



Annual Report 2020



Mission:

To support and provide information and advocacy for people associated with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).

Vision:

Universal awareness and acknowledgement of ME/CFS as a medical condition.

Values:

To serve the best interests of people affected by ME/CFS with integrity, compassion and empathy.

About Emerge Australia:

Emerge Australia exists to give hope and help to people living with myalgic encephalomyelitis/chronic fatigue syndrome, and has members from around Australia.

The condition is widely misunderstood and support, research and medical education are seriously under-resourced. In addition to poor health, people with the condition experience stigma and misunderstanding, and are often socially isolated.

Our role in supporting and advocating for people with the condition is of vital importance.

The landscape in which we work is slowly changing, with increasing recognition of the condition and increased biomedical research.

We are working to ensure that people affected by ME/CFS have access to a broad range of accessible and affordable programs that enhance their quality of life, by building strong partnerships and a financially sustainable and transparent organisation.





Chief Executive Officer's Report

The 2019/20 financial year was my second full year in the role and I'm pleased to report that our friends and supporters, and – most importantly – people with ME/CFS in Australia started to really see new offerings and initiatives from us here at Emerge Australia.

Our completely updated new website went live at the beginning of December. It has been great to see this improved web presence take our mission out into the world, and how the new styling really resonated with our community.

After winning a place on the Centre for Community Driven Research's pilot program to offer Telehealth Nursing within Patient Organisations, one of our most notable achievements was launching the service. Our first consultations were held in August 2019. The service has grown from small beginnings with just a few cases per month to a fully-fledged telehealth offering with two registered nurses in post. Our nurses are developing a deep expertise around managing cases and coordinate 30-plus self-referrals each month. We are now also starting to see other services begin to refer patients to us.

Also in the clinical sphere, we were so pleased to see our first accredited GP education module launched through Think GP. A fantastic campaign saw patients taking postcards about the education to their own practices and two additional local practices. On track to reach our goal of 500 completions in the year, we began developing a second module, focusing more on young people with ME/CFS and more severe patients. I'd like to thank the six doctors who made up our pilot Medical Advisory Committee and the staff who supported this initiative.

In the first few months of 2020 we also worked on another new offering, recruiting a small crew of dedicated patient volunteers to test a number of online forums. This was part of the planning process for a new two-part support program – a non-social media based patient forum with accompanying virtual support groups. We are grateful to everyone in the community who gave their input into the development of this project and we look forward to seeing it progress.

We also began to move more firmly towards supporting research into ME/CFS in Australia, beginning work with the UTAS team on the epidemiology and health economics impact of ME/CFS, and also on the Mason Foundation-funded Australian ME/CFS Biobank and Registry. Our research digest has continued from strength to strength, with a dedicated team of specialist volunteers providing simplified versions of biomedical research papers about ME/CFS for time-poor doctors and scientists.

There were a number of advocacy campaigns undertaken in 2019/20 aided by our highly active advocacy community. July 2019 saw us distributing a petition requesting fairer access to the NDIS by patients with more than 10,000 signatures. We also ended the financial year with big community-involvement numbers as COVID saw our annual Awareness Day – the #Millions Missing campaign – become fully virtual. Our event centred around two elements: a stylised selfie with a message about being missing and a more light-hearted take on awareness-raising as we asked people to take the #MECFSChallenge and record themselves (in a single take) saying 'myalgic encephalomyelitis'. We were thrilled to see the campaign reach more than 100,000 people and had unanimously positive feedback that especially noted how inclusive this year's campaign felt.

The final quarter of the year was undeniably tough as we pivoted to a fully remote, working-from-home model. I am so grateful to our team for their compassion and 'can do' attitude during these challenging times. We provided a constant stream of COVID updates in an easy-read format to support our community. This was warmly received and we were also pleased to hear that other disability organisations were pointing people towards our information.

I hope for a brighter, COVID-normal 2021 as we continue our mission to make lives better for people living with, and affected by, ME/CFS.

Dr Heidi Nicholl
Chief Executive Officer



President's Report

It is with great pleasure that I am writing to you in the 2019/20 Emerge Australia Annual Report.

