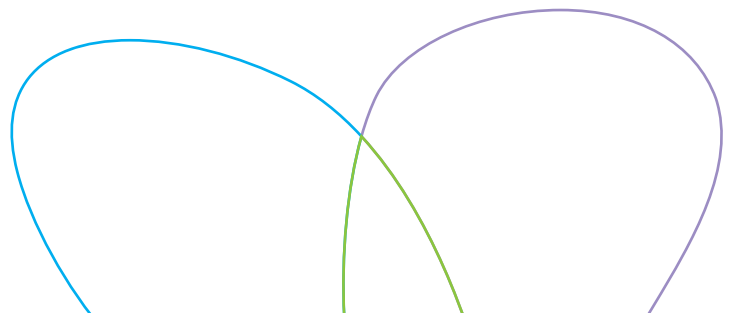


# emerge

australia

Annual Report 2018



## 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.

## About Emerge Australia

Emerge Australia has been supporting people with ME/CFS and associated conditions for 37 years, and has members from around Australia.

The condition is widely misunderstood, and support, research and medical education are seriously under-resourced. In addition to their 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 research collaboration.

Our immediate task is to improve how ME/CFS is understood and supported in Australia.

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.





## CEO Report

Since joining Emerge Australia in February 2018, I have been privileged to be in place for a number of exciting developments. I have enormous gratitude to our previous CEO John Jeffries, especially for the fact that he remained with the organisation, transitioning into a new role as Emerge Ambassador.

I am also proud of how our little team has grown - we now have seven part-time staff! This can be directly attributed to the extremely welcome Federal Government grant funding that we received in winter 2018. This has meant that there are more resources to support more people, enabling us to develop better ways to help those in the community.

We have been busy refining and developing the member journey, and have welcomed many new members after a 'My Giving Circle' grant enabled us to reduce the membership price for people experiencing financial hardship.

I have overseen the production of two editions of the Emerge journal and thank outgoing volunteer editor Naomi Sherborne for her expertise in getting such a high-quality publication delivered. I also wish to welcome a new journal editor, James Borucinski. We wish him every success in continuing this historic and valued magazine.

I have been privileged to meet with a good number of patients and carers, and to develop relationships across many geographical lines. I was welcomed to South Australia where I met with their state society, and I enjoyed a farm visit in Henty after attending a fundraiser for the National Centre for Neuroimmunology and Emerging Diseases (NCNED) at Griffith University.

On May 12, we had our - now annual - Federation Square afternoon tea. This was a huge success and is an event that continues to grow every year. We teamed up with #MEAction and welcomed a host of speakers, including a keynote from federal MP Chris Crewther.

We also took part in hosting a highly successful screening of Unrest at Bio 21 Institute. We were lucky enough to have another federal MP - Adam Bandt - to open this, and there was a much higher than expected turnout. We were especially lucky to welcome so many scientists and potential collaborators — relationships that we hope to build on at our Research Symposium next year.

**Heidi Nicholl**  
*Chief Executive Officer*





## President's Report

This has been an excellent year for Emerge Australia in many ways: in growing awareness of the condition, in becoming more financially secure, in strengthening our links with key stakeholders, and in arriving at a position where we are able to increase our support to members.

The growing awareness of the condition has been evident in the increased media coverage and interest of politicians. This is largely due to the tireless efforts of Emerge Australia and other patient advocacy groups around Australia.

As a result of lobbying, an NHMRC Expert Advisory Group has been established to advise on the state of national and international research into ME/CFS and current research gaps, as well as on the status of clinical guidance and opportunities to improve this for ME/CFS. This is a significant opportunity to shape the direction of future research and point the way to improved clinical guidance.

The growth in our funding base is especially welcome, as it affords us the opportunity to expand our programs and support. I would like to thank our outgoing CEO John Jeffries and current CEO Dr Heidi Nicholl for all their work.

