



emerge  
australia

**ANNUAL REPORT**  
**2024**

# Mission

- Every Australian diagnosed with ME/CFS receives effective medical and other services without stigma or discrimination.

# Vision

- Australians with ME/CFS achieve the highest quality of life possible

# Values

- We are committed to understanding and supporting our community with empathy, compassion and integrity.
- Our ethical leadership, knowledge and communication builds awareness, credibility and trust.
- We are evidence based, results orientated, transparent and accountable.

# Strategy

- Emerge Australia is the only national patient organisation delivering professional services across clinical education, patient support and patient education, advocacy and biomedical research for those with ME/CFS and Long COVID in Australia.

# Contents

Our Ambassadors	02	Research	13
Contents, Mission, Vision, Values, Strategy	03	Advocacy	14
Message from the Chair	04	Community Fundraising	15
Message from CEO	05	Building Our Capacity	16
The Year in Numbers	06	Message from the Treasurer	18
Shining a Light on ME/CFS	08	Financial Reporting	20
Patient Services	10	Our People	23
Education	12	Our Supporters	23
		Support Us	24



# New Ambassadors

We are delighted that in 2023/4 Professor David Putrino and Sophie Scott OAM became Emerge Australia ambassadors.

Professor David Putrino, a leading expert in long COVID, has been named an Emerge Australia Ambassador. A physiotherapist and neuroscientist, Prof Putrino heads the Cohen Centre for Recovery from Complex Chronic Illness at Mount Sinai in New York City. He's been instrumental in treating thousands of long COVID patients and has published extensively on the topic. In 2019, he was named "Global Australian of the Year.



Emerge Australia welcomes mental health expert Sophie Scott OAM as an Ambassador.

A former award-winning medical journalist, Sophie empowers people globally to manage stress, prevent burnout, and build resilience through science-based methods.

Visit Sophie's website today – <https://www.sophiescott.com.au>

Australians impacted  
by ME/CFS

250,000

Emerge Australia's wonderful ambassadors support our work in giving a voice to people with ME/CFS and long COVID with government and in evidence-based research, advancing the understanding and awareness of these disabling conditions.

See our ambassadors at [emergeaustralia.org.au](https://emergeaustralia.org.au)



# Inspiring Success



## Message from the Chair



There is a natural evolution for charities: from small start-up towards a mature, collaborative, system wide even international player. Along this journey charities find their place, their audiences, their imperatives. This requires decisions: what to do, what not to do. What to say or not say. Who to work with or not.

As a charity the temptation is to try to be all things to everyone. This spreads resources thinly, invites criticism, tempts the tailoring of programs, messaging, and strategy. A maturing organisation plays to its agreed and obvious strengths.

This last 12 months has been a time of maturing and consolidation, and a clarity of purpose:

- We do provide excellent services and want to improve and grow these.
- We do educate and inform the community, health professions, governments and government providers and want to strengthen this.
- We are the provider of Australia’s ME/CFS Registry and Biobank, partnering with the Mason Foundation and seek to secure this ongoing.
- We partner and collaborate with like-minded organisations, who together, allow us to further our aims.
- We do aim high with our plans, expectations and advocacy.

We responded to major change: community, government, societal, cost of living and its impact on our fundraising, declining trust in organisations. We are comfortable with the Emerge strategy, overall direction and our place in the health ecosystem. Our Theory of Change, the Monitoring, Evaluation and Learning Framework, our emerging Research Plan and our soon to be revised Strategic Plan point to those directions and strategies. Our investment in re-engineering all of our support infrastructure and systems and our engagement points to our confidence that we are ready for what lies ahead.

We continue to communicate across all our constituent individuals, groups and organisations. We communicate regularly, openly and transparently. We are speaking to a diverse audience not all of whom agree with what we do and say or how we do and say it. Part of being an open and transparent organisation is to listen to those voices, to consider what is being said and to weigh it. Weigh it against what we have decided to work on, with whom and how. Weigh it against our plans, against pragmatism, against perfection. As a maturing organisation we strive to be the best we can be at leading, managing and governing all that we do - for the benefit of those we serve.

The Board offers its sincere thanks to all our supporters, to those who give their time to us, to all our corporate and philanthropic donors and individual givers, and to our Ambassadors. We need your ongoing help and support and thank you on behalf of the community.

The Board again congratulates CEO Anne Wilson for her vision, leadership and drive to make Emerge Australia the mature and influential organisation that it is today and we sincerely thank all staff, contractors and volunteers who directly contribute in so many ways towards making this happen.

**Mark Clisby**  
Chair



# Leading with Vision



## Message from the Chief Executive Officer

Percentage women  
with ME/CFS

75%

Over the past year, Emerge Australia has made significant strides in clinical education, advocacy, biomedical research, and patient support. It is often said that organisations in the 'for purpose' sector operate on 'the smell of an oily rag' and for those of us privileged enough to be at the helm of these organisations one of the main constants in our thinking is financial sustainability. We cannot deliver on our mission and vision without the necessary funds to do so.

This has meant building diverse revenue streams and fostering long-term relationships with governments, donors, corporate partners, and our community.

Despite global instability, economic challenges, and the aftermath of the pandemic, Emerge Australia has exceeded expectations. With a dedicated team of nine staff, representing five full-time equivalent positions, and with the support of contractors, we have achieved remarkable outcomes. I dedicate this CEO message to our Emerge Australia team for their professionalism, loyalty and unwavering support.

This year, we have contributed to numerous government inquiries, including NDIS reform and the National Framework for Chronic Conditions Refresh, producing a record number of submissions, letters, and reports. We hosted our first Roundtable meeting at Australian Parliament House, Canberra to Shine a Light on Recommendation 8 of the long COVID inquiry. Additionally we worked with others in the sector to stage the inaugural Parliamentary Friends of ME/CFS group meeting, with another planned for November 2024.

Our media engagement has significantly raised awareness and engagement with the ME/CFS and long COVID communities. This effort is supported by our new website, logo, and social media presence, all contributing to our goal of influencing public health policy. Our fundraising efforts included a successful event at the Oud Gallery, thanks to our Ambassador Kristan Oud.

COVID impacted our work with the Emerge Australia/La Trobe University Mason Foundation Biobank. Despite these challenges we proudly launched the AusME Data Registry, supporting various Medical Research Future Fund projects nationwide.

Our patient services continue to provide exemplary telehealth and online patient support, with service navigation expanded through a government grant.

We launched a podcast series featuring interviews with patients, carers, clinicians, and researchers globally, further strengthening our community engagement. Our communications consultants have been instrumental in these achievements, and their dedication is detailed further in this report.

I am delighted to report that Emerge Australia ended the financial year positively. We extend heartfelt gratitude to our donors, supporters, corporate partners, and high net worth individuals for believing in our capacity to deliver and our strategic objectives. We can't thank you enough. We could not serve the ME/CFS and long COVID communities without you. In June 2024, I celebrated three years as CEO of Emerge Australia, a role made rewarding by a dedicated Board whose wisdom and support have been invaluable. I thank our Chair Mark Clisby and all Directors for your assistance and support.

