



**Empowering People Towards Wellness** 

2024

PREPARED BY Miranda Whitwell - CEO

# ANNUAL REPORT & FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 MARCH 2024

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## Vision, Mission, Purpose & Values

#### VISION

Complex Chronic Illness Support's vision is to Empower People Towards Wellness.

#### MISSION

The vision focuses our mission to improve the quality of life of people who live with a complex chronic illness, as well as that of their loved ones.

#### PURPOSE

The vision and mission drive our purpose to empower and educate members and advocate for their needs and their lives.

#### VALUES

These concepts fit the values like a jigsaw puzzle. Together they complete the picture that embodies our organisation. In determining values appropriate for the organisation, we considered the use and application of the values, including our culture, brand value, what drives decision-making, and how we support and deliver our services. The values that underpin our organisation are:

Empowering – People move forward with their journey towards wellness when they are empowered to take charge of their own health, with knowledge and boundaries. Person-centred – People are at the heart of everything we do, and we are led by their needs. We design services to meet people's needs now and in the future.

Collaborative – We believe to make change happen, we need to bring people, ideas and resources together. Partnerships and teamwork are fundamental to our success.

Adaptable – We acknowledge the world around us is changing and we need to change by innovating and applying creative solutions to move forward. We are resourceful in response to this change.

Accountable – We deliver on our promises and hold ourselves responsible. We are honest, candid, transparent and respectful in all aspects of our work, applying good judgement for effective decision-making.

Culturally Responsive – Our organisation reflects the cultural context of NZ/Aotearoa through the recognition and understanding of Te Tiriti o Waitangi, with cultural competency and ability to relate to diverse needs - ensuring holistic management plans are individualised to encompass the beliefs, values, and customs of their user.

# OUR STORY

#### **Background Information**

CCI Support is a non-profit Incorporated Society in New Zealand / Aotearoa. We are the largest Oneon-One support service for people with ME (Myalgic Encephalomyelitis) / CFS (Chronic Fatigue Syndrome) in NZ. We are made up of many small regional groups that provide personalised support and care for people with complex chronic illnesses, including Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME / CFS), Fibromyalgia, Post-Viral Fatigue / Syndrome, some Dysautonomia conditions, and Long-COVID. This is achieved through trained volunteers placed throughout the country to facilitate social groups and provide support for the Health & Wellness Facilitators, as well as manage our social media.

Our roots date back to 1981 with the formation of ME / CFS Support (BoP) Inc., which became incorporated as a registered charitable trust (No. CC20874) in 2008. In 2017, it was rebranded to our current name – Complex Chronic Illness Support. In these recent years under the stewardship of the CEO, the organisation has made remarkable progress, including the establishment of The Towards Wellness Programme (TWP) in 2015, which is considered the jewel in the crown of the organisation.

Those with complex chronic illness experience symptoms which severely impact their day-to-day life, such as extreme physical and mental fatigue, muscle and joint pain, impaired memory and concentration, sleep disturbance, headaches, gastrointestinal issues, and anxiety.

In line with contemporary research, our innovative services deliver superior support services to empower people to navigate their own individual wellness paths skillfully. Positive change in our CCI Support clients is achieved by offering a range of services backed by a team of qualified Facilitators, supportive staff and Board, and members who find connections, encouragement, and relief in a safe community.

CCI Support members progress from a life of fatigue, pain, and isolation towards an improved quality of life, re-engaging with their whānau and community, with an increased ability to participate in a life which is meaningful – And achieving our purpose to 'Empower People Towards Wellness.'

#### OUR KEY POINTS OF DIFFERENCE

- Our services are here to facilitate positive change in people's lives
- We are research-informed, not research-driven
- We focus on the now Not the cure
- We are more than just a support group, we offer holistic and practical support, for the entire whānau.



# STRATEGIC PLAN

There are a number of strategic initiatives under each of our six foundational pillars – Leadership / Advocacy, Education, Knowledge, Membership Engagement, Cultural Responsiveness and Sustainment.

Imperative actions are the significant tasks and projects that must be completed alongside and in addition to business-as-usual activity, if strategic priorities are to be achieved.

า 2023 - 2028	Values	Empowering, Person-Centred, mplex Collaborative, Adaptable, Accountable, Culturally Responsive.	Strategic Priority ess Funding & Sustainment	the second statement The organisation is fully funded and sustainable their through the volumed	and	Key Focus Areas	alth Governance and operational d excellence	i o Efficiency and effectiveness of our operational systems and processes	eliefs, Capability and productivity not of our people	lusive Prudent stewardship of ext of financial resources	al Establishment and maintenance of key d and relationships with investors
rategic Plar	Mission	ove the quality of life of people who live with a co chronic illness, as well as that of their loved ones.	<b>Strategic Priority</b> Cultural Responsiveness	Success statement All members feel that their individual cutture is respected	valued, understood, and integrated into their individualised holistic management plans.	Key Focus Areas	staff trained to use health models in NZ context	Recognition of Te Tiriti o Waitangi	Inclusion of members' beliefs, values, and customs into management plans	Support services are inclusive of the multicultural context of NZ/Aotearoa	Member feedback on organisational cultural competence is evaluated and recommendations acted on.
Complex Chronic Illness Support Inc. Strategic Plan 2023 - 2028	Mis	To improve the quality of life of people who live with a complex chronic illness, as well as that of their loved ones.	<b>Strategic Priority</b> Membership Engagement	Success Statement We provide an essential support service to current	members improving their quality of life. Membership includes all people with the conditions we support, in all regions we service.	Key Focus Areas	Providing professional support and resources to members	Encouraging members to be engaged with services provided	Encourage self-management of symptoms	Whanau engage with services and get involved in management plans	Increasing brand visibility and awareness in target areas
Chronic Illness	Vision	e Towards Wellness	<b>strategic Priority</b> Knowledge	Success Statement CCI Support is the hub for knowledge sharing. We professionally deliver initi-fives	support our members innum as support our members' needs by conducting, gathering, and sharing research, and facilitating learning.	Key Focus Areas	Keeping up to date with relevant national and international research	Measure staff knowledge and understanding through membership feedback	Members successfully engage and complete WWP, and integrate learning into practice through self-management of symptoms	Measure member knowledge and understanding of their wellness journey through feedback administered by surveys	Continue to grow our support forum and membership
Complex (	Vis	Empowering People Towards Wellness	<b>Strategic Priority</b> Education	Success Statement High-quality evidence-based	education and resources fosters empowered, knowledgebable members, whanau, and community	Key Focus Areas	Evidence-based resources are obtained, developed, and delivered	Developmental growth and understanding of the conditions we support	Reviewing new methods, tools that help build and support members	Key resources available to educate and help whanau and carers	Regular upskilling and training of staff through attendance of industry educational programmes
8	Purpose	Empower and educate members and advocate for their needs and their lives	<b>strategic Priority</b> Leadership / Advocacy	success statement As the authoritative voice of and for those with ME/CFS, FM	and Long COVID, we ensure that our members are understood and valued in NZ. We are recognised as an essential service.	Key Focus Areas	Open dialogue and key processes to engage with members/stakeholders	Engagement with government agencies and like-minded organisations	Recognition as an essential service for the conditions we support, by government and health agencies	Board and staff reflect organisational values in all interactions	Board and operational excellence

## CEO SUMMARY

Reflecting on the past year, it is clear that 2023/24 has been exceptionally busy for us. Condensing the breadth of our achievements and events into a single article proves a challenging task.