The CEO role is especially demanding in a tiny organisation, requiring people to be a Jack-of-All-Trades. I would particularly like to note both John and Heidi's success in building relationships with our donors and key stakeholders, as this has significantly contributed to our ability to grow the organisation and improve our services.

I was very pleased that we were finally able to release the results of the Emerge Australia Health and Wellbeing Survey. Over 600 of you contributed to this long survey, and we know how much energy that required, so thank you to everyone who participated. We know you will find the results very interesting.

This is my last annual report as president as I will be stepping down in November, but will remain on the committee. I've really enjoyed my time in this role and it has been very rewarding to see the evolution of the organisation into a more professional and strategic body. There has been

an improved level, and coordination, of advocacy across the country, increasing public awareness and, lately, long overdue political interest. There is still a very long way to go before patients have effective treatments and adequate support, but the momentum is encouraging.

Lastly, I would like to thank my fellow committee members. We are fortunate to have such a skilled and committed team who all contribute their time and expertise in so many ways, and have had a huge impact on the leadership and governance of the organisation.

### **Sally Missing**

*President*



## Treasurers Report

### ***Treasurer's Report 30 June 2017***

Emerge Australia Inc. has experienced another financially successful year after receiving Federal Government grants and continuing increases in donations, which has resulted in a surplus of \$124,031.

Special thanks to CEOs John Jeffries and Dr Heidi Nicholl for their outstanding efforts in managing the organisation's funds. We continue to gather support from a wide variety of people and areas, providing us with a platform to enhance the lives of those in the ME/CFS community.

### **Russell Smith (MIPA; CTA)**

*Treasurer*



## Ambassador Report

In stepping down as CEO earlier this year, I indicated to the Committee of Management that I would be happy to do whatever I could to continue to promote the great work of Emerge Australia with, and for, people impacted by ME/CFS.

I was honoured when they asked me to be the first Ambassador.

Each week I am confronted by the impact of the illness on my daughter, so I am very motivated to do whatever I can to build community knowledge, raise political awareness and generate funding for Emerge Australia's great work.

And I get to work with some amazing people.

It has been wonderful to work alongside a dedicated and passionate Committee of Management — and also to see how Heidi's professional approach is bringing ME/CFS issues to the forefront of political, medical and community leaders. She is building a talented team of staff and volunteers who share her drive and commitment.

I am also excited to see the establishment of Emerge Australia's Florence Nightingale Society. This initiative is a wonderful 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 the office.

I look forward to meeting many of our members in the coming year.

**John Jeffries**

*Ambassador*

# Florence Nightingale Society

We are proud to announce 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 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 will be 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](mailto:information@emerge.org.au)

## Balance Sheet - Emerge Australia Inc.

	As at 30 June 2018	As at June 2017
<b>Assets</b>		
Current Assets		
Cash at Bank	\$691,678.18	\$157,726.56
Accounts Receivable	\$0.00	\$1,000.00
Cash on Hand	\$83.90	\$227.75
Stock on Hand	\$1,989.00	\$1,989.00
Security Deposit	\$1,012.30	\$1,012.30
<b>Total Current Assets</b>	<b>\$694,763.38</b>	<b>\$161,955.61</b>
<b>Total Fixed Assets</b>	<b>\$5,028.02</b>	<b>\$2,123.38</b>
<b>Total Assets</b>	<b>\$699,791.40</b>	<b>\$164,078.99</b>
<b>Liabilities and shareholder's equity</b>		
Current Liabilities		
Accounts Payable	\$486.60	\$663.17
Income in Advance	\$408,712.10	\$35,712.10
Other Current Liabilities	\$43,603.29	\$4,765.92
<b>Total Current Liabilities</b>	<b>\$452,801.99</b>	<b>\$41,141.19</b>
Shareholder's equity		
Retained Earnings	\$122,937.80	\$80,195.01
Net Income	\$124,031.61	\$42,742.79
<b>Total Shareholder's Equity</b>	<b>\$246,969.41</b>	<b>\$122,937.80</b>
<b>Total Liabilities and Equity</b>	<b>\$699,771.40</b>	<b>\$164,078.99</b>

