



**21st September 2022 (FY 2022)
ANNUAL REPORT**

**Fibromyalgia ME/CFS Gold Coast Support Group Inc.
ABN: 12 618 317 229**



Fibromyalgia ME/CFS Gold Coast Support Group Inc. proudly acknowledges the Traditional Custodians of Country throughout Australia. In particular we pay our respects to the people and elders, past, present and future of the Yugambeh lands.



Our mission

Our mission is to bring about sustainable change and acceptance of ME/CFS and Fibromyalgia into the mainstream of Gold Coast community including health care, education, disability and support services, with dignity.

Our vision

Our vision is for the Gold Coast and Queensland communities, health and community services to extend compassion and empathy to people living with fibromyalgia and ME/CFS and provide consumer orientated, accessible, safe and effective quality services.

Our History

The original Fibromyalgia ME/CFS Gold Coast Support Group was established in 1998 by a group of people living with these conditions, on an informal and voluntary basis, with the aim for others with these conditions to create connections in a safe environment - to be able to share experiences of their health journey, learn to manage the conditions and to navigate the health care system.

Demand grew over the years and the volunteers of the group found it difficult to maintain the desired level of support to the almost 600 people reaching out through our various platforms; a private Facebook group; closed email group; Zoom and Skype sessions; telephone calls and in-person.

With sustainability and desire to increase support in mind, a group of our regular volunteer facilitators came together in early 2021. The result being, after many months of work, Fibromyalgia ME/CFS Gold Coast Support Group Inc. is now registered as a not-for-profit incorporated association under Queensland law, and is registered with the ACNC as a Health Promotion and Advancing Health Charity with DGR endorsement.

INTRODUCTION

Carol Baker is our inaugural President / Chairperson, which was only fitting seeing as she has been the backbone of the grass roots support group on the Gold Coast for many, many years.

PRESIDENT'S REPORT

Just over a year ago a few of us were at the Emerald Lakes Golf Club for one of our support group lunches. Kathy Dallest and I had talked about a dream that we both shared to see the support group become incorporated. I had tried in 2013 but it was difficult to get enough people to help me at the time. I mentioned it to a couple of people at this particular lunch and the support and feedback was very positive. I rang one person that I thought might also be interested, Wendy Bennett, who joined the team and look where we are now!

We have come a long way from that day and finally achieved my long standing dream of an Incorporated Association as well as being a registered Charity. But then the work really began, and many of us had no idea just how much work would be involved in setting up the Governance, Policies and Procedures. I would like to thank the members of the Board, in particular Wendy Bennett and Kathy Dallest for the constant effort of setting up and keeping the governance in order.

The support group has always been about giving support and information to its members and to help raise awareness for Fibromyalgia and ME/CFS.

Earlier this year Wendy Bennett and myself had a meeting with Sam O'Connor MP for Bonney QLD about raising funds for our group. At first, he was thinking that a "chook raffle" might be a good idea but by the time we explained our day to day living, and then when we mentioned "NCNED", he started to take more interest. He checked out the NCNED website, and ME/CFS, he knew a little about Fibromyalgia but he knew more by the end of our conversation. I remember saying to him something like, "so you see that having a chook raffle might not be a good idea"? He replied with something like "Oh no, you couldn't do that". He had listened and he understood that something like a chook raffle would be daunting for people living with these conditions.

We had a number of highlights over the last year. The NCNED's International RID Conference held in November 2021 on the Gold Coast, which allowed a number of our support group members to attend. Great information and lots to learn about the research around the world for ME/CFS as well as the presentation from NCNED.

Unfortunately, COVID prevented us from having many meetings that we wanted and planned but there is always the future and we managed to have some Zoom "get togethers" and lunches when we could. It's not easy to get out to a lunch for many of us as we never know if we can make it until that day!

I enjoyed seeing so many people at the International Awareness Day, May 12 lunch. Wasn't it wonderful to see how many buildings were lit up in blue and purple in Brisbane and the Gold Coast! Not to mention around Australia and the world! People with Fibromyalgia, ME/CFS get a chance to speak about their struggles with their illness on this special day knowing that they are not alone.

