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

Strategic Plan 2014-2017
Established in 1980, the Society has been working with people affected by ME/CFS and associated conditions for over 3 decades. In an environment where the condition has received very little acknowledgment, even less research has been undertaken and people affected have been unacknowledged and suffered for that lack of recognition, the work of the Society has been necessary and appreciated. This has provided a solid basis for moving into the future.

The landscape in which we undertake our work is slowly changing. Research into ME/CFS is gradually increasing, the impact of chronic illness in general is being acknowledged, and international acceptance of ME/CFS as a real condition is greatly increased. It is up to Australia to catch up to the rest of the world and to ensure that those affected in our own country are not left behind when we see how this condition is understood, managed and treated.

The most immediate task for the Society is to improve how ME/CFS is understood and supported in Australia.

We will achieve this by building strong partnerships that will ensure that people affected by ME/CFS have access to a broad range of accessible and affordable programs that enhance their quality of life. And to ensure this, we need to build a financially sustainable and transparent organisation.

Objective 1:
Improve how ME/CFS is understood and supported

Objective 2:
Build strong partnerships

Objective 3:
Facilitate access to a broad range of accessible affordable programs to enhance quality of life

Objective 4:
Build a financially sustainable and transparent organisation
The past year has been one in which Emerge Australia has had to address a challenging financial environment and to review its operations accordingly, with the aim of ensuring positive long-term outcomes. This consolidation resulted in a reorganisation, although a number of core programs and services were retained with the view that there are many people in the community who desperately need them. Along with our programs and services were a number of other highlights.

An influential and exciting advocate for our cause came to the fore during the past 12 months with WA Greens Senator Scott Ludlam keen to learn more about the illness and to provide assistance. After a briefing by Emerge Australia he asked a series of probing questions in Parliament about the lack of funding for research and support for people with ME/CFS. Senator Ludlam later took time out of his busy schedule to join us for the screening of the movie The Forgotten Plague and showed compassion and interest in hearing guests’ stories.

The Forgotten Plague, which was shown at the Victorian State Library, formed part of the activities undertaken for Awareness Week. During this time we supported the Millions Missing campaign and were active in helping to raise the profile of ME/CFS in various ways such as lighting up landmark buildings in blue.

As well as these new activities we continued to maintain communications with the community through our informative Emerge Journal, published quarterly, which members can now choose to receive electronically or in hard copy. Regular editions of the e-newsletter were sent out to over 4,000 subscribers and our Facebook page was updated constantly with current news and reports and continued to provide a good forum for discussion.

There are other sites from which we have disseminated information about ME/CFS too. Our relationship with Healthshare, a digital health platform provider, has been ongoing which means that our fact sheet (to inform newly-diagnosed ME/CFS patients) remained available to GP’s nationally from within their clinical software package. We have also been a Content Partner for some time with the Better Health Channel which is managed by the Department of Health and Human Services (DHHS).

The Self Support Groups grant from DHHS over the past two years enabled us to increase our direct support of people with ME/CFS. We were also able to pilot our Connect with ME program which extended this assistance. The cessation of this funding in early 2016 left us without dedicated resources to adequately run this important program. Therefore a focus of our fundraising was to seek sufficient resources to continue the Connect with ME program.

The extensive analysis of the Health and Welfare survey, facilitated by Federation University School of Health Sciences and Psychology, progressed this year. A number of researchers have been looking at different aspects of the survey responses so that there will be a large volume of research data available for publication in peer reviewed journals. This in turn will provide high quality and validated information to support education about, information on, and acceptance of the disease.

During the year a number of people were farewelled including Amanda Kelly, CEO, who resigned in August 2015 (but who has continued to work tirelessly as a volunteer); Leisl Jackson, Acting Executive Officer (September 2015 to March 2016); Elizabeth Raut, Committee of Management member and; some of our volunteers. All of these people were instrumental in shaping the organisation and are to be commended for the time that they dedicated to Emerge Australia and for their valuable input.