As for many other organisations across the country, 2019/20 has been a challenging year for Emerge Australia – our staff and volunteers, and our members and community. On behalf of the Committee of Management I would like to acknowledge the way our staff have come together to support each other and our community to face these difficult times. We recognise and appreciate the hard work and dedication of the whole Emerge Australia team under the direction and leadership of our CEO Dr Heidi Nicholl.

It has been remarkable to see all the amazing work that Heidi and the team have managed to achieve, despite having to reorientate and rethink how we work. 2019/20 has again been a year of significant progress at Emerge Australia.

The Committee of Management has seen changes with several retirements. I would like to acknowledge the work the committee does in supporting Emerge Australia and, in particular, I want to recognise the work of three members who have recently retired: Leo Orland, Sally Missing and Irene Herzog. Sally was President of Emerge Australia for many years, and Leo and Irene were constant and valued members of the CoM.

Advocating for our community has been an important component in the work we do at Emerge Australia. Working in partnership with our amazing community of activists and advocates for people with ME/CFS, we have managed to make significant inroads in raising awareness with our political leaders, which is vital to secure appropriate funding and support for Australians and their loved ones living with ME/CFS.

Our telehealth nursing service is a great example of a really practical, on-the-ground service which has been much utilised by our community. Telehealth services are vital for our members, especially during the pandemic lockdown, so I want to commend the team at Emerge Australia delivering the service and to thank our generous donors and partnering organisations for their continued support for this program. The high demand for the service

shows the latent need and importance of the work the team is doing.

Our new website was launched this year and is a great avenue for us to interact with anyone seeking to understand more around ME/CFS, where to get support, news and research. I encourage you all to regularly check in and have a look at what is going on in the world of Emerge Australia.

This has been a challenging time and I want to wish you all health, hope and happiness as we look forward to a brighter 2020/21.

We thank all our members and donors as you continue to contribute to the important life and work of Emerge Australia.

Martin Wilkinson

President



Treasurer's Report

Emerge Australia Inc recorded another significant surplus of \$143,106 for the 2019/20 financial year. This is the third year in a row where we have achieved a surplus in excess of \$100,000 with our equity reserves climbing to just under \$630,000.

Continued government funding, the loyal support of our donors new and old and the hard work of our expanding staff headed by CEO Dr Heidi Nicholl allow the organisation to extend, enhance and expand its activities supporting those with, and affected by, ME/CFS.

A big thank you to our donors, supporters, members, staff and volunteers who make our activities possible.

Russell Smith (FIPA; FFA; FNTAA)

Treasurer



Ambassador's Report

It has been truly wonderful to see such an uplift in community understanding of the issues relating to people impacted by ME/CFS.

Over the past year Emerge Australia has had numerous engagements with broadcast and narrowcast media, which has taken our key messaging to a wide audience across Australia. On these occasions our CEO, Dr Heidi Nicholl, has done an excellent job of promoting our key messages – and handling the odd tricky question!

We are also thankful to many others who have engaged with their local media.

This has led to increased activity on our website – which has been further enhanced for ease of access, and is a helpful starting place for people who are new to the world of ME/CFS.

The roll-out of the GP education program is helping to increase medical professionals' knowledge of ME/CFS issues – which is immensely beneficial for people who are yet to be diagnosed with ME/CFS.

We are thankful to our friends at Maurice Blackburn who have helped us draft an Advanced Care Planning document as a helpful resource for people who have been impacted by ME/CFS. It is especially relevant for anyone who wishes to have their illness taken into account should they experience significant health issues in the future.

I have also been excited to let people know of our Florence Nightingale Society, which is a significant way of honouring those who have had the foresight to include Emerge Australia in their estate planning.

For many people, their last gift is their most significant – and this is a very special way your support can have an ongoing impact on the lives of people with ME/CFS.

If you would like more details about the Florence Nightingale Society, please contact me through the office.

John Jeffries
Ambassador

Florence Nightingale Society

We are proud to present the Florence Nightingale Society to honour those who have left a gift in their will to Emerge Australia.

The society has been named after the famous nurse, known as the 'Lady with the Lamp' because of her efforts in the Crimean War to tend the wounds of soldiers during the night. From the age of 35, Florence was often disabled by poor health, which some suggest may have been caused by ME/CFS.

Our Florence Nightingale Society honours supporters of Emerge Australia who, by leaving a gift in their will, make a powerful commitment to a better future for people impacted by ME/CFS.