We began with a successful World ME Day Open Day at our Welcome Bay premises. Additionally, we were honored to join the Generosity Generator project by the Funding Network NZ, alongside 46 other non-profits.

Addressing the increased demand, our team welcomed Marika as a National Facilitator, providing vital online and phone support across New Zealand. In the Nelson region, Florence joined us as a regional support group coordinator, while Phil assumed roles in mindfulness meditation and men's mentorship, generously funded by the Tauranga City Council.

Our administrative strength grew with the addition of Morgan, enhancing our operational capacity. Acknowledging the persistent need for counseling, we expanded our team from 3 to 5 counselors, supported by partnerships with Bethlehem Training Institute and Wintec in Hamilton, alongside new provisional counselors Tracey and Jan.

We have a strong team, who are individually caring and professional people. As a team, they are incredible.

We are grateful to those who have raised their hands to volunteer this year for CCI Support. Our fabulous and dedicated social media team, led by Kaye and also new to the team this year are our support welfare checkers and regional support group volunteers. Supporting the Facilitators at the grassroots.

Tauranga City Council helped with some much-needed funds for a security system, IT, and other items to modernise our offices, the painting guru painted the bathroom and good neighbour helped get the gardens in top shape.

In terms of projects, our Towards Wellness Hub continued to provide essential resources for individuals with ME/CFS and Long COVID, with over 45 participants currently enrolled.

SPAN Trust in the Waikato kindly offered 20 Waikato members the opportunity to access this course for free.

Funded by the Tauranga City Council and Eastern Bay of Plenty Disability Community Trust we have been able to expand the Towards Wellness Programme and we filmed the Support Persons Workshop in the studio and part 2 of the Towards Wellness Programme, Mindfulness and Restorative Movement Programmes. These are available to our members from the comfort of their own homes, supporting them whilst maintaining their limited energy capabilities.

A new project came to fruition this year with the Care Kete being launched, sponsored by the Steadfast Foundation, Network Tasman Trust, Rehabilitation Welfare Trust, and the Helen Stewart Royle Fund. As well as discounts and products from Abbot, Dilmah and Reynard Health. A care kit are resources that we can send to people who are in a crash, and something for their caregivers too. This is a unique to CCI Support service and its importance of caring for those at a very vulnerable time is invaluable. In addition to the Care Kete, we can also have frozen pre-prepared meals delivered by Kai2You and Mealbox. We are very grateful for their ongoing support this year.

We now provide free wills to anyone interested in non-complicated wills. It is a free service with an option for those who use the service to leave a legacy gift to CCI Support. More information can be found on our website.

Jo has done an amazing job at being the Funding Manager for CCI Support, we are truly grateful for her skills. Without her dedication to the role, we truly wouldn't be where we are today.

As funding is more scarce and more people vying for contestable grants, it has become apparent that we need to diversify our funding strategy. This year we started an online shop on our website. At the moment it only has a small amount of items to replenish a care package/crash kit and a few merchandise items. We are hoping to grow this over time.

### CEO SUMMARY CONTINUED

CCI Support were asked to work with Whaikaha (Ministry of Disabilities) for a Review of Eligibility for Disability Support Services Advisory Group Workgroup. Unfortunately with the Government's budget cuts and review of Whaikaha, this workgroup ceased without warning. We currently are advocating for all members in NZ with ME/CFS and Long COVID etc, to be able to access Disability Support Services. This is ongoing.

Marika and I were asked to do a presentation to MSD regional team leaders with Marika, addressing the needs of our people and clarifying with MSD what support can be provided to our members. In turn the Ministry of Social Development's Principal Health Advisor Dr. Cathy Stephenson and Disability Co-ordinator Tess Low came and spoke with our members.

We were also asked to present to the physiotherapy and occupational therapy departments at both Wellington and Tauranga Hospitals. These were well received.

We also had stands at Disability Support Inclusion community gatherings, as well as other networking events with disability groups, MSD, other health departments, and local Maraes.

Annabelle also became an Approved Assessor for the Total Mobility Scheme for Tauranga.

Our annual Staff Training, featuring notable speakers, facilitated a productive period of learning and planning, with the knowledgeable Dr Jacqui Clarke, Prof Warren Tate, Lynette Hodges, and Rose Silvester. We also held Christmas Functions with members at the regional Social Groups held in person.

All of the above is on top of our core services, supporting, educating and advocating for the people in New Zealand with ME/CFS, Long COVID, Fibromyalgia and Dysautonomia.

As a team this year we were working with 940 people and their whanau. Monthly educational member meetings attendance increased significantly and we also set about creating social groups for smaller interactions, in line with need. We now provide 22 regular small group meetings online and throughout New Zealand on a monthly basis.

It's been a pleasure being able to lead such an amazing dedicated team and organisation. I'm looking forward to the next year as we continue to develop the service and continue to work towards meeting the needs of our members.

Miranda Whitwell

MIRANDA WHITWELL Chief Executive



# FUNCTIONALITY

Functionality scales are tools used to assess the impact of chronic illnesses like ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), Fibromyalgia, and Long COVID on daily life and functioning. These scales help quantify symptoms, assess severity, and track changes over time.

They can also empower patients by providing a quantifiable way to track their symptoms and communicate their experiences to healthcare providers.

This year we did a survey with our members to assess and subjectively report on their level of functionality at that point in time.

The scale we used was developed by Dr. David Bell as a clinically useful way to assess response to treatment - it combines physical and mental activity with levels of wellness. This is not entirely satisfactory because different people suffer in different ways but it does give an idea of the level of disability.

It is:

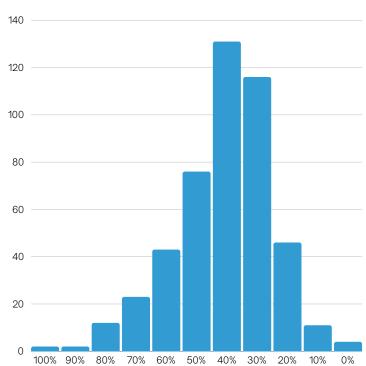
- Self-scoring
- Comprised of eleven statements
- Scale is scored from 0 (very severe, bedridden constantly) 100 (healthy)
- 0 10% is considered Very Severe
- 20 30% is considered Moderate to Severe
- 40 50% is considered Moderate
- 60 80% is considered Mild
- 90 100% is considered to be 'Well'

# LEAVING A LEGACY

#### What will your legacy be?

Sadly, traditional will-writing can cost hundreds or even thousands of dollars which makes it difficult for many people to write a will or plan to support the causes they care about.