I’d also like to gratefully acknowledge the many supporters that have assisted us, some over many years. These include donors, fundraisers, DHHS, sponsors and philanthropic trusts whose financial assistance played a significant part in enabling us to continue our work. There are also many who freely gave of their time and expertise this year including the Committee of Management, volunteers in the office, the editorial team and the various individuals on sub-committees. All of these people are to be recognised for their commitment to ensuring the ongoing success of our operations. I wish to also thank our staff, Elaine and Laura, for their enthusiasm and passion for our cause, as well as our many members for your sustained support.

We are looking forward to a positive year ahead and anticipating further exciting developments in our work within the ME/CFS and related-conditions community.

Elizabeth Logan (BA, MA, FAIM)
Executive Officer
This has been both a challenging and an exciting year for our organisation. Towards the end of last financial year the Committee of Management had to make the difficult decision to reduce the staffing hours of the organisation to ensure that we did not make a financial loss. Whilst the decision was a sound one from a governance point of view and has ensured that we finished the year with a small surplus, it has been challenging to meet the growing demands on the organisation - due to increased interest in the condition - with reduced staffing.

On a more positive note, there is hope that things are at last beginning to change for people with ME/CFS, with growing international collaboration, research break-throughs and increasing awareness of the condition. The growth of patient advocacy groups around the world and at home who are finding their voice and beginning to work together is very exciting.

In August 2015 we farewelled CEO Amanda Kelly. Amanda did an excellent job of transforming our organisation from a state-based to a national body including improving our communications, and building partnerships with a wide range of organisations. Amanda re-designed our website and established the e-bulletin, all with minimal funding – initiatives that have led to greatly increased reach of our website and other social media. When Amanda left, Leisl Jackson stepped into the role at short notice and did a terrific job of holding the fort at a time when there was increasing media and political interest in the condition. In 2016 we were pleased to welcome our new Executive Officer Elizabeth Logan - Elizabeth has a strong background in working at executive level in the disability sector. She also has a background in public relations and marketing - all important skills in taking the organisation forward.

This year Senator Scott Ludlam contacted us to ask for a briefing on the situation for people with ME/CFS and offered to raise questions at the Senate Estimates Committee. In October he spoke at the Senate Estimates Committee about the lack of funding for research and support for people with ME/CFS. The video clip of that seven minute speech has had over 26,000 hits and there were 216 comments. The comments reflected a huge and moving outpouring from people who are doing it tough. Overwhelmingly they came from people with ME/CFS, wanting to share their story and expressing their appreciation to a politician who was finally giving them a voice and hope for change.

Through Senator Ludlam’s questioning, the Department of Health revised their figures on NHMRC funding downward, from $2.4 million to a tiny $1.6 million spent on two studies and two fellowships since 2000. Disappointingly this funding was also focused on the controversial treatments of Graded Exercise Therapy and Cognitive Behaviour Therapy. This is most disappointing, when we have world class researchers in Australia undertaking research that is focused on the development of diagnostic testing and treatments that target the pathophysiology of the condition. We will continue to advocate for increased funding that targets diagnosis and the development of effective treatments.

We hope to work with Senator Ludlam in the future to establish a Parliamentary Friends group with representation across the political spectrum.

In May 2016, patient advocacy group MEAction staged a “Millions Missing” event in a number of cities, including Melbourne - supported by a newly formed local advocacy group. Their key message was to draw attention to the millions of people around the world who are missing from their former lives due to ME/CFS. For people that are very unwell, social media is proving a great avenue for communication and connection and a vehicle for advocacy. Emerge Australia supported this event and will look to collaborate with MEAction further in the future.

An exciting development has been the increasing focus on ME/CFS internationally with the US senate enquiry stating that the condition has been seriously underfunded to date and suggesting that it be re-named Systemic Exertional Intolerance Disease “SEID”.