To our supporters, ME/CFS and long COVID communities, including patients, carers, and family members, we exist to ease your challenges. We value your support and look forward to working with you on exciting developments in the months ahead.

*Anne Wilson*

**Anne Wilson**  
Chief Executive Officer



# The Year in Numbers

5,536

Biosample aliquots created

Registry participants (individual)

1,792

438

Clinicians attended plenary/ education sessions at GPCE

Completions ThinkGP training modules 1&2

1,472

404

Allied health professionals engaged in educational events

Health professional connections at events

562

241

GP Aware Directory clinics

Telehealth patient support calls

1,815

300+

People enrolled in patient/carer learning modules

Percentage of those with ME/CFS who are house/bed bound

25%

# The Year in Numbers

**801,467** People reached through Facebook

Emerge Australia website visits **279,907**

**174,749** Emerge Australia total website unique page views

Social media followers Facebook, Instagram, Twitter, LinkedIn **13,511**

**6,234** E-newsletter subscribers

Podcasts listens **11,773**

**18** National news articles e.g. TV, radio, print, online for ME/CFS + long COVID

Submissions for notable inquiries and advocacy letters **18**

**5.6k** Engagements Shining a Light on ME/CFS Australian Parliament House Roundtable March 2024  
(260 online registrants, 40 in person attendees, 1.5k podcast listens, 3.8k YouTube video views)

Meetings with MPs, government officials and key stakeholders **41**

On 27 March 2024, Emerge Australia, in collaboration with the Open Medicine Foundation Australia, convened a pivotal meeting at Parliament House in Canberra. This gathering aimed to address the urgent needs of the estimated 250,000 Australians affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), representing individuals across all ages and regions.

The meeting was framed within the context of Recommendation 8 from the "Sick and Tired: Casting a Long Shadow" Inquiry into long COVID, conducted in 2023. This recommendation emphasised the necessity for funding dedicated to ME/CFS research and patient support. It highlighted that such funding should be allocated in consultation with peak bodies for ME/CFS and consider the recommendations from the ME/CFS Advisory Committee's 2019 report to the National Health and Medical Research Council.

Engagement was pleasing with over 260 individuals impacted by ME/CFS registering to join via audio, alongside 40 attendees present in person.

Subsequently presentations were repackaged into a podcast season with 1,457 listens, and two presentations (Simone Eyssens and Professor David Putrino) were shared online with close to four thousand views.

The discussions underscored the critical need for new clinical guidelines for ME/CFS, enhanced education for clinicians, expanded specialist Telehealth services, and increased support for biomedical research focused on the diagnosis, management, and treatment of ME/CFS.



### Speakers at the meeting included:

- Tracey Spicer AM, Ambassador of Emerge Australia and patient with long COVID experience
- Anne Wilson, CEO of Emerge Australia
- Bill Ranken, Chair of Open Medicine Foundation Australia
- Dr. Mike Freeland, Federal Member for Macarthur
- Senator Jordon Steele-John, Co-Chair of the ME/CFS Parliamentary Friends Committee
- Senator the Hon. Anne Ruston, Shadow Minister for Health and Aged Care
- Simone Eyssens, a person living with severe ME/CFS
- Tori Sommer, carer for a husband living with ME/CFS
- Dr Christopher Armstrong, Director of Melbourne ME/CFS Collaboration (OMF Australia)
- Dr Mark Donohoe, GP President of ACNEM, Founder and Director of Mosman Integrative Medicine
- Professor Paul Fisher, Chair of Emerge Australia's Medical and Scientific Advisory Committee
- Dr Gabriela Khoury from the Burnett Institute
- Professor Peter Schofield AO, Chair of Mason Foundation's National Medical Advisory Panel
- Professor David Putrino, Director of Rehabilitation Innovation at Icahn School of Medicine, Mount Sinai
- Dr Leanne Laajoki, Director of the Department of Health and Aged Care

*Thank you for believing me, offering advice and understanding me, thank you for advocating for us as a group. I live alone and knowing that I can reach out to you at any time reassures me. Thank you.*  
2024 Community Survey Respondent





*It's heartbreaking to me when I see ME/CFS patients today in 2024 still struggling to get access to accurate information and not being warned. It's sad that we still face stigma and disbelief and that we so often are still harmed by medical providers who just don't understand the condition.*

Simone Eyssens, living with severe ME/CFS and former psychologist

Following the event, a report was tabled with the Minister summarising proceedings and providing the following actionable recommendations:

#### **1) Fund the development of new ME/CFS clinical guidelines**

Australia's ME/CFS clinical guidelines have not been updated since 2002. They are out of date. Contemporary evidence shows that ME/CFS is not temporary and treatable, but the current guidelines characterise it by the symptom of fatigue (rather than PEM) and state that it is treatable with exercise and cognitive behaviour therapy.

#### **2) Increase investment into clinical education about ME/CFS**

Increased investment into education of doctors and allied health professionals to improve diagnosis and support for people with ME/CFS will improve peoples' health and wellbeing, as well as reduce the burden of disease on the economy and health system.

#### **3) Expand telehealth access and services**

Telehealth opens up healthcare to all people with ME/CFS, especially those who are most unwell. This is due to PEM, the core feature of ME/CFS. An estimated 25% of people living with ME/CFS are housebound or bedbound.

#### **4) Allocate \$50 million to ME/CFS research**

Research funding in Australia for ME/CFS has been grossly inadequate over many decades. Government research funding for ME/CFS is insignificant by comparison with funding of other chronic diseases of similar complexity, prevalence and level of disability experienced.

The Minister confirmed that his department is working with the National Health and Medical Research Council (NHMRC) to commission this vital work.

*"The guidelines will follow the rigorous NHMRC guideline standards and will include an opportunity for all Australians to have their say on draft guidelines. The guidelines will take two to three years to develop and the NHMRC will consult broadly with all stakeholder groups representing patients and with health professional groups and experts in the evaluation of scientific evidence,"* Minister Butler said.

In welcoming this significant milestone, Anne Wilson explained that she is looking forward to continuing this vital trajectory with ongoing, advanced discussions unfolding around much needed funding for clinical education, patient support and research.

*"We welcome this first step and will continue to emphasise the urgent need for more to be done for those living with ME/CFS and long COVID."*

For more information, visit: [emerge.org.au](https://emerge.org.au)



#### **Update Clinical Guidelines Announcement**

On 20 June 2024 Emerge Australia welcomed Federal Government \$1.1m funding to update evidence based clinical guidelines, so health professionals can better diagnose and manage ME/CFS and long COVID.

CEO, Anne Wilson said *"we congratulate the Federal Health and Aged Care Minister Mark Butler for his government's leadership on this critical and long awaited decision and express our appreciation to the Minister's team and the Departmental personnel who have shown courage and thought leadership on behalf of over 250,000 Australians with ME/CFS alone."*

*"Australia's ME/CFS clinical guidelines are over 20 years old. This is the first government who has been willing to address these outdated clinical guidelines that do not reflect international best practice in the care of patients. We are truly grateful for the advocacy from many people, over many years that has led to this announcement."*

## Support, Information, and Telehealth Service

This reporting period witnessed significant growth in the Patient Support and Telehealth Service at Emerge Australia. While the volume of phone calls has remained stable, we have expanded engagement options to enhance how the community receives information. This includes online and self-paced resources that cater to the varying energy levels within our community.

