

Financial and Service Statements *

M.E./CFS Group (Canterbury) Inc

For the Year Ended 31 August 2023

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* The Financial and Service Statements comprise the 'Performance Report' for Charity reporting purposes.

M.E./CFS Group (Canterbury) Inc

Entity Purpose

Type of Organisation

M.E./CFS Group (Canterbury) Inc is a Society under the Incorporated Societies Act 1908 and is registered as a charity (CC32072). Also known as MECFS Canterbury.

Address

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Purpose of Organisation

The organisation was established in 1985 to support and assist people with ME/CFS* in the management of the illness and with the aim of improving their quality of life.

*ME/CFS is Myalgic Encephalomyelitis /Chronic Fatigue Syndrome, also known as Tapanui Flu in NZ.

ME/CFS is a serious long-term illness that involves an abnormal physiological response to exercise, altered immune function, and impaired energy production. There is a fluctuating spectrum of symptom severity, with many people being house-bound, and the most severely affected are bed-bound. Most people with ME/CFS are socially isolated, are unable to work, and do not have access to adequate financial, home and mobility supports through the welfare and health systems. There are a conservative estimate of 2,661 people with ME/CFS in Canterbury, with 362 of them being young people and children. The ME/CFS community in the West Coast is estimated at 130.

As a result of the COVID-19 pandemic, it is estimated that between 5-50% of people who have had an infection may develop LongCOVID and go on to meet the criteria for ME/CFS. Using an estimate of 10%, this would suggest that there may be 35,858 long haulers in Canterbury and 1,049 in the West Coast requiring the services and support offered by MECFS Canterbury.

In 2023, we are a growing community health and clinical service organisation serving our chronically ill community.

Our Vision - Tā Mātou Aronga

That every person with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS) in Canterbury lives the best quality of life possible.

Our Mission – Tā Mātou Whaingā

To improve the wellbeing of people, families and carers affected by ME/CFS by providing information, validation, clinical support, connection, and advocacy.

To improve the quality of care available for those affected by ME/CFS by providing education, direction, and support to health professionals and the wider community.

Our Values – Ā Mātou Uaratanga

Compassion, Respect, Equity, Patient-centred, Collaboration

We acknowledge Te Tiriti o Waitangi as a founding document in New Zealand and demonstrate a commitment and special obligation to its principles.

M.E./CFS Group (Canterbury) Inc

Statement of Receipts and Payments (Cash Flows)

For the period 1 September 2022 to 31 August 2023

	2023	2022
	\$NZ	\$NZ
Operating Cash Received		
<i>Donations, Fundraising and other similar receipts</i>		
Donations and Fundraising	\$ 4,168	\$ 8,767
Grants (Note 4)	\$ 144,212	\$ 79,043
<i>Receipts from providing goods or services</i>		
Sub-Lease	\$ 7,644	\$ -
Other Income	\$ 910	\$ 125
<i>Interest, dividends and other Investment Receipts</i>	\$ 566	\$ 36
<i>Other Receipts</i>		
Government COVID Support	\$ 600	\$ 6,159
Total Operating Cash Received	\$ 158,099	\$ 94,130
Operating Cash Paid		
<i>Expenses related to public fundraising</i>	\$ 251	\$ 256
<i>Volunteer and employee-related payments</i>		
Salaries and Wages	\$ 94,685	\$ 64,264
Volunteer Expenses		\$ -
<i>Expenses related to providing goods or services</i>		
Accounting/Auditing	\$ 863	\$ 680
Education, Youth and Intervention Support	\$ 1,647	\$ 575
General Expenses	\$ 2,369	\$ 1,976
Group Meeting Expenses and Resources	\$ 2,536	\$ 1,603
Insurance	\$ -	\$ 3,604
IT Website, Software and Phone	\$ 7,123	\$ 4,520
Library and other resources	\$ 1,517	\$ 1,020
Office Facility	\$ 22,148	\$ 4,695
Postage, Photocopying and Stationery	\$ 3,710	\$ 4,472
Staff Training, Supervision and Fees	\$ 2,434	\$ 1,396
Travel	\$ 5,830	\$ 2,512
Total Operating Cash Paid	\$ 145,114	\$ 91,574
Total Operating Cash Flow	\$ 12,986	\$ 2,556
Capital Cash Applied		
Equipment Purchases	\$ 6,336	\$ 480
Total Capital Cash Applied	\$ 6,336	\$ 480
Net Cash Flow	\$ 6,650	\$ 2,075
Add Opening Cash Balance	\$ 25,126	\$ 23,050
Closing Cash Balance	\$ 31,775	\$ 25,126
Represented by:		
Bank Accounts	\$ 31,775	\$ 25,126

