



P.O. Box 29 Carlton South, Vic. 3053

Phone: (03)9330 0441 . Fax: (03) 9330 0441

Email: info@aapec.org.au . Web: www.aapec.org.au

Winter 2014 edition

A member's story

Hailey and Blake

"Your baby looks to be a girl!" the technician announced to Daniel and I at our 20 week ultrasound. We were over the moon to have been pregnant with a little princess. Straight afterwards we headed for the shops and went crazy on pink! She was to be named Hailey Louise.

Our story began on Sunday, April 1st, 2012 when my mum took me for a day out to *The Baby and Toddler Show* in the city. I was at this stage, almost 23 weeks pregnant. It was a great day and I got heaps for Hailey and even two pairs of maternity jeans! Later that night I noticed my feet had puffed up a bit. I showed Daniel and, thinking it was just because of all the walking I had done, we laughed about it.

The Tuesday morning mum and I had plans to meet up in Pakenham and walk around a lake with the dogs. As I was wearing shorts, she noticed the bottom half of my legs had blown up and were very tight. I told her I was in no pain and they felt fine. After our walk, mum insisted I see someone about my legs. We went into a local pharmacy and, after seeing and feeling my legs, they put it down to extra fluid which can be common in pregnancy.

After the pharmacy I returned home to get ready for work, but not long after, mum called me saying "hey, I've just Google searched your symptoms and it's come up with Pre-eclampsia. I don't know much about it but I know that's what our cousin Jodie had with her pregnancies and that caused her to deliver all her babies early".

As I was unable to make an earlier appointment with my obstetrician, I called my doctor. I showed him my legs and straight away he checked my blood pressure and the amount of protein in my urine. He never told me the blood pressure results, only that it was high, and that the protein in my urine was showing more than normal amounts. Without delay, mum met me at the hospital. We were sent up to Maternity where the doctor checked my protein levels and my blood pressure. Again, they were both high and she insisted I would not be leaving anytime soon.

Hours had passed, so had tests and test results, and they were all gradually continuing to rise. After waiting 7 hours at the hospital, the doctor arranged for an ambulance to transfer me to another medical centre. Now I was starting to get nervous and scared.

Daniel met me at the medical centre, and I was sent to the Pregnancy Assessment Unit (PAU). After listening to Hailey's heartbeat, I was admitted to the ward at 1am. After Daniel left I tried my best to fall asleep with a horrible IV Cannula in my inner elbow. (*I hate needles!*)

The next day, we were booked in for an ultrasound to see how Hailey was going and growing.

She was perfect, bouncing around, measuring a little smaller than average but nothing to worry about. The following day, Thursday 5th April, I was sent home just in time for Good Friday and Easter.

Over the Easter weekend I had my family over. At this time, I was lucky enough to have my sister's friend lend me a Doppler. This was great and it gave my grandparents the opportunity to hear Hailey's heartbeat.

Wednesday, 11th April, I headed to work. After a three hour shift, my mum picked me up as I was not able to drive on the blood pressure medication. She insisted I go to the chemist and have my blood pressure checked as I had now begun to have puffiness in not only my legs, but my hands and my face and neck. I agreed. My blood pressure read 190 over 111. This was not good. I immediately called the PAU and told them my blood pressure results, and they told me to come in as they didn't like the sound of those numbers.

On arrival at the PAU they took my blood pressure and again it was too high. They then put a Doppler on me to listen to her heartbeat. After five minutes they couldn't find it. "She's right there," I said, "I can feel her." A lovely nurse then came and escorted me into an ultrasound room. Looking up at the screen, I could see her. The nurse then told me, "I can't seem to find her heartbeat, but I'll have a doctor come in and double check, as I don't usually perform ultrasounds". I started to panic: this couldn't be happening. I was then introduced to another doctor. After looking at the ultrasound, she said "I'm sorry Jess, your baby has died." My heart dropped. My stomach dropped. My tears dropped. I hugged my mum. I then had to call Daniel, but wasn't able to speak. I gave the phone to my mum to tell him that our baby girl had died, and to come in. He was already on his way.