Each person who leaves a gift in their will to Emerge Australia is recognised by the Society and recorded for posterity in our official records.

It's a way for us to pay a small tribute of thanks to our generous supporters.

If you would like details about how to be part of the Florence Nightingale Society, please contact our office:

Phone: (03) 9529 1344

Email: information@emerge.org.au

Statement of Profit and Loss

	Note	2020 \$	2019 \$
INCOME			
Sales		3,119	2,878
Government Grants - Recurrent		48,923	47,969
Government Grants - Non Recurrent		289,028	370,000
Grants - Tied		56,161	39,066
Grants - Non Tied		16,000	-
Membership		14,215	17,572
Gifts and Donations		751,613	404,176
Interest		1,209	2,275
Other Income		93,903	13,856
		<u>1,274,171</u>	<u>897,792</u>
EXPENDITURE			
Accommodation		26,258	20,167
Facilities and Equipment		7,281	9,394
Staffing Costs		542,643	309,032
Communication		10,806	8,981
Insurance		996	1,040
Emerge Journal Costs		9,178	14,631
Administration		40,261	13,608
Program Costs		493,642	282,677
		<u>1,131,065</u>	<u>659,530</u>
Surplus/(deficit) for the year before income tax		143,106	238,262
Income tax expense	1a	-	-
Other comprehensive income for the year net of income tax		<u>-</u>	<u>-</u>
Total comprehensive income after income tax for the period		<u>143,106</u>	<u>238,262</u>

Statement of Financial Position

	Note	2020 \$	2019 \$
CURRENT ASSETS			
Cash and cash equivalents	2	1,721,424	1,301,824
Trade and other receivables	3	37,553	1,554
Inventory	4	-	1,989
TOTAL CURRENT ASSETS		<u>1,758,977</u>	<u>1,305,367</u>
NON-CURRENT ASSETS			
Property, plant and equipment	5	4,440	2,569
TOTAL NON-CURRENT ASSETS		<u>4,440</u>	<u>2,569</u>
TOTAL ASSETS		<u>1,763,417</u>	<u>1,307,936</u>
CURRENT LIABILITIES			
Payables	6	1,107,865	804,062
Provisions	7	27,215	18,643
TOTAL CURRENT LIABILITIES		<u>1,135,080</u>	<u>822,705</u>
TOTAL LIABILITIES		<u>1,135,080</u>	<u>822,705</u>
NET ASSETS		<u>628,337</u>	<u>485,231</u>
MEMBERS' FUNDS			
Retained surplus		628,337	485,231
TOTAL MEMBERS' FUNDS		<u>628,337</u>	<u>485,231</u>

Statement of Cash Flows

	Note	2020 \$	2019 \$
CASH FLOWS FROM OPERATING ACTIVITIES			
Receipts from sales		3,119	2,350
Grants		327,279	760,969
Other receipts		822,706	435,604
Payments to employees and staffing costs		(534,071)	(294,042)
Payments to suppliers and others		(194,089)	(295,244)
Interest received		1,209	2,275
Net cash provided by/(used in) operating activities	8	426,153	611,912
CASH FLOWS FROM INVESTING ACTIVITIES			
Payments for purchase of property and equipment		(6,553)	(1,830)
Net cash provided by/(used in) investing activities		(6,553)	(1,830)
Net increase/(decrease) in cash held		419,600	610,082
Cash at the beginning of the year		1,301,824	691,742
Cash at the end of the year	2	1,721,424	1,301,824

Our full audited financial report is available on request or can be obtained from the Australian Charities and Not-for-profits Commission website (www.acnc.gov.au). The information presented in this report has been extracted from the audited financial statements.

**INDEPENDENT AUDIT REPORT TO THE MEMBERS OF
EMERGE AUSTRALIA INC.**

Opinion

I have audited the accompanying financial report, of Emerge Australia Inc., which comprises the statement of financial position as at 30 June 2020, statement of changes in equity, statement of cash flows and the statement of profit or loss and other comprehensive income for the year then ended, notes comprising a summary of significant accounting policies and the certification by members of the committee.