M.E./CFS Group (Canterbury) Inc

Statement of Resources and Commitments (Assets and Liabilities)

As At 31 August 2023

		2023	2022
		\$NZ	\$NZ
Schedule of Resources (Assets)			
Bank Accounts and Cash			
Cash at Bank		\$ 31,775	\$ 25,126
Money Owed to the Entity			
Significant Accounts Receivable		\$ -	\$ 50
Other Resources			
Significant Fixed Assets at Cost	(Note 3a)	\$ 9,222	\$ 7,930
Prepaid Services		\$ 2,208	\$ 1,830
Schedule of Commitments (Liabilities)			
Money Payable by the Entity			
Significant Accounts Payable		\$ 533	\$ 1,374
Other Commitments			
Holiday Pay Owed to Staff		\$ 3,647	\$ 2,088
Schedule of Other Information			
Unexpended Grants	(Note 4)	\$ 17,251	\$ 13,923

M.E./CFS Group (Canterbury) Inc

Statement of Service Activity

Outputs

Although employee levels have increased slightly, we continue to operate with a bare minimum of staff due to the lack of sustainable funding sources. As a result we are not able to promote our services widely, and are not reaching all of the people in our ME/CFS and Long COVID community who we believe would benefit from our support.

Despite the challenging funding situation, MECFS Canterbury has increased its reach and service levels during the September 2022 – August 2023 year, as detailed in the Table of Key Measured Outputs and in the Service Delivery Description below. As evidenced by the feedback received (see excerpts in the Feedback section below), we are making progress towards improving the quality of life for people living with ME/CFS in Canterbury and the West Coast.

Table of Key Measured Outputs:

	2023	2022
People with ME/CFS*:		
*Based on low estimate of 4 in 1,000 people		
Canterbury:	2,661	2,584
North Canterbury	338	
Christchurch & Banks Peninsula	1,610	1,550
Outside Christchurch		1,033
Mid Canterbury	439	
South Canterbury	274	
West Coast	130	130
New Zealand	20,892	20,449

People with LongCOVID*:		
*Based on estimate of 10% of people recovered from COVID-19		
Canterbury	35,858	25,678
West Coast	1,049	1,049
New Zealand	245,665	177,745

Our ME/CFS Community:		
Members	316	186
With Long COVID	40	
Llfe Members	4	4
Facebook Closed Support Group	349	264
Facebook Public Page - Followers	504	364
Meetup page members	33	28
Instagram	97	
YouTube subscribers	444	59

Staff:		
Number of Employees:	5	3
Hours employed per month	208	165
Number of Volunteers:	57	9
Hours volunteered per month	195	111

Support Group Meetings:		
In-person Meetings:	19	8
Total in-person attendance	148	74
Virtual Meetings:	13	16
Total virtual attendance	149	228
Total meetings:	32	24
Total attendance	297	302
Watches on YouTube	16,180	2,509
Guest expert speakers	10	9

Registered Nurse Services:		
New Clients:	99	60
Health professional referrals	19	7
Self referrals after recommendation by health professional	15	21
Self referrals	65	32
Active Clients at end of year	147	79
Total Clients over the year	178	113
RNS Key client interactions:	1,537	686
Home /In-person Consults	100	70
Virtual consults	51	43
Phone consults	187	133
Email & text communication supports	744	271
External Referrals	34	25
Management Plans for Health School students	52	17
Advocacy with GPs, SRHS, Employers, Allied Health, etc	107	72
Other Contact with GPs, Whanau, Allied Health, etc	262	37
Health School - supported students	15	13
Rural clients (outside urban Christchurch City):	65	27
Rural Visits	18	20
Individual Support by Registered Nurses:		
Hours	1,139	647
Travel - kilometers	2,203	2,167

