

Australian Action on Preeclampsia (AAPEC) Annual Report

September 2023



AAPEC
AUSTRALIAN ACTION
ON PREECLAMPSIA

September 2023 AGM President Report

Dr Lynne Roberts

I am pleased to provide the President's Report for AAPEC in 2023, my 30th year of being involved with AAPEC but my first year of being President. It has been very rewarding to be the AAPEC President over the past 12 months, but the success of AAPEC is truly a team effort. I thank the committee members for their support, encouragement, and enthusiasm; always generously contributing their skills, time, and efforts to attend meetings and participate/help with everything AAPEC is involved in. We made a great team and we achieved many of our goals, always working with AAPEC's aims in the foreground.

This report describes the AAPEC Committee, summarises the work the Committee has done over the past 12 months and includes what was achieved and some ideas for what could be done in the coming year.

AAPEC Committee:

President	Dr Lynne Roberts
Vice President	position vacant
Medical Advisor	A/Prof Amanda Henry
Midwifery Advisor	Dr Heike Roth
Secretary	Camilla Hirsch
Treasurer	Karla Hobley
Web Manager	Senad Hadzikadic/Karen Savins
Social Media	Milena Marcetic
General Committee Members	Prof Shaun Brennecke, Sarah Frayne, Tracey Haimes, Sarah Hens Emily Ramage, Sharon Ramsay, Adrienne White

There were changes to the committee during the year: Senad Hadzikadic stepped down from his role in July but remains available for technical advice as needed. Senad handed over to the new Web Manager, Karen Savins, before he stepped down. General Committee Member Sarah Hens stepped down from her position in May but remains an AAPEC member.

Meetings:

Over the past 12 months we held monthly Committee meetings that were well attended. Minutes were taken and circulated shortly after each meeting. In addition, there were several Sub-Committee meetings, for example, planning the webinars, and changes to the AAPEC website.

A new partner: AAPEC partnered with 'Earlybirds', a small Australian company selling clothing for preterm and small babies, in recognition of the work they do promoting and supporting AAPEC.

Meeting AAPEC's aims:

Throughout the past year, the AAPEC Committee has worked hard to meet our aims, as outlined below:

1. Support women and their families who experience preeclampsia.

We are unable to offer a formal counselling service, so we rely on women contacting us through the AAPEC website and social media platforms. We responded to three women who contacted us through the website seeking support and/or advice. We followed up these women with a personal phone call from a relevant Committee member (Amanda Henry, Medical Advisor and Sarah Hens, Committee member).

Prompt responses to social media questions were made either via the platform or by a more private means.

There continues to be useful information and links on the website for women to access for more information and support.

2. Educate, inform, and advise the public and health professionals on preeclampsia:

We held two webinars and have another one planned for November.

- The February webinar was in 'Questions and Answers' format. Panel members: Amanda Henry, Heike Roth, Sarah Hens, and Prof Jeanie Cheung (invited paediatrician from the Women's Hospital in Melbourne), moderated by me. There were 45 registrations and about 20 attended the live stream. Very positive feedback was received.
- The July webinar was four presentations on 'Latest Research', moderated by Amanda Henry.
 - Predicting and preventing preeclampsia – where are we at? Prof Shaun Brennecke
 - Understanding and improving heart disease for women after hypertensive disorders of pregnancy in primary care Kaylee Slater
 - New biomarkers for prediction and diagnosis of preeclampsia, in the point of care setting A/Prof Lana McClements
 - Growth, development, and health of children following preeclampsia exposure Dr Megan Gow

There were 125 registrations and 40 attended the live stream. Very positive feedback was received.

- The November webinar theme is 'What happens after preeclampsia?' and is currently in the planning phase.

An online education session was held for midwives at Casey Hospital, Monash Medical Centre, and Dandenong Hospital. Shaun Brennecke, Sarah Frayne, and I presented.

We were approached by Adelaide University to share a lived experience with student midwives. As we didn't have a member in Adelaide to do this, Sarah Frayne and I sent recorded videos to Adelaide University. We received a lovely email from the lecturer.

I was interviewed by a local Sydney radio station, 2SSR, for a show named "Babies on Air". The interview was about preeclampsia and AAPEC.

3. Campaign for greater awareness of preeclampsia and AAPEC:

Regular posts on social media about preeclampsia including stories and information.

I spoke about AAPEC at the Australian Preeclampsia Network meeting, as part of the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) conference in Hobart in October 2022. This promoted the existence of AAPEC to a group of health care workers who have an interest in hypertension in pregnancy care and research.

Promotion of the Earlybirds keepsake charm. 100% of profits from the sale of the charms during May were kindly donated to AAPEC. AAPEC was promoted on the Earlybirds social media platforms during this campaign.