## Profit and Loss - Emerge Australia Inc.

	As at 30 June 2018	As at June 2017
<b>Income</b>		
Sales	\$2,365.00	\$3,496.37
Government Grants	\$47,165.59	\$46,021.09
One-off Grants	\$0.00	\$26,287.90
Tied Grants	\$0.00	\$4,000.00
Membership	\$15,357.93	\$15,350.07
Gifts and Donations	\$252,494.02	\$116,756.99
Interest	\$818.42	\$923.60
Fundraising	\$0.00	\$0.00
Other Income	\$0.00	\$0.00
<b>Total Income</b>	<b>\$318,200.96</b>	<b>\$212,836.02</b>
<b>Gross Profit</b>	<b>\$318,200.96</b>	<b>\$212,836.02</b>
<b>Expenses</b>		
Accommodation	\$15,180.28	\$12,888.53
Facilities and Equipment	\$6,339.07	\$5,500.22
Staffing Costs	\$139,668.59	\$117,795.32
Communication	\$6,771.34	\$6,041.66
Insurance	\$1,328.75	\$0.00
Emerge Costs	\$8,038.62	\$10,492.80
Administration	\$10,711.09	\$8,219.52
Program Costs	\$5,221.82	\$9,154.60
Other Costs	\$909.79	\$0.58
<b>Total Expenses</b>	<b>\$194,169.35</b>	<b>\$170,093.23</b>
<b>Net Earnings</b>	<b>\$124,031.61</b>	<b>\$42,742.79</b>

## 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.

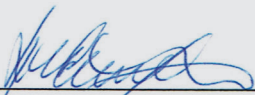
My audit has been conducted in accordance with Australian Auditing Standards to provide reasonable assurance as to whether the financial statements are free of material misstatement. My procedures included examination, on a test basis, of evidence supporting the amounts and other disclosures on the financial 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 2018 and of the results of its operations for the period ended 30 June 2018
- b) In accordance with applicable Accounting Standards; and
- c) In accordance with the provision of the Association Incorporation Act.

  
\_\_\_\_\_  
Signature of Auditor

08/10/2018  
\_\_\_\_\_  
Date

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

## Highlights

### Emerge Australia Health and Wellbeing Survey of Australians with ME/CFS

We are pleased to announce that we released our ground breaking new National Survey on the Health and Wellbeing of People with ME/CFS. The survey, carried out in conjunction with ASDF Research, highlights the need for greater understanding of ME/CFS, which is estimated to affect 1 in 100 Australians, and the way it is diagnosed and treated.

Despite compelling scientific evidence that ME/CFS is a serious, complex, acquired, multi-system disease, there is significant under funding of biomedical research, treatment and support for people with ME/CFS in Australia.

Our new survey provides credible, hard evidence of the terrible impact that ME/CFS has on the lives of patients and those caring for them:

- 46% of patients surveyed report that they are mostly bed bound or housebound.
- 57% of those who had a full-time job prior to becoming unwell were unemployed at the time of completing the survey.
- 74% said the condition had a strong impact on, or stopped, their participation in paid work.

In addition to this, patients and their carers are not getting a fair go from doctors or the health system:

- 44% of respondents rated their doctor's level of being informed as poor / very poor.
- 42% rated the service provided by their doctor as poor / very poor.
- 80% reported that it took a year or more for them to receive a diagnosis.

An additional key finding was that the vast majority (89%) of ME/CFS sufferers feel worse after increasing exercise and/or activity:

- 54% reported feeling worse straight away.
- 35% reported feeling better initially, but worse later.
- Just 5% reported that increasing activity or exercise helped them to feel better.

This finding supports EmERGE Australia's recommendation of a very precautionary approach

to all exercise for ME/CFS sufferers, in order to minimise the risk of post-exertional malaise (PEM) and symptom worsening. It also adds urgency to our call for the Australian clinical guideline (which still recommends Graded Exercise Therapy as a treatment) to be updated.