In my opinion, the accompanying financial report of Emerge Australia Inc. has been prepared in accordance with Div 60 of the *Australian Charities and Not-for-profits Commission Act 2012 (ACNC Act)* including:

- a) giving a true and fair view of the Association's financial position as at 30 June 2020 and of its financial performance for the year then ended; and
- b) complies with Australian Accounting Standards to the extent described in Note 1 to the financial statements, and the requirements of the *Associations Incorporation Reform Act 2012 (Vic)* and Div 60 of the *Australian Charities and Not-for-profits Commission Regulation 2013*.

Basis for Opinion

I conducted my audit in accordance with Australian Auditing Standards. My responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Report section of my report. I am independent of the association in accordance with the *Associations Incorporation Reform Act 2012 (Vic)* and the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 Code of Ethics for Professional Accountants (the Code) that are relevant to my audit of the financial report in Australia. I have also fulfilled my other ethical responsibilities in accordance with the Code.

I believe that the audit evidence I have obtained is sufficient and appropriate to provide a basis for my opinion.

Emphasis of Matter - Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared for the purpose of fulfilling the association's reporting responsibilities under the *Associations Incorporation Reform Act 2012 (Vic)* and the *Australian Charities and Not-for-profits Commission Act 2012*. As a result, the financial report may not be suitable for another purpose. My opinion is not modified in respect of this matter.

Responsibility of the Committee for the Financial Report

The committee of the association are responsible for the preparation of the financial report that gives a true and fair view and have determined that the basis of preparation described in Note 1 of the financial report is appropriate to meet the requirements of the *Associations Incorporation Reform Act 2012 (Vic)* and the *Australian Charities and Not-for-profits Commission Act 2012* and the needs of the members. The committee's responsibility also includes such internal control as the committee determine is necessary to enable the preparation of a financial report that gives a true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the committee are responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless the committee either intend to liquidate the association or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibility for the Audit of the Financial Report

My objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes my opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of the financial report.

As part of an audit in accordance with Australian Auditing Standards, I exercise professional judgement and maintain professional scepticism throughout the audit. I also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for my opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the committee.
- Conclude on the appropriateness of responsible entities' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the association's ability to continue as a going concern. If I conclude that a material uncertainty exists, I am required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify my opinion. My conclusions are based on the audit evidence obtained up to the date of my auditor's report. However, future events or conditions that may cause the to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

I communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that I identify during my audit.



Sean Denham

Dated: *4th November 2020*
Suite 1, 707 Mt Alexander Road
Moonee Ponds VIC 3039

IMPACT REPORT

In 2019/20 Emerge Australia has continued to provide hope and help to Australians living with ME/CFS, through the increased scope of services and programs delivered by our team. In this impact report we share the main outcomes achieved across our program delivery areas.

Two of the major highlights for the year include the establishment of the Mason Foundation-funded Biobank and Patient Registry and the launch of the Telehealth Nurse Service. Both of these projects are landmark achievements, with the biobank enabling patients to contribute to the global biomedical ME/CFS research effort, while the Telehealth Nurse Service provides much needed one-to-one patient support.

The Telehealth Nurse Service was launched in September and is delivered in partnership with the Centre for Community Driven Research. The service aims to test if embedded telehealth services will provide high impact support for patients. The service is growing from strength to strength, with considerable demand from patients and carers. Since launch day, the service has more than doubled its capacity, now providing 35 hours of support each week.

INFOLINE



67 AVERAGE MONTHLY PHONE CALLS RECEIVED BY THE INFOLINE



OF CALLS RESPONDED TO WITHIN 24 HOURS



192 AVERAGE MONTHLY EMAIL ENQUIRERS CONTACTING THE INFOLINE



AN AVERAGE OF 235 EMAILS SENT IN RESPONSE



OF EMAILS ARE ANSWERED WITHIN 24 HOURS

ENQUIRY REASONS

- Telehealth Nurse Service
- General Information (newly diagnosed patients, general service information)
- Peer support group information
- Health practitioner list
- GP Education module information

TELEHEALTH NURSE SERVICE

259

TELEHEALTH NURSE SERVICE APPOINTMENT REQUESTS RECEIVED

21.5

AVERAGE MONTHLY APPOINTMENT REQUESTS

429

OUTGOING CLIENT CALLS COMPLETED BY THE TELEHEALTH NURSES

ENQUIRY REASONS

1

ASSISTANCE TO COLLABORATE MEDICAL HISTORY

2

EMOTIONAL SUPPORT

3

ACCESS TO NDIS

CAMPAIGNS

MILLIONS MISSING

The #MillionsMissing ME/CFS Challenge campaign engaged over 102,000 people on social media across Australia, in addition to reaching 12 countries worldwide. The online campaign aimed to bridge the gap left by the cancellation of in-person events and resulted in it being our most successful and most accessible event to date!