So, we've partnered with Gathered Here, to offer our supporters access to a FREE online will. It is as easy as possible for people to write a FREE will and if they want to, include a gift to charity too





# NEW PROGRAMMES



INTRODUCING THE
SUPPORT
PERSONS
WORKSHOP

Join us to explore our resources, stories, and tips to discover the profound impact that your support can have and find inspiration in the journey of supporting your loved one on their journey to wellness

CCI Support, Supporting People with Myalgic Encephalomyelitis (ME), Long COVID and Fibromyalgia, and their Whānau

> www.ccisupport.org.nz info@ccisupport.org.nz 0800 658 0251

### **Support People**

A workshop that has been developed to support those caring for people with ME/CFS and Long COVID. Professionally recorded and available online throughout Aotearoa New Zealand.

Free Workshops

for members

**Online Groups with Phil** 

Online Mindfulness Orientation to introduce

you to Mindfulness and Meditation.

### Men's Mentoring

A new service for men with ME/CFS, Long COVID and Fibromyalgia. Providing much needed support from Phil, one of our Facilitators who understands the specific needs of men.



### Mindfulness & Meditation



New material will be added to the members' area of the website every week for 6 weeks





### **Care Ketes**

Provided to members in need/in a crash.

#### In 2023/24 year we provided

- 15 care ketes
- 168 meals
- 19 memberships given for hardship

### STATEMENT OF SERVICE PERFORMANCE

#### The Need in our Community

Our members are either self-referred or referred to us by their doctor, local hospital, WINZ staff, support agencies or counselling providers or receive word of mouth recommendations from members who have benefitted from our support.

CCI Support meets a community need where there is an absence or little support from the health sector for those experiencing chronic complex illness. CCI Support provides an essential service, supporting, connecting, educating, and providing advocacy to clients who experience complex chronic illness, their whānau, and their communities.

The nature of complex chronic illness means many who were once active members of their community have, due to their illness, resigned themselves to a life where isolation, confusion, pain, and depression are part of their world, with few resources or support to see a way forward.

CCI Support gives hope and a new direction to our clients, and the skills to once again lead a life which is fulfilling and meaningful.

We further know our services are needed as we continuously meet with community groups, government agencies and other charities, updating them on our service while nurturing relationships. We also have pre-existing and valuable relationships with funders who see the genuine need and importance of our cause.

The fact that our membership continues to grow is also evidence that we deliver an important and essential service to our community.

#### CCI Support provides support and advocacy:

In line with contemporary research, our innovative services deliver community health and support services to empower people to skilfully navigate their own individual wellness path. CCI Support member's progress from a life of fatigue, pain and isolation towards an improved quality of life, re-engaging with their whānau and community, with an increased ability to participate in a life which is meaningful – And achieving our purpose to 'Empower People Towards Wellness.'



## SERVICES PROVIDED BY CCI SUPPORT

#### Health and Wellness Facilitators

We have qualified Health & Wellness Facilitators based in the Bay of Plenty, Wellington, Nelson and Waikato who work with members and the community to provide support, mentoring, advice, counselling, and advocacy. This essential role is undertaken through telehealth visits, phone, and where possible in person and suitable home visits, in addition to guidance and support through regular support and social group meetings, education sessions, access to counselling services, and the CCI Support library and newsletters. We also provide our award winning Towards Wellness Programme and mindfulness meditation and restorative movement workshops.



Our staff has a range of qualifications including a Registered Comprehensive Nurse, Bachelor of Community Health, Diploma of Rehabilitation, Yoga teacher and Massage therapist, Certificate in Adult Teaching, Human Anatomy and Physiology, BAppSocSci Counselling Major, and Diploma in Health and Human Behaviour, Bachelor of Science in Psychology with Clinical and Health, Post Graduate Certificate in Health Psychology and a Masters in Health Psychology. Bachelor of Consumer & Applied Science, Diploma of Health Science & Nutrition

We have adapted our services to meet the needs of those we support. Providing older person assessments in their homes when suitable, needs assessments for all clients and individualised management plans to focus the journey.

#### Support Group Meetings



The support group meetings offer the opportunity for members to have a group catch-up with our Facilitators, and to share ideas and support with one another. These are held online, as this helps with the management of energy envelopes and works towards mitigating Postexertional Malaise. The objective of the group meetings is to give members access to tools and resources to enable them to develop their own solutions to issues, and manage their own illness, developed from conversations in a confidential and safe space.

#### Support Persons' Workshops

Complex chronic illnesses affect not only the individual, but also those people around them. Compounded by illnesses where symptoms and their effects fluctuate, and which are hard to manage, difficult to understand and often misunderstood, can prove to be challenging for whanau, friends, carers, and the wider community. CCI Support provides workshops to assist in educating those surrounding an individual so they can understand and support their loved ones.

## THE SERVICES WE PROVIDE CONTINUED...

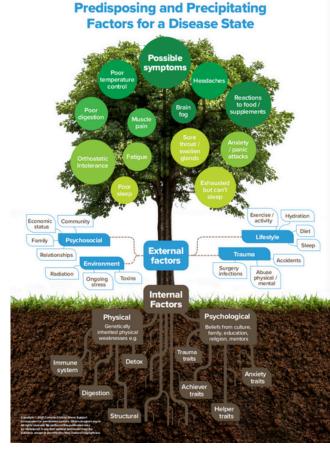
#### The Towards Wellness Programme

The CCI Support Towards Wellness Programme offers the best of research-based knowledge into an easyto-understand package to help people living with complex chronic illness begin to find their next steps towards wellness. Participants learn foundation principles to assist them in navigating their journey, and in creating an individual road map to support increasing health and wellness.

The programme is the first of its kind in New Zealand, winning the Highly Commended Innovative Provider Award at Adult Learner's Week in 2016, and is endorsed by New Zealand's leading authority on CFS / ME, Doctor Ros Vallings.

#### Towards Wellness Hub

The new Towards Wellness Hub is an online knowledge base of content, resources, and services, available 24 / 7 for those in the community with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia, Dysautonomia and Long-



COVID, their whānau, and their communities, throughout New Zealand. It's also a resource for health professionals and other organisations and individuals who wish to learn more about complex chronic illness.

The Towards Wellness Hub is a new way of delivering the resources and services of CCI Support to clients and interested parties, which they can access as needed, from their own home and environs. As with many health issues and disabilities, the hardest time to cope is when people are alone. With access to the hub, clients can feel accepted and safe, with access to a familiar support system at their most vulnerable times.

TWP was designed as a comprehensive, holistic educational package for those with ME / CFS & FM and related conditions. This is especially important for those who are newly diagnosed so they get the right information as soon as possible to maximise their chances for improvement. It was found that, through the TWP, people who had been ill for several years were, for the first time, 'joining the dots' and making sense of what had previously seemed like disparate pieces of the chronic illness and wellness puzzle and seeing how they all fit together.

Guest speakers have also been filmed, and include a nutritional coach, physiotherapist, and general practitioner. Workshop topics include Understanding the Conditions, Systems and Stages, Pacing – Balancing Activity and Rest, Stress Management, Sleep, Nutrition, Pain Management – A GP's Perspective, and Building Your Support Network.