*The survey was reported in the Sydney Morning Herald, the Age and the Canberra Times.*



### Emerge Australia Welcomes Federal Funding

We are so pleased to announce that we have been given a very welcome \$370,000 by the Federal Government in a grant that will provide much-needed support for people with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome.

The grant covers three main areas:

- Hosting an International Research Symposium
- Conducting an Updated Health and Wellbeing Survey
- Consolidating and 'future proofing' our Support Services

The funding also helps to support our information service meaning that we have a better platform to listen to patients. This, and the establishment of patient advisory groups, means that we should be able to deliver what members feel is most needed and useful for them.

Securing this funding is a hugely important step for EmERGE Australia as we begin to secure our place as a leading voice in support and advocacy for people with ME/CFS in Australia.



## Highlights

### Events

We held a number of events this year. We also had our first attempts at live streaming events, starting with the visit from Dr David Tuller back in March.

Dr Tuller is a Berkeley University-based campaigner on public health issues who has focused on ME/CFS in recent years.

Thirty people attended this small event in person - but it was **viewed by more than 2500** through the Facebook livestream video.

### Annual Awareness Day - May 12, 2018

Once again we booked a room at ACMI in Federation Square in Melbourne.

We had a brilliant day, combining forces with #MEAction who helped create awareness through protest, setting up a #MillionsMissing installation outside. This was followed by the Emerge Australia speaker program inside.



We also livestreamed the entire event, which has had more than 1800 views. More people attended the event than ever before. There were emotional parts to the day but overall we felt that we had properly marked the occasion, having spread the word and acknowledged each other in the community.

Alongside the physical events, we also organised a couple of **High Impact: Low Effort** things that members could do to make their mark on the day.

These were:

#### 1. Send a letter to your MP or to one of our targets recipients -

This went really well and we still have the draft letters for anyone who wishes to send something.

So far this year, Emerge Australia CEO Heidi has met with two federal ministers, we've had two federal MPs open our events, and CEO, President and Ambassador have been to Canberra a number of times and met with a number of back bench MPs.

We've also developed support packs for people who manage to get meetings with their local, state or federal MP.

#### 2. Print out a copy of our petition -

This petition is campaigning for better access to the NDIS for people with ME/CFS. To date, we have received around 1000 signatures and will be taking it to parliament in November 2018.



## Growing Media Interest



### “The Feed – Fighting Disbelief: Chronic Fatigue Syndrome”

Emerge Australia has been involved in a lot of media interest surrounding ME/CFS. Back in April, we participated in the SBS program The Feed. The program, titled “Fighting Disbelief”, focussed on Australians with ME/CFS being rejected by the National Disability Insurance Scheme (NDIS).

ACT based patient, Susan Hutchinson, was at the centre of the story, sharing her NDIS rejection. The program highlighted that the rejection was because her illness showed neither a “substantial reduction in functional capacity” or “permanent impairment”, despite her continued suffering and deterioration for the last six years.

This video can be found on ‘The Feed SBS Viceland’ Facebook page. At the time of writing it has had 467,000 views.

### 7:30 – ABC TV

In July, Dr Heidi Nicholl was invited to be on 7:30 to discuss the National Health and Medical Research Committee’s (NHMRC) review of current treatments for ME/CFS. The program explored the illness and the often-severe condition of patients. The focus of the report was questioning if Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) were outdated as a treatment for ME/CFS.

Dr Nicholl explained that when looking at ME/CFS as a pathophysiological illness, it puts into question how GET/CBT can be useful for sufferers.

Dr Nicholl expressed hope that the current NHMRC review will recommend that funding into the biological underpinnings of ME/CFS should be increased.

### Radio shows

Emerge Australia has also been on Triple R in Melbourne as part of an expert panel and on ABC Illawarra, speaking to Nick Rheinberger on his program’s health section. Finally CEO Heidi Nicholl also spoke on Community Radio WBC 94.1 FM with Iain Messer in Melbourne and on student radio for Edith Cowan University. These interviews gave us an opportunity to educate people on ME/CFS and dispel some of the misconceptions that people who have this condition are “just really tired.”