This year we were pleased to recruit some excellent new members to the committee: Leo Orland: CFRE FFIA, Senior Partner at Robejohn & Associates. Leo is a Fellow of FIA, past Chairman of FIA, and CFRE board member. In 2013
It is with great pleasure and satisfaction that I present the Treasurers Report for 2015/16 where a significant surplus was achieved. The strategies implemented by the Committee of Management throughout the year along with outstanding efforts by our team has shone through with a net surplus of $36,793. Our work is ongoing with many strategies in place to progress the national status of the organisation and continued support of our members.

Like similar organisations, secured funding continues to be our main roadblock and it was unfortunate that DHHS project funding for the Peer Support Program ‘Connect with ME’ ceased at the end of December. However this has not swayed the enthusiasm nor determination of our team in continuing the much needed support of our ME/CFS community.

Special thanks to the CEO’s - Amanda Kelly who left the CEO position towards the end of 2015, Leisl Jackson who took up the reins whilst a replacement for Amanda was found and current incumbent Elizabeth Logan.

We are fortunate to have a strong committee, with a depth and breadth of skills who put in many hours of their time to support the organisation and who work effectively together. I would like to thank all the committee members for the important contribution that they make.

I would also like to thank the staff, our volunteers and the many supporters that have contributed financially or with their time and skills to enable us to continue the important advocacy and support work of our organisation.

Sally Missing (RN, BA Media, MA Health Admin)
President
### Balance Sheet - Emerge Australia Inc.

<table>
<thead>
<tr>
<th></th>
<th>As at 30 June 2015</th>
<th>As at June 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assets</strong></td>
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<td><strong>Total Assets</strong></td>
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<td><strong>Liabilities and shareholder’s equity</strong></td>
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<tr>
<td><strong>Current Liabilities</strong></td>
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<td>Accounts Payable</td>
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<td>Income in Advance</td>
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<td><strong>Total Current Liabilities</strong></td>
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<td>Retained Earnings</td>
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<td>Net Income</td>
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<td><strong>Total Shareholder’s Equity</strong></td>
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<td><strong>Total Liabilities and Equity</strong></td>
<td>$101,015</td>
<td>$150,699</td>
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</tbody>
</table>

### Profit and Loss - Emerge Australia Inc.

<table>
<thead>
<tr>
<th></th>
<th>As at 30 June 2015</th>
<th>As at June 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Income</strong></td>
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<td>Gifts and Donations</td>
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<td><strong>Total Income</strong></td>
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<td><strong>Gross Profit</strong></td>
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<td><strong>Expenses</strong></td>
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<td>Emerge Costs</td>
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<td>Program Costs</td>
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<td>Rounding</td>
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<td><strong>Total Expenses</strong></td>
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<tr>
<td><strong>Net Earnings</strong></td>
<td>($19,887)</td>
<td>$36,794</td>
</tr>
</tbody>
</table>
INDEPENDENT AUDITOR’S REPORT TO THE MEMBERS OF Emerge Australia Inc

Scope

I certify that I have audited the attached financial statements of Emerge Australia Inc for the period ended 30 June 2016, consisting of statement of financial position and notes to and forming part of the financial accounts.

The Organisation’s Committee of Management is responsible for the financial statements and I have determined that the accounting policies used are appropriate to meet the requirements of the members. I have conducted an independent audit of these financial statements in order to express an opinion to the members of the organisation.

The financial report has been prepared for the distribution to members for the purpose of fulfilling the Committee’s financial reporting requirements under its constitution. I disclaim any assumption of responsibility for any reliance on this report or on the financial report to which it relates to any person other than a member, or for any purpose other than that for which it was prepared.

