood attachment types to tools and strategies to restore resilience. The book expertly outlines the physiology of the Autonomic Nervous System and Stephen Porges 'Polyvagal Theory'. This book is well laid out so you can choose the chapters that most interest you. *Charlotte*



Chronic Fatigue Syndrome M.E. Symptoms, Diagnosis, Management

by Dr Rosamund Vallings MNZM, MB BS

A big thank you to ANZMES who have donated four new copies of Dr Rosamund Vallings fully revised and updated book. We are so excited to have this latest edition of a book that has been so helpful and informative to so many. Dr Vallings is a leading expert in the field of ME/CFS with more than 40 years experience of helping people with chronic conditions. The book describes accurate diagnosis, the bodies systems and functions, strategies for dealing with symptoms and includes the latest research. Each CCI Support area has a copy of this book so speak to you Field Officer if you would like to borrow one.

Creamy White Chocolate Mousse

I am Tabitha (Lakes FO) and I'm addicted to baking/making tasty treats.

I really cannot help myself especially if my tummy is happy to eat it. Here is a simple and very tasty recipe I made recently.



This recipe is by Chef Bridget Davis, she lives in Australia but is a kiwi, she experiments with healthy and gut friendly recipes. The recipe below can be found from the following link:

Creamy white chocolate mousse

Gluten free | Dairy free | Sugar free | Vegan friendly

Makes enough for 2 serves

You will need to start this recipe the day before you intend to serve it as you will need to leave a can of coconut cream overnight in the fridge.

Ingredients

75 g (2.6 oz) sugar free, dairy free, gluten free white chocolate chips or pieces

1 x 400 g (14 oz) can of full fat coconut cream, left overnight in the fridge.

1 tsp pure vanilla extract

Topping choices

7-10 whole raspberries or other fresh berries

1-2 chopped nuts/seeds

Method

Place the chocolate into a small heatproof bowl and position the bowl over a small pot of simmering water, ensuring that the base of the bowl does not come in contact with the water. Using a spatula or spoon, stir the chocolate a few times as it melts till it's smooth and liquid.

Carefully remove the cold can of coconut cream from the fridge and using a tablespoon extract the firm coconut cream from the top of the can until you have 150 g (5.2 oz) in a bowl. Whisk the thick cream in a bowl with the vanilla extract. Add the melted chocolate to the coconut and whisk well to combine.

Spoon the mousse into 2 decorative glasses or bowls and if the mousse is a little liquid, cover with cling film and leave in the fridge for 30-60 minutes to firm up a little. If your mousse is already fairly firm, evenly portion into your serving glasses or bowls and finish with your chosen toppings.

Serve or store in the fridge for up to 3 days.



The Community Noticeboard

This is a space we have created in our newsletter to give locals and members the opportunity to share notices. Please email or call a Field Officer to add your notice for our next bimonthly newsletter.

Keeping yourself and clients safe online

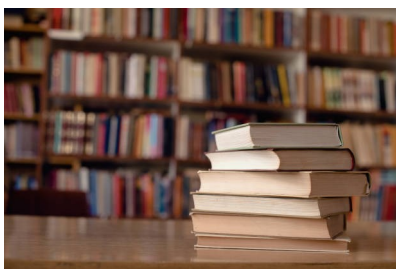
"A local social enterprise, Safe Surfer, is working hard to keep people and children safe online. They have a free app that allows you to block ads, pornography, gambling and manage screen media over use. This can be a useful tool for assisting clients struggling with these types of issues. There are lots of other services as well, check it out for yourself and for your clients".

www.safesurfer.co.nz



It's important for planning, it's important for funding and it's important we get the service right for you. Please fill in the annual members survey attached and return to CCIS.

Thanks so much!! The team at CCI Support.



LIBRARY UPDATE

The Library Catalogue is now online or just drop in after the members meeting and have a look at the treasures on offer.

The CCIS Library is online, which means you will be able to browse through our library book titles from the comfort of your home. If you spot a title you would like to read, we can reserve it for you until you stop by and collect it. If you are interested in reading one of our many treasures, please stop by and check out a book, we have lots to choose from! We also aim to provide short book reviews to give you a quick synopsis of the books content for your online perusal. If you would like to support this mammoth bookworm task, we would love your short book review for our library. If you have any book recommendations to add to our library, relevant to the conditions we support, please contact your Field Officer to make a request. If you have borrowed a book that has passed its **4 week** return date, please could it be returned to the office ASAP. Please do not pass on books to other members of CCIS, they need to be returned and checked out by that person, you are responsible for any books checked out under your name. Thank you



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.

It is important to get a sensible amount of unfiltered light directly on the skin each day (for vitamin D absorption and melatonin release).



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.

COMPLEX CHRONIC ILLNESS SUPPORT

Complex Chronic Illness Support Inc. is a charitable organisation that was set up in 1981 in the Bay of Plenty region to support, connect, advocate and educate people diagnosed with Complex Chronic Illnesses to improve the quality of their lives. We provide this service across the Bay of Plenty including Tauranga, Whakatane and Rotorua.

THANK YOU TO OUR AMAZING SPONSORS AND DONORS



BOARD OF MANAGEMENT:

Keith Appleton: President and Treasurer

Matt Appleton: Vice President

Sarah Davey: Board Member

David Harris: Board Member

Karen Moulton: Board Member

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