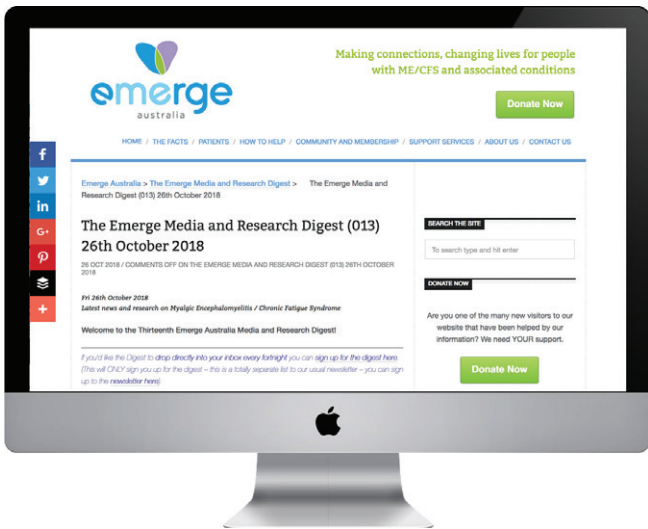


### Newspaper coverage

There have been a number of print articles this year about ME/CFS. Some that Emerge Australia contributed to are a piece in The Courier Mail focusing on Emerge member Ketra, “**Young people with chronic fatigue syndrome call for diagnostic test**”.

A piece in GP magazine The Medical Republic focused on how GP guidelines for ME/CFS are ‘dangerously out of date’ and finally there was a long piece written by Aisha Dow for Fairfax which was published in the Age, The Sydney Morning Herald and The Canberra Times. This explored the personal story of Emerge Australia member Krista Callinan and drew on the results of our Health & Wellbeing Survey.

## Highlights More!



We launched the **Emerge Australia Media and Research digest** this year. This is separate to our usual newsletter or membership list, and growing numbers of people are opting to receive it. The digest is enabling us to provide something that can be shared with doctors and will be useful to scientists and people working in the field, as well as to patients.

Our new **storytelling project** is up and running! All new and renewing members are now asked if they would like to volunteer to tell their story.

We have a tight crew of volunteer storytellers who have amazing experience in the fields of journalism and creative writing. We launched this project in September and are just receiving our first stories. We're looking forward to sharing these at a later date.

education information ME/CFS  
not-for-profit peer-support  
**ME/CFS** help  
(CFS) Connect  
Myalgic Encephalomyelitis (M.E.) links  
volunteer service grow  
federal-funding kindness connections  
support friendship  
understanding serve support-groups

## Staff, Management and Volunteers

### Staff List

Heidi Nicholl	CEO
John Jeffries	Ambassador
Danielle Griffin	COO
Simone Eyssens	Research Director
Lauren Ginn	Membership Officer
Jose Ortiz	Fundraising Officer
Amy Gibson	Information Officer

### Committee of Management

Sally Missing	President
Martin Wilkinson	Vice President
Russell Smith	Treasurer
Andrew Bretherton	Secretary
Nola Miles	
Leo Orland	
Irene Herceg	
Caitlin Phillips-Peddlesden	
Rebecca Davey	

### Current Volunteer List

Kevin Li	Digest coordinator
Maria Stamartakos	Info Line (phone)
Carol van Eerden	Info Line (email)
Jenny Meagher	Political / advocacy
Naomi Sherborne	Outgoing journal editor
James Borucinski	Incoming journal editor
Sundeeep	Admin and membership assistance

### Storytelling crew

Jen, Claudia, Astrid, Beth, Carly and Jop.

*Thanks to all other staff and volunteers who have contributed this year!*





## Membership & Information:

 03 9529 1344

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

**Emerge Australia**

 PO Box 120 Prahran VIC 3181

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

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