

NEWSLETTER

June 2018 Edition



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2018 WALK REPORT

It was pleasing to see all of the wonderful walkers who came out and joined us on our annual walk in recognition of **World Pre-Eclampsia Day (22nd May)**. This fantastic event occurs once a year and this time it was held on the 27th May, 2018. In previous years, we have had more people attend and we wish the same for next year. **Mark World Pre-Eclampsia Day down on your calendars** and know that our next annual walk will be held during the same month. Let's aim to improve our numbers for next year and create a sea of purple t-shirts walking around Albert Park Lake! It's truly a great family day out. Many thanks to everyone that attended, as well as Gloria Pegler for coordinating the BBQ, and Margaret Cozzolino and Adrienne White for selling raffle tickets and checking walkers in and out. Thanks also to St John Ambulance, who accompanied us around the lake, and who also enjoyed their post-walk sausage!

ST GEORGE

Thanks to Associate Professor Greg Davis, Lynne Roberts and Dr. Amanda Henry for spending **World Pre-Eclampsia Day** outside Sydney's St. George Hospital. The trio administered free blood pressure checks and reminded people of the importance of regular check-ups.



(L to R): Associate Professor Greg Davis, Lynne Roberts, Dr Amanda Henry



PRE-ECLAMPSIA & HELLP SYNDROME:

A Mother's Reflection

The moment I knew I had developed pre-eclampsia post-birth, I didn't know the severity of the situation. I was young, just 21. I had just been through labour and the subsequent emergency c-section that followed. There lying next to me was the most beautiful baby I had ever seen. My baby; my entire world.

This isn't a birth story, so to speak. It's more of a reflection of how my perspective of birth was forcefully changed. I honestly thought at the time that every woman who had just given birth would have felt like this. Flat, lethargic and swollen were just some of the symptoms that emanated from my body.

I couldn't understand why my healthy, full-term baby and I had to stay in hospital. At no time did I fully understand why. It wasn't until years later during the early birth of my second child that I finally 'got it' and I could never have anticipated what was to come. This time, my body had been invaded by the destruction that is HELLP Syndrome. This devastating diagnosis caused a myriad of problems. This time, it was the upper right quadrant pain that presented first. I recall being on the floor of my bedroom, trying to 'stretch away' the pain. Little did I know but my organs were under pressure and beginning to fail.

As I write this, I recognise that I am one of the lucky women who made it through and sadly there are some that don't. If anything is to change, awareness is key. Empowering and educating women and their partners to be aware of pre-eclampsia and HELLP Syndrome is in my opinion, key to saving more lives. Ladies, if you feel there is something wrong, please see a health professional. Partners, take care of your pregnant spouses and if you notice a problem, please speak up.



HOW YOU CAN HELP AAPEC

Are you wondering about how you can help AAPEC?

- Become a member or renew your membership. It's just \$20 per year.

- Apply to join our committee. We currently have roles available.

- Make a donation or purchase from our online shop - www.aapec.org.au.

- Attend our events. Stay up to date with what is happening by liking and following our Facebook page.

- Follow us on social media. Just search 'AAPEC' and you'll find us on Facebook, Instagram and Twitter. Be sure to click 'Get Notifications' so that you see our posts!

- Share AAPEC with your friends and family.

www.aapec.org.au

OUR CARA

By Lee Hosking

Cara (our niece) was a bright, hard-working, fun young lady who loved her family, she had travelled and made the most of her life. Cara and her husband were looking forward to the next step in life – parenting. Then, the true definition of tragedy occurred.

On October 1st, 2017, Cara was rushed to the hospital with **severe abdominal pain while 35 weeks pregnant** with her first child. There were no warning signs prior, no pre-medical conditions and she had been given a clean bill of health, just days before. Complications arose while trying to locate the illusive source of her pain, and medical professionals had no choice but to deliver Cara's healthy baby girl when Cara's heart stopped and she remained unresponsive after resuscitation. Tragically, Cara slipped into a coma and passed away 4 days later surrounded by her husband and loved ones.