My audit has been conducted in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the financial statements are free of material misstatement. My procedures included examination, on a test basis, of evidence supporting the amounts and other disclosures on the financial statements. These procedures have been undertaken to form an opinion as to whether, in all material respects, the financial statements, are presently fairly in accordance with applicable Australian Accounting Standards and other mandatory professional reporting requirements, so as to present a view which is consistent without understanding of the Organisation’s financial position and the results of its operations.

Audit Opinion

The audit opinion expressed has been formed on the above basis.

In my opinion, the financial statements of Emerge Australia Inc are drawn up:

a) So as to give a true and fair view of the state of affairs of the Organisation as at 30 June 2016 and of the results of its operations for the period ended 30 June 2016

b) In accordance with applicable Accounting Standards; and

c) In accordance with the provision of the Association Incorporation Act.

Name of Auditor: Karla Lee Eldridge
Professional Membership: B.Bus MIPA 216588
Firm: KARLA ELDRIDGE AND ASSOCIATES PTY LTD
Address: Unit 4/458 Middleborough Rd Blackburn Vic 3130
Phone: (03) 9898 3800
Awareness Week 2016

The key event during Awareness Week this year was the screening of the documentary Forgotten Plague and the attendance of more than 100 guests including WA Greens Senator Scott Ludlam. The movie details the daily struggles that many people with ME/CFS face, from initial diagnosis to the failure of health care practitioners to adequately treat and understand the condition.

Senator Ludlam spoke to the audience after the film about the questions he posed to the Senate Estimates Committee in Parliament and the issues he raised including the lack of funding for research in this area, the lack of support for people with ME/CFS and the need for a stronger public profile.

During Awareness Week there were many activities and events managed by a dedicated band of volunteers aimed at educating and informing the wider community about the illness. Most notably the inaugural Millions Missing campaign was held on the lawns in front of the Victorian State Library. This event featured a display of shoes which symbolised the many patients missing from their careers, schools, social lives and families due to the debilitating symptoms of the disease.

Emerge Australia produced awareness ribbons and new informational leaflets which were distributed widely and with much enthusiasm by many volunteers. The leaflets were also handed out in front of the Melbourne Town Hall which was lit in blue as were a number of other landmark buildings.
Highlights
Emerge Australia Communications

Throughout the year Emerge Australia continued to provide information using a variety of mediums including its website, eBulletin, Facebook site, Information Line and Emerge Journal as well as the news media.

Having launched the new website in late 2014 it was necessary to update some of its contents. Volunteers provided expert assistance in maintaining the information as new research findings and other more current details became available. The number of users of our site continued to grow. The Emerge eBulletin was distributed regularly throughout the year with 27,329 copies sent out, an increase of 14 percent of recipients from last year.

Social media continues to be used extensively by Emerge Australia members and our Facebook page has been a constant source of information on news articles, the latest research and activities. This year we had more than 12,000 accessing the site and the number of ‘likes’ totalled 32,848, which was a notable increase from the previous year.

The Information Line, as promoted on our website, received 215 requests for advice and support. A very small team of dedicated volunteers regularly responded to these queries as they came in.

There were 3,204 copies of the Emerge Journal, which has been published quarterly, delivered by post and by email to interested readers.

During the year representatives from Emerge Australia provided comments to the media which resulted in informative reports in a range of news outlets. These included an article in The Australian Women’s Weekly, an interview on the Today Extra program televised on the Nine Network and an interview on Sunbury Radio 3NRG.
Highlights

Health Professional Engagement

Emerge Australia continues to provide health information directly to General Practitioners this year through its association with Healthshare. This organisation provides a digital health platform for the distribution of health information.

A four-page fact sheet on ME/CFS is available for health practitioners to download from their clinical software package and to give to patients who are newly diagnosed with the illness. This health promoting and self-care information resource was developed in consultation with the Healthshare medical advisory board and independent medical advisers supporting Emerge Australia.

Ongoing generous support from the Gourlay Charitable Trust is gratefully acknowledged, as it has ensured that Emerge Australia can provide this service over the long-term.