The doctor gave my mum and I some time on our own while we waited for Daniel to arrive. She then came back in and said "we need to get you into birth suite and induce you." I was to give birth to Hailey straight away because of the Pre-Eclampsia. At this point, I was scared and petrified. I didn't want to give birth. I honestly didn't know what I was in for. "Please can you knock me out and take her out via C-section?" I asked. "Due to the Pre-eclampsia, if we knock you out Jess, you won't wake up." I then began to freak out. The Pre-eclampsia had killed my daughter and it was now attacking me. The only cure for Pre-eclampsia is birth and removal of the placenta.

At about 6 p.m Daniel arrived and met me in the birthing suite. I had never seen him so white and emotional. I asked the doctors and nurses if it was possible to have one last ultrasound to just make sure she had really gone, and also for Daniel to see. They didn't decline, and so they brought it in and there she was on the screen, and again no heartbeat. Straight away I was hooked up to drips, one in each hand, and induced. At this stage, I had my dad and sister with me. I also had some close friends come in for support. I had so much love and support from many. /over

Membership Renewals due this month.

(Don't forget to up-date your email address)



AAPEC Annual General Meeting
Tues 7th Oct
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CURRENT COMMITTEE

President	Troy Shiels (NSW)
Vice President	Alison Campbell (VIC)
Secretary	Karla Hobley (QLD)
Treasurer	Gloria Pegler (VIC)
Medical Adviser	Prof. Shaun Brennecke (VIC)
Midwifery Adviser	Prof. Chris East (VIC)
Newsletter Editor	Joan Bird (VIC)
Publicity Officer	Alison Campbell (VIC)
Grant Seeker	Stacey Elliot (VIC)
Fundraising Officer	Sharon Ramsay (VIC) Kamila Van Weeghel (VIC)
Events Organisers	Margaret Cozzolino (VIC)
General Committee	Anne Hally (VIC) Suzi Pawley (NSW) Kelli Wain (VIC) Tammie Leamon (VIC) Jacqui French (VIC) Chris Bottos (VIC) June Fitzsimmonds (SA) Sarah McGee (SA) Andrena McGovern (VIC) Sue Curtis (VIC) Natalie Shiels (NSW)

Hailey & Blake..

As I was hooked up to Morphine I was continuously in and out of sleep. Time was non-existent at this moment. As I had been induced, it was pretty much a waiting game. When awake my family and friends gathered around at my side; I remember seeing people once I woke, then waking up again and seeing others there. My mum, dad, sister and Daniel never left my side.

As we headed into the early hours of Thursday I was still in and out of sleep with no signs of Hailey arriving. It was a long wait, with hours passing and nurses in and out. It was late when my parents decided to go home for some much needed rest. My sister and close friends stayed with us. I didn't remember much, but my contractions were getting closer and things were starting to look promising. I was finally fully dilated and our beautiful Hailey Louise Wright was born sleeping at 11:18 p.m, Thursday, 12th April, 2012. She was more beautiful than ever: blonde with beautiful red lips. She weighed 386grams and 27.5cm long. My first cuddle I will never forget. I couldn't stop staring at her.

The next day I was transferred to the ward with Hailey. Our closest of closest friends and family came in to see us and also cuddle Hailey. It really meant the world to Daniel and I to have so much support and love, with friends and family taking the time to see us and Hailey. We had three days with our Hailey, and those three days I will never forget.

After leaving the hospital and saying goodbye to Hailey, I began to experience excruciating pain in my left leg. I waited a couple of days for it to heal but it got worse. I ended up seeing my doctor who booked me in for an ultrasound. There it was, a Deep Vein Thrombosis, aka blood clot. I was then told to head back to hospital to discuss treatment. Daniel never left my side that day and night. After waiting hours for a doctor, I was sent home on Clexaine injections for the next four to six weeks.

We then had a beautiful private funeral for Hailey and she is now home with us on her bookcase.

Six weeks after having Hailey, I was still showing signs of Pre Eclampsia: my blood pressure was still quite high, and I had a large amount of protein in my urine. Doctors were thinking I might have a problem with my kidneys, and wanted to perform a biopsy on them. Six weeks later I was feeling better but still having check-ups due to the protein levels in my urine.

Then Daniel and I discovered that we were expecting baby no.2! We were over the moon, but also very nervous. I sat down with an obstetrician and, after chatting with her, she offered me the option of termination, but I declined straight away. She will now be helping me through this pregnancy.

