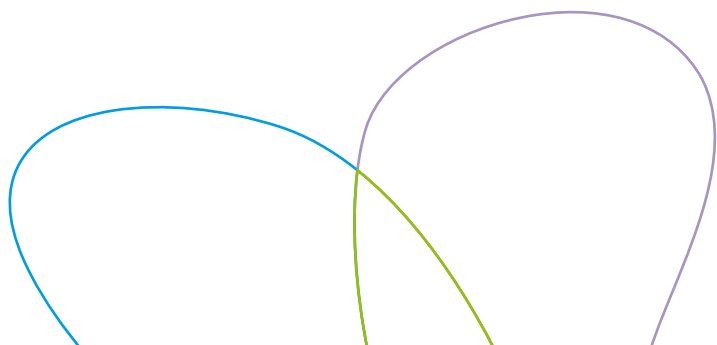




emerge
australia

Annual Report 2019



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 has been supporting people with ME/CFS and associated conditions for 38 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 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.





Chief Executive Officer's Report

This is now my second Annual Report as CEO of Emerge Australia and it has been a time of growth and many exciting developments. I am so pleased to report that after our first federal funding in 2018 we have successfully shown the Government that we are an organisation they can have confidence in. A key factor in building this confidence came from the delivery of our International Research Symposium in March. This was a huge piece of work and the benefits have been immense as we extended our networks of clinicians and researchers, and became better connected to biomedical researchers across Australia and the world.

This confidence has been demonstrated by the renewal and extension of our federal funding for a further three years. The total funding from the Federal Department of Health adds up to an incredible \$1,030,000 over four years, and I would like to take this opportunity to thank Minister Greg Hunt for his support of Emerge Australia as the leading national organisation working with people with ME/CFS.

As a result of this, and the amazing support from the many donors and philanthropists in our community, our team has grown significantly. I would like to say a particular thank you to the McCusker Charitable Foundation who provided a grant to us in early 2019 which significantly increased our ability to help people with ME/CFS and greatly contributed to our success. We now have a professionally run InfoLine taking up to 90 calls and sending up to 250 emails each month to resolve enquiries, and we have staff to work with our productive team of volunteers. We have people updating our website, engaging on social media, helping with advocacy, providing direct support to patients by phone, and updating everyone on progress in medical research – amongst many other activities. Having the backing of this incredible team of experienced professionals enables us to achieve more, and deliver more impact for more people.

There are more details on our federally funded projects later in the report but our key achievements include finding out in June that we had won \$1 million over five years from

the Mason Foundation to establish the first Australian ME/CFS Biobank. Emerge Australia is a key partner in the project, working on a global scale with La Trobe University, Australian National University, Bio21 and the University of Melbourne, BC Women's Hospital in Canada, the London School of Hygiene and Tropical Medicine, the CureME research group, Macquarie University, Murdoch Children's Research Institute and Victorian Paediatric Rehabilitation Service, and Solve ME/CFS Initiative. I look forward to reporting on our progress next year.

We are also thrilled to be part of a \$0.5 million project funded by the Medical Research Future Fund, to look into the epidemiological data and economic impacts of ME/CFS in partnership with Menzies Institute at UTAS and Deakin University. This project will give us much needed confidence in figures that we quote in our advocacy efforts, and will enable us to campaign more effectively. Again, as this funding announcement was made late in the financial year, we will report progress next year.

Launching the Telehealth Nurse program in collaboration with the Centre for Community-Driven Research and with match-funding from the Phyllis Connor Memorial Trust has been exciting. Welcoming a telehealth nurse into our office and hearing from patients about being fully HEARD with this illness, often for the first time, has been really special. This three-year project will truly help us create huge impact and deliver direct support to the community, including patients in rural and remote Australia.

Finally we developed and launched a small Financial Literacy project to teach people about how to successfully access NDIS, DSP and Centrelink. Funded by a small grant from the Victorian Women's Trust, we have assisted patients who have overcome previous rejections from the schemes. Hearing directly from patients that our work is truly 'life-changing' continues to drive and inspire me.

Dr Heidi Nicholl
Chief Executive Officer



President's Report

2018/19 has been a year of significant program growth and public advocacy at Emerge Australia. It is really pleasing to see that the wider community looks to be finally waking up to ME/CFS, its impact and the need to improve resources for research and support. Government and media interest is increasing and Emerge Australia is increasingly being seen as the go-to organisation as we take our place front and centre of the conversation.