Key achievements during this period include:

- An 88% increase in email activity
- 51 individuals participated in live information sessions
- 80 patients and caregivers attended online support groups
- Over 300 people enrolled in our learning modules

The demand for our cost-free services continues to be robust, with individuals seeking support for diagnosis, disease management, and assistance with the National Disability Insurance Scheme (NDIS) and Disability Support Pension (DSP). Feedback from our callers has been overwhelmingly positive, illustrating the impact of services. For instance, one caller expressed, "For the first time, I felt our experience was heard and understood. I felt hope that there are people who get it, believe it, and there are things we can do that may help." Another shared how a Telehealth appointment equipped them with valuable information about ME/CFS, praising the kindness and support of our staff.

To better meet the growing demand for our services, we have welcomed Fairley McPherson as a Patient Support Officer. Fairley holds a Bachelor of Biomedicine (Honours) and brings a diverse background in biomedical research, research administration, and NDIS support work. Her passion for disability inclusion and mental health is evident as she pursues a Certificate IV in Mental Health. Fairley is already utilising her skills in scientific communication and psychosocial support to empower individuals living with ME/CFS and long COVID.

In addition to our Telehealth services, the team has actively expanded the Learn with Emerge Australia (LEA) initiative, online support groups, and resources for caregivers.

*Your telehealth support was amazing! It has been the best support and reference to information and doctors who can help us, that we have ever received. Thank you!*  
2024 Community Survey Respondent

For more information, visit: [www.emerge.org.au/learn-with-emerge-australia-lea/](http://www.emerge.org.au/learn-with-emerge-australia-lea/)



## Carers' Hub

In March 2024, with generous support from Carers Victoria and funding from the Victorian Government through the "Connecting Carers In Their Community Grant," Emerge Australia launched a dedicated section on our website for caregivers. This resource hub consolidates valuable content from Carers Victoria and Carer Gateway, offering a comprehensive set of resources, including:

- Practical tips and information
- Daily caregiving strategies
- Planning for the future
- Caring basics
- External support and training opportunities

*I'm very thankful for the work Emerge do - especially advocating with the medical community and politicians for changes to guidelines and further research requirements. Thank you so much for all the work you do! It can be lonely and frustrating having ME (I'm 30 years in now) but it's wonderful to know we have such dedicated advocates on our side. You make me feel like at last there is a friend out there who understands and is lobbying on my behalf. Thank you.*  
2024 Community Survey Respondent

Learn with Emerge  
Australia (LEA)  
enrollments

300



### Live Working Groups and Virtual Support Groups

From February to June 2024, we hosted 15 live working groups focused on enhancing understanding and management of post-exertional malaise. Feedback has been encouraging, with participants expressing gratitude for the knowledge shared.

In February 2024, we also relaunched our online support groups for patients and caregivers, facilitated by professionals. Due to high demand, these groups reached capacity quickly. To ensure sustainability, we are training volunteers from each group through our “Community Champions” program, enabling them to facilitate ongoing support. Participants can choose to remain affiliated with Emerge Australia or establish independent groups, ensuring continuous community support. Through these initiatives, Emerge Australia remains committed to empowering individuals affected by ME/CFS and long COVID, providing essential resources and support to enhance their quality of life.

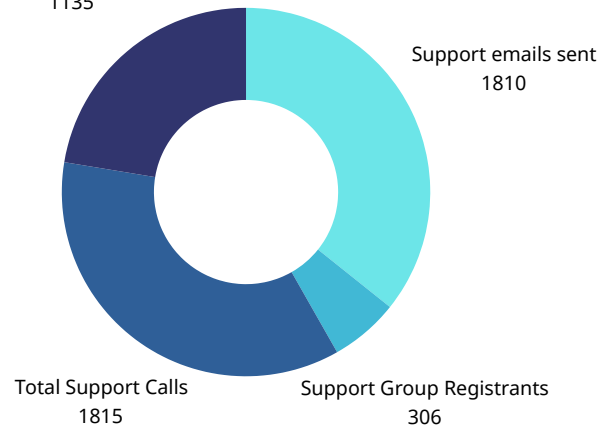


*Emerge has helped me so much to understand the condition that I have, to validate my feelings and experience of medical disinformation. To learn how to support myself and where to look for a team of knowledgeable professionals to help me improve and manage my symptoms. Emerge Telehealth helped me successfully access the DSP. The Emerge podcast brings vital information from people and professionals in the know. It's made a huge difference to my life.*  
2024 Community Survey Respondent

Patients/carers attending live information sessions **51**

For more information, visit:  
[www.emerge.org.au/learn-with-emerge-australia-lea/](http://www.emerge.org.au/learn-with-emerge-australia-lea/)

Completed TH consults  
1135



### Learn with Emerge Australia (LEA)

January 2024 marked the launch of our new online learning platform, Learn with Emerge Australia (LEA). This platform is tailored for:

- Individuals living with energy-limiting diseases like ME/CFS and long COVID
- General practitioners and health professionals
- Family members and caregivers

LEA aims to create an inclusive online environment that fosters community among those affected by ME/CFS and long COVID. It offers a variety of resources, including online learning modules, live working groups, and virtual community support groups. Current learning modules cover essential topics such as:

- The fundamentals of ME/CFS and its relationship with long COVID
- Understanding post-exertional malaise (PEM)
- Effective pacing strategies

New modules are continually being developed to provide up-to-date, evidence-based resources that empower our community and address knowledge gaps.



## GP and Allied Health Education

At Emerge Australia, we remain committed to ensuring that all Australians living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) or long COVID have access to General Practitioners (GPs) and Allied Health professionals who are equipped to provide safe and effective care. Throughout this financial year, we have made significant strides toward achieving this goal.

One of our primary initiatives involves conducting face-to-face training sessions for healthcare professionals. These training sessions are instrumental in fostering valuable networks among practitioners, many of whom operate independently. They also offer us a platform to share information about our services and address any queries healthcare professionals may have.

A key highlight of this year was our participation in the General Practitioner Conference and Exhibition (GPCE) held in Melbourne. The GPCE is Australia's premier professional development conference for GPs, where attendance at each session contributes towards their annual Continuing Professional Development (CPD) requirements. This event presents a unique opportunity to engage with a large cohort of healthcare professionals simultaneously.

In November 2023, our team actively participated in GPCE Melbourne by hosting a stand and presenting our advanced education course. This course, developed in collaboration with Emerge Australia's Medical Director, Dr Richard Schloeffel, OAM, aims to enhance clinical competency by providing in-depth insights into the diagnosis, management, and emerging evidence related to long COVID and ME/CFS. Feedback from the 130 GPs who completed the course was overwhelmingly positive, with most attendees indicating that their learning outcomes were fully met.

In a significant development, Emerge Australia has been recognized as an approved CPD provider by the Royal Australian College of General Practitioners (RACGP). This accreditation allows us to create and deliver high-quality GP CPD programs under our own branding and in various formats. To further expand our reach, we launched an online, revised version of our GPCE course in 2024, supported by an unrestricted educational grant from Moderna.