What about the Speaker of the House of Queensland Parliament, announcing after prayers, the difficulties that people living with this illness face every day? It was a heartfelt speech and one I will never forget. A big thank you to Sam O'Connor MP, for his donation which allowed us to buy ribbons for our special day not only for us to but for Queensland parliament to wear on that memorable occasion.

There are many people in the Gold Coast Community who need help and understanding that they may not get from medical professionals. The difficulties of diagnosis and treatments are complex and not always suitable for everyone because as we know “not one treatment suits all”.

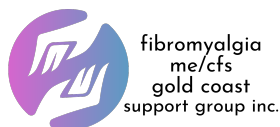
We endeavour to give support to those that need it through meetings, Facebook, phone calls, video chats and information.

I know that the Association has many exciting new ideas for the future and hopefully with grants, donations and more memberships these ideas will come to fruition.

It has been a pleasure being the inaugural president of Fibromyalgia, ME/CFS Gold Coast Support Group Inc.

Carol Baker

Carol Baker
President



There is no "right way"
to live with a
chronic illness.
We can only do our best
on each given day



fibromyalgia me/cfs gold coast support group inc.

SECTION 1**AN OVERVIEW OF FIBROMYALGIA ME/CFS
GOLD COAST SUPPORT GROUP INC.****ABOUT US**

We are a Health Promotion Charity whose purpose is to advance health by:-

- promoting activities to help manage suffering or distress and to prevent further ill health and disability;
- facilitate regular support group informative meetings and social lunches;
- provide a safe and supportive environment where people can share their stories and feel validated;
- promote awareness, develop local media campaigns, promotional materials and website information so that more people are aware of and understand the effects of FM, ME/CFS;
- advocate for improved access to care by connecting with GP's, nurses and allied health to promote the importance of early diagnosis;
- support newly diagnosed people navigate the paperwork and requirements for disability claims with Services Australia or through insurance.



Our core objectives as set out in our Constitution are:-

- to provide support for and information to people living with ME/CFS and FM on the Gold Coast;
- to raise awareness of ME/CFS and/or FM in the Gold Coast community;
- to advocate for people living with ME/CFS and/or FM in the Gold Coast community;
- to raise funds to help and support people living with ME/CFS and/or FM who are physically and socially isolated in the Gold Coast community.

OUR PEOPLE

Board members/Trustees

Name	Position	Dates acted (if not for whole year)
Carol Baker	President	28-06-2021 - 14-09-2022
Wendy Bennett	Vice President Treasurer	28-06-2021 - 14-09-2022 31-10-2021 - 14-09-2022
Kathy Dallest	Secretary	28-06-2021 - 15-08-2022
Wendy Nicholas	Treasurer Board Member	28-06-2021 - 31-10-2021 01-11-2021 - 14-09-2022
Stuart Irwin	Board Member	28-06-2021 - 14-09-2022
Eric Middleton	Board Member	28-06-2021 - 14-09-2022
Robyn Hevgold	Board member	28-06-2021 - 15-08-2021
Karli Moulston	Board member	07-06-2022 - 14-09-2022







Employees

Name	Position	Dates acted (if not for whole year)
Nil		

Volunteers

Name	Position	Dates acted (if not for whole year)
All Board Members noted above		

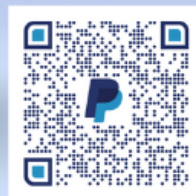
OUR SUPPORTERS

 <p>SAM O'CONNOR Member for Bonney</p>		
Sam O'Connor MP for Bonney	Professor Sonya Marshall Gradisnik	The team at NCNED
 <p><i>Persistent Pain Program</i></p>		 <p>National Advisory Advocacy Council for ME/CFS research</p>
Joyce McSwan, Persistent Pain Program, GHPHN	Gold Coast Primary Health Network	The National Advisory Advocacy Council for ME/CFS Research Ltd.

ME/CFS, Fibromyalgia - can take someone who is educated, ambitious, hardworking and tireless and rob them of the ability to work, clean house, exercise or think clearly or to **EVER FEEL AWAKE AND HEALTHY AGAIN.**



fibromyalgia me/cfs gold coast support group inc.