## THE SERVICES WE PROVIDE CONTINUED...

#### Facebook Community

CCI Support has an active online community, comprising two Facebook pages – A public page to raise awareness, and a closed private members page to provide connections and reduce isolation, providing a way to keep in contact and give group support to each other.



#### **Newsletters**

CCI Support creates and distributes a comprehensive newsletter to our members and members of the public, including up-to-date research, information, strategies, techniques, wellness stories, plus links to events and meetings. This is a key tool to keep members involved with our organisation and other members.

#### Library

We offer a comprehensive library service to our members, with access to specialised books and information to help them through their journey to wellness.





#### Seminars

We provide events, specialised speakers, doctors, nutritionists, mindfulness coaches, physiotherapists and other experts in this area.

We organise these to keep our members, the medical community and other interested groups up to date with the latest worldwide research about these illnesses and how to best manage them.

#### **Online Support**

Supporting people virtually via telehealth, phone, and email appointments. We have found them so beneficial to clients who would otherwise have been restricted to their support and have decided to adapt our services to make this a permanent structure to our support system for clients throughout New Zealand.



#### Advocacy and Awareness

At CCI Support we are continually striving to raise awareness of all complex chronic illnesses. Increasing awareness is a key goal, ultimately enabling us to support more people, increase our membership and develop our services further. Recently we started a dialogue with the Ministry of Health about the services available for ME / CFS and Long-COVID. It was well supported by the NZ community.

Alongside this, we also have regular media coverage, with articles and videos through local and national media outlets, bringing awareness to the available support and the conditions we support.

#### Volunteers

We have a good pool of Volunteers to help with administration tasks, Board meetings, IT work, Counselling, Facebook Moderation, running Social Groups throughout the country, event planning and other tasks. In the 2023 / 2024 year, our volunteers did 1414.5 hours of work with CCI Support. We also have 7 student and provisional counsellors.

#### CCI SUPPORT | 12

# STATISTICS

# 73% INCREASE

### REFERRALS AND ENQUIRIES

In the April 22 - March 23 financial year we had 363 people request help

In the April 23 - March 24 financial year we had 514 referrals and a further 117 enquiries

### **17% INCREASE** IN STAFFING HOURS

From 178 hours in 2022/23 to 207.5 hours per week in the 2023/2024 year.

We now cover Lakes. Eastern Bay of Plenty, Western Bay of Plenty, Waikato, Wellington and Nelson with local Facilitators.

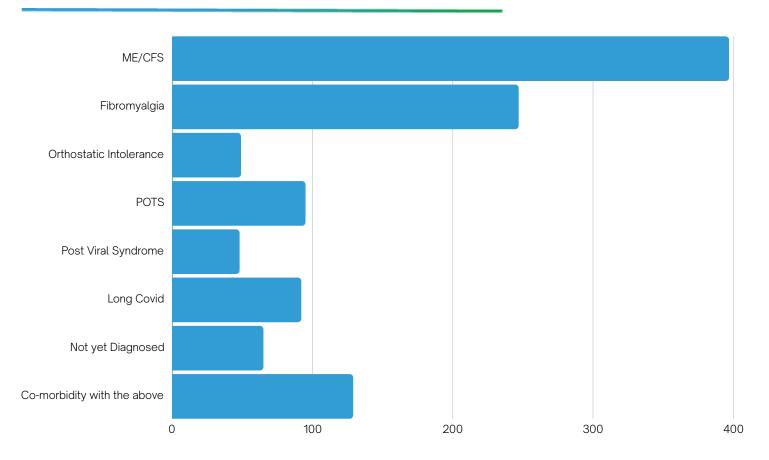
We also provide support online and virtual support nationally to those outside of regions with local support.

And yet we could still use more staffing hours as the workload increases and the complexity of cases means more individual support is required. This is only limited by funding.

Paid Staff include 4 Full-time and 2 Part- time Facilitators and 1 psychology intern (Total of 325 hours per fortnight) working across Tauranga & Western Bay of Plenty, Eastern Bay of Plenty, Lakes District (Rotorua & Taupo), Wellington, Nelson and the Waikato. A Facilitator Assistant is working 20 hours per week and a Funding manager works 6 hours per week. The Chief Executive Officer is employed for 25 hours per week. CCI Support Member Volunteers also curate CCI Support Facebook pages, provide IT Support, Admin support and facilitate Social Groups within the regions. We also have 7 student and provisional counsellors volunteering with us on placement.



# WHO ARE WE SUPPORTING?



### We offer support to people with the following conditions (and their families)

#### Myalgic Encephalomyelitis (ME) also known as chronic fatigue syndrome (CFS)

an abnormal immune/neuroendocrine multi-system response to any number of infectious or environmental triggers, causing a long-term illness that can result in significant disability.

#### Post Viral Syndrome (PVS)

In most straight-forward viral illnesses, recovery takes 2 - 4 weeks, with symptoms disappearing by six weeks. However, a small percentage of PVS's patients will take several months to recover. If symptoms remain after 3 - 6 months, with the illness unchanged, a change of name / diagnosis to CFS / ME is appropriate.

#### Long-COVID

Long-COVID is a condition that "occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis". For some people, SARS-CoV-2 coronavirus (COVID-19) can cause symptoms that last weeks or months after the infection has gone. This is sometimes called post-COVID-19 syndrome or "Long-COVID".

#### Fibromyalgia (FM)

A chronic condition that causes fatigue, widespread pain, and tenderness throughout the body and often co-exists with CFS/ME and/or many of the symptoms of this condition. People with Fibromyalgia generally experience pain in specific points around the body and these points are used as a gauge for diagnosis.

## WHO ARE WE SUPPORTING CONTINUED

#### Dysautonomia

Dysautonomia is a term used to describe autonomic nervous system dysfunction. Our autonomic nervous system acts largely unconsciously and regulates body functions.

A common symptom of Dysautonomia for people with ME/CFS is Orthostatic Intolerance, which is often caused by Neurally Mediated Hypotension (NMH) or Postural Orthostatic Tachycardia Syndrome (POTS). CCI Support only supports a few Dysautonomia conditions;

#### Orthostatic Intolerance (OI)

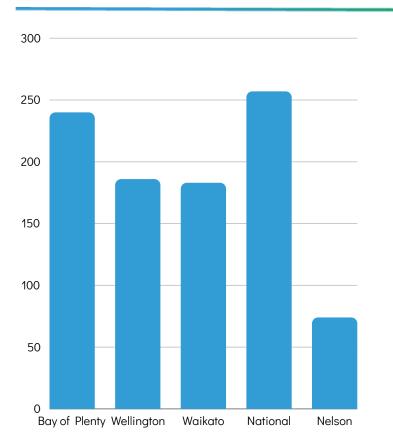
An umbrella term for the development of symptoms when in an upright posture. OI can be caused by standing in an upright position for long periods of time, after being in a warm environment, immediately after exercise, after an emotionally stressful event, after eating (blood flow moved to digest food) or if salt and fluid intake is inadequate. These symptoms subside when returning to a horizontal position.