Work and Income Advocacy Service (new):		
Clients active during the year	38	

Outreach Service for Practical Supports:		
(For housecleaning, gardening, dog walking, tech support, etc)		
Clients active during the year	53	8
Clients at end of year	27	
Clients awaiting volunteer placement	6	
Volunteers involved during the year	45	
Volunteers at end of year	38	

Newsletters:		
Number of issues	6	6
Number of subscribers	326	206

Library		
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Number of titles	135	111
Total number of books	169	133

Education for Health Professionals:		
Events with Presenters provided by us	1	2
Other activities	4	2

Education for the Public:		
Specific permanent content	5	2
Content in Traditional Media	2	0

Organisation Advocacy /Networking:		
Meetings	36	26
Conferences/Training attended	15	11
Other interactions	8	8
Professional Memberships	6	5

Service Delivery Description:

Formal Membership

Registered members of MECFS Canterbury increased 70% from 186 to 316.

Long COVID

We welcomed over 40 members who are experiencing ME/CFS symptoms as a result of the COVID-19 pandemic. We expect this number to increase markedly, especially with the closure of the Long Covid Hub in Christchurch in September 2023.

Online Support Group

Our online peer support group on Facebook continues to provide a supportive environment for people living with ME/CFS to connect, share experiences and information. Membership of this group increased 68% (264 to 349).

Group Support Meetings

Our group meetings are an important opportunity to share information and enable connections with other people who understand life with a chronic illness.

To include those that are unable to attend, we share recordings of presentations and share information and summaries in our newsletter, Facebook group, and by email to our members.

This year, we held in-person meetings in Christchurch (monthly) and Rangiora (bi-monthly). We also visited the West Coast for the first time in March 2023, holding in-person meetings in Westport, Greymouth and Hokitika.

Our monthly online Zoom meetings enable participation by people who are unable to attend the in-person meetings, for various reasons such as being bed- or house-bound, or not living near the places we meet.

Topics for our group meetings in 2023 financial year included;

- Breathing Techniques - Catherine George, Physiotherapist.
- Reducing the risk of infections – Ben Harris, Medical Microbiologist
- tVNS with a TENS device – Dr Paul Bunton, MBChB
- Living with Fibromyalgia - Dr Bronwyn Thompson, Occupational Therapist
- Analeptic Exercises - Catherine George, Physiotherapist
- Mindfulness - Di Robertson, Psychotherapist
- Finding Resilience - Elizabeth Hamilton, Social Worker
- Online Resources at the CCC Library - Paul Focamp, Librarian
- Services from On The Go Physio - Jessie Snowdon, Physiotherapist
- Gut Health and ME/CFS - Dr Richard Garry, Consultant Gastroenterologist
- Young Adults Catchup
- Art, Craft and Chill sessions
- Various discussion topics

We provide funding to ME Support - NZ, so that young people aged 13 to 17 in our region can join their facilitated Discord Youth Support Group. In addition, a parent-led in-person social gathering for young people ages 12 to 19 has operated, with catchups normally occurring every two months at Escape Artists.

Registered Nurse Services:

We welcomed another part time nurse and this team is now at 0.75 FTE. There was a 58% increase in the number of clients enrolled in our Registered Nurse Service, all of whom had struggled to obtain a diagnosis or receive symptom management support elsewhere (from 113 to 178 clients over the year).

The Registered Nurse Service is delivered through home visits, zoom consultations, and other interactions to people of all ages. It makes a difference for individuals in the following areas:

- Advocacy with GPs, Physicians, allied health, schools, employers, Work and Income NZ, whānau and others
- Clinical support for obtaining a diagnosis and symptom management
- Supporting clients with hospital admissions
- Loaning activity trackers to enable clients to identify their activity capacity
- Management plans for students throughout the South Island to enable enrolment at the Southern Regional Health School (The SRHS is a state school for children in Years 1 to 13 who are unwell.)

- Referrals to allied health and other external supportive services (including CDHB Occupational Therapy, CDHB LTS-CHC (Long Term Support – Chronic Health Conditions), Pegasus Health PCW (Partnership Community Workers), Comcare – Peer Support, Total Mobility Card)

- Planning and supporting care for severely unwell clients, and providing education for their health teams.
- Applications for the Hāpai Access Cards that give people with disabilities better access and support from retailers and public areas.