The online course, consisting of three lectures, provided 76 GPs and Allied Health professionals with a comprehensive framework for diagnosing and managing complex chronic conditions such as ME/CFS and long COVID. Topics included safe strategies for symptom management, the importance of pacing, and effective management of comorbidities. Dr Schloeffel also discussed emerging research and the necessity of limiting COVID-19 infections through a multifaceted approach that includes vaccination, masking, and maintaining good air quality. Each lecture concluded with a half-hour question-and-answer session.

Prior to the training, many participants expressed concerns about potentially overlooking critical aspects during the diagnostic process or assessing vaccine safety and eligibility for patients with ME/CFS and long COVID. Practical questions regarding booking and billing were also raised. The feedback we received was encouraging, indicating that our educational initiatives are enhancing GPs' ability to diagnose and manage these conditions effectively. Many participants reported increased confidence in their ability to care for patients with ME/CFS and long COVID, citing that they now feel equipped to make informed recommendations and referrals.

Moreover, we have received requests for more case-based learning and recognition of the vital role that Allied Health professionals play in the healthcare team for ME/CFS and long COVID. We are excited to explore these opportunities further.

In November 2023, we launched the ME/CFS and long COVID GP aware directory. The initial phase included GP practices where at least one GP has engaged with Emerge Australia at our GPCE events. The second phase, rolled out in March 2024, features individual GPs who have consented to be included in the directory. Currently, we have 60 GPs listed, many of whom have completed our advanced clinical education course or have been referred by community members.

As we plan the third phase, which will incorporate Allied Health practitioners, we remain acutely aware of the urgent need for healthcare professionals who understand ME/CFS and long COVID.

Developing a comprehensive directory is a meticulous process, and we are committed to ensuring its accuracy and effectiveness.

We look forward to continuing our efforts and making a meaningful impact in the lives of those affected by ME/CFS and long COVID.

For more information, visit [emerge.org.au](https://emerge.org.au)



*Keep up the good work. Every doctor must be trained in assessing and treating people with ME/CFS.*  
2024 Community Survey Respondent



**Behind every data point, there's a person, a story, and a chance for a better tomorrow.**

This year has seen significant progress in research capability with transition from the You+ME registry in the United States to the establishment of the AusME Registry and Biobank here in Australia - the first of its kind in this country, collecting data from those who live with ME/CFS, those who live with long COVID, and also those healthy individuals who act as a control group.

The registry, is already supporting 12 approved research projects and with its current 1,792 participants, will provide more and more researchers with important insights into the lived experiences of people living with post-viral illnesses.

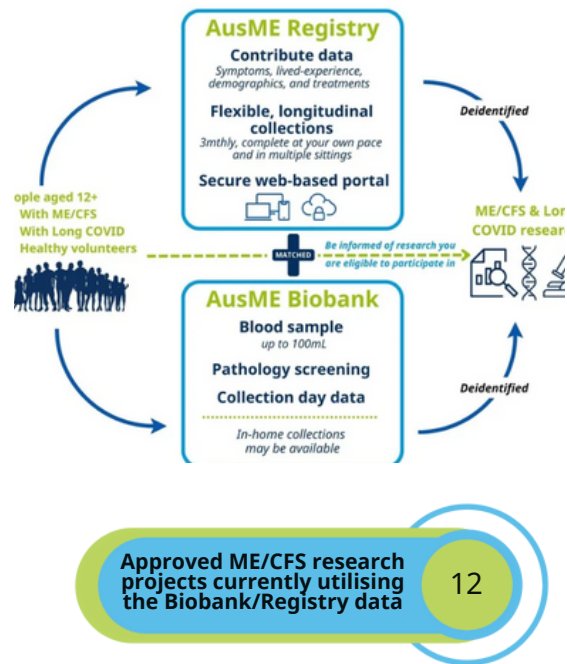
Participants also have the option of donating blood for the Biobank, which may help discover disease causes and treatments. The vision is for the registry to collate big data from the very patients affected by these diseases, to transform ME/CFS and long COVID research capability.

These developments are critical as ME/CFS has historically been neglected, leading to a lack of understanding and treatment options. More research is needed to discover biomarkers, effective management strategies, and validate the biomedical basis of the illness. The AusME Registry can facilitate this by providing recruitment support and access to de-identified clinical information for research efforts.

Since its launch, participation in Registry and Biobank has steadily increased with 147 blood donors to the Biobank date. We encourage all former You+ME participants to sign up for the registry, to stay informed and support Australian research on ME/CFS and long COVID.

Currently, blood collections are active in New South Wales and Victoria, with plans to expand to more metropolitan and regional areas in Victoria, Queensland, and Western Australia. With over 5,500 bio-sample aliquots created and 556 already released for research, we see significant opportunity to advance progress. We do understand that many wish to contribute blood samples but may not be near a collection point, and we are committed to expanding collection sites nationwide in the time ahead.

Looking ahead, we are grateful for the continued support from Equity Trustees/Mason Foundation, who have renewed funding for the AusME Registry and Biobank from July 2024 to June 2029. This support is vital for connecting individuals with researchers focused on ME/CFS and long COVID.



**Approved ME/CFS research projects currently utilising the Biobank/Registry data** 12

**International Research**

During the reporting term the International Research Roundup reporting has continued to give a snapshot of some of the ME/CFS research funding, clinical care and advocacy actions around the world. Examples this year have included the Unite to Fight 2024 conference, major funding for clinical trials by BioVie, updates on the UK DecodeME study, and the US NIH's ME/CFS Research Roadmap. Alongside this global research, international advocacy efforts have included parliamentary debates in the UK as well as awareness campaigns throughout multiple continents.

**Research Digest**

This year Emerge Australia launched a text-to-speech feature for the Research Digest that shares recent articles and publications, expanding accessibility options to the latest ME/CFS research, news and developments.

*Emerge has been a literal life saver for me in helping me to understand my daughter's illness and start finding a way forward. Also in assisting me to advocate for her right to accurate and helpful diagnosis, treatment and management options, rather than just taking the unfortunately regularly wrong and damaging advice and her ending up worse. Emerge has helped direct me to current best practice and helped me to speak up for my beautiful brave girl who is suffering and scared every time we have to see a new health professional. I can't wait for the Australian guidelines to be "fixed"! I've also appreciated connecting with other parents in a support group by Emerge, and the compassion and help we received via the telehealth service (thanks Laura)! I haven't yet got to understanding the research you are doing or other ways you are serving the community of ME/CFS people and their carers/families but am so grateful for the great work you do. I have already recommended Emerge to family, others in the same boat, some of our health care team and will continue to do so. Thankyou!!!!!!!*  
2024 Community Survey Respondent

For more information, visit [emerge.org.au](http://emerge.org.au)



This year marked a significant milestone for the Advocacy team at Emerge Australia, as we produced the largest number of submissions, letters, and reports in our organisation's history.

Our commitment in collaboration with community, to advocating for people affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and long COVID has supported noteworthy developments and achievements. Below are some of the highlights from this year in advocacy.