180 VIDEOS

#ME/CFS CHALLENGE

12 
DIFFERENT COUNTRIES

INCLUDING:

11 AUSTRALIAN STATE AND FEDERAL POLITICIANS
18 SCIENTISTS AND THEIR STAFF FROM ME/CFS RESEARCH TEAMS

GP EDUCATION PROGRAM

475

HEALTH PROFESSIONALS SUCCESSFULLY COMPLETED THE ONLINE ME/CFS EDUCATION LAUNCHED IN AUGUST.

1000+

GP EDUCATION PROMOTIONAL FLYERS DISTRIBUTED TO ME/CFS PATIENTS TO BE USED WHEN ENGAGING WITH THEIR HEALTHCARE TEAM.

REACH

14% INCREASE IN SOCIAL MEDIA FOLLOWERS

NEW WEBSITE LAUNCHED IN DECEMBER 2019
WITH 119,361 PAGE VIEWS SINCE LAUNCH DAY.

174,461

TOTAL WEBSITE REACH IN 2019/20

10% INCREASE IN MONTHLY NEWSLETTER SUBSCRIBERS

BETTER ACCESS TO THE NDIS

Our online petition requested that the Australian Government and National Disability Insurance Agency recognise ME/CFS on List B of the NDIS closed with 10,273 signatures with 2,558 shares and 67 pages of comments.



ACCESS TO TELEHEALTH

40

Federal MPs received letters requesting the inclusion of people with ME/CFS and other chronic illnesses in the Australian Government's 10-year plan for telehealth services.

419

ME/CFS patients provided consumer feedback on their experiences with temporary telehealth medical services, enabled by the COVID-19 pandemic, informing our advocacy efforts to encourage telehealth to become permanently available for ME/CFS patients.

RESEARCH

MASON FOUNDATION-FUNDED BIOBANK

KEY PROJECT MILESTONES ACHIEVED:

- Biobank Coordinator recruited
- Ethics approval gained
- Steering and Access committee positions filled
- 714 individuals subscribed to receive updates on the Biobank

RESEARCH DIGEST

24

RESEARCH DIGEST EDITIONS PUBLISHED

37%

INCREASE IN SUBSCRIBERS, WITH AN AVERAGE OPEN RATE OF 58%

ANCHOR PROJECT

In September, the Medical Research Future Fund (MRFF) announced funding for the ANCHOR Project, a partnership with University of Tasmania, Deakin University and Emerge Australia to establish the prevalence and economic costs of ME/CFS in Australia and its impacts on patients, carers, the broader community and the health system.

8

MEETINGS ATTENDED OF THE CHIEF INVESTIGATOR GROUP FOR THE ANCHOR RESEARCH

PROJECT

20

PATIENT ADVISORY GROUP MEMBERS ENGAGED IN CONSULTATIONS REGARDING THE ECONOMIC IMPACT OF ME/CFS

55,000

WORDS FROM PATIENT FOCUS GROUPS TRANSCRIPTED FOR ANALYSES

CONSUMER ENGAGEMENT

MEDICAL ADVISORY COMMITTEE

Pilot Medical Advisory Committee formed with six doctors appointed, representing specialisations in: Rheumatology, Internal Medicine and specialist General Practice.

Committee members are based in Tasmania, New South Wales, Victoria and New Zealand.



PATIENT ADVISORY GROUP

36 PATIENTS

3 CARERS

**30
FEMALE**



**9
MALE**



OUR IMPACT REPORTING

Emerge Australia has made a commitment to become an impact-driven organisation. We conceptualise impact as the collective change we are making in the world. This is a big change for any organisation, and our introductory impact reports have a focus on key outcomes achieved to date. As we further develop our evaluation capacity within the organisation, our reports will increasingly focus on impact rather than outcomes. We are grateful to have the community and donors on this journey with us.