In May we ran a campaign "AAPEC is walking all around Australia" attempting to have people walking in every State and Territory in recognition of World Preeclampsia Day. We hosted successful walks in Adelaide, Melbourne, Perth, and Sydney (despite the miserable weather in Adelaide and Melbourne!) on Sunday 21st May and had a small interest in the virtual walk option with people walking in the Gold Coast, outside Perth in WA, New Zealand, and Portugal. Although we did not have walkers in every State and Territory, this was a pleasing improvement to the 2022 walk which was hosted in Melbourne and Sydney only. Many thanks to everyone who had a part to play in organising and running the walks. Special thanks to Annette Garvey, Lecturer in Midwifery at the University of Adelaide. Annette organised the Adelaide walk as a way of saying thanks to AAPEC for sending the lived experience stories to her to be used as a teaching resource.

I represented AAPEC at an international on-line meeting held on World Preeclampsia Day May 22. This was hosted by the US based Preeclampsia Foundation and included people representing organisations from US, Canada, UK, Ghana, and India. There was a lot of discussion around how to promote awareness and improve care for women diagnosed with preeclampsia.

4. Promote and support research:

It is well recognised and expected that researchers have consumer involvement in research grant applications, study design and recruitment processes, and implementation of the study. AAPEC has been increasingly asked to support research grant applications and research projects. Over the past 12 months AAPEC promoted and/or supported the following:

Continued to support the Medical Services Advisory Committee (MSAC) submission for Medicare to fund the PERT and PIGF ratio test. This submission was made in 2021 and has made progress to the next stage of approval. I submitted the 'Consumer survey' on behalf of AAPEC to support this next stage of the approval process.

AAPEC is currently supporting the following NHMRC grant applications:

- Implementation, process evaluation and cost-effectiveness of the Australian Tommy's App – a digital clinical decision tool to improve maternal and perinatal outcomes. Griffith University and Gold Coast University. Application successful. \$740,000 granted for the first phase of the project.
- A mother's risk of future cardiovascular disease following preeclampsia: is early detection and prevention possible? University of Melbourne. Grant decision pending.
- Getting to the heart of the matter: A Novel 'Omics' Risk Score for CVD Risk Assessment in Women Following Pre-Eclampsia. University of Tasmania. Grant decision pending.

AAPEC has assisted with the promotion of, and recruitment to, several studies by posting study flyers on our social media platforms. We are currently assisting with recruitment to Deb Parkinson's Masters project "Women's experiences of follow up medical care for pre-eclampsia".

We were approached by two researchers asking for an AAPEC member to be a consumer representative on their Steering Committee. Thanks to Milena Marcetic for joining the "Understanding and improving heart disease for women after hypertensive disorders of pregnancy in primary care" Committee as the consumer representative. The other study, looking at the association between pregnancy complications and loss and future heart disease, request has been posted on AAPEC social media asking for a volunteer.

Website upgrade:

Senad continued to make improvements to the website throughout the year and has now handed that task over to Karen. The website is looking good and flows better than it used to. Karen will continue to modify the website as required. Karen has re-established the AAPEC YouTube channel for sharing videos such as webinar recordings and walk footage.

Gift packs:

Sharon Ramsay continued to put together and distribute the gift packs. Generous donations allowed AAPEC to hand out very nice and useful giftpacks to new mothers on Christmas, Mothers Day, and during Preeclampsia Awareness Month in May. Sharon has made more than 1800 packs this year that have been distributed in Sydney – St George Hospital, Melbourne - Monash, Frankston, Casey, Sunshine, Northern, Wangaratta Base, Warragul, and Dandenong Hospitals, and Alice Springs. Thankyou Sharon – a lovely way to help new mothers and promote AAPEC.

Still to do:

AAPEC certainly achieved a lot over the past 12 months but there is still more work to do:

- Continue the great work we have done this year, into the next – let's keep the momentum going!
- The information on the website needs to be updated and re-written, including referencing. This should be a priority for the next committee.
- Promoting membership so that we have members from every State and Territory
- Re-introduce the newsletter to help keep members engaged and informed of AAPEC's activities.
- Make good use of our funds. Consider offering a grant, for example a travel grant for a researcher to assist them presenting their work at a conference, or for a nurse/midwife to attend a relevant conference.

I extend a very big thankyou to the Committee for their great work over the past 12 months and the confidence, trust, and support you gave me. It has been my privilege to have worked closely with all of you throughout the year. For those who are stepping down from your position, I wish you all the best and hope to see you again. I will be nominating for the position of President again and, if successful, look forward to progressing AAPEC further with the new committee elected.

September 2023 AGM Secretary Report

Milena Marcetic and Camilla Hirsch

As AAPEC co-secretaries during 2022/23 we were able to assist the AAPEC President and committee with respect to AAPEC's regular activities, planning of events, and logistical matters.

At the commencement of our role, we took time to consolidate passwords and gain access to AAPEC's email accounts and social media accounts. Since then, we have continued regularly monitoring AAPEC's webmail inbox, answering and forwarding emails to the relevant people for advice where appropriate.

Throughout the year we maintained the expected secretary responsibilities of sending meeting reminders and agendas and taking and distributing meeting minutes. Further to this we supported the organisation of AAPEC's two webinars this year, organising the Zoom upgrades, event scheduling, invitations, correspondence with speakers and creation of poster for promotion. Finally, we continued supporting researchers on social media, regularly posting promotion for participant recruitment, and giving input on website updates.