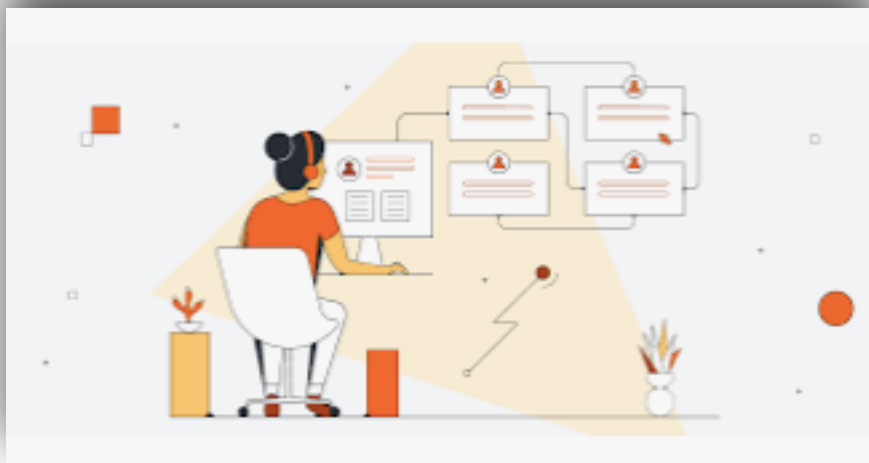
SECTION 2**GOVERNANCE****STRUCTURE & MANAGEMENT**

Fibromyalgia ME/CFS Gold Coast Support Group Inc. is registered with the Australian Charities and Not-for-profits Commission (ACNC) and as an Incorporated Association with Office of Fair Trading Queensland.

We adopted the Office of Fair Trading model rules as our Constitution, with one additional clause, to satisfy ACNC being a Deductible Gift Recipient Revocation clause.

At this early stage of our Association, our Structure and Management is, simply put, our seven Board Members noted in the previous section. They have been serving as Board Members, as the Operational team and Volunteers. We do not have any employees or paid volunteers.

We have established a Board Manual and numerous Policies & Procedures which set out the processes to be followed.



BRIEF OVERVIEW

We started with 6 members on 28th June 2021 - six individuals that felt the compassion to give up some of their time to get this Charity up and running. Since then we have had some big achievements!

- ★ 7 Grant Applications completed and lodged;
- ★ 35% increase in our Facebook presence;
- ★ 4 Advocacy Submissions to Government Agencies;
- ★ 600 telephone support calls;
- ★ 150 emails of support or providing information
- ★ organising the historical speech made by Curtis Pitt MP, Speaker of the House of Parliament, on May 12th recognising the debilitating effects of Fibromyalgia and ME/CFS;
- ★ All Members of Parliament receiving and wearing our custom made Awareness Ribbons on May 12th;
- ★ Media coverage on Seven News and in the Gold Coast Bulletin raising awareness for ME/CFS
- ★ A Poster Presentation at the ME/CFS International Conference hosted by NCNED, Kathy Dallest was a keynote speaker at the conference and also chaired the consumer perspectives session;
- ★ Hosting an Event where Professor Sonya Marshall-Gradisnik and the team from NCNED presented their latest research findings on ME/CFS and LDN

DETAILED TIMELINE OF BOARD ACHIEVEMENTS

APRIL 2021 On the 21st April 2021 we held a special meeting where it was proposed and seconded that the Fibromyalgia ME/CFS Gold Coast Support Group would become an Incorporated Association and apply for charity status with the ACNC.	JUNE 2021 On 28th June 2021 we received confirmation that our application to be incorporated had been approved and we now had 6 members.
JULY 2021 We applied for and received our ABN, opened a society bank account with the CBA, ordered and received our Common Seal, applied for and received Charity status from ACNC as well as Deductible Gift Recipient endorsement and charity tax concession endorsement. Substantial work went into setting up our operational files and documents in Google Drive, in order to comply with all our Governance and reporting requirements.	AUGUST & SEPTEMBER 2021 The Board continued to work on setting up Membership Applications, Policies & Procedures, creating our Logo and branding, etc.
OCTOBER 2021 It was at our social lunch in October that we announced about our success in becoming an Incorporated Association with charity status. From this we gained another 5 members. The Board also began preparations for the International ME/CFS Conference which was being held in November.	NOVEMBER 2021 The first major event for our Association was the ME/CFS International Conference 2021 - Research, Innovation & Discovery sponsored by the National Centre for Neuroimmunology and Emerging Diseases. Our very own Kathy Dallest was a Keynote Speaker presenting on "Value-Based Healthcare - whose value is it anyway?" and also chaired the consumer perspectives session on day 1. A Poster Presentation on "Co-creation of value for people with ME/CFS; a consumer led initiative in Queensland" was also on display. Both of these were BIG achievements for any Association, let alone one only been running for a few months.