We had our first ultrasound at five weeks, and there we saw a blob with a heartbeat. I was very nervous looking at the screen, but all looked good. Due to my history with Pre-eclampsia, the doctor prescribed Clexaine injections every day and also 100mg of Aspirin. This was to thin my blood and help it flow through easier to and from bubs.

The months flew by, and I was feeling great. Bub was growing and I was being monitored every month. At 23 weeks, we learnt that we were having a boy! Again, we already had a name picked out

and for him: Blake Malcolm. He was thriving and very active and my due date was April 20th, 2013.

By 25 weeks I was on fortnightly check-ups and ultrasounds. At 27 weeks they began foetal monitoring of the blood flow in the umbilical cord and the placenta, and Pre-eclampsia was mentioned, again. Whilst the doctors wanted to keep him in as long as possible, they feared that he may have to come out very soon.

On Tuesday 22nd January, I was given the first of 2 steroid injections to mature his lungs as they are the last organ to develop in a baby in the womb. I wasn't admitted, but I had to come in everyday for foetal monitoring/ultrasound. By Friday, as my ultrasound showed that he needed to come out that day, I was admitted. An ultrasound that night showed a false alarm with no changes from the morning one, so they would not be delivering after all. After three nights in hospital, I was discharged. On Friday 1st February, 2013, I was again admitted to hospital until our little man was born.

On Saturday, my parents, sister and Daniel gather around to watch an ultrasound: things still hadn't changed dramatically, and our little man didn't appear to be coming that day. Later on in the afternoon I noticed bub had slowed down in movement. I pressed the button for the nurse to come in, and she brought in a Doppler; although his heartbeat was perfect, I was getting a little nervous. I had feelings and thoughts that although he was ready to come out, things weren't exactly right.

On Sunday morning I was told not to eat until after my ultrasound, as results may have shown the need to go into theatre for a C-section. At 8 a.m. Daniel wheeled me down for the ultrasound – by this time we had learnt read them, which is not necessarily a good thing. As we both looked up, we were thinking the same thing: it doesn't look good, and he may be coming today. Two hours later, after checking the results, our doctor told us that our little man would be delivered in about 30 minutes! Oh God! It was really happening! My midwife prepared me for theatre, and Dan contacted our families. My parents and sister made it in to see me before I went in, also Daniel's mum and little sister.

I was taken into the theatre room for an epidural. Afterwards Daniel came in and did a great job at holding my hand and preparing the camera for photos. I had one amazing team of doctors in the theatre with me. One nurse told me they had cut me open already and that in 5 minutes I would be a mummy! I patiently waited, feeling like I was on a roller coaster ride, and then there it was - the beautiful sound of our little man's cry. He was out! He was beautiful and tiny.

Blake Malcolm Wright, was born 3rd February 2013, at 29 weeks weighing in at 943 grams and 36.5cm long. After Blake was born he was immediately taken up to NICU where he was put on breathing equipment. He did so well in hospital, but it would be 3months before he came home. He had been diagnosed with Chronic Lung Disease, and required oxygen for the first 10.5 months of his life.

Without the help of a wonderful team of doctors and nurses, and the love and support of our families, we wouldn't have been here today enjoying our Blake who is now a healthy 17 month old toddler. We also believe that our Hailey Louise not only saved her little brother, but she was watching over him every step of the way.

Thankyou for your story Jess. Ed.

President's Report

How time flies, and what a year it has been for AAPEC.

Adopting new association rules was the first task accomplished, providing AAPEC with a simplified constitution and aligned with Consumer Affairs Victoria. Immediate past President, Sharon Ramsay, introduced cupcake classes as a fundraising initiative and these were a terrific success. AAPEC was also very grateful for the support of Tabitha Thompson and Little Miracles, a partnership which generated much needed funds. The Melbourne Pre-eclampsia Walk was very well organized and continues to be a strong event.

By far the greatest achievement for the year was the well-attended talk staged by Professor Shaun Brennecke at the Royal Women's Hospital. The most powerful asset AAPEC has are the stories of its members. Many of those stories are challenging and some are heart-breaking. All of these stories inspire because of the courage and bravery shown in the face of uncertainty and fear. Our stories must be shared as frequently as possible in as many forums as are available. Only by sharing these stories will others become aware of pre-eclampsia, not only at a personal level but also as a public health issue.