#### Postural Orthostatic Tachycardia Syndrome (POTS)

A condition in which a change from lying to standing causes an abnormally large increase in heart rate. Symptoms that may include light-headedness, trouble thinking, blurred vision or weakness due to the autonomic nervous system (ANS) being dysregulated. Other commonly associated conditions include irritable bowel syndrome, insomnia, chronic headaches, Ehlers-Danlos syndrome, chronic fatigue syndrome and fibromyalgia.

#### Neurally Mediated Hypertension (NMH)

Abnormal reflex lowering blood pressure during upright posture. (low blood pressure created via the nervous system)



# MEMBERS BY REGION

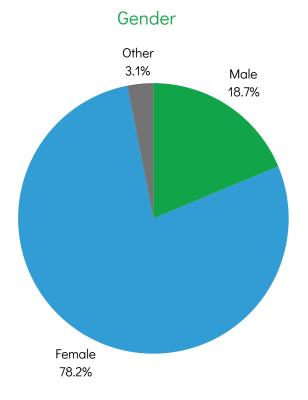
The Bay of Plenty has always been our stronghold, as this is where we started in New Zealand. We are also one of the world's oldest social services for myalgic encephalomyelitis, starting in 1981.

With so much need in the community, we now provide support throughout New Zealand.

The National support service had over 221 referrals in only 12 months up till 31 March 2024, up from 187 the year prior.

At 31 March 2024 we have supported 940 people and their families, up from 703 people the previous year.

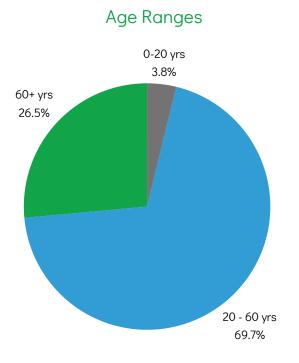
# ABOUT OUR MEMBERS



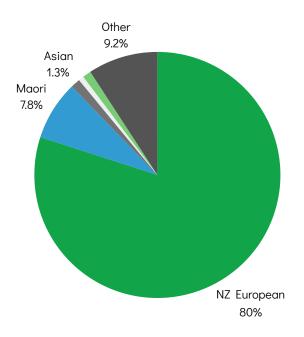
#### **NEW REFERRALS**

We are constantly growing as a communitybased social support service. With 631 new referrals to our service last year, up from 363 in the previous year. Not every referral will end up with needing extra support, but we still provide assessment support and refer on to more appropriate services if possible, On average we spend 20 hours on each new referral, before they are integrated into our service.

Nineteen Hardship Grants for memberships were granted, for those that would have otherwise been unable to get any support for their conditions.



#### Ethnicities



# MEMBER CONTACT

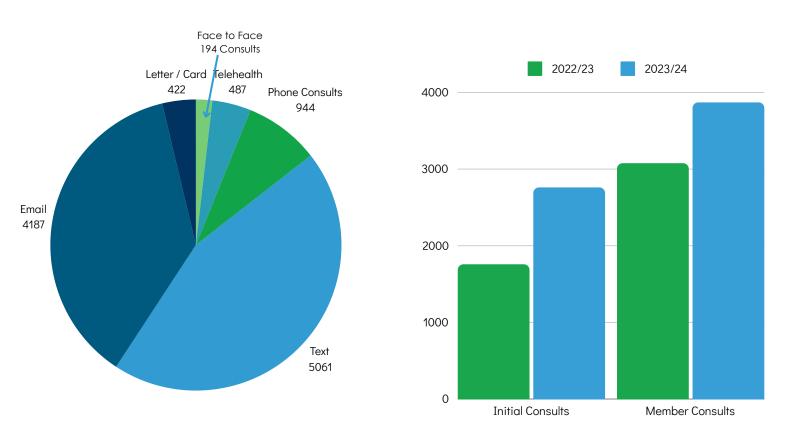
#### CURRENT ACTIVITIES, SERVICES, AND PROGRAMMES

On 31 March 2024 CCI Support was working with 940 people, up from 703 in 2023 with 631 new referrals and enquiries for help since 1 April 2023. As part of this, some members feel they are well supported and are able to move forward in their lives. This is fantastic. But the door is open for them to return, should they require further help in the future.

### AN INCREASE IN CONTACT 7069 CONSULTS IN 2022/23 TO 11,306 CONSULTS IN 2023/24

Increasing our interactions from 7,069 in 22/23 to 11,306 in 23/24, an increase of 60%. We continuously adapt our services to interact with our members in a way that works within their energy capabilities.

Many of the new referrals we received were very complex, on average a new referral can take up to 20 hours before a person is assimilated into the service completely. A consult is a 1:1 session with the member and/or their whānau. A consultation may be via Telehealth, in-person meetings, home visits, email, letter, or text, and it completely depends on the member's state of health and ability to meet with us.



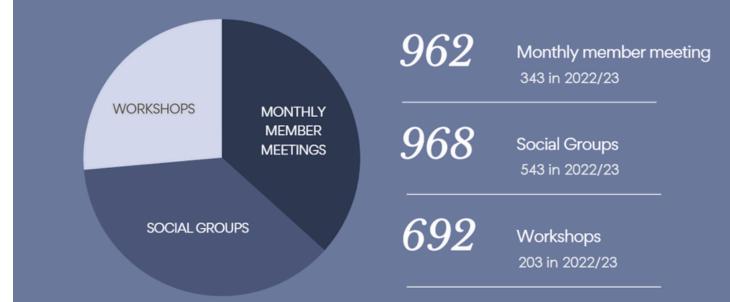
# MEETINGS HELD

### THE IMPORTANCE OF MEETINGS

Meetings are incredibly important to the members of CCI Support. It's a time to connect and a way for Facilitators to see members in a regular way, cost effective manner.

### ATTENDANCES AT MEETINGS

We continue to have an increase in attendances at the meetings we are providing. Which is testament to the quality of the resources, information and staff dedication to provide a quality service.



### Monthly Member Meetings

Educational in manner - is the focus topic for a month on all Social Media. Often 40 + come to the online meeting and a further 40+ watch it online after the event.

### Workshops

- Mindfulness Meditation Workshop
- Restorative Movement Workshop
- Support Person Workshop
- Towards Wellness Programme

### Social Groups

Smaller groups - with a niche topic

Smaller Groups - held both online and in person regionally. No topics, this is all about connection, one of the first things to disappear with a chronic illness. Connection is a basic human need.