<p>DECEMBER 2021</p> <p>Covid was spreading fast in other States, but we were lucky enough to be able to hold a lovely Christmas lunch at Le Vintage Cafe, which was a lovely catchup with good attendance, good friendship, good support, good food and good service.</p> <p>Carol Baker, Kathy Dallest and Wendy Bennett met with Sam O'Connor MP for Bonney to introduce ourselves on behalf of Fibromyalgia ME/CFS Gold Coast Support Group Inc., as our registered place of business is within the Bonney division. He showed great interest in our Group and was not previously aware of the NCNED at Griffith (also within Bonney division). Sam O'Connor wrote to the Gold Coast Primary Health Network which has resulted in the GCPHN inviting our Group to submit information to them for their further needs assessment activities.</p> <p>A grant application was lodged for the Damien Greet Lawyers Community Grant.</p> <p>A joint submission was lodged to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.</p>	<p>JANUARY 2022</p> <p>COVID was now circulating and the Board took a well deserved break for a few weeks.</p>
<p>FEBRUARY 2022</p> <p>We held the first of our Zoom social lunches for safety reasons due to COVID. We prepared and submitted 4 grant applications during the month, which was a substantial effort by the Board.</p> <p>A joint submission was lodged in relation to the Review of the Anti Discrimination Act.</p>	<p>MARCH 2022</p> <p>We held another Zoom social lunch, 2 more grant applications prepared and lodged and the Board commenced preparations for International Awareness Day which is on 12th May.</p> <p>Our Association formally took over the Facebook Private Support Group Page, updated the Rules and incorporated our logo and branding. A public Facebook page was also created.</p> <p>The Board recognised that we needed additional support to help with the administration and running of the Association, and an invitation was presented for Karli Moulston to join the Board.</p> <p>We also acknowledged the need for more volunteers to help, which will be an ongoing discussion.</p>

<p>APRIL 2022</p> <p>Several Board Members had contracted COVID and were generally unwell, so there was no Zoom social lunch this month.</p> <p>Many negotiations and discussions were underway in relation to May 12th.</p>	<p>MAY 2022</p> <p>Thankfully COVID had eased and we were able to hold a social lunch on May 11th. It was a big turnout, with lots of blue and purple outfits.</p> <p>All the work done during April, resulted in:-</p> <ul style="list-style-type: none"> * Sam O'Connor MP providing us with a generous donation. * This allowed us to design and purchase a combined Fibromyalgia and ME/CFS Awareness Ribbon * On 12th May, all members of Qld Parliament wore our ribbons * On 12th May, the Speaker, Curtis Pitt MP, made a historic and heartfelt speech acknowledging the debilitating effects of ME/CFS and Fibromyalgia * Parliament House was lit up in Blue * Seven News interviewed Kathy Dallest and Professor Sonya Marshall-Gradisnik and ran a story on the effects of ME/CFS * Gold Coast Bulletin interviewed and published a story about Karli Moulston and her journey with ME/CFS. <p>Another big event for our group was on Wednesday 25th May, when the team from NCNED came to speak to us to provide an update on their latest research. There has been a lot of talk in our group recently about LDN (low dose naltrexone), and Professor Sonya Marshall-Gradisnik explained, in layman terms, how LDN is helping people with ME/CFS and Fibromyalgia. Attendance at this Event was significant, and resulted in numerous more members joining and several donations being made.</p>
<p>JUNE 2022</p> <p>After such a big month of May, several Board Members needed time to recoup and recover. A social lunch was still held.</p> <p>Preparations began for the new round of grants that were to be completed and lodged by 31 July</p>	

OUR OBJECTIVES AND ACTIVITIES

We are registered with ACNC as a Health Promotion Charity with a purpose to Advance Health by:

1. promoting activities to alleviate suffering or distress caused by Fibromyalgia and ME/CFS;
2. fostering a lived experience and a research evidence based understanding of Fibromyalgia and ME/CFS;
3. preventing Fibromyalgia and ME/CFS from causing further ill health and disability.