It has been the most wonderful privilege to be President of AAPEC during this period. I am very grateful to all on the committee for their support, in particular Alison Campbell. A better Vice-President could scarcely be imagined. I am also grateful to Sharon Ramsay for her guidance through our transition.

All things must pass, alas. A new career episode requires my attention, as does my family with a big school adventure beginning next year for Amber. Consequently, I will not be seeking to renew my term as President. I have every faith the committee in place and that which succeeds it at the AGM will be the right team to take AAPEC forward.

Troy Shiels

Back in August 2012 we featured an article titled '**Could Pre-eclampsia Affect your Brain**' which related to a dissertation by researchers at the Groningen University Medical Center, and the University of Washington, in collaboration with the Pre-eclampsia Foundation; this study examined cognition, quality of life and social functioning after a hypertensive pregnancy (see <http://www.preeclampsia.org/component/lyftenbloggie/2012/04/04/126-could-preeclampsia-affect-your-brain>).

We thought our members might be interested in the following summary of this large body of research from the Netherlands:

The maternal brain in Pre-eclampsia: long-term neurocognitive functioning

(2014) Postma, Ineke Rixt

Cognitive complaints following Pre-eclampsia

This thesis investigates cognitive functioning in women who experienced preeclampsia, also known as toxemia of pregnancy, and its relationship with brain scans. Preeclampsia is diagnosed when a pregnant woman develops high blood pressure and an excess of protein in her urine. Around five percent of pregnant women develop this condition. Hospital admission is almost always necessary. In some cases preeclampsia can be complicated by eclampsia, a life-threatening complication characterized by seizures (fits). The exact cause of preeclampsia is currently unknown.

It is notable that mothers report cognitive complaints until years after experiencing pre-eclampsia, such as forgetfulness and attention difficulties. In addition, they have more complaints of anxiety and depression. This thesis shows, however, that women who had

pre-eclampsia have similar scores on cognitive tests compared to women who had a pregnancy without pre-eclampsia. Complaints mainly occur in complex and stressful daily life circumstances. Women who, in addition, experience symptoms of anxiety and depression may be more susceptible to these cognitive complaints. Altogether these complaints do seem to have an impact in daily life.

In the last few years it has become evident that a percentage of women with pre-eclampsia seems to be at higher risk of developing cardiovascular disease in later life. This may explain why small changes on brain scans, normally present with ageing, are seen more often in these women, compared to women who had a pregnancy without pre-eclampsia or women who were never pregnant. These brain changes are normally seen with ageing. This thesis shows that women who experienced pre-eclampsia perform similar on cognitive tests compared to women who had pregnancy without preeclampsia, and that there is no relationship with changes on brain scans.

Future research needs to elucidate whether the experienced cognitive complaints in daily life and brain scan changes are a herald for impaired cognitive functioning at a later age.

<http://irs.ub.rug.nl/ppn/376801417>

The Link Between Pre-eclampsia and Heart Disease

Last Updated on Wednesday, May 21, 2014

By Beth Battaglino, RN, CEO of HealthyWomen

You may think of pre-eclampsia as high blood pressure that occurs during or immediately after pregnancy. That's simply not the case. Preeclampsia can occur up to six weeks postpartum. And that's not all: Research is finding that preeclampsia appears to be a significant warning sign for heart disease after pregnancy. In fact, the American Heart Association's guidelines on cardiovascular disease in women consider preeclampsia as strong a risk factor for heart disease as a failed stress test—a test commonly used to identify existing heart disease.

Recognizing this important risk factor is vital to women's heart health because heart disease is the leading cause of death in women in the United States.

Medical researchers do not yet know exactly how or why pre-eclampsia and future heart disease are linked, but they do know:

1. A history of pre-eclampsia doubles the risk of heart attack, stroke and blood clots within 5 to 15 years after pregnancy.
2. Women who have repeat or severe pre-eclampsia or pre-eclampsia accompanied by stillbirth are at greater risk of heart disease than women who have high blood pressure only or pre-eclampsia during a single pregnancy.

Many women may not be aware that pre-eclampsia and other pregnancy complications can signal heart disease risk. A study found that 13 percent of women screened for heart disease risk factors during an OB/GYN visit had three or more cardiovascular disease risk factors they were not aware of.