Starlight Children’s Foundation
Livewire partnership

Emerge Australia became an organisational partner with Starlight Children’s Foundation’s online community called ‘Livewire’ this year. The aim of the partnership has been to provide support and to meet the needs of young people dealing with the issues and impact associated with having ME/CFS.

The Livewire program is a fully-moderated, safe online community for young people aged 10 to 20 years old, along with their siblings and carers. Similar to the Connect with ME program, it helps alleviate loneliness and isolation and connects teenagers and young people experiencing serious illness or disability. Teenagers are helped to deal with their illness, support each other and focus on the positives of what they can do, not what they can’t. The Livewire program currently has numerous young Australians diagnosed with ME/CFS benefitting from being involved with it.
**Highlights**

**Connect with ME**

The aim of the Connect with ME program is to provide social support and connections for people with ME/CFS experiencing social isolation in the community.

Research indicates that there is a great sense of loneliness among people with this illness due to a lack of contact with others and society in general. The reasons for this isolation is that many suffering ME/CFS are unable to work or study and because the illness is still misunderstood in the wider community.

The Connect with ME program has three components which provide people with various levels of support. These components include one-to-one support for those who are housebound or bedbound; support group meetings in a social setting and; the opportunity to start a new support group as a volunteer group leader.

Despite funding for this program ceasing early in 2016 and the loss of the coordinator, volunteers have continued to respond to people’s requests to connect with peer support groups, to hold meetings and start new groups. These volunteers are to be applauded.

**Health and Welfare Survey**

The aim of the Health and Welfare survey has been to seek evidence on the impacts of ME/CFS on the education, employment and interpersonal interaction of people with the illness. This research also attempts to document how people access healthcare and support services, and what hinders their ability to benefit from these services.

This study is unfunded and Emerge Australia is grateful to Federation University, School of Health Sciences and Psychology, for providing ethics oversight and supervising the researchers undertaking the analysis on a pro bono basis.

A group of volunteers continues to analyse the data and to work through a substantial amount of information provided by hundreds of participants.

The findings of this survey will assist in the development of education and advocacy programs as well as resources for people who care and/or work for, and live with ME/CFS.

Once the analysis is completed a number of papers will be written and submitted to journals for peer review. It is hoped then that this information will educate the medical, political and research communities due to having undergone rigorous review processes.
Highlights

Knitting for ME
To coincide with Awareness Week the first Knitting for ME stall was held in May. Due to the success of this activity in both raising awareness and funds another was planned for early in the new financial year.

Emerge Australia would like to thank Forest Hill Chase Shopping Centre for providing a space and supporting this activity. Appreciation is also extended to everyone who donated knitted items to sell and to the volunteers who managed the stall and answered many questions about ME/CFS.

Health Coaching for ME/CFS
Emerge Australia has partnered with Cohealth Footscray, a leading community health organisation, to offer people in the area the opportunity to participate in their Living Well Program. This program encourages people with chronic illnesses to develop self-management techniques through the support of one-on-one health coaching.

Committee of Management members

Pictured from L-R: Russell Smith (Treasurer), Andrew Bretherton (Secretary), Kath Ferry (Vice-President), John Jeffries, Sally Missing (President), Martin Wilkinson and Leo Orland (Chair, Fundraising and Communications sub-committee). Absent: Wes Fawaz, Irene Herceg, Nola Miles and Astrid Sweres.
Major Donors
We acknowledge the ongoing support provided by the Victorian Government Department of Health and Human Services, and would like to sincerely thank those individuals and organisations who have made financial contributions to support the organisation in the past 12 months.