SPOTLIGHT: TELEHEALTH NURSE SERVICE

ABOUT THE PROGRAM

In 2019 Emerge Australia won a place in a three-year federally funded pilot project, delivering telehealth nurse services to ME/CFS patients in partnership with the Centre for Community Driven Research (CCDR). The broad aim of the pilot is to provide a cost effective route to high impact support for patients. We are incredibly grateful for additional support for this project from the Phyllis Connor Memorial Foundation and the McCusker Charitable Foundation.

Emerge Australia launched our Telehealth Nurse Service in the Spring of 2019, providing patients and carers Australia-wide with telehealth consultations with a qualified nurse. The program was built from the ground up, with major milestones including the recruitment and onboarding of telehealth nurses, the development of policy and processes, data collection methodology and reporting capabilities. In addition, tools were developed for use in the delivery of consultations, such as templates for assessing post-exertional malaise, symptoms and functional domains. As the program has progressed, additional needs have been identified, with the telehealth nurses devising materials to support advanced care directives for people with ME/CFS, and a mental health first aid policy.



**"THANK YOU SO MUCH FOR
AN EXCELLENT SESSION LAST
WEEK. NOTHING SHORT OF
EXCEPTIONAL FOR RANGE,
CONTENT AND DELIVERY."**

**— CARER OF AN ADULT
CHILD WITH ME/CFS**

THE DEMAND

The ME/CFS community did not hesitate to access this new service. By Christmas 2019 the demand for the service was so great that initial contact with the telehealth nurse was delayed in excess of six weeks. An additional nurse was recruited with the express focus of providing initial 20-minute consultations to bridge the gap between first-time callers to the service and extended case-management support.

The Telehealth Nurse Service had increased its hours of support from 12 hours per week in September 2019 to 35 hours per week by April 2020. The demand for support from the ME/CFS community is now relatively stable at around 20-25 new appointment requests each month.



**"THANK YOU SO MUCH FOR EVERYTHING,
I FEEL LISTENED TO, IT'S HUGE".**

– ME/CFS PATIENT

PATIENT STORY

BOB LAVENDER, 71-YEAR-OLD RETIRED PRINCIPAL BASED IN NSW.

Bob turned to the Emerge Australia Telehealth Nurse Service out of desperation. He had been living with moderate ME/CFS symptoms since June 2019, after experiencing a two-and-a-half year remission from his initial onset of symptoms in 2009. Bob's health declined rapidly after a low-grade viral infection and he was experiencing a difficult phase, struggling to connect with a knowledgeable health practitioner and he was increasingly becoming more isolated as he went missing from his typical social gatherings.

When engaging with the Telehealth Nurse Service, Bob was seeking a sounding board, some form of help to take the next step in his health journey and support to deal with the frustrations of life with ME/CFS. Through the support of Telehealth Nurse Laura, Bob found reassurance and practical support which empowered him in furthering his medical journey and, at the same time, accept the impact ME/CFS was having on his life. Laura was able to provide tangible supports to Bob, which included guidance to improve his pacing strategies and management of his energy envelope.

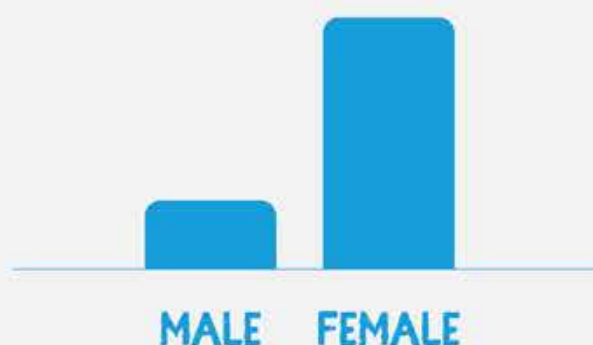
Being a self-confessed 'alpha-male', pacing had always been a challenge for Bob but with the support of Laura to work through the four steps to pacing, he has been able to improve his approach. This was a key step in enabling Bob to start to stabilise and improve his energy management. In addition, Bob was empowered through the use of the symptom and severity hierarchy profile, completed during a consultation. This document provided Bob with the language to communicate his experience of ME/CFS with his current general practitioner and subsequently an additional specialist general practitioner who he engaged with as part of his ongoing medical journey.