We look forward to hopefully another great year on the committee in respective roles.

September 2023 AGM Treasurer Report

Karla Hobley

The last twelve months has seen a lot of activity in APPEC generally, the cash position has increased by \$4,332 from the previous 12 months and at the end of June 2023 the Cash in the bank amounts to \$29,122

The increase is a result of a combination of items including successful walks in Sydney, Melbourne, Perth, Adelaide and online in the "AAPEC is walking all around Australia" campaign resulting in Money raised of \$1,480 and seeing a lot more engagement in our communities and an increased awareness of the work that AAPEC does. PayPal contributes Giving Income to recognised charities and has donated \$1,162 to AAPEC during this financial year.

Membership Fees are kept low to encourage members to join up to APPEC but has still contributed \$564 this year and most importantly the increase in funds can also be attributed to the generosity of a number of specific donations including

- Larissa Hogan \$500
- Rebecca Pollard (who has donated for many years to the amount of \$2,400 annually)
- Yvette Puckey \$5,560

Without our generous donors, we would not be able to reach the amount of people that we do. We truly are grateful to the support that Individuals and like-minded associations give us.

Our largest expenses this year was Insurance (which we managed to reduce from last year) and promotional materials that were used to raise the visibility of the APPEC logo using printed Bandannas and tote bags for the walk. Participants were given these items as gifts for their involvement and appreciation. They are also included with the gifts that Sharon Ramsay prepares for the mothers at many hospitals in Sydney, Melbourne and Alice Springs.

We try to keep expenses low to ensure that the as much as possible stays in the bank account to be available for worthwhile projects.

Australian Action for Pre Eclampsia

Profit and Loss July 2022 - June 2023

	TOTAL
▼ Income	
AAPEC Walk Income	1,480.00
Gift Income	6,560.42
Membership Income	564.96
Pay Pal Giving Income	1,162.25
Sale of Books and Merchandise	35.00
Total Income	A\$9,802.63
GROSS PROFIT	A\$9,802.63
▼ Expenses	
Advertising and marketing	2,725.25
Bank and Paypal fees	47.96
Fundraising Expenses	99.00
Insurance	1,556.95
Office expenses	61.92
Postage & shipping	505.60
Printing, stationery & supplies	152.50
Website and Hosting Expenses	320.90
Total Expenses	A\$5,470.08
NET EARNINGS	A\$4,332.55

September 2023 AGM Medical Advisor Report

A/Prof Amanda Henry

As AAPEC Medical Advisor during 2022/23 I have assisted the AAPEC President and the Committee with respect to education and research webinars, with ensuring that information distributed by AAPEC through its website and social media is evidence-based and up-to-date, and with the regular business of AAPEC including the International Preeclampsia day walk and responding to medical queries received by AAPEC.

I wish to also acknowledge the contributions of the previous longstanding Medical Advisor Professor Shaun Brennecke, who has remained on the Committee this year in a general advisory capacity. Prof Brennecke this year has in particular continued to champion the process of seeking Medicare funding (through the Medical Services Advisory Committee process) for the sFlt-1/PIGF blood test in relation to the prediction, diagnosis and management of preeclampsia, and (supporting Prof Jon Hyett's application) for a first trimester prediction test for preeclampsia.

I have also advocated for the work and aims of AAPEC through my professional roles, including by inviting and sponsoring Dr Lynne Roberts to attend and present at the Australian Preeclampsia Network meeting at Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) 2022 in Hobart, and through ensuring AAPEC partnership involvement on research submissions. Looking ahead, there will be increasing opportunities for AAPEC involvement in research submissions and promotions, including Dr Roberts being an Invited Speaker for a panel regarding research priorities in preeclampsia at the upcoming 2023 SOMANZ ASM. This, coupled with ongoing webinar plans and potential podcast series, as well as the continuing website refresh and regular posting to Facebook, will help ensure AAPEC continues to improve its support, awareness, education, advocacy and research promotion aims.

September 2023 AGM Midwifery Advisor Report

Dr. Heike Roth

In 2022, I joined as Midwifery Advisor within the AAPEC committee.

Activities undertaken since my commencement include promotion of AAPEC related communications on social media (Twitter/X, Facebook) and attended monthly AAPEC Committee meetings and webinars organised by AAPEC.

In February 2023, with the aim to provide education, information and advice to the public and health professionals on preeclampsia, I was one of the panellists alongside A/Prof Amanda Henry, Sarah Hens, and Professor Jeanie Cheung, moderated by Dr Lynne Roberts. This webinar was presented in a 'Question and Answer' format where enrolled participants were able to submit preeclampsia related questions to the panel prior to and during the webinar.

On Sunday, 21 May 2023 AAPEC hosted a successful walk around Oatley Park to acknowledge World Preeclampsia Day (22 May). This was followed by some official speeches, morning tea and socialising.

I have been involved in the decision making regarding AAPEC promotional materials and have developed a brief for proposed Podcast activities. Further contributions include the development of feedback surveys and forwarding of results to the President for AAPEC webinar events in 2023.

I look forward to further contribution as Midwifery Advisor in 2023/2024.