The cause of Cara's pain and sudden passing was due to **HELLP syndrome** which is a complication of **pre-eclampsia**.

Who would have thought that a woman can die during pregnancy in this day and age!

As a group of family and friends to Cara, we would do anything to prevent this illness effecting another pregnant mother. **Raising awareness is one way we can all help.**

Since raising the idea of the Picnic for pre-eclampsia we have received such great support in donations for prizes.

We have also had many conversations about the tragic circumstances of Cara. How this illness is still not widely known and how there seems to be someone who knows someone who perhaps had Toxemia (often referred to in older generations) or someone they knew had an early delivery due to pre-eclampsia or blood complications.

There is no doubt that our sadness is experienced by many others both in Australia and across the globe. If we can help just one person be aware of the symptoms and prompt a discussion or review with the doctor, then we will have done what we aimed to do.

In the meantime we focus on the blessing of a little girl Blakely, who has an angel watching over her, and a large group of family and friends determined to see her path in life is filled with much happiness.

Continued pg. 4



RAISING AWARENESS OF HELLP SYNDROME

We urge all our members in and around Sydney to join Cara's family and friends at 'Cara HELLPs BBQ Picnic' to be held on the **1st July 2018**. You'll find full details below.

We at AAPEC wish to pass on our condolences to Cara's husband, beautiful daughter, Blakely, her extended family and friends. Out of a devastating situation, you are bringing attention to a condition that affects many women across Australia and the world. Thank you so much for joining in the fight for HELLP Syndrome awareness.

May your efforts help other women who are faced with this harrowing condition.



JULY 1st 2018. 11 am

Cara HELLPs BBQ Picnic

Daramu Pavilion, Parramatta Park

Enter at 1 Queens Rd, Westmead

Please join us for a (gold coin donation) sausage sizzle and some fun as we aim to raise much needed funds for Pre-eclampsia.

We will have a raffle draw with over \$3,000 value in prizes.

Preeclampsia is the most common serious medical disorder of human pregnancy. HELLP syndrome is the medical name given to a serious complication of preeclampsia involving a combination of liver and blood disorders.

HELLP stands for

H (haemolysis – red blood cell damage);

EL (elevated liver enzymes, indicating liver damage); &

LP (low platelets in the blood leading to a bleeding tendency).



1 in 20 women develop preeclampsia during pregnancy



1 in 100 women develop severe preeclampsia, HELLP Syndrome or eclampsia

Early diagnosis leads to better outcomes. A world-first blood test that can help predict the potentially deadly pregnancy condition pre-eclampsia is being introduced at Melbourne's Royal Women's Hospital.



Prizes include: Purina Pack (\$1,000.) Envy Jewellery, Castle Hill Lodge Voucher, Moose outdoors Tent, Parklea Markets Voucher, Wine packs, Hair Care package, Happy Hop Jumping Castle, Toys, and many more great prizes 😊

COMING UP: AAPEC'S AGM

Our Annual General Meeting is coming up in late August / early September - date to be confirmed.

All committee positions will be open. If you would be interested in volunteering some time to help with AAPEC and can spare at least one hour per month, then please email info@aapec.org.au to ask for more information.

We would love to have your ideas!



HELP
NEEDED
!

UNDER PRESSURE: DOCUMENTARY

Interview with Pre-Eclampsia survivor and film maker, Dr. Kristine Weatherston.

Tell us about your project! How did it come about?

My project is a short documentary film that highlights preeclampsia survivor stories and explores the signs, symptoms, and the various factors and outcomes surrounding the disease.

What was your main method of spreading awareness about your project?

My main method for spreading awareness about my project is through the film's website and the film's Facebook page. This page serves not only as a promotional device to send out updates about the film, but also a place where I share related articles, information, research, and survivor stories.

How long did your film take to create?