#### In Person

- Papamoa
- Greerton
- EBOP Coffee Group
- Lakes Coffee Group
- Te Awamutu
- Cambridge
- Morrinsville

- Waikato Young Ladies
- Hutt Valley
- Kapiti Coast
- Mens Group
- Hobbies and Games

#### • Wellington

#### Online

- Nelson / Marlborough
- After Work Social Group
- Coffee Catch up for long time members
- Coffee Catch up for new members
- Supporters Group
- Under 25's
- Doing it alone
- Parents Group
- Rainbow Group

## THE BOARD



**PRESIDENT** Fiona Charlton



VICE - PRESIDENT Prue McCallum



**TREASURER** Bronwyn McRostie



David Harris



Kirby-Lee Ormond



Alan Withy



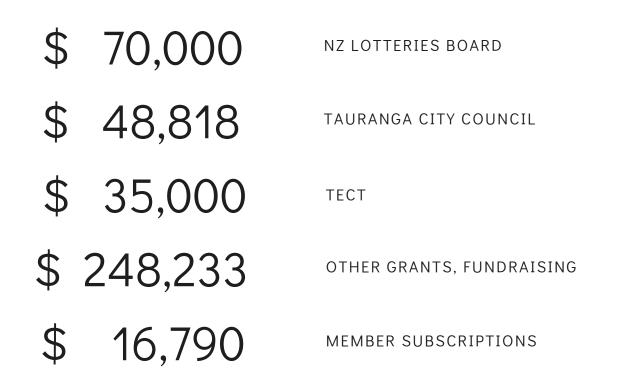
Sally Dunbar



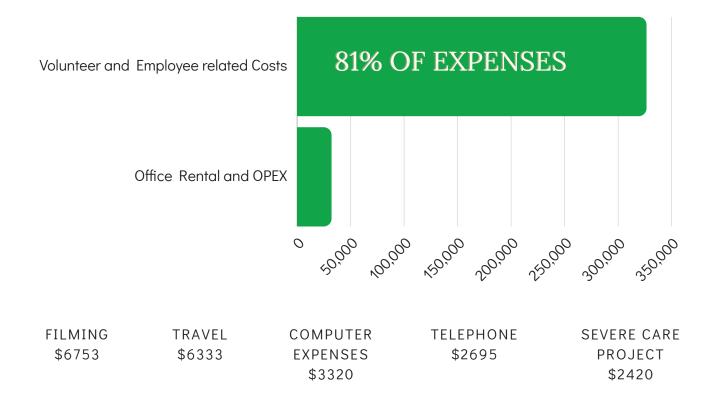
Thérèse Jeffs

## 2023 / 24 AT A GLANCE

#### MAIN SOURCES OF REVENUE



### MAIN EXPENSES FOR CCIS



# **Entity Information**

Legal Name of Entity:Complex Chronic Illness Support Inc.Other Name of Entity:previously named ME/CFS Support BoP Inc.Type of Entity and Legal Basis:Incorporated SocietyRegistration Number:CC 20874NZBN:9429042591948

#### Entity Structure

The board of management (including the President, Vice President and the Treasurer), shall be not less than three (3) or more than nine (9) members (excluding the Secretary) Board members shall be elected at the Annual General Meeting each year.

The CEO has been appointed as the board secretary for the society. CCI Support employ Facilitators based in Tauranga, Whakatane, Waikato, Wellington, Nelson and Rotorua.

Paid Staff include 4 Full-time and 2 Part- time Facilitators and 1 Health Psychologist Intern (Total of 325 hours per fortnight). A Facilitator Assistant is working 20 hours per week and a Funding manager works 6 hours per week. The Chief Executive Officer is employed for 25 hours per week. We also have 7 student and provisional counsellors volunteering with us on placement.

CCI Support Member Volunteers also curate CCI Support Facebook pages, provide IT Support, Admin support and facilitate Social Groups within the regions.

#### Main Sources of the Entity's Cash and Resources:

CCI Support is predominantly funded by grants from various funding agencies and philanthropic trusts applied to, as well as donations, member subscriptions and interest

#### Main Methods Used by the Entity to Raise Funds:

Funding grant applications submitted to various funding agencies and Philanthropic trusts are the main source of funding.

#### Entity's Reliance on Volunteers and Donated Goods or Services:

CCI Support relies on volunteers for Board Governance as well as assistance with Administration, IT support, Counselling, Facebook curation, Instagram, Facilitator Support, Fundraising and facilitation of Social Groups.

Volunteer hours across the organisation including the Board Members totalled approximately 1414.5 hours over the last year.



## STATEMENT OF SERVICE PERFORMANCE

Description and Quantification (to the extent practicable) of the Entity's Outputs:*	This Year	Last Year
As at 31 March 2024 CCI Support was working with 940 people.	940	703
New Referrals	514 and a further 117 enquiries	363
Facilitator Consults	3870	3077
Referrals and Initial Consults	2761	1758
Face to Face Consults	194	195
Home Visits	11	13
Online Consults	487	145
Phone Consults	944	947
Txt Messenger Consults	5042	433
Email - individual, not group emails	4187	2917
Letter	422	303
Advocacy support provided for individual members with health Practitioners and WINZ	208	58
Networking	217	120
Newsletters	5 Newsletters sent to 634 people each time	4 Newsletters sent to 583 people each time
Members Meetings	11 meetings 962 participants	11 meetings 343 participants
Social Meetings	174 meetings 968 participants	94 meetings 543 participants
Towards Wellness	46 online 49 attended extra workshops	30 online 11 attended extra workshops
Community Meetings - Caregivers, Supporters	now online and available for free to 117 support members	1 meetings with 5 participants
Other meetings: Mindfulness, Restorative Movment etc	90 workshops 643 participants	34 workshops 286 participants

### APPROVAL OF THE PERFORMANCE REPORT

For the year ended 31 March 2024

This performance report has been approved by the Board, for and on behalf of, Complex Chronic Illness Support (Inc.)

Signature:

fincharto

Signature:

Name: Position: Date: Fiona Charlton Board President 13 August 2024

Name: Bronwyn McRostie Position: Treasurer Date: 16 August 2024

BMA



### STATEMENT OF FINANCIAL PERFORMANCE

#### **Complex Chronic Illness Support (Incorporated)**

#### Statement of Financial Performance

"How was it funded?" and "What did it cost?" For the year ended 31 March 2024

	Note	Actual*	Actual*
		This Year	Last Year
		\$	\$
P			
Revenue Donations, fundraising and other similar revenue*	1	402,051	303,971
Fees, subscriptions and other revenue from members*	1	23,766	22,679
Revenue from providing goods or services*	1	1,490	637
Interest, dividends and other investment revenue*	1	5,414	2,531
Total Revenue*		432,721	329,818
Expenses			
Expenses related to public fundraising*	2	-	51
Volunteer and employee related costs*	2	326,531	266,450
Costs related to providing goods or services*	2	69,597	62,825
Other expenses	2	8,327	5,679
Total Expenses*		404,455	335,005
Surplus/(Deficit) for the Year*	5	28,266	(5,187)