### Updated State of the Nation Report

Originally published in 2022, our "State of the Nation" report serves as a comprehensive overview of ME/CFS, its relationship with long COVID, and Emerge Australia's five priorities for change. In late 2023, we updated this report to reflect the latest research and respond to evolving dynamics within the post-infection disease landscape. The "State of the Nation" report continues to be an evidence-based reference point that we share with Members of Parliament, General Practitioners, and other influential leaders in the health sector. We encourage everyone to read and share this vital resource, which is available on our website.

### Submissions and Letters

The advocacy team dedicated considerable time this year to writing submissions in response to the National Disability Insurance Scheme (NDIS) reforms and other initiatives affecting people with ME/CFS and long COVID. Our efforts included several submissions for the NDIS review, advocating for the recognition of post-infection diseases within the National Strategic Framework for Chronic Conditions Refresh, and calling for greater inclusion of individuals with ME/CFS and other invisible illnesses in the Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research. Additionally, Emerge Australia reached out to the Royal Australian College of General Practitioners (RACGP) regarding their updated HANDI guide entry for ME/CFS. We continue to advocate for corrections in this guide, highlighting the need for accurate representation of ME/CFS in medical resources.



*Emerge does a brilliant job of advocating for real change for this desperately ill cohort. As a full time carer I thank you for that and for providing excellent resources for the community.*  
2024 Community Survey Respondent

### Media Engagement

Emerge Australia is evolving as a trusted voice in the media regarding ME/CFS and long COVID. Advocacy focus is crucial in raising awareness within the broader community about energy-limiting conditions and attracting the attention of both Federal and State Governments.

This financial year, we were featured in eighteen media articles, including in prominent outlets such as ABC, SBS, Medical Republic, and NewsGP.

One notable feature involved Emerge Australia's Nurse Educator, Kate Herbert, who spoke to the ABC about the importance of inclusive disaster planning for individuals with chronic illnesses. In her interview, she emphasised that many people with ME/CFS face significant challenges during emergencies, particularly those who are housebound or bedbound. The need for a new approach to disaster management that prioritizes care for all was echoed by community organizations Australia reMADE and Women's Health Goulburn North East.

On International Day of People with a Disability, we highlighted the experiences of individuals living with ME/CFS through a story produced by Samantha Tindall from Wollongong. This initiative aimed to amplify the voices of those affected by invisible illnesses, fostering greater understanding and empathy within the community.

In an article for ABC News, Emerge Australia CEO Anne Wilson discussed the stark differences between ME/CFS and everyday tiredness, emphasizing the often-invisible nature of the condition. She articulated the struggles faced by individuals with ME/CFS and long COVID, underscoring the urgent need for recognition and support within the health system.

Furthermore, a discussion on ABC's Nightlife program featured Dr. Richard Schloeffel, Anne Wilson, and Professor Paul Fisher, exploring the historical neglect faced by women with chronic fatigue conditions. The emergence of long COVID has opened new avenues for understanding and addressing these post-infection illnesses.

As we reflect on the past year, it is clear that our advocacy efforts in collaboration with so many wonderful supporters across the community have made significant strides in raising awareness, influencing policy, and supporting individuals affected by ME/CFS and long COVID. We remain committed to our mission and look forward to continuing our work in the coming year.

For more information, visit [emerge.org.au](https://emerge.org.au)



### Community Fundraising

We are so very grateful to our committed supporters who help Emerge Australia continue to make lasting, positive change in the lives of Australians living with ME/CFS and long COVID.

Donations are critically important for Emerge Australia because these funds enable us to offer more targeted services, the latest information and resources to meet the diverse needs of our community.

Your support is vital to build awareness and education about the condition, to reduce stigma and improve healthcare.

We are diligently working to build our network of donors and philanthropic partnerships and request your support to build these connections and diversify our streams of income.

### Oud Gallery

Ambassador Kristan Oud, artist and gallery owner generously opened his gallery for two events in July and October 2023. Attendees had the opportunity to purchase Kristan's works, which feature some of Melbourne's most iconic locations as part of a project he ignited during lockdown in 2021. Funds were kindly donated to Emerge Australia.

Kristan's journey with ME/CFS began in his first year of university leaving him confined in a darkened room, unable to see the sky or sunlight for nearly seven years. This experience helped him realise how precious the things we take for granted can be, and as an artist, has helped him capture the beauty of light, nature, and especially the skies above us. His journey from bed-bound to now has been one of acceptance that this is a serious condition that can only be treated with respect. While he has improved to a point that living a relatively normal life has become possible, it was while he was most unwell that he rekindled his love for art. We proudly welcome Kristan Oud as an ambassador to Emerge Australia and thank him for opening his gallery and sharing so much with us.

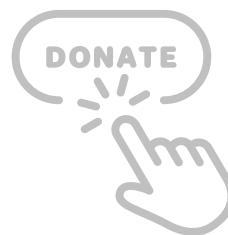


### Fun Runs

On a cold winter's morning on Sunday 16 July 2023, members of the Emerge Australia Team, along with some from the community, participated in a walk to raise funds and awareness of ME/CFS and long COVID. We know it is neither appropriate, nor possible, for many of our community to participate in these types of events. Our team proudly wore bright blue wigs to bring visibility to those so who are so often missing from their lives. Thank you to everyone who participated, donated, and fundraised for an extremely successful event. We raised close to \$8k! We then extended this approach across the country and are extremely grateful to so many especially John Nicoll and his wonderful family who made this possible and helped us raise pivotal funds.



Join Emerge Australia's community fundraising efforts in the Melbourne Marathon on 15 October 2023. You can support Team Emerge Australia with our fundraising or walk or run on the day, on behalf of those who can't. Make a donation or register now here: <https://vist.ly/awu7>  
 #mecs #chronicillness #myalgicencephalomyelitis #chronicfatiguesyndrome #invisibleillness #fibromyalgia #chronicpain #chronicfatigue #mecsawareness #disability #me #spooniesupport #chronicallyill #mentalhealth #longcovid



### Digital Transformation, Communications and Business Development

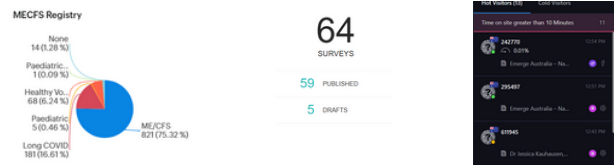
This year has seen much progress in digital transformation, communications and business development as we seek build organisational sustainability, futureproofing our capacity to deliver vital services and resources for our community.

Leading the way has been a transition from Little Green Light CRM to introducing the comprehensive Zoho suite, prioritising CRM development, customisation and integrations in patient services, membership and friend/fund raising. In this workflow the Zoho ecosystem of 50+ apps has leveraged CRM, Forms, Bookings, Campaigns, Sign, Survey, Flow, Sales IQ and WorkDrive.