Haha! This is a good question. I first had the idea in December 2014, almost one year after I was diagnosed with preeclampsia. I had just finished my PhD and thought, now what? So I decided to merge my 20 years of media and film experience with my own life changing experiences with preeclampsia and HELLP. It took time to get approval for the project because I work for a University, and they require that all employees run their external projects or research through them first. Once I got approval in spring 2015, I actively searched for participants, and over the course of the next year, we shot over 25 Skype interviews, 15 studio interviews, and travelled multiple times to interview doctors and researchers. We launched a crowdfunding campaign to help offset some costs, but for the most part, this film was privately financed by me. In 2016, I took a year off from the project when my dad got sick with cancer and died. In spring 2018, I re-opened my files and finished editing the final film. So from initial idea to completion (December 2014 - July 2018), it took 3.5 years to complete this film. Talk about a labor of love!



Kristine Weatherston

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FAST FACTS

Pre-eclampsia can affect as many as 10% of pregnancies, which makes it one of the most common pregnancy complications.

UNDER PRESSURE: DOCUMENTARY

How did you ensure that you were presenting the most up-to-date pre-eclampsia data?

One of my interviewees, Dr. Jim Roberts, is considered the most respected and published preeclampsia researcher in the world. He was incredibly gracious with his time and provided an interview for me at Magee-Womens Research Institute. If you look him up, you'll see he's published hundreds of studies and clinical trials, he heads the Global Pregnancy Consortium which looks at preeclampsia on a global scale, and he has helped redefine preeclampsia as more than a hypertensive disorder of pregnancy. After his interview, he gave me leads on two other researchers, Dr. Mandy Schmella, and Dr. Janet Catov, who are active researchers and practitioners looking at genetic susceptibility to preeclampsia, overall causes of pre-term birth in otherwise "healthy" women, and who participate in education in terms of public health and maternal health. To cover signs and symptoms, I interviewed Dr. Kecia Gaither, a maternal fetal medicine specialist, to provide the core explanation of what these diseases are and how they present differently in pregnant women. Finally, I interviewed Perri Shaw Borish, a post-partum mental health specialist, to discuss the trauma associated with the experiences of preeclampsia, loss, and grief. My goal was to weave medical and scientific data and facts as a foundational tool to compliment the lived experiences of survivors.

Did you make any discoveries during the process?

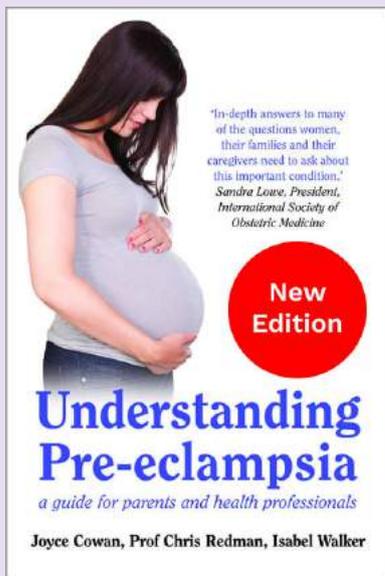
I made so many discoveries along the way! Many of the discoveries I made came naturally along with the in-depth interviews with the medical and research oriented interviewees, but the greatest discovery I made is really connected to the survivors I met and worked with. Before I started making this film, I felt very alone in my experience, and certain that no one could ever understand the trauma of what I went through. But I discovered that I am not alone; I discovered there is an entire global network of women who are all searching for answers, for knowledge, and for community. With this discovery, I reshaped my focus of the film to lean much less on the scientific theories and studies, and more on the community of women who shared their stories with me. I think, in the end, it's a much more compelling film because it's a collage of first-hand experiences accompanied by medical information, instead of the other way around.

The precise cause of pre-eclampsia is unknown. However, genetic factors are probably involved, given women whose mothers and/or sisters have suffered Pre-eclampsia are at increased risk of the disease themselves.

Women should always report worrying signs or symptoms to their doctor during pregnancy.

AAPEC SHOP

Visit www.aapec.org.au and pick yourself up a copy of 'Understanding Pre-eclampsia - A Guide for Parents and Health Professionals.' It's just another way you can support AAPEC's important work.



SHARE YOUR STORY

Did you know that you can share your own pre-eclampsia story with us? We'd love to hear from you! AAPEC have opportunities coming up where your story could be featured in upcoming editions of our newsletter.