### STATEMENT OF FINANCIAL POSITION

#### Complex Chronic Illness Support (Incorporated) Statement of Financial Position "What the entity owns?" and "What the entity owes?" As at 31 March 2024 Note Actual\* Actual\* This Year Last Year \$ \$ Assets Current Assets Bank accounts and cash\* 3 124,286 138,544 Debtors and prepayments\* 3 8,004 2,609 **Total Current Assets** 132,290 141,153 Non-Current Assets Property, plant and equipment\* 4 13,153 3,520 **Total Non-Current Assets** 13,153 3,520 Total Assets\* 145,443 144,673 Liabilities **Current Liabilities** Creditors and accrued expenses\* 805 з 1,505 Employee costs payable\* 21,372 17,382 3 Unused donations and grants with conditions\* 90,066 3 116,190 **Total Current Liabilities** 112,243 135,076 Non-Current Liabilities Other non-current liabilities 3 4,662 Total Non-Current liabilities 4,662 -Total Liabilities\* 112,243 139,738 Total Assets less Total Liabilities (Net Assets)\* 33,201 4,935 Accumulated Funds Accumulated surpluses or (deficits)\* 33,201 4,935 5 Total Accumulated Funds\* 33,201 4,935



This Statement should be read in conjunction with the accompanying Notes and the Independent Assurance Practitioner's Report

## STATEMENT OF CASHFLOWS

#### **Complex Chronic Illness Support (Incorporated)**

#### Statement of Cash Flows

"How the entity has received and used cash"

#### For the year ended 31 March 2024

	Actual*	Actual
	This Year	Last Yea
	\$	
Cash Flows from Operating Activities*		
Cash was received from:		
Donations, fundraising and other similar receipts*	402,053	419,002
Fees, subscriptions and other receipts from members*	24,055	21,892
Receipts from providing goods or services*	1,490	637
Interest, dividends and other investment receipts*	5,414	2,531
Net GST	(723)	(674
Cash was applied to:		
Payments to suppliers and employees*	433,415	419,428
Net Cash Flows from Operating Activities*	(1,126)	23,960
Cash flows from Investing and Financing Activities*		
Cash was received from:		
Proceeds from loans borrowed from other parties*	-	
MSD Covid19 Subsidy	-	1,200
Cash was applied to:		
Payments to acquire property, plant and equipment*	13,036	
Other Cash items from Investing	- 95	-
Net Cash Flows from Investing and Financing Activities*	(13,131)	1,200
Net Increase / (Decrease) in Cash*	(14,257)	25,160
Opening Cash*	138,544	113,384
Closing Cash*	124,287	138,544
This is represented by:		
Bank Accounts and Cash*	124,287	138,544

# STATEMENT OF ACCOUNTING POLICIES

#### Basis of Preparation\*

Complex Chronic Illness Support (Incorporated) has elected to apply PBE SFR-A (NFP) Public Benefit Entity Simple Format Reporting - Accrual (Not-For-Profit) on the basis that it does not have public accountability and has total annual expenses of equal to or less than \$2,000,000. All transactions in the Performance Report are reported using the accrual basis of accounting. The Performance Report is prepared under the assumption that the entity will continue to operate in the foreseeable future.

The Performance Report is presented in New Zealand dollars (NZ\$) which is Complex Chronic Illnes Support (Incorporated)'s functional currency and has been prepared on an accrual and historical cost basis. All values are to the nearest \$.

The statement of cash flows has been prepared using the direct method.

#### Specific Accounting Policies

The following specific accounting policies which materially affect the measurement of the Statement of Financial Performance and Statement of Financial Position have been applied:

#### Goods and Services Tax (GST)\*

All amounts are recorded exclusive of GST, except for Debtors and Creditors which are stated inclusive of GST.

#### Income Tax

Complex Chronic Illness Support (Incorporated) is wholly exempt from New Zealand income tax having fully complied with all statutory conditions for these exemptions.

#### **Bank Accounts and Cash**

Bank accounts and cash in the Statement of Cash Flows comprise cash balances and bank balances (including short term deposits) with original maturities of 90 days or less.

#### **Revenue Recognition**

Revenue from providing services and sale of goods is recognised as it is received. Revenue from grants is recognised by reference to the use of the grant by balance date.

## STATEMENT OF ACCOUNTING POLICIES

#### **Complex Chronic Illness Support (Incorporated)**

#### Statement of Accounting Policies

"How did we do our accounting?"

For the year ended 31 March 2024

#### Expenses

Salaries and wages are recorded as expenses as staff provide services and become entitled to them. Other costs associated with the delivery of services are expensed when the costs are incurred.

#### Fixed Assets

All fixed assets are initially recorded at cost with depreciation being deducted on all fixed assets at rates calculated to allocate the assets costs, less estimated residual value, over their estimated useful lives.

#### Depreciation

Depreciation has been calculated using rates considered reasonable to allocate the cost of an asset, less any residual value, over its useful life.

#### Changes in Accounting Policies\*

There have been no changes in accounting policy.

#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

For the year ended 31 March 2024

#### Note 1 : Analysis of Revenue

		This Year	Last Year
Revenue Item	Analysis	\$	\$
Donations and other similar	Grants for current operations	402,051	302,771
revenue	Donations - Specfic	-	-
	Covid 19	-	1,200
	Total	402,051	303,971

		This Year	Last Year
Revenue Item	Analysis	\$	\$
Fees, subscriptions and other	Donations, koha or offerings from members	6,237	6,292
revenue from members	Course Fees	739	2,604
	Fees and subscriptions from members	16,790	13,783
	Revenue from sales to members	1,490	637
	Total	25,256	23,316

		This Year	Last Year
Revenue Item	Analysis	\$	\$
Interest, dividends and other	Interest	5,388	2,531
investment revenue	Sale of Asset	26	-
	Total	5,414	2,531

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report



#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

#### For the year ended 31 March 2024

#### Note 2 : Analysis of Expenses

		This Year	Last Year
Expense Item	Analysis	\$	\$
Expenses related to public	Fundraising	-	51
fundraising			
	Total	-	51

		This Year	Last Year
Expense Item	Analysis	\$	\$
Volunteer and employee	Salaries and Wages	296,518	223,190
related costs	KiwiSaver contributions	7,839	5,534
	Contractors	17,200	27,868
	ACC levies	-	499
	Supervision	1,461	1,470
	Training	1,656	1,186
	Leave Accruals	1,857	6,703
	Total	326,531	266,450

		This Year	Last Year
Expense Item	Analysis	\$	\$
Costs related to providing	Direct costs relating to service delivery	6,333	6,329
goods or services	Administration and overhead costs	63,264	56,496
	Total	69,597	62,825

		This Year	Last Year
Expense Item	Analysis		\$
Other expenses	General Expenses	1,875	2,499
	Accounting and Assurance	2,556	2,318
	Finance Costs	493	326
	Depreciation	3,403	536
	Total	8,327	5,679

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report...