One of the other benefits that Bob noted was the validation gained through his interactions with the telehealth nurse. The combined impact of cognitive dysfunction and his low energy levels meant that Bob had begun to struggle with his confidence. Having the support of a medical practitioner to talk through his experience provided validation and reassurance that positive strides forward were possible. Having Laura's support meant that Bob no longer felt alone facing the challenge of ME/CFS. While Bob is still on his health journey, he comments that he has had an improvement since engaging with the service and support gained from a specialist general practitioner, but there is still a long road ahead.

CLIENT DEMOGRAPHICS: LOCATION



CLIENT DEMOGRAPHICS: GENDER



Staff, Management & Volunteers

Emerge Australia Staff

Heidi Nicholl	Chief Executive Officer
Simone Eyssens	Research Director
Jen Temm	Communications Director
Amy Gibson	Project Officer
Jess Kauhausen	Biobank Coordinator
Rebecca Bramley	Information Officer
Danielle Martin	Information Officer
Laura Allen	Telehealth Nurse
Marie Cameron	Telehealth Nurse
Wendy Foster	Finance Officer
John Jeffries	Ambassador

Committee of Management

Martin Wilkinson	President
Mark Clisby	Vice President
Andrew Bretherton	Secretary
Russell Smith	Treasurer
Rebecca Davey	
Nola Miles	
Caitlin Phillips-Peddlesden	

Fundraising Committee

Stephen May
John Jeffries

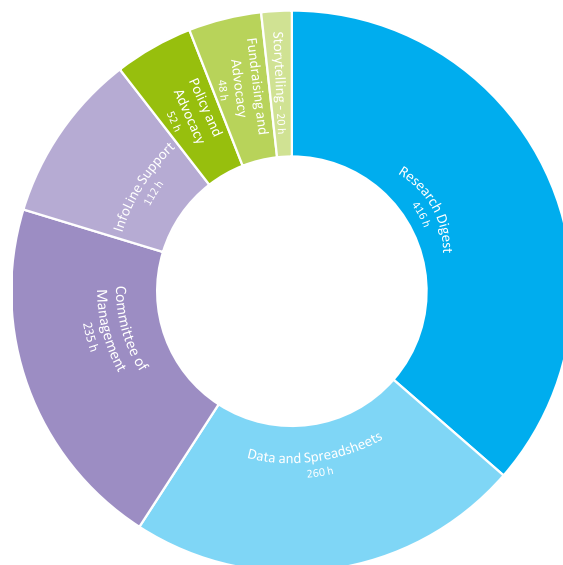
Volunteers

Emerge Australia is incredibly grateful for our steadfast volunteers who contribute invaluable support to the organisation. In this last financial year, the contribution from volunteers was impacted by the necessity for office closures due to the COVID-19 pandemic, as well as a scheduled shutdown of the lift access at Ross House for maintenance over a three-month period.

Carol van Eerden – Data & Spreadsheets
Jenny Meagher – Policy & Advocacy
Maria Stamatakis – InfoLine
Jop Purnell – Storytelling
Bethany Freeman – Storytelling
Dani Kline – Storytelling
Claudia Heath – Storytelling
Kevin Li – Research Digest
Jennifer Smallridge – Research Digest
Ashleigh Zerk – Research Digest
Eileen Tey – Research Digest
Warren Young – Research Digest

We would also like to acknowledge Fiona Cheng and Anna Kerr who supported Emmerge Australia to complete print and radio media pieces.

In addition, we would like to acknowledge the 54 community members who volunteered to test and provide feedback on a range of online community forum options. We estimate that the collective contribution for this project is equal to 216 hours.



Emmerge Australia – Volunteer Hours

1143 total hours | .63 FTE
Or 1x person working 3 days per week for a year

- Research Digest
- Data and Spreadsheets
- Committee of Management
- InfoLine Support
- Policy and Advocacy
- Fundraising and Advocacy
- Storytelling



Providing hope and help for people with ME/CFS

Emerge Australia

Ross House

247-251 Flinders Lane
Melbourne VIC 3000

Email: information@emerge.org.au

Website: www.emerge.org.au