If you're interested, please get in touch with us www.aapec.org.au/our-stories



UNDER PRESSURE: DOCUMENTARY

Did you find the process difficult due to your own personal connection with pre-eclampsia?

The process was incredibly difficult due to my own experiences. I developed severe pre-eclampsia at 35 weeks, and I went into eclampsia (I had a seizure) and then Class I HELLP syndrome within 24 hours after being admitted to the hospital for induction. I would have died if I had not had an emergency C-section under general anesthesia. I was put on magnesium sulfate for 3 days, and did not see my son until 36 hours after he was born. He was in the NICU for seven days, but he did great! It took some time for me to recover, and now 4.5 years later, I still have issues with my blood pressure and blood platelets, in addition to difficulty with processing the emotional trauma of the experience overall.

To combat reliving my own trauma over and over again with each interview, and to make sure I honored each interviewee's story as they told it on camera, I hired a crew and an interviewer to conduct the survivor interview shoots. So, rather than crying the whole time through someone else's interview while it's being recorded, and taking their moment away from them, I stepped away from this part of the production process and only looked at the interviews after they were done.

What are your plans after the film's release? Where will it be available?

My plans for the film are to enter it into film festivals in the United States and around the world. I want this film to be seen and shared, for free, at any time.

There are dozens of festivals that focus on female filmmakers, women's health, pregnancy, women's issues, feminism, and other related categories where the film is an eligible candidate. I will submit it University's television station, TUTV, and public television stations in the U.S. I plan to subtitle the film in Spanish for the Latinx community and Spanish-speaking populations. Once the film has screened at a few festivals, it will be available for free to view on Vimeo as a link on the film's website and Facebook page.

At that point, it will be accessible worldwide at no cost. This is a not-for-profit production, and my estimate is that by December 2018, it will be fully available online to be screened or shared by anyone at anytime!





ROYAL WOMEN'S HOSPITAL SEMINAR

The Royal Women's Hospital together with AAPEC ran a seminar titled "Preeclampsia: Progress and Possibilities" to mark World Preeclampsia Day on May 22nd, which was held in the larger lecture theatre at the Royal Melbourne Hospital. Four speakers gave very different perspectives on pre-eclampsia, beginning with Professor Shaun Brennecke of the Royal Women's Hospital, who gave an overview of pre-eclampsia from both an Australian and a global perspective, including the confronting fact that globally approximately 72,000 women die each year from the effects of pre-eclampsia.

Ms Emily Lavis, who spoke about her experience of developing pre-eclampsia during her first pregnancy.

Professor Brennecke spoke again about the newly developed test being run at the Royal Women's Hospital, which has a very high level of accuracy in predicting whether a woman who has been identified as being at risk of pre-eclampsia will develop pre-eclampsia during the following week, and a high level of accuracy in predicting whether she will develop pre-eclampsia during the following four weeks. Using this test has meant that women have been able to come in for fewer monitoring appointments if they test as low risk and has been able to successfully allow women who test as high risk to be appropriately monitored and cared for. Professor Ben Mol, who has recently moved to Melbourne to join the Monash Health Network, spoke about changes in practice in the management of women with pre-eclampsia, and how research is always necessary to continue to improve the outcomes for women and babies.

Dr Stefan Kane, also from the Royal Women's Hospital, spoke about the longer-term effects of pre-eclampsia on both mothers and babies, covering a wide range of effects that have been proposed to be attributable to pre-eclampsia. The main confirmed long-term effect on mothers is an increased risk of developing cardiovascular heart disease, while the long-term effects on babies are complicated to determine by so many babies being born prematurely, which also has long term effects.

AUSTRALIAN PRE-E NETWORK MEETING

AAPEC President, Alison Campbell had the pleasure of speaking at the Australian Pre-Eclampsia Network Meeting, joining a myriad of experts from around the world.

Researchers and clinicians from Melbourne, Sydney, Brisbane, Adelaide and Auckland were present, as well as – for the first time – a cardiologist and a representative from the Heart Foundation.

Read more about Alison's wonderful experience in her President's Report on page 10.