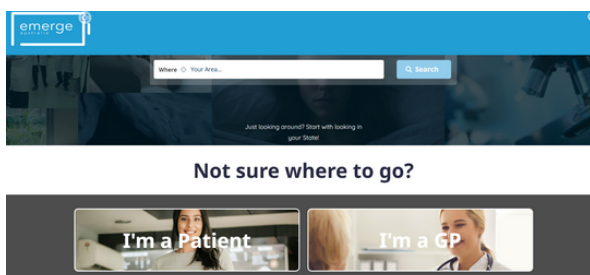
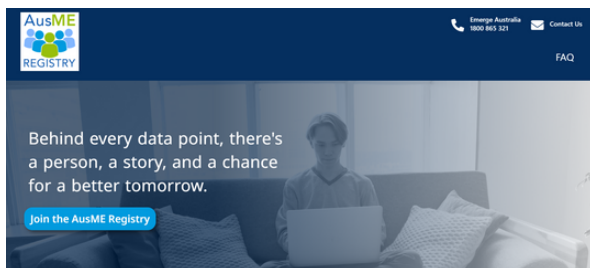
The term has seen an uplift in cybersecurity challenges and work has included staying abreast of latest threats, implementing robust security measures, conducting regular security audits, engaging the team, and having response mechanisms in place in cases of security incidents.

A plethora of security incidents have been effectively managed with an average of ten thousand website cyber-attacks weekly. In this context advanced protections have been introduced including customised firewalls, AI, international database checks and multiple layered backup systems, all ensuring 100% HIPAA Compliance SOC3.

Report Name	Description	Last Accessed Date
Top 10 Users	Top 10 users based on Mails Sent Rate	-
Top 10 Templates by Open Rate	Top 10 templates based on percentage of recipient...	19/07/2023
Top 10 Templates by Click Rate	Top 10 templates based on percentage of recipient...	-
Sent Email Status	Emails sent by users to all records and their status	21/09/2023
Email and Call Analytics Report	No. of mails sent and replied, calls attended and mi...	27/07/2023
Email and Activities Analytics Report	No. of emails sent and replied, calls dialled and rec...	-
Email Analytics	Summary of the email status(sent, bounced, open...	21/03/2024
Bounce Report	Summary of bounced emails, reason for the bounc...	-



Mon	Tue	Wed	Thu	Fri
1 10:00 am Rachel O'Connell 11:00 am Chiropractic 01:00 pm Community Cha + 3 more	2 09:30 am DGH & Carers gr 11:00 am Staff WIP 12:00 pm Meeting to disc 01:00 pm Laura Allen Work	3	4 01:00 pm Partners of people 01:00 pm Partners of peop 02:00 pm CC - Carers of ac	5
8 01:00 pm Artistic Interest gro 01:00 pm VSO - Artistic Int	9 01:00 pm Carers of adults whic 01:00 pm Carers of Adults	10 01:00 pm Carers of school 02:00 pm Carers of school age	11 11:30 am Molly Hersee - (D 02:00 pm CC - Parents whi 06:30 pm Emerge Australia	12 10:00 am Luke Gary Robbins 10:30 am Megan Milner (Fol 11:00 am Robyn Anderson (F 11:30 am Helena Stendourakis + 5 more
15 08:00 am Laura in the offic 09:00 am Faculty's first day 02:30 pm CC - Carers of ge	16 11:00 am Staff WIP 12:00 pm IMAACC and Eme 02:00 pm ME/CFS for Stora 01:00 pm ME/CFS for thes	17 01:00 pm Meeps 01:00 pm Meeps	18 02:00 pm CC - Carers of ac	19 10:30 am Patricia Hecking (P 11:00 am Maree (New Appoin 11:30 am Linda (New Appoin 12:00 pm David S (New Appoin

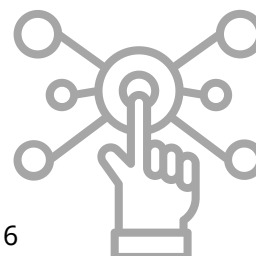


Three websites have been built during this period with the primary site - emerge.org.au transitioned from offshore hosting and rebuilt including rebrand, restructure, content expansion and enhanced functionality with custom pages, mega menu, accessibility, cybersecurity, analytics, short link capability, a more sophisticated donation system with Charitable, capacity for PDF receipting, dark mode, podcasting system integrated with multiform distribution.

Two additional websites have also been established for the AusMe Registry and GP Directory.

It's pleasing to see these three new sites operational, with significant uplifts in performance such as in emerge.org.au where unique visits have grown from 101k June 2023 to 174k June 2024. Many challenges as a consequence of customisations have been overcome including multiple device responsiveness; and to support continuous improvement the term has seen two server upgrades to meet increased demands and risks.

The second website - the national health registry AusME has been transitioned from an offshore externally hosted facility SolveME, bringing both capacity for direct control/modification and an onshore hosting system with a WordPress frontend and Zoho backend.





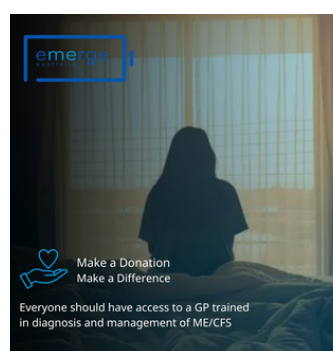
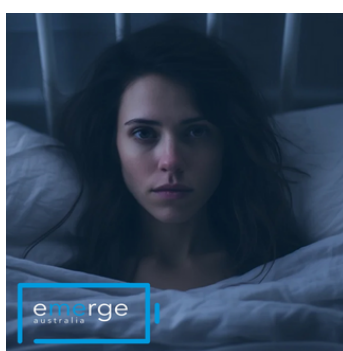
It has been a great achievement to realise the Registry and its BioBank digital system. There are now 987 patients in the registry.

Internal team capacity building has been significant, as have process optimisations and automations enabling streamlining of surveying, data management and reporting, along with critical enhanced visibility on the participant journey.

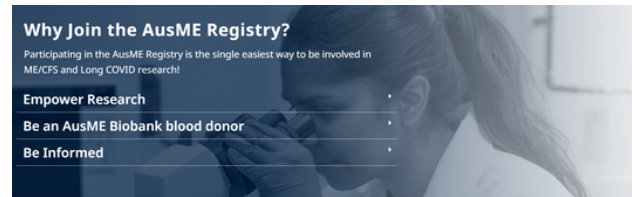
The third website - a national ME/CFS and long COVID GP Aware Registry has also been built including geo-search capacity and self-registration capacity – with 254 clinics and 52 GPs included.

The 2023/4 year has seen several key digital events produced including during Awareness Weeks (online symposia - recording, editing, risk management; campaigns – poster, video, socials engagement); Parliament House Canberra Round Table (broadcast – editing, risk management); and GP Education (recording, editing, risk management).

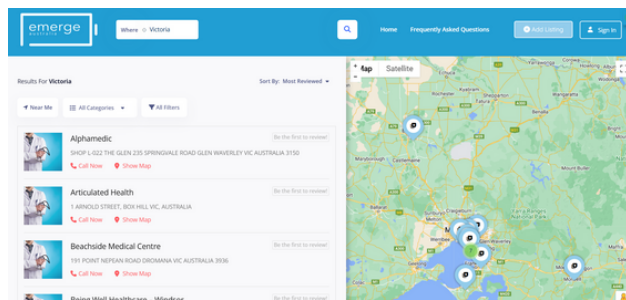
It's been great to enable online and hybrid events, uplift engagement in these events including strong open rates for Federal MPs; and expand the repertoire in the participant event experience with videos, posters, interactivity and live broadcasting.