Dr Heidi Nicholl and the team at Emerge Australia have been instrumental in this awakening – leading the advocacy effort, developing programs, talking to supporters and people of influence and contributing greatly to the public discourse around ME/CFS. Emerge Australia's active engagement with the Commonwealth's National Health and Medical Research Council advisory committee, established to report on the research and clinical guidance needs for ME/CFS in Australia, is a good example of our advocacy work.

2018/19 has been a big year for our organisation. We held our first ever research symposium – a gathering of like-minded researchers from across Australia and overseas. Bringing together research in the area of ME/CFS will hopefully raise the profile and better coordinate efforts designed to support our members. The symposium was an enormous success thanks to the hard work of our staff and volunteers.

Closer to home, Emerge Australia was on the move with our new office in Ross House, allowing us to expand our staffing base while bringing us under the same roof as other not-for-profit organisations. We have also received funding to professionalise a telephone support line – another way for us to engage with and support our members.

After many years of dedicated support, a number of our Committee of Management members have indicated they intend to resign. Leo Orland, Sally Missing and Irene Herceg have

been integral to the success of Emerge Australia and both they and their contributions will be greatly missed.

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

The 2018/19 financial year produced an outstanding result with a surplus of \$238,262.

The hard work of our staff, headed by CEO Dr Heidi Nicholl, our fundraising committee chaired by Leo Orland, and the support of many volunteers and donors is seeing Emerge Australia being recognised as a national leader in supporting and advocating for people suffering with ME/CFS.

This recognition has seen the receipt of various government grants and donations, enabling our organisation to increase staffing levels and lead many projects and activities aligning with our purpose.

Well done to Heidi and her team and a big thank you to the many donors who make our activities possible.

Russell Smith (FIPA; FFA; FNTAA)

Treasurer



Ambassador's Report

Over the past year the profile, publicity and public acknowledgement given to Emerge Australia and ME/CFS has skyrocketed. It seems that every week I meet new people who share with me how their lives have been dramatically altered by ME/CFS.

Many know of my role with Emerge Australia and feel free to share some of their struggles with me, and I am able to respond with empathy as I know how it has impacted my daughter Amy. And many people are quite surprised to meet someone who has an understanding of how ME/CFS affects individuals.

I use these opportunities to let people know of the important work Dr Heidi Nicholl and the team are doing to communicate, inform and advocate to patients, doctors, political leaders and the wider public.

And still there are thousands of Australians who have limited knowledge or understanding of how ME/CFS impacts individuals and families.

This means there is so much more we need to do to build community knowledge, raise political awareness and generate funding for Emerge Australia's growing work.

I am also excited to let people know about 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

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 2019, 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 2019 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: 18th October 2019

Suite 1, 707 Mt Alexander Road
Moonee Ponds VIC 3039

Profit and Loss – Emerge Australia Inc.

	As at 30 June 2019	As at 30 June 2018
Income		
Sales	\$2,878	\$2,365
Government Grants – Recurrent	\$47,969	\$47,166
Government Grants – Non Recurrent	\$370,000	\$0
Grants – Tied	\$39,066	\$0
Membership	\$17,572	\$15,358
Gifts and Donations	\$404,176	\$252,494
Interest	\$2,275	\$818
Other Income	\$13,856	\$0
Total Income	\$897,792	\$318,201
Expenditure		
Accommodation	\$20,167	\$15,180
Facilities and Equipment	\$9,394	\$6,339
Staffing Costs	\$309,032	\$139,669
Communication	\$8,981	\$6,771
Insurance	\$1,040	\$1,329
Emerge Journal Costs	\$14,631	\$8,039
Administration	\$13,608	\$10,711
Program Costs	\$282,677	\$5,222
Other Costs	\$0	\$910
Total Expenditure	\$659,530	\$194,170
TOTAL INCOME	\$238,262	\$124,031

Financial Position – Emerge Australia Inc.

	As at 30 June 2019	As at 30 June 2018
Assets		
Current Assets		
Cash and Cash Equivalents	\$1,301,824	\$691,742
Trade and Other Receivables	\$1,554	\$1,012
Inventory	\$1,989	\$1,989
Total Current Assets	\$1,305,367	\$694,743
Non-Current Assets		
Property, Plant and Equipment	\$2,569	\$5,028
Total Non-Current Assets	\$2,569	\$5,028
TOTAL ASSETS	\$1,307,936	\$699,771
Current Liabilities		
Payables	\$804,062	\$449,149
Provisions	\$18,643	\$3,653
Total Current Liabilities	\$822,705	\$452,802
TOTAL LIABILITIES	\$822,705	\$452,802
TOTAL NET ASSETS	\$485,231	\$246,969
Members' Funds		
Retained surplus	\$485,231	\$246,969
TOTAL MEMBERS' FUNDS	\$485,231	\$246,969

Federal Projects

In 2018/19 Emerge Australia was awarded its first federal grant of \$370,000. This Department of Health funding has now been renewed and extended to a total of \$1.03 million over four years, a boost that will ensure considerably expanded services and support for more people with ME/CFS, their families and carers.

