Patient Perspectives Impact Quality Care

Courtney Smith's Story

Disclaimer

The terms 'woman', 'momma', 'mother', 'mom', 'she', and other terms are used throughout in reference to the pregnant and postpartum person. We acknowledge and respect the variations that exist in gender identification, and emphasize strongly that all people, regardless of their gender identity, deserve the best medical care, representation in research, and validation as human beings.

Note: the contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by the Preedampsia Foundation or any of our programs.

About Me

- C Idaho born & raised
- Cave birth to both children in Idaho
- CMom of 2 girls
- Currently reside in Idaho Falls
- CSenior Program Coordinator, Social Media
- CBeen with working for Preeclampsia Foundation 3 years





- Got pregnant end of 2018
- 22 years old
- First clinically recognized pregnancy
- Any typical pregnancy at first
- No family history of preeclampsia or hypertension in pregnancy



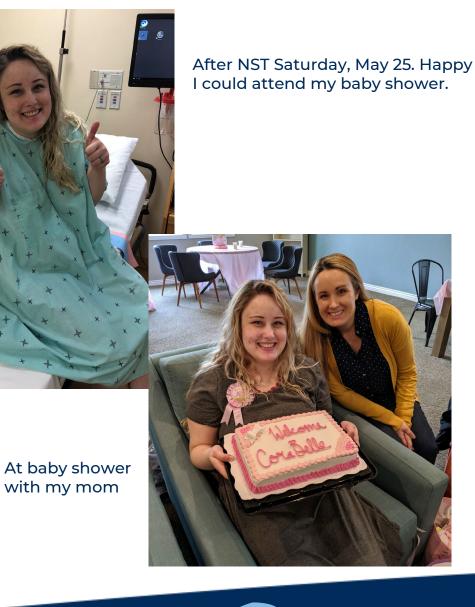
- About 29 weeks gained 5 lb in less than a week, was told to watch what I ate by a provider in practice
- Midwife at practice told me to take BP at home
- Was told to call if 140/90 or go into office if it was opened
- Called a week later, I got 140/90 reading from a borrowed BP cuff
- Met with a new doc, diagnosed with gestational hypertension, told it was good I came in. Scheduled follow up appointments
- A week later then hospitalized
- 3 day stay due to high BP, round of antenatal corticosteroids

Never understood why...





- Released on strict bedrest, anti-hypertensive medication and told a new BP number when to call or go to L&D
- First time I ever heard the word "preeclampsia", didn't have understanding
- A day later, medication was not reordered and BP skyrocketed and I threw up severely. Husband called nurse line they ordered the medication
- I did not experience neurological symptoms, which is what is asked about
- I thought everyone was overreacting because I didn't know it was life threatening
- Memorial Day weekend, ultrasounds at hospital and NST, biophysical profile released because I reported no symptoms









- May 28 saw provider in office first in the morning
- At hospital day before, I was experiencing contractions, but I did not notice them. Provider asked to check dilation, I consented
- 3-4 dilated at 35+3, BP was high and was sent straight to hospital to deliver
- Water was broken, Pitocin, magnesium sulfate, anti-hypertensives, Intermittent pneumatic compression, epidural, pads on bed
- BP high, baby's heartrate was decelerating. Provider spoke with me and husband about c-section and we agreed it was the best action. I was quickly wheeled to OR



- Baby and whisked directly to NICU team through a window in the OR (never saw her)
- Husband followed her into NICU and took pictures
- I spent 2 days on magnesium sulfate, off next night (May 29)
- Met and saw baby for the first time, not through a phone 27 hours after birth.





- Next day, (May 30), my eyes swelled shut
- "Huh never seen that before." from provider
- Ice pack and rest
- Had a chest x-ray and EKG due to concerns from doc because couldn't understand why BP wasn't decreasing
- 15 day NICU stay for feeding support
- 6 day stay for me







- Going to NICU for a week, made recovery difficult
- Saw provider once a week after discharge for blood pressure checks
- Slowly weaned off medication
- By 8 weeks postpartum I was off medication and haven't been on antihypertensive medication since
- Recovered quickly physically
- Emotionally and mentally was much tougher
- Postpartum depression and anxiety.



Preeclampsia Story: Another Pregnancy

- Decided to have another pregnancy after a preconception visit with a high risk provider
- Started LDA prior to conception (blood clot 2 years after preeclampsia)
- Ectopic pregnancy
- Pregnant again 2 cycles later
- LDA and calcium supplement combined with prenatal to get me 1000 mg
- No HBP in pregnancy, preeclampsia or postpartum.
- Tracked self-measured BP, brought logs to office, more knowledgeable provider
- Planned and uneventful c-section at 39+3





How I got Connected with the Preeclampsia Foundation

- Googled preeclampsia once home
- Drawn to the patient support and education provided by Preeclampsia Foundation
- Started an IG account and got involved in community
- Applied for a contractor position and started working remotely.
- Hosted Idaho Falls Promise Walk (3 years)
- Now employee

Other Idaho Stories



KELCEYMARIE:

"This was my third time experiencing severe preeclampsia—what were the odds? This time, it was much worse. [...] My blood pressure started to rise, I occasionally saw flecks in my vision, and my face and hands were becoming puffy. My provider wasn't concerned."



EMILY:

"The trauma of my birth experience, hospital stay, and short-term memory loss brought its own set of challenges."



KRISTINA:

"I began experiencing new symptoms at 30 weeks—blurred vision, a sharp pain on my right side, and rising blood pressure. I repeatedly voiced my concerns, but my doctor dismissed them."