SURVIVOR Q&A'S

BELINDA MAHONEY

State: QLD

What were your pregnancy complications?

HELLP syndrome first pregnancy; HELLP, pre eclampsia, pulmonary embolus and influenza B second pregnancy.

What were your symptoms?

First: vomiting, no movement from baby and severe liver pain for over a month prior. Second: swollen ankles, chest pain and BP was gradually increasing.

At what gestation were your babies born?

35+5 and 29 weeks.

What advice would you give to others thinking of having a second baby?

Make sure you have a great team who will take you seriously. Be mindful of symptoms but also try to not be paranoid. Easier said than done but tell your Drs everything regardless. Make sure you also have great people supporting you, and don't tell people you think might try and cause you stress.

What did you learn from your experiences?

I learnt that I will never get the privilege of a healthy pregnancy or a term baby.



KATE THOMSON

State: WA

What were your pregnancy complications?

Pre-eclampsia during the birth of my son.

What were your symptoms?

Severe vomiting and high blood pressure.

At what gestation was your baby born?

37 weeks.

What are your thoughts about having more children?

We have decided that going through pre-eclampsia once is enough.

What did you learn from your experiences?

I now know that most births don't go to plan and no amount of preparation could have helped. Listening to my body and knowing the signs of pre-eclampsia was what saved my son and I. I'm thankful that I knew what it was and fearful for the women who don't.



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PRESIDENTS REPORT

The second World Preeclampsia Day has just passed, and again it was a very successful one. St George Hospital in Sydney again got into promoting awareness of preeclampsia with a stall in the main hospital entry, where women coming in could have blood pressure checks and learn more about preeclampsia. Meanwhile in Melbourne another very successful seminar was held by the Royal Women's Hospital, with over 90 people registering to come and listen to updates on research in preeclampsia. Information about the screening protocol now being used at the Royal Women's Hospital to determine which high risk women are likely to develop preeclampsia in the next week or month, and on the clinical trials now running around Australia was very well received – particularly information on the ESPRESSO trial, which has just started and which is looking at whether Nexium, a common heartburn drug, can prevent the onset of preeclampsia entirely.

I was honoured to be asked to represent AAPEC at the Australian Preeclampsia Network meeting, where I was able to speak on the importance of engaging women who have experienced preeclampsia, eclampsia and HELLP Syndrome in research, and of listening to our stories. The Australian Preeclampsia Network was formed to facilitate connections between groups doing research and groups doing clinical work around Australia and New Zealand – it was fantastic to see how much research and progress is being made here, and it's exciting to think that so many discoveries about the development of preeclampsia, eclampsia and HELLP Syndrome are in progress.

Researchers and clinicians from Melbourne, Sydney, Brisbane, Adelaide and Auckland were present, as well as – for the first time – a cardiologist and a representative from the Heart Foundation, which is a very welcome collaboration between medical specialties which will hopefully lead to better information flow to women.

As part of that it is great to see that the Heart Foundation are recognizing preeclampsia, eclampsia and HELLP Syndrome as risk factors for the later development of cardiovascular disease, and are running an awareness month in June for women's heart health with the title "Making the Invisible Visible". As well as providing information to women at www.invisiblevisible.org.au, there is an information sheet for clinicians specifically covering pregnancy-related risk factors for heart disease at: <https://www.heartfoundation.org.au/professionals/clinical-information/pregnancy-and-heart-disease> which may be useful for women who want to discuss the risks with their GP.

It is great that information not only about the risks of developing preeclampsia during pregnancy, but also awareness that having had preeclampsia etc. is a risk factor that should be considered in future discussions with medical practitioners, and information on how to reduce and manage these risks is something that should be being routinely given to women.

Finally, it is still worth keeping in mind that although there is a lot of promising research occurring we still need to raise awareness of the signs and symptoms of preeclampsia, eclampsia and HELLP Syndrome so as to give pregnant women the best chance these issues being detected and managed early, therefore giving both them and their babies the best possible outcomes.

Tell anyone you know who is pregnant, who might become pregnant, or who knows anyone who might become pregnant. Even one mother, even one baby is too many.



Alison Campbell