This year we focused our efforts into four key projects and built our organisational capacity and capability, engaging closely with the ME/CFS community to develop strong foundations for the future.

1 InfoLine

In July 2018 Emerge Australia employed a full-time staff member on the InfoLine. For the first time we could offer an informed, understanding contact point to answer general questions and provide information resources. Our key performance indicator was to respond and resolve inquiries within 48 hours on weekdays.

The InfoLine team includes our dedicated part-time staff members Amy Gibson and Rebecca Bramley, and our wonderful volunteer Maria Stamatakos. Together they bring a broad skillset and expertise in health promotion, social work and counselling to the service, as well as the lived experience of ME/CFS.

By the end of the 2019 financial year the service was answering an average of 289 queries per month, and meeting a range of needs including:

- helping people at early stages of diagnosis to access information,
- connecting people to their local ME/CFS community, and
- providing a range of information resources and offering support or advice.

2 Patient Advisory Group

Establishing the Patient Advisory Group (PAG) has been our first supporter service milestone and a great success. Our project officer Georgia Ransome has developed and managed the PAG, recruiting a diverse group of patients and carers from around the country to represent the experience and needs of the ME/CFS community.

The first PAG consultation was conducted between December 2018 and February 2019 and involved 21 patient/carers interviews to fully understand the support services people accessed, and what barriers existed.

3 Health & Wellbeing Survey

Building an evidence base of the current perspectives and lived experiences of people with ME/CFS in Australia is critical to building awareness and removing stigma around the condition.

In order to find these insights we conducted the 2019 Health and Wellbeing Survey of people with ME/CFS between March and May this year. We're pleased to report that the survey attracted 1091 individual responses.

Once again Emerge Australia harnessed the ME/CFS community to guide this important work. Following established research practices we utilised social media to ask for feedback on the accuracy of questions in the context of the condition. This approach also allowed us to manage participant expectations and to promote the questionnaire.

We look forward to publishing the results following careful analysis. We are very grateful to the support of Roger Dench of Dench Analytics, who advised us in the development of the survey questionnaire and technology platform.

4 ME/CFS International Research Symposium

Emerge Australia hosted the *2019 ME/CFS International Research Symposium: The biomedical basis, diagnosis, treatment and management*, at the Novotel Geelong on March 12-15. The symposium was a significant event for ME/CFS science, clinical practice and patient support, both within Australia and also overseas. Over three days the event comprehensively covered eight areas of scientific research specific to ME/CFS, and provided a space where we could bring together clinicians, patients and carers.

Highlights of the symposium included:

- Keynote and abstract presentations from 13 Australian and 12 international experts.
- 100+ people attended across the three days including scientific researchers, clinicians, allied health services professionals, ME/CFS patients and carers, and philanthropic supporters.
- Minister for Health, Hon. Greg Hunt opened the conference via video.
- All video presentations and abstracts have been made available on a dedicated website, which has been referenced and shared internationally.



Millions Missing

As many people will know, May 12 is the annual awareness day for ME/CFS. In recent years it has been marked by a global campaign called #MillionsMissing, which usually takes place in the week of the awareness day with displays of 'empty shoes' representing people missing from their lives. Rallies to mark #MillionsMissing and the May 12 awareness day take place in cities around the world.

Emerge Australia has been involved in the event for several years and this year, was proud to work with #MEAAction Network Australia to deliver #MillionsMissing Melbourne, and to support the Sydney and Perth events to raise awareness of people with ME/CFS, their families and friends.



Media Interest

We have seen an enormous increase in mainstream media interest in ME/CFS over the past 12 months, which has positioned Emerge Australia as the key contact point for media engagement, as an information resource and the leading national consumer support and advocacy group for ME/CFS.

Highlights included appearances on Channel 9's *Today* show in November 2018, with Channel 9's *Today Extra* in May and Channel 7's *The Daily Edition* in June. Radio interviews included a segment with ABC Melbourne alongside Professor Paul Fisher, discussing the International Research Symposium in March.