Our Registered Nurse Service continues to engage with medical and allied health professionals through cases for individual clients, and this also increases understanding of ME/CFS and appropriate clinical management and supports.

Work and Income Advocacy Service:

We engaged staff to focus solely on providing assistance with accessing financial support from Work and Income. Amongst the successes, the team supported several clients onto the higher Support Living Payment which is appropriate for many people with ME/CFS.

Volunteer Outreach Services:

We developed our Volunteer Outreach Service further, involving 45 volunteers to provide one-off and ongoing practical supports to 53 people with ME/CFS. Support provided included house cleaning, gardening, dog walking, plus more and is not available to them elsewhere. This support helps clients to feel cared for and can help them to avoid exceeding their activity limits and worsening their symptoms.

Newsletter:

Our newsletter continues to be well received and members elect to receive it by email and/or post. Main themes during the year were;

- October 2022 – Common Co-existing Conditions with ME/CFS
- December 2022 – Take a Breath
- February 2023 – PEM and Pacing
- April 2023 – Finding Easier Ways
- June 2023 – Shining a Light on ME/CFS
- August 2023 – The Gut and ME/CFS

Library:

Our library is accessible to home-bound and out-of-town members through an online catalogue and delivery through the post. We also provide post paid bags for the return of the books.

Education and sharing information about ME/CFS

As a result of our education programme and partnership with Te Whatu Ora - Waitaha (Health New Zealand - Canterbury), we have observed that more General Practitioners are comfortable assessing, diagnosing, and supporting people with ME/CFS. Appropriate information about ME/CFS is available to health professionals on the community and hospital Health Pathways website, as well as the Allied Healthways website. Information about ME/CFS for the public is available on the HealthInfo website.

Our Registered Nurse Service continues to engage with medical and allied health professionals through cases for individual clients, and this also increases understanding of ME/CFS and appropriate clinical and other management and supports. Our staff were also involved in presentations about ME/CFS to a medical centre and met with several health professionals.

We continued to share research news and other material on our public Facebook page and our new Instagram profile.

We developed additional information handouts for living with ME/CFS including topics 'Working with your doctor' and 'Low Dose Naltrexone'.

Recordings of the educational sessions delivered at our group meetings received 16,180 views on our YouTube channel.

Participation in Networking and Advocacy events

A highlight this year was the Christchurch City Council and Ashburton District Council illuminating public landmarks in blue for World ME Day on 12th May 2023, at our request.

Representatives of MECFS Canterbury are meeting frequently with leaders at the Te Whatu Ora to further develop our partnership. This is assisting us in raising awareness of ME/CFS, educating health professionals, and ensuring that people with ME/CFS have access to standard services from Te Whatu Ora where entry criteria is met.

In September 2022, we re-submitted a business case to Te Whatu Ora for service provision funding. This is unable to progress further, until the new entity Te Whatu Ora (Health New Zealand) has established their commission framework and teams.

Health professionals who are experts in their field have made themselves available to present for us, showing that they see us as a professional service provider. They have also taken the opportunity to learn more about ME/CFS and this will have a ripple effect through their interactions with patients and colleagues in their workplaces.

During the year, staff of MECFS Canterbury have facilitated and attended regular networking meetings with other ME/CFS agencies in New Zealand, including ANZMES, M.E. Awareness NZ, Complex Chronic Illness Support, and ME Auckland. The meetings have allowed the sharing of information and approaches, as well as enabled collaboration on projects such as an awareness campaign for World ME Day, on 12th May 2023.

During the year, with the aim of improving understanding of ME/CFS and improving our organizational framework and connections, representatives of MECFS Canterbury have met with a wide range of individuals and organisations including:

- Attended health sector forums in Christchurch, Timaru and Greymouth.
- Connected with volunteering staff and their networks, Disability Leadership Canterbury, and the Beneficiary Advisory Service.
- Connected with leaders and staff involved in the shortly lived Long Covid Hub in Christchurch.