HOW WE HAVE ACHIEVED OUR OBJECTIVES AND PURPOSE IS BY:-

Promoting activities to alleviate suffering or distress caused by Fibromyalgia and ME/CFS

- we have hosted monthly social lunches, when safe to do so due to COVID, and when restrictions were in place we held monthly Zoom social catch ups;
- these provide a safe space for people living with Fibromyalgia and ME/CFS to be amongst their peers and feel validated, promotes relationship building and reduces social isolation and loneliness
- we run a private support group page on Facebook which is actively monitored by admins. This allows people living with Fibromyalgia and ME/CFS to connect virtually with others on the Gold Coast to seek help or support, or even just to vent.
- Sharing experiences with others living with these chronic conditions can help to alleviate suffering or distress
- Organising the May 12th International Awareness Day Event and NCNED community meeting gives hope to those living with Fibromyalgia and ME/CFS that they are being seen and heard and that research is continuing in an effort to provide further relief.

Fostering a lived experience and a research evidence based understanding of Fibromyalgia and ME/CFS

- All Board Members themselves suffer from Fibromyalgia and/or ME/CFS, so we can share our lived experiences and knowledge gained with our Members and also to anyone living with these conditions in the Gold Coast Community;
- We have established connections with universities, health services and community care organisations which allows us to promote credible information sources and education and development activities for best self-care practice, self management and self advocacy strategies
- fostering education and development opportunities increases personal capabilities and resilience

Preventing Fibromyalgia and ME/CFS from causing further ill health and disability.

- We have been collaborating with the Brisbane ME/CFS Support Group and The National Advisory Advocacy Council for ME/CFS Research Ltd and have presented four Submissions advocating for people living with Fibromyalgia and/or ME/CFS.
- We have been working with Queensland Health to create and ME/CFS Pathway;
- We have established connections with Gold Coast Primary Health Network to work with them on their Needs Assessment;
- We have connections with, and support from, NCNED and the Gold Coast Persistent Pain Program facilitator;

All of these collaborations and connections are working towards improving the current understanding of Fibromyalgia and ME/CFS amongst GP's, Health Providers and Specialists, Services Australia and NDIS so that people living with these conditions can receive support in a dignified manner.

OUR OBJECTIVES FOR THE NEXT YEAR

Our core objectives will remain the same.

However, we are proposing to increase our support in the community by holding two meetings a month at a central Gold Coast community centre (subject to funding).

This will create a place where people can come together, without the costs associated with the social lunches.

We have also established that the Board requires additional support with administrative duties and with providing peer support.

We have a Peer Support Program in the planning (subject to funding) which will allow us to provide training to volunteers.

SECTION 3**OUR FINANCES****TREASURER'S REPORT**

The financial information presented in this report is for the financial year 1 July 2021 to 30 June 2022. Due to the size of our Association and newly passed legislation changes in Queensland, we are not required to have our accounts audited. As Treasurer, I have provided a Verification Statement to comply with regulations (see Appendix "A")

We have established a PayPal Giving account and are registered with all States & Territories to allow for fundraising.

PROFIT & LOSS

REVENUE	2022
Membership Fees	\$520.00
Donations	\$1,061.00
TOTAL	\$1,581.00

EXPENDITURE	2022
Domain Name Registration Fee	\$74.00
Office of Fair Trading fee	\$22.00
Awareness Day Ribbons & Cards	\$620.00
Stationery supplies	\$25.00
Consumables (coffee cups, spoons, etc)	\$27.00
Meeting Room Hire	\$70.00
TOTAL	\$838.00
NET PROFIT:	\$743.00