And finally, social media has escalated this year with considerable growth in Followers to 13,503. Facebook Fans have lifted from 5.9k last June to 9.6k this June, Instagram from 728 to 988; and LinkedIn from 423 to 586. Growth in Facebook Reach has been significant from 741k last June to 823k this June; and it's been pleasing to see strong responses to boosted campaigns for example with the end of financial year appeal successfully targeting actual and look alike lapsed donors.



*"Nobody knows the lived experience of ME/CFS or Long COVID better than those who have it, and research can only go so far without your help."*



**Partnerships** have been developed with community and corporate collaborators during this term, and digital engagement has focused on database management (cleansing, segmenting, enriching) and internet marketing (fundraising appeal boosting and email campaigns to MPs and media).

**Results** in this part of the business have included the establishment of new partnerships with for example Moderna and Carer Gateway Victoria; substantial data enhancement/cleansing, and email communications database growth from 5,955 to 6,234 June on June 23/4.

This year has seen the **Emerge Australia Imagine Podcast Series** launched to reach a wider audience, build the brand, engage with our community, diversify how we deliver content, create funding opportunities, build networking and collaboration opportunities and improve search engine optimisation.

It's been gratifying to have attracted over fourteen thousand listens, to be listed in the Top 10 Apple Australian Health segment; and to have published 32 podcasts so far.



# Positive Financial Performance



## Message from the Treasurer

In FY24, Emerge Australia continued to build on the positive financial performance and position trend from the previous year – closing the year with a modest \$26K surplus compared to a \$27K deficit in FY23 and a \$205K deficit in FY22.

Total Income grew by 5.6% year on year – from \$1.27M to \$1.34M. Income from Grants and Partnerships grew from 0.41% of Total Income in FY23 to 0.49% in FY24, whilst Donations Income decreased from 0.58% of Total Income in FY23 to 0.49% in FY24 – a positive shift in terms of diversifying / balancing the organisation’s income streams.

Total Expenditure grew by 1.3% year on year – from \$1.29M in FY23 to \$1.31M in FY24 – reflecting tight and disciplined cost control by Management during the year.

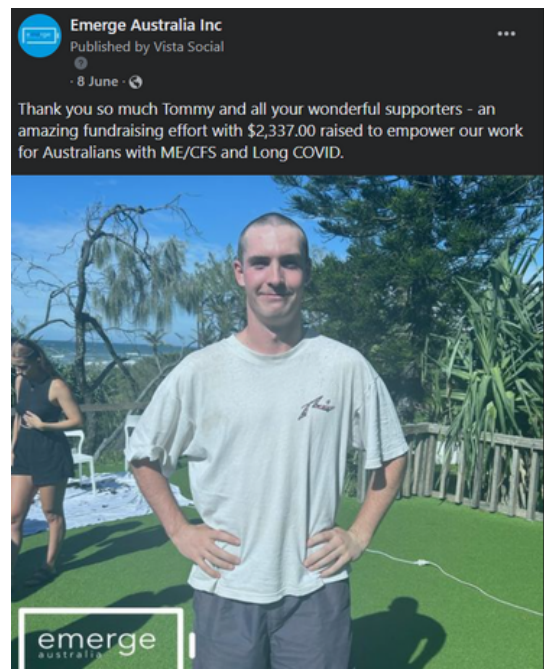
Total Equity for the Association grew by the corresponding \$26K surplus for the year, while the Association’s Current Ratio improved from 1.84 at 30 June 2023 to 2.31 at 30 June 2024.

A big thank you to our donors, supporters, members, staff, and volunteers who make a difference in our community.

**Nicolas Porter**  
Treasurer

On a blustery autumn day in March, Tom reached out to tell us he would be shaving his head. Tom’s older brother Zach has been suffering with ME/CFS since he was 12 years old. He is now 20 and is bedbound. Tom decided to shave his head to raise awareness about the impacts of ME/CFS. Not only did Tom’s fundraising efforts succeed, he smashed it out of the park reaching nearly \$2,500!

Thank you Tom and the Nicoll family for your incredible support!





McBAIN  
McCARTIN & Co

CHARTERED ACCOUNTANTS  
AUDIT & ASSURANCE SERVICES

PO BOX 82 BALWYN  
VICTORIA, AUSTRALIA 3103  
ABN 26 028 714 960

**Auditor's Independence Declaration under  
The Australian Charities and Not-for-profits Commission Act 2012**

**To the Committee Members of Emerge Australia Inc.  
ABN: 22 385 438 041**

In accordance with Subdivision 60-C of the *Australian Charities and Not-for-profits Commission Act 2012*, I am pleased to provide the following declaration of independence to the Committee Members of Emerge Australia Inc. As the lead audit partner for the audit of the financial report of Emerge Australia Inc. for the year ended 30 June 2024, I declare that, to the best of my knowledge and belief, during the year ended 30 June 2024 there have been no contraventions of:

- (i) The auditor independence requirements as set out in the *Australian Charities and Not for Profits Commission Act 2012* in relation to the audit; and
- (ii) any applicable code of professional conduct in relation to the audit.

**McBain McCartin & Co**  
**Chartered Accountants**

**Simon Aukstin (CA)**  
**Partner**

Melbourne  
9<sup>th</sup> October 2024

13.

Liability limited by a scheme approved under Professional Standards Legislation

Level 1, 123 Whitehorse Road Balwyn VIC 3103

Phone: +61 3 9817 0700 Facsimile: +61 3 9817 0799 E-mail: [office@mcbaismccartin.com.au](mailto:office@mcbaismccartin.com.au) Web: [www.mcbaismccartin.com.au](http://www.mcbaismccartin.com.au)



# Statement of Financial Position

Emerge Australia Inc.  
As at 30 June 2024

	NOTES	30 JUN 2024 \$	30 JUN 2023 \$
<b>Assets</b>			
<b>Current Assets</b>			
Cash and Cash Equivalents	2	850,177	1,026,525
Trade and other receivables	3	26,237	6,387
<b>Total Current Assets</b>		<b>876,414</b>	<b>1,032,912</b>
<b>Total Assets</b>		<b>876,414</b>	<b>1,032,912</b>
<b>Liabilities</b>			
<b>Current Liabilities</b>			
Trade and other payables	4	60,308	93,951
Contract Liabilities	7	256,405	434,185
Provisions	5	61,955	33,346
<b>Total Current Liabilities</b>		<b>378,668</b>	<b>561,481</b>
<b>Total Liabilities</b>		<b>378,668</b>	<b>561,481</b>
<b>Net Assets</b>		<b>497,746</b>	<b>471,430</b>
<b>Equity</b>			
Retained surplus		497,746	471,430
<b>Total Equity</b>		<b>497,746</b>	<b>471,430</b>