- Met with grant advisors and funders, including the Maia Health Foundation.
- Attended Stakeholder events regarding the transformation of the health system held by the Ministry of Health, Te Whatu Ora - Waitaha | Health New Zealand and Te Aka Whai Ora | Māori Health Authority.
- Corresponded with Members of Parliament, including the Hon Dr Ayesha Verrall, Minister of Health, regarding lack of public funding, knowledgeable GPs, and access to supports such as home help.
- Held professional memberships with Social Equity and Welfare Network (SEWN), ANZMES, Christchurch Community House, Volunteering Canterbury, Mid and South Canterbury Volunteering, Exult.

Organisational Development

New Office Premises:

On 1st December 2022, we moved from Christchurch Community House at 213 Lichfield St, to office space at 71 Orbell St, Sydenham, Christchurch. The new premises provided our team with two offices and also a meeting room shared with other tenants in the building. Additional and unused office space was leased to a sub-tenant, bringing welcome untagged income.

Access to Health Sector Systems:

Our Registered Nurses can now:

- Search for the National Health Identity (NHI) numbers for our clients, to aid communication with medical centers and making referrals
- Make referrals to other health practitioners and services through the Electronic Referral Management System (ERMS). We are not accepting referrals through this as yet, due to fear of being overwhelmed
- Access health records for clients through the Health Connect South system.

Operations Manual:

We finalized and adopted an additional two sections of our Operations Manual and have the remainder of the Policies and Procedures in draft.

Training:

Staff have participated in a variety of training activities including:

- MyHealth Hub ME/CFS Webinar
- ThinkGP ME/CFS Modules 1 & 2
- ANZMES Education for ME/CFS and Long Covid
- Visit to the Essex Community ME/CFS clinic (UK)
- International Research Conference in UK (IIMEC15)
- CPR and First Aid
- Community Engagement, Community Governance, and Volunteering Management Systems

Webinars

- Empathy and Compassion Fatigue, MHERC
- Assistance from Work and Income, GPCME South
- Post-Viral Fatigue and Long Covid, GPCME South

Feedback

We received the following feedback in our 2023 Annual Survey and directly throughout the year:

Feedback #1

"Again I just feel amazed that the organisation exists, that I know that if I have an issue related to CFS that I cannot resolve myself, there is someone I can ask who will understand, and who may know how to get me the help.

I also appreciate the kind and social nature of much of the communication; this is a health condition but it affects every domain of our lives, and so the efforts to connect and facilitate care and fun and connection even beyond the healthcare domain feel especially profound.

You'd only set up your organisation that way if you understood what weird and indirect impacts this illness can have on your life, so to me the whole thing communicates understanding and an approach of "you are welcome here". What a beautiful thing to have when you are dealing with such a complex and overwhelming illness."

Feedback #2

"(the nurse) was amazing! We did a phone consult and she sent her findings to my doctor... Who, once she received them, confirmed that yes, I "undoubtedly" have ME.

The relief! It's really hard to explain how validating it is when someone is finally able to see each of your symptoms as one part of a whole picture rather than each thing in isolation from the other. For years I've been trying to be seen by doctors... years! ...

My new doctor has said yes, I have ME and Fibro and has signed a 2 year medical certificate. The nurse made that happen - thank you so much!"

Feedback #3

"It was completely unexpected to have this kind of support! To have the nurse come to my home and ask all about my experience, connect me with supports, and check in again just recently. I feel like I have someone I can call if I need specific help or advocacy in the future."

Feedback #4

"The lady who does housework for me is amazing. These sorts of things are game changers and help SO much."

M.E./CFS Group (Canterbury) Inc

Additional Entity Information

Organisation Structure

The affairs and funds of MECFS Canterbury are managed by the Society's committee. Members elect the Executive Committee at the Annual General Meeting. The committee comprises a Chairperson, Secretary, Treasurer and up to three other members.

Staff, including employees and volunteers, are engaged to deliver the services of MECFS Canterbury.

Executive Committee

Chairperson – Rose Camp

Treasurer – Rose Camp (Acting until September 2023)

Secretary – Nicola McDowell

Committee Members – Jan Barber, Karen Lawton, Tom Harris

Employees

Manager – Nicola Stokes RN – 0.3FTE (12 hrs/week)

Registered Nurse – Clare Lawrence – 0.5FTE (20 hrs/week)

Registered Nurse - Amanda Wyatt - 0.3FTE (12 hrs/week) - started 9th January 2023

Work and Income Advocate – Rose-elle Ross – 0.05FTE (2 hrs/week) - started 30th March 2023

Accounts Administrator – Hannah Maxwell – 0.05FTE (2 hrs/week)

Volunteers

Various other roles and tasks are carried out by Committee members, Society members and supporters. For example, grant applications, office administration, newsletter curation & contributions, Group Meeting facilitation, social connections, and practical supports.