Our own media channels have seen a similar surge of signups and engagement. We continue to see good traffic coming to our website and we have great feedback for our flagship quarterly journal *Emerge*, revamped this year under a new, experienced editor. Our social media accounts, the fortnightly *Media and Research Digest*, and the monthly e-newsletter are all growing and helping to deliver our message of hope and support to people with ME/CFS. As an example of our incredible reach into the community, the announcement of \$3 million in federal funding into ME/CFS research in March reached more than 32,000 people (with 349 shares and 2513 reactions) on Facebook alone.

Staff, Management & Volunteers

Emerge Australia Staff

Heidi Nicholl	Chief Executive Officer
Danielle Griffin	Chief Operating Officer
Simone Eyssens	Research Director
Georgia Ransome	Project Officer
Bridget Willett	Comms Officer
Kate Mills	Advocacy Officer
Amy Gibson	Information Officer
Rebecca Bramley	Information Officer
Laura Allen	Telehealth Nurse
Wendy Foster	Finance Officer
John Jeffries	Ambassador

Committee of Management

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

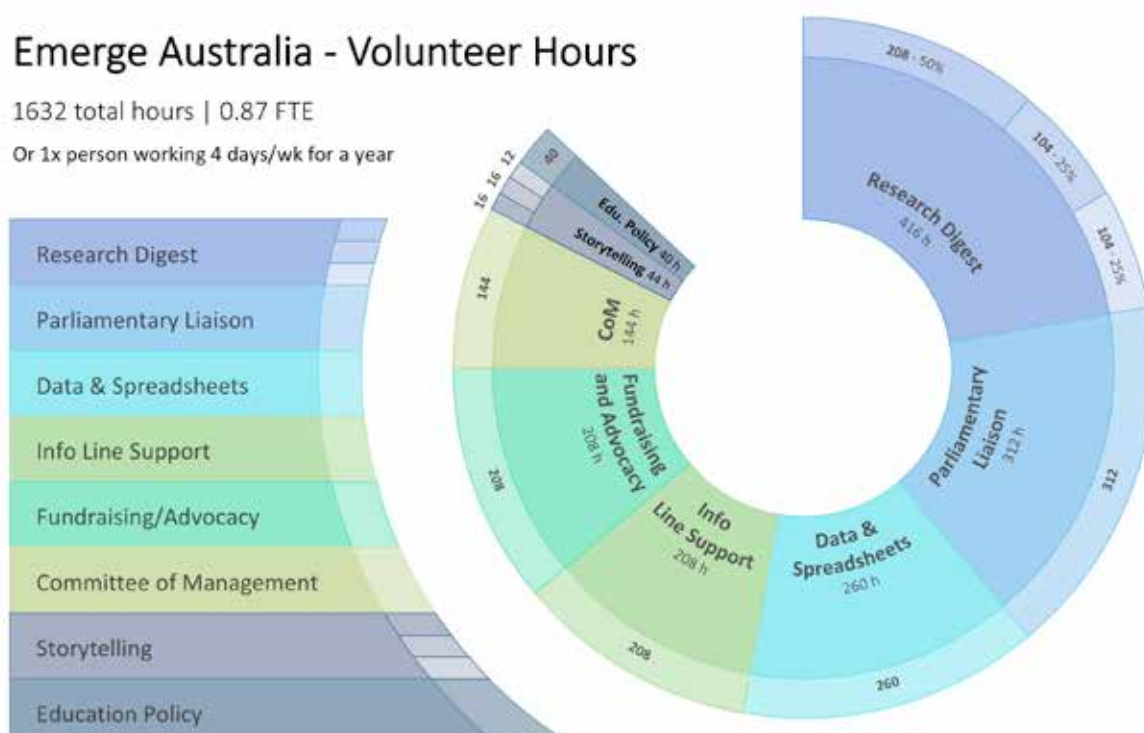
Volunteers

Carol van Eerden	Data & Spreadsheets	Jop Purnell	Storytelling
Luke Fletcher	Education Policy	Bill Ranken	Advocacy & Guidance
Bethany Freeman	Storytelling	Maria Stramatakis	InfoLine
Claudia Heath	Storytelling	Eeleen Tey	Research Digest
Kevin Li	Research Digest	Ashleigh Zerk	Research Digest
Jenny Meagher	Parliamentary Liaison		

Emerge Australia - Volunteer Hours

1632 total hours | 0.87 FTE

Or 1x person working 4 days/wk for a year





Membership & Information: ☎ 03 9529 1344

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

*free call back to anywhere in Australia

Emerge Australia

Ross House

247-251 Flinders Lane
Melbourne VIC 3000

☎ 03 9529 1344

Email: information@emerge.org.au

Website: www.emerge.org.au