## Statement of Profit or Loss and Other Comprehensive Income

Emerge Australia Inc.  
For the year ended 30 June 2024

	NOTES	2024 \$	2023 \$
<b>Income</b>			
Interest Income		9,020	5,698
Donations and Fundraising		659,599	731,754
Grants		612,147	517,193
Partnerships		45,000	-
Membership Income		10,545	9,020
Other Income		-	1,900
<b>Total Income</b>		<b>1,336,310</b>	<b>1,265,564</b>
<b>Expenditure</b>			
Direct Program Costs		677,959	530,048
Employment Cost		463,568	561,504
Communication		42,907	84,221
Administration		94,024	82,959
Audit Fees		6,000	6,000
Depreciation		-	6,203
Rent Costs		25,537	21,935
<b>Total Expenditure</b>		<b>1,309,994</b>	<b>1,292,870</b>
<b>Surplus/(Deficit) before income tax expense</b>		<b>26,316</b>	<b>(27,306)</b>
<b>Other comprehensive income for the year net of income tax</b>		<b>-</b>	<b>-</b>
<b>Total comprehensive income/(loss) after income tax for the period</b>		<b>26,316</b>	<b>(27,306)</b>

## Statement of Changes in Equity

Emerge Australia Inc.  
For the year ended 30 June 2024

	2024	2023
<b>Equity</b>		
Opening Balance	471,430	498,736
<b>Decreases</b>		
<b>Loss for the Period</b>		
Surplus/(Deficit) for the Year	26,316	(27,306)
<b>Total Surplus/(Deficit)</b>	<b>26,316</b>	<b>(27,306)</b>
<b>Total Increase/(Decrease)</b>	<b>26,316</b>	<b>(27,306)</b>
<b>Total Equity</b>	<b>497,746</b>	<b>471,430</b>

Complete Audited Financial Statements are available on request at  
[information@emerge.org.au](mailto:information@emerge.org.au)

### Board of Management

Mark Clisby	<i>President</i>
Martin Wilkinson	<i>Vice President</i>
Andrew Bretherton	<i>Secretary</i>
Nicolas Porter	<i>Treasurer</i>
Rebecca Davey	<i>Board Member</i>
Caitlin Phillips-Peddlesden	<i>Board Member</i>
Roseda Campbell	<i>Board Member</i>
Kerryn Simmons	<i>Board Member</i>

### Staff

Anne Wilson	<i>Chief Executive Officer</i>
Dr Richard Schloeffel	<i>Medical Director</i>
Laura Kool	<i>Operations Manager</i>
Rochelle Lade, PhD	<i>Advocacy Manager</i>
Sarah Brown	<i>Policy Manager</i>
Kate Herbert	<i>Nurse Educator</i>
Laura Allen	<i>Patient Services Manager</i>
Camille Williams	<i>Telehealth Nurse</i>
Jenna Brindley	<i>Social Worker</i>
Michelle Tavoletti, PhD	<i>Research Manager</i>
Jessica Kauhausen, PhD	<i>Biobank Coordinator</i>
Simone Eyssens	<i>Research Director</i>
Jane Sydenham-Clarke	<i>Business Development</i>
Jonathan Stavridis	<i>Digital Comms Manager</i>

### Ambassadors

Tracey Spicer AM	Bloom
Kristin Oud	John Jeffries
Professor David Putrino	Sophie Scott OAM

### Medical and Scientific Advisory Committee (MSAC)

Professor Paul Fisher	Dr Elisha Josev
Dr Richard Schloeffel	Mark Clisby
Dr Mark Donohoe	Anne Wilson
Dr Daniel Lewis	Dr Michelle Tavoletti
Dr Chris Armstrong	Laura Allen
Kate Baychek	Kate Herbert
Jess Freeman	

### Volunteers

Lauren Ahern, Elizabeth Branigan, Adam Finucane, Solène Grosdidier, Jolien Hendrix, Sarah Hookey, Amanda Johnson, Shan Kornfeld, Dave Long, Ella Mansfield, Denise McKellar, Rebecca McKerrow, Jenny Meagher, Gretchen Netterfield, Jyothsna Rao, Clare Reardon, Kristen Roode, Deb Sytema, Emma Townsend, Carol van Eerden, Ella Whistlecroft

### Funders

Commonwealth Department of Health + Aged Care  
 Victorian Department of Families Fairness + Housing  
 Carers Victoria, Merri Health, Moderna Australia

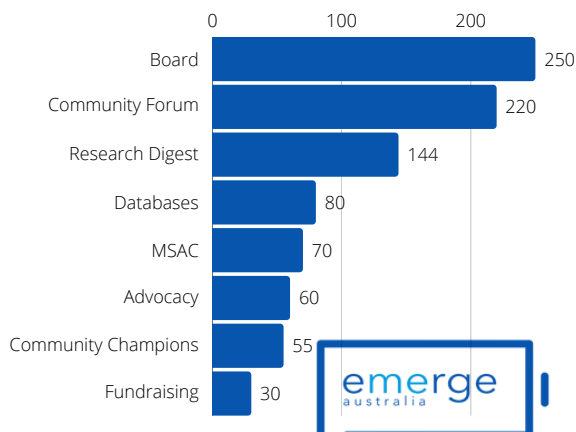
### Major Donors

Anne Kennedy  
 Australian Philanthropic Services Foundation  
 ARA Consultants Inc  
 Barwon Foundation  
 Blake Beckett Trust  
 Icehouse Capital  
 Julie Barnett  
 Jo and John Grigg  
 Lawrence Cram  
 McCusker Charitable Foundation  
 Michaela Arnott Foundation  
 Open Medicine Foundation Australia  
 Pauline Kanhalikham  
 Phyllis Connor Memorial Trust  
 S.L Bray Memorial Foundation  
 The Marion R Stobbo Endowment  
 The Mason Foundation  
 William Angliss Charitable Fund  
 Vivienne Court Trading

### Lifetime Members

Helen Clark	Nola Miles
Jennifer Droop	Simon Molesworth AO QC
Yvette Gebert	James Oakley
Lia Henry	Margaret Pianella
Irene Herceg	Marianne Punshon
Maureen Jepson	Pamela Saunders
Bernhard Liedtke	

### Volunteer Hours



# Join us in improving the lives of Australians living with ME/CFS and long COVID

## Make a Donation

### Single Donation

Every donation is an act of support which enables us to empower Australians living with ME/CFS and Long COVID.

### Give Regularly

By becoming a monthly giver you can support the ongoing financial sustainability of the organisation.

### Leave a Gift in Will

Support the next generation of Australians impacted by ME/CFS and Long COVID.

## Join our Network

### Become a Member

Your support and voice helps us make the decisions that support Australians living with ME/CFS and Long COVID.  
[emerge.org.au/membership-information](https://emerge.org.au/membership-information)

### Join our Socials

Support the next generation of Australians impacted by ME/CFS.

Search [@emergeaustraliainc](#) across all social media platforms





[emerge.org.au](http://emerge.org.au)



1800 865 321



[information@emerge.org.au](mailto:information@emerge.org.au)



@emergeaustralia



Emerge Australia Inc



@emergeaustraliainc



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Melbourne Victoria Australia 3000



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