If you have ever had pre-eclampsia, it is vital your primary care doctor is aware of your heart disease risk factor. Your health care professional can help you determine next steps for your heart health.

<https://www.preeclampsia.org/the-news?id=368>

New Members

Natalie Pitaro
Cheri-lee Bothma
Kerry Willis
Hayley Ness
Karen Cliffe
Debbie Yolland
Jessica Yolland
Alicia Ferris
Jason Bryne
Donna Groves
Nicole Hampton Prem
Kim Szubert
Nicole Tomamichel
Adrienne White
Judy Dwyer
Gerry Downard
Hayley O'Hanlon

Donations

Rebecca Pollard \$20
(in memory of Courtney Anne Pollard)
Dorothy Shaw \$30.00
Adrienne White \$80
Natalie Pitaro \$500
Bartek Szkandera \$25
Chris Rawlinson \$10
Alison Armstong \$10

*Thankyou for your
generous donations*

Royal Womens' Hospital Public Seminar on Pre-eclampsia

A free public seminar was organised as part of AAPEC week at the Royal Women's Hospital in Melbourne. Professor Shaun Brennecke, Dr Stefan Kane and Professor Christine East spoke on various topics, including the current state of knowledge about pre-eclampsia, the development of new tests to predict who is more likely to develop pre-eclampsia and the longer-term impact of pre-eclampsia on women and their families.

The seminar was well attended, with around 60 audience members including AAPEC members, members of the public, and medical staff, and a lively discussion ensued during question time.

AAPEC would like to thank all three speakers for providing a very informative and educational evening, as well as Professor Brennecke and Jo Bruhn for organising the event. Alison Campbell.

Monash Pre-eclampsia Seminar



AAPEC members Sharon Ramsay, Jess Yolland, Tabitha Thompson and Alison Campbell were pleased to be asked to give a seminar on the patient perspective of pre-eclampsia to Monash midwives as part of AAPEC week.

The stories of the four women covered five separate episodes of pre-eclampsia, one of HELLP Syndrome, one of eclampsia and one loss of a beloved baby, giving a broad overview of what patients can and do experience with pre-eclampsia and its complications.

The seminar was well attended, with many questions being asked during and after the stories had been told. We would like to thank Professor Chris East for organising the seminar, and inviting us to speak. AAPEC would like to arrange more patient perspective seminars – if you are interested in organising one then please contact us on info@aapec.org.au.

Members' Stories Needed !!!

The personal stories that we publish in our newsletter are among our most popular features, and we invite members—old and new—to tell us of their Pre-eclampsia/Eclampsia/HELLP experience (it need not be recent). Fathers are also encouraged to write about how it impacted upon them. Furthermore, it is not only parents who suffer the horrors of this insidious disease—siblings, grandparents, other family members and friends are often affected by the distressing situation.

Many members have discovered that writing about their grief, loss or pain is therapeutic; so, also, is writing about those joyful, memorable moments.

If you would like to share your experience with us, just email your story of around 800 words to info@aapec.org.au together with a photo (optional), or post to AAPEC, P.O. Box 29, Carlton Sth. Vic. 3053.

'Pre-eclampsia - The Australian Experience' 2nd Edition

This book is a moving collection of AAPEC members' experiences with either Pre-eclampsia or HELLP Syndrome. It includes a concise medical overview of Pre-eclampsia, its symptoms and the medical interventions currently in use, whilst highlighting the importance of greater awareness of this disease among Australian pregnant women. If you would like a copy, please go to our website www.aapec.org.au for an order form; alternatively, write to AAPEC at P.O. Box 29 Carlton South, Vic. 3053 or call our office on (03) 9330-0441



Melbourne Pre-eclampsia Walk

The Melbourne Pre-eclampsia Awareness Walk was held on the 24th August at Albert Park Lake. We had a lovely morning for it, with overcast but dry conditions and mild temperatures. In an increase on last year's walk numbers over 100 people assembled to walk around the lake, and have a post-walk sausage, drink and chat. Children were entertained by Kamila Van Weegel from A Dash of Colour Face Painting, who kindly volunteered her time and expertise.