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#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

For the year ended 31 March 2024

#### Note 3 : Analysis of Assets and Liabilities

		This Year	Last Year
Asset Item	Analysis	\$	\$
Bank accounts and cash	Kiwibank	123,892	138,214
	Debit Card	278	320
	Cash	-	-
	Stripe	115	9
	Total	124,286	138,544

		This Year	Last Year
Asset Item	Analysis	\$	\$
Debtors and prepayments	GST Receivable	2,493	1,770
	Debtors	549	839
	Prepayments	4,962	
	Total	8,004	2,609

		This Year	Last Year
Liability Item	Analysis	\$	\$
Creditors and accrued	Creditors	805	1,506
expenses	GST Payable	-	-
	Total	805	1,506

		This Year	Last Year
Liability Item	Analysis	\$	\$
Employee costs payable	Inland Revenue Payable	7,036	4,903
	Holiday Pay Accrual	14,336	12,479
	MSD Subsidy - Covid19		-
	Total	21,372	17.382

		This Year	Last Year
Liability Item	Analysis	\$	\$
Unused donations and grants with conditions	Unexpended Grants	90,066	116,190
	Total	90,066	116,190

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report



#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

For the year ended 31 March 2024

	Note 3 : Analysis of Assets and Liabilities		
		This Year	Last Year
Liability Item	Analysis	\$	\$
Other current liabilities	ME/CFS Charitable Trust	-	-
	Allocated unspent funds provision	-	4,661
	Total	-	4,661

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report...



#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

For the year ended 31 March 2024

#### Note 4 : Property, Plant and Equipment

This Year					
Asset Class*	Opening Carrying Amount*	Purchases	Sales / Disposals	Current Year Depreciation and Impairment*	Closing Carrying Amount*
Office equipment*	3,520	13,036		3,403	13,153
Total	3,520	13,036	-	3,403	13,153

Last Year					
Asset Class*	Opening Carrying Amount*	Purchases	Sales / Disposals	Current Year Depreciation and Impairment*	Closing Carrying Amount*
Office equipment*	4,056	-	-	536	3,520
Total	4,056	-	-	536	3,520

#### Note 5: Accumulated Funds

This Year				
	Capital			
	Contributed by	Accumulated		
	Owners or	Surpluses or		
Description*	Members*	Deficits*	Reserves*	Total*
Opening Balance	656	4,279	-	4,935
Prior Year Adjustment		-		-
Surplus/(Deficit)*		28,266		28,266
Closing Balance	656	32,545	-	33,201

Last Year				
	Capital			
	Contributed by	Accumulated		
	Owners or	Surpluses or		
Description*	Members*	Deficits*	Reserves*	Total*
Opening Balance	656	9,466	-	10,122
Prior Year Adjustment		-		-
Surplus/(Deficit)*		(5,187)		(5,187)
Closing Balance	656	4,279	-	4,935

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report.

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#### **Complex Chronic Illness Support (Incorporated)**

#### Notes to the Performance Report

For the year ended 31 March 2024

#### Note 6 : Commitments and Contingencies

#### Commitments

There are no commitments as at balance date (Last Year - \$nil).

#### **Contingent Liabilities and Guarantees**

There are no contingent liabilities or guarantees as at balance date (Last Year - \$nil).

#### Notes 7-8

Note 7: Related Party Tra	ansactions*	This Year	Last Year	This Year	Last Year
		\$	Ş	\$	Ş
Description of Related Party Relationship*	Description of the Transaction (whether in cash or amount in kind)*	Value of Transactions*	Value of Transactions*	Amount Outstanding*	Amount Outstanding*
Bluesky Data Limitied	A Board Member is also a Director of this company. BlueSky Data Limited is an Internet Service Provider for the Trust, at a fee.	1,548	1,601	-	-

#### Note 8: Events After the Balance Date:

There were no events that have occurred after the balance date that would have a material impact on the Performance Report.

These Notes should be read in conjunction with the accompanying Performance Report and Independent Assurance Practitioner's Report...

#### Contact details

Physical Address:	43 Welcome Bay Road, Welcome Bay, Tauranga 3112
Postal Address:	43 Welcome Bay Road, Welcome Bay, Tauranga 3112
Phone:	07 281 1481, 022 658 0251 or 0800 ccisup (224787)
Email:	info@ccisupport.org.nz
Website:	www.ccisupport.org.nz
Facebook:	https://www.facebook.com/mecfsbop

### INDEPENDENT ASSURANCE PRACTITIONER'S REVIEW REPORT

LACA Limited Serving with Excellence A fresh approach to assurance services



lauraRilaca.net.re; www.isca.net.re; Director: Laura Addinail (CA) Registered Office: 1 Surreybrooke Close, Welcome Bay, Tauranga, 3112

#### INDEPENDENT ASSURANCE PRACTITIONER'S REVIEW REPORT

To the Trustees of Complex Chronic Illness Support Incorporated

We have reviewed the accompanying Performance Report of Complex Chronic Illness Support Incorporated, which comprises the Statement of Financial Position as at 31 March 2024, and the Statement of Financial Performance and Cash Flows for the year then ended, and Notes to the Performance Report.

#### Board of Trustees' Responsibility for the Performance Report

The Board of Trustees are responsible for the preparation and fair presentation of this Performance Report in accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit), and for such internal control as the Board of Trustees determine is necessary to enable the preparation of a Performance Report that is free from material misstatement, whether due to fraud or error.

The Board of Trustees are also responsible for the other information. The other information comprises the entity information and statement of service performance but does not include the performance report and our conclusion thereon.

#### Assurance Practitioner's Responsibility

Our responsibility is to express a conclusion on the accompanying Performance Report. We conducted our review in accordance with International Standard on Review Engagements (New Zealand) (ISRE (NZ)) 2400, *Review of Historical Financial Statements Performed by an Assurance Practitioner who is not the Auditor of the Entity.* ISRE (NZ) 2400 requires us to conclude whether anything has come to our attention that causes us to believe that the Performance Report, taken as a whole, is not prepared in all material respects in accordance with the applicable financial reporting framework. This Standard also requires us to comply with relevant ethical requirements.

A review of the Performance Report in accordance with ISRE (NZ) 2400 is a limited assurance engagement. The assurance practitioner performs procedures, primarily consisting of making enquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

Our conclusion on the performance report does not cover the other information (the entity information and statement of service performance) and we do not express any form of assurance conclusion thereon.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing (New Zealand). Accordingly, we do not express an audit opinion on the Performance Report.

Other than in our capacity as assurance practitioner we have no relationship with, or interests in, Complex Chronic Illness Support Incorporated.

#### Conclusion

Based on our review, nothing has come to our attention that causes us to believe that the accompanying performance report does not give a true and fair view of the financial position of Complex Chronic Illness Support Incorporated as at 31 March 2024, and of its financial performance and cash flows for the year then ended, in accordance with Public Benefit Entity Simple Format Reporting – Accrual (Not-For-Profit).

LACA Limited

LACA Limited 20 August 2024 Tauranga

### THANK YOU TO OUR SUPPORTERS

### Meet Our Sponsors

These companies support us with either financial contributions, products or discounts. Thankyou!!!



### Meet the business that directly support our members

The companies support our members with products or discounts, We are grateful.













### THANK YOU TO OUR FUNDING PARTNERS CCI SUPPORT | 36

We are very grateful to out Funding partners for supporting Complex Chronic Illness Support in 2023/2024 Financial year.