Main Sources of Funds

MECFS Canterbury relies almost exclusively on discretionary grants from government and philanthropic organisations. Additional funding is sourced from donations.

Main Methods of Fundraising

Our volunteers complete grant applications to cover expenditure.

Volunteers and in-kind Donations

MECFS Canterbury relies heavily on volunteers for completing its governance, administrative and general tasks. However, it is important to note that our community suffer from ME/CFS which impacts their ability to do even normal activities of daily living, and certainly restricts their ability to volunteer. Many also live on very low incomes and are unable to make donations or get involved in fundraising.

M.E./CFS Group (Canterbury) Inc

Notes

1 Basis of Preparation

M.E./CFS Group (Canterbury) Inc is permitted by law to apply standard SFR-C(NFP) and has elected to do so.

Transactions are reported on the basis of cash received and spent in the Statement of Cash Flow. Significant amounts owed or owing are accrued in the Statement of Assets and Liabilities.

2 Taxation

As a Registered Charity the organisation is exempt from Income Tax.

The organisation is not registered for GST, and all figures are shown inclusive of GST.

3 Schedule of Fixed Assets

Items of Property, Plant and Equipment are shown at Cost. Applying depreciation is not permitted under this Reporting Standard.

a. Significant Purchased Assets

	2023	2022
Asset	Cost	Cost
Books	\$ 1,020	\$ 1,020
Office Equipment	\$ 5,303	\$ 4,508
Services Equipment	\$ 2,899	\$ 2,402
Total	\$ 9,222	\$ 7,930

4 Grants

The following table shows grants that were received during the year, and any money not yet spent:

2023			
Grantmaker	Purpose	Received	Unexpended
Air Rescue Trust	Operational costs	\$ 5,546	\$ -
Aotearoa Gaming Trust	Staff wages	\$ 10,140	\$ -
Christchurch Casino Trust	Operational costs	\$ 1,500	\$ -
Christchurch City Council	Operational costs	\$ 6,000	\$ -
COGS	Operational costs	\$ 2,500	\$ -
Kiwi Gaming Foundation	Operational costs, staff wages	\$ 28,634	\$ 10,959
Lion Foundation	Staff wages	\$ 4,000	\$ -
Mainland Foundation	Staff wages	\$ 16,240	\$ 3,896
NZ Community Trust	Operational costs	\$ 11,186	\$ 896
Lottery Grants Board	Operational costs	\$ 15,000	\$ -
One Foundation	Equipment	\$ 2,966	\$ -
Pub Charity	Staff wages	\$ 9,000	\$ -
Rata Foundation	Operational costs	\$ 30,000	\$ -
West Coast Community Trust	West Coast service provision	\$ 1,500	\$ 1,500
Total		\$ 144,212	\$ 17,251

2022			
Grantmaker	Purpose	Received	Unexpended
Air Rescue Grant	Operational costs	\$ 1,552	\$ -
Aotearoa Gaming Trust	Staff Wages	\$ 6,760	\$ -
CCC Strengthening Communities Grant	Staff Wages	\$ 4,000	\$ -
Kiwi Gaming Foundation	Operational Costs, Staff Wages	\$ 19,546	\$ 7,687
Lion Foundation	Staff Wages	\$ 3,000	\$ -
Mainland Foundation	Staff Wages	\$ 14,105	\$ -
NZ Lottery	Operational Costs, Office Facility	\$ 15,000	\$ 183
Pub Charity	Staff Wages	\$ 7,580	\$ -
The Trusts Community Foundation	Staff Wages	\$ 7,500	\$ 6,053
Total		\$ 79,043	\$ 13,923

5 Related Parties

There were no reportable transactions involving related parties during the financial year. (2022- Nil)

6 Events After Balance Date

There were no events that have occurred after the balance date that would have a significant impact on the Performance Report. (2022- Nil)