Generous contributions have been gratefully received from the following:

- Gourlay Charitable Trust
- Harper Bernays Charitable Trust
- ME/CFS (Australia)
- The Lord Mayor’s Charitable Foundation
- The Marion R Stobo Endowment
- The Sir Wilfred Brookes Charitable Trust

Community Donors
Awareness Week participants
- Blackmores Ltd Staff Community Chest
- Andrew Bretherton
- Susan Brookes
- Jocelyn Cairns
- Michelle Carey
- Caringbah High School
- James Chambers
- Paul Dunstan
- Else Gingold
- John Jeffries
- Karma Currency – Workplace Giving
- Knitting for ME supporters
- Sally Missing
- Wendy Murray
- Joanne Musgrove
- Judith Overbeek
- Maurice Blackburn
- Minter Ellison Foundation
- Peter Owen
- Pamela Stone
- Catherine Trinca
- Victorian Managed Insurance Agency
- Our members and supporters

Volunteers
Many loyal volunteers provided more than 1,050 hours of service and assistance in helping to keep programs and services going for Emerge Australia again this service. Their dedicated roles included:

Committee of Management
- Sally Missing, Kath Ferry, Andrew Bretherton, Russell Smith, Wesley Fawaz, John Jeffries, Irene Herceg, Nola Miles, Leo Orland, Astrid Sweres and Martin Wilkinson

Connect with ME Facilitators
- Lee Fisher & Jessica Wynne

Editor (Emerge Journal)
- Angus Tonkin

Information Line
- Iris Kucuk, Louise de Pino, Irene Herceg, Anna Murphy & Charlotte Williamson

Researchers
- Nanette Gerlach & Cara Busst

Research Assistants
- Anna Murphy & Charlotte Williamson

Website Technical Editor
- David Price

Patron
Her Excellency the Honourable Linda Dessau, AM, Governor of Victoria

Life Members
- Helen Clark
- Jennifer Droop
- Richard Dunstan
- Yvette Gebert
- Lia C Henry
- Marie James
- Maureen Jepson
- Bernhard Liedtke
- Nola Miles
- Simon Molesworth AO QC
- James Oakley
- Margaret Pianella
- Marianne Punshon
- Pamela Saunders
Support Groups

The following groups provided much-needed support to people with ME/CFS in their communities. The regular gatherings were largely face-to-face meetings in local cafes, neighbourhood and community houses and in people’s homes. Some groups also keep in touch over social media, through newsletters and email lists. Approximately 1,000 people affected by ME/CFS were connected via the peer support network during the year.

The Connect with ME Peer Support program had groups operating in the following areas in 2015/16:

**Melbourne**
- Bayside ME/CFS Support Group
- Café Club (Inner Melbourne Social Group)
- Café Club (Outer East Social Group)
- Café Club Eastern Suburbs ME/CFS Support Group
- Café Support Group for CFS and Fibromyalgia (Pakenham)
- Frankston FMS/CFS (Self Help) Support Group
- Inner North ME/CFS Café Club (Coburg)
- North-East ME/CFS Peer Support Group (Eltham)
- North-West All Rounders Support Group (Keilor)
- Richmond ME/CFS Café (over 40s)
- St Kilda Support Group

**Regional Victoria**
- Ballarat FM/CFS Self Help group
- Bendigo CFS/ME/FM/Lyme Support Group
- Geelong Support Group
- ME in Mildura
- Sale ME/CFS Support Group
- Shepparton Goulburn Valley ME/CFS/FM Support Group

**Tasmania**
- Hobart Support Group (there are two options)

**New South Wales**
- Albury/Wodonga ME/CFS Support Group
- Inner-West (Sydney) ME/CFS & FM Support Group
- Laurieton Support Group
- Port Macquarie/Hastings Peer Support Group
- Tweed Heads Support Group
- Wollongong ME/CFS/FM (Also MCS) Support Group
Membership & Information:

✆ 03 9529 1344

Phone and leave a message at any time, and we will call you back.

Emerge Australia
(formerly ME/CFS Australia (VicTasNT))

✉ PO Box 120 Prahran VIC 3181

Email: information@emerge.org.au

www.emerge.org.au