In a small ceremony to honour the memory of infants lost as a result of pre-eclampsia sparklers were lit by each walker, before Jackie French and Alison Campbell shared their pre-eclampsia stories.

The raffle was drawn and winners were Dean White, Vito, Susan Lee and Ruby Wells. We would like to thank the donors of the raffle prizes - Lamb Direct, who donated a \$100 voucher, Big 4 Holiday Parks, who donated a membership; AromaBaby, who donated a selection of their products and Sharon Ramsay who donated a gingerbread house.

Many thanks to the St John's Ambulance volunteers who were present and walked with us; Parks Victoria for their assistance with booking Albert Park; Brian and Gloria Pegler, Sharon Ramsay, Margaret Cozzalino and Alison Campbell for setting up and pulling down again and to everyone who came along and walked. We hope to expand the walk further next year!

Lamb Direct – <http://www.lambdirect.com.au>
 Big 4 Holiday Parks – <http://www.big4.com.au/>
 Aromababy – <http://www.aromababy.com>
 A Dash of Colour Face Painting



AAPEC
 Educate.
 Provide Support.
 Campaign for greater awareness.
 Promote research.

Melbourne Pre-eclampsia Walk





AAPEC Annual General Meeting

The AAPEC Annual General Meeting will be held via teleconference on Tuesday 7th October, to which all financial members are invited to attend and vote. Please email info@aapec.org.au or phone (03)9330 0441 with expressions of interest/apologies, and for teleconference access details. All the following positions are declared open with a commitment of **one full year**. Interstate members are most welcome.

President

Act as figurehead of AAPEC as required. Co-ordinate the activities of the Committee and develop proposals for obtaining financial grants. Chair all Committee meetings. Public speaking as required.

Vice-president

Stand in for the president as required. Liaise with regional and interstate local organisers. Co-ordinate information seminars. The vice president may take on an additional committee role.

Secretary

Take committee minutes in all meetings and ensure all office bearers receive a copy. Prepare agendas and advertise meetings. Collate and respond to all incoming correspondence.

Treasurer

Prepare budget for AAPEC committee business. Keep records of all monetary transactions and liaise with the bank regarding any financial matters. Collect membership fees.

Fundraising Officer

Organise and co-ordinate all fundraising activities. Distribute fundraiser goods where applicable.

Publicity Officer

Promote the existence and the activities of AAPEC throughout the year, in particular during Pre-eclampsia Awareness Week which is held annually in August. Produce and circulate regular publicity material.

Grant seeker

Research current grant possibilities to increase AAPEC's funds, thereby enabling achievement of organisational aims.

Newsletter Editor

Request and collate contributions from committee and other sources for quarterly newsletters. Prepare, and organise printing and distribution of newsletters (minimum 4 per year).

Medical Advisor

Shall be a practising physician with relevant experience.

Midwifery Advisor

Shall be a practising midwife with relevant experience.

General Committee

Attend meetings and contribute ideas and knowledge to the association. When a project is underway an ordinary member may be asked to actively volunteer at events.

Join the AAPEC Committee!

Please consider becoming part of this organization and return some of the support that AAPEC has given you; the small commitment required in fulfilling a committee position is far outweighed by the personal rewards gained. AAPEC is YOUR organization, and new committee members bring an innovative approach to the campaign to educate women about this insidious disease. Take up the challenge — join the committee and help promote awareness of Pre-eclampsia. We also urge interstate members to take up active committee positions to ease the pressure on Melbourne based members.

If you do not feel confident to take on a specific role at this stage, perhaps you could begin by becoming a general committee member. Whatever your capacity to contribute, AAPEC needs your support NOW.

Committee positions require a home based computer and internet connection, plus a passion for advocating awareness of Pre-eclampsia among the Australian Community. For those members who have a small amount of time to spare, who work well with the support of a team and who would like a new challenge with the benefit of operating from within their home, this could be your perfect opportunity. Committee meetings are held once every 6 weeks (and take up to 1.5 hours) and members are able to take part via phone teleconferencing (**interstate members for the cost of a local call**). These meetings are where all the planning and brainstorming takes place.....

All committee positions are declared open. Please email expressions of interest to info@aapec.org.au or mail to P.O. Box 29 Carlton South, Vic. 3053.

This is *your* opportunity to take action on Pre-eclampsia.