Importance of Patient Perspectives

Can improve healthcare practices, increase patient education, reduce barriers, save lives and ultimately find a cure

- "Our Stories" section of website
- Story Saturday/Story Sunday on social media
- The Registry (research)
- Patient Advocacy (MoMMA's Voices)
- Patient Advisory Council
- Patient stories in various community events such as focus groups, gathering tables and awareness walks
- Co-create education materials

Stories on Website/Social Media

OUR STORIES

Stories of our brave women and families who have been affected by preeclampsia and HELLP syndrome. Please note that due to a technical issue, we are currently fixing the images on this page.

"Black women are five times more likely to die from preeclampsia. Let's change the narrative. Black birth is beautiful! A safe, enjoyable, healthy pregnancy begins with knowledge and resources. I will continue to advocate and amplify my voice.

In doing so, I am honoring my daughter Mia and keeping her memory alive."



Celebrating 25 Years PREECLAMPSIA

Trashaun Powell

www.preeclampsia.org/Take10

I started having odd symptoms. Headaches, nausea, vision changes, horrible neck pain , and no strength. I told the nurses and they told me it was from the epidural and I needed a blood patch. I refused multiple times and they said if I didn't want it then they couldn't help me. I was sent home two days later and 24 hours after being home my symptoms intensified. I went to the er up the street

I had suffered an hemorrhagic stroke and there was an active bleed in my brain. I was airlifted twenty minutes later to a different hospital where I spent two weeks in the icu.













PREECLAMPSIA"

MoMMAs Voices Audiences

People with Lived Experience

- Patient Family Partner Certification
- Continuing Education
- Ongoing Support
- Community
- Matchmaking opportunities
- MoMMAs Voices Summit

Healthcare Providers

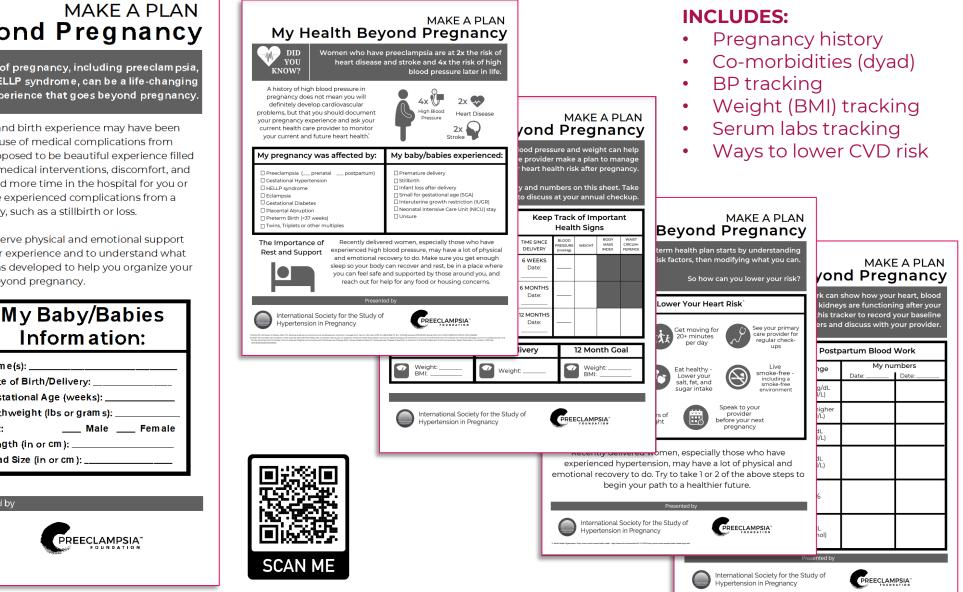
- Lived Experience Integration.
- Matchmaking
- Technical Assistance

MV Partners (Patient Advocacy Organizations)

- Networking
- Leadership Summit
- Development webinars
- Opportunities for spotlight
- Community growth
- Access to PFP training



BEYOND PREGNANCY – Decreasing Long-Term CVD Risk



My Health Beyond Pregnancy

A hypertensive disorder of pregnancy, including preeclampsia, eclampsia, or HELLP syndrome, can be a life-changing experience that goes beyond pregnancy.

Your pregnancy journey and birth experience may have been difficult to process because of medical complications from preeclampsia. What was supposed to be beautiful experience filled with joy was instead full of medical interventions, discomfort, and fear. This may have included more time in the hospital for you or your baby. You may have experienced complications from a premature delivery, such as a stillbirth or loss.

You are not alone. You deserve physical and emotional support around you to process your experience and to understand what happens next. This sheet was developed to help you organize your care beyond pregnancy.

My Inform ation:	My Baby/Babies Information:	
Nam e:	Name(s):	
My Date of Birth:	Date of Birth/Delivery:	
Age:	Gestational Age (weeks):	
With which race/ethnicity do you identify?	Birthweight (lbs or gram s):	
White/Caucasian Asian	Sex: Male Female	
Native/Indigenous Mixed	Length (in or cm):	
Black/African Other:	Head Size (in or cm):	

Presented by



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YOU

KNOW?

International Society for the Study of Hypertension in Pregnancy

Patient Education Materials

Do your patients know about preeclampsia?

Preeclampsia

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Preeclampsi:

Brochures | Posters | Tearpads | Videos Available in multiple languages Order materials online at www.preeclampsia.org/store

PREECLAMPSIA[™]



What made my 2nd experience different. . .



- I gave myself the best possible chance through patient education
- I had a provider that would have cared for me, even if I were to have get it again.
- I knew what to look for
- I knew how to talk to a provider
- Good patient provider relationship



When we include patient perspectives, it leads to more positive patientprovider relationships and helps improve quality and safety.

Thank you for being here and allowing me to share my story.



Get social with us!

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