IN KIND SERVICES RECEIVED	
Whilst we do not have any paid Board Members or Volunteers, it is important to recognise the monetary value of the In Kind services that Board Members have donated to the Association	
The accepted rate for Volunteer's is \$31.50ph	
Based on this, the value of the In Kind Services to the Association is:	\$94,500.00

BALANCE SHEET

ASSETS	2022
Bank account	\$743.00
TOTAL ASSETS:	\$743.00
LIABILITIES	
Nil	\$0.00
NET ASSETS:	\$743.00
EQUITY	
Current year Earnings	\$743.00
TOTAL EQUITY:	\$743.00

INSURANCE

At this stage we do not have Public Liability Insurance in place due to funding, especially in the early stages. To mitigate this, we have only held lunches and Events at places which have their own Public Liability Insurance in place. We have a quote of \$1,725.00pa for a combined policy including Public Liability, Association Liability and Voluntary Workers Group Personal Accident.





SECTION 4**OUR OTHER IMPORTANT INFORMATION****HOW YOU CAN HELP****Become a member**

Membership is only \$20 per annum. A copy of the Membership Form is attached as Appendix "B".

Volunteer your time

We are actively seeking the help of volunteers to help with either administrative tasks, help with fundraising, or help with the organisation of meetings / social lunches. We will provide training as required. If Centrelink requires you to do a number of Voluntary hours per week, this could be a great opportunity!

Make a donation

Our account details are:-

CBA

BSB: 064-430

Account: 1161 7201

Name: Fibromyalgia ME/CFS Gold Coast Support Group Inc.

PayPal link:

https://paypal.me/fibromecfsgoldcoast?country.x=AU&locale.x=en_AU

Living with Fibromyalgia, ME/CFS



Waking up each and every day knowing you
have **NO CONTROL** over the **PAIN** your
body will endure!

A warrior does not have to achieve success -
they just have to get up each and every day
and try their best despite



the pain they cannot control.

fibromyalgia me/cfs gold coast support group inc.

CONTACT US

1/281 Government Road, Labrador, QLD 4215

Ph: 0406 154 766

E: fmmeccfs.goldcoast@gmail.com

F: @Fibro.ME.CFS.GoldCoast

APPENDIX "A"

TREASURERS VERIFICATION STATEMENT



fibromyalgia me/cfs gold coast support group inc.

ABN: 12618317229
1/281 Government Road, Labrador, QLD 4215
e: fmmeccfs.goldcoast@gmail.com
ph: 0430 482 736

TREASURER'S VERIFICATION STATEMENT

I, Wendy Ann Bennett, Treasurer of Fibromyalgia ME/CFS Gold Coast Support Group Inc. confirm that I have prepared the Association's Profit & Loss Statement and Balance Sheet which are presented in the Annual Report.

I have sighted the Association's financial records and the financial records show that the Association has book keeping processes in place to adequately record the Association's income and expenditure and dealings with its assets and liabilities'

Dated: 8th August 2022

Wendy Bennett
Treasurer



APPENDIX "B"

MEMBERSHIP FORM



fibromyalgia me/cfs gold coast support group inc.

ABN: 12618317229
1/281 Government Road, Labrador, QLD 4215
e: fmmeccfs.goldcoast@gmail.com
ph: 0430 482 736

Membership Application Form

Name: _____

Address: _____

Postcode: _____

Ph Number: _____ Email: _____

Age Group_ (to help us learn about our members)

Under 18 18-24 25-34 35-44 45-54 55-64 65+

Please circle all that apply to you:

Fibromyalgia ME/CFS Carer Other (e.g. family)

The annual subscription is **\$20** and can be paid; in cash; by cheque; by Electronic Bank Transfer; or via a bank branch using the following details:

Bank: Commonwealth Bank of Australia
Account name: Fibromyalgia ME CFS Gold Coast Support Group Inc.
BSB: 064-430
Account No: 1161 7201

To help us with our planning, could you please tell us why you want to become a member of the association and what you hope to get from your membership.

I have read the information provided about the Fibromyalgia ME/CFS Gold Coast Support Group Inc. and I support the objectives of the association.

If you are under 18 years a parent/guardian must sign the application and include their details as well.

Signature: _____ Date: _____

We look forward to welcoming you to the association.

Membership Approved on
Proposed by:

Seconded by:

