

# 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 Preeclampsia Foundation or any of our programs.*

# About Me

- Idaho born & raised
- Gave birth to both children in Idaho
- Mom of 2 girls
- Currently reside in Idaho Falls
- Senior Program Coordinator, Social Media
- Been with working for Preeclampsia Foundation 3 years



# My Preeclampsia Story



- 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

# My Preeclampsia Story

- 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...

# Preeclampsia Story

- 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



After NST Saturday, May 25. Happy I could attend my baby shower.



At baby shower with my mom

# Preeclampsia Story



- 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

# Preeclampsia Story

- Baby 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.



# Preeclampsia Story

- 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



# Preeclampsia Story



- 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

**“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.”**



Trashaun Powell



[www.preeclampsia.org/Take10](http://www.preeclampsia.org/Take10)

## 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.

[All](#)
[Eclampsia](#)
[Multiples](#)
[Long-Term Impact](#)
[COVID-19](#)
[NF](#)
[PPCM](#)
[HELLP Syndrome](#)
[Preeclampsia](#)
[NICU Baby](#)
[ICU Mom](#)

[Infant Loss](#)
[Maternal Loss](#)
[Postpartum Preeclampsia](#)



♥ Donate

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 a 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.**

**BRIANNA'S STORY**





# 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<sup>®</sup>
- 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

## MAKE A PLAN 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 Information:	My Baby/Babies Information:
Name: _____	Name(s): _____
My Date of Birth: _____	Date of Birth/Delivery: _____
Age: _____	Gestational Age (weeks): _____
With which race/ethnicity do you identify?	Birthweight (lbs or grams): _____
<input type="checkbox"/> White/Caucasian <input type="checkbox"/> Asian	Sex: _____ Male _____ Female
<input type="checkbox"/> Native/Indigenous <input type="checkbox"/> Mixed	Length (in or cm): _____
<input type="checkbox"/> Black/African <input type="checkbox"/> Other: _____	Head Size (in or cm): _____

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## MAKE A PLAN My Health Beyond Pregnancy



Women who have preeclampsia are at 2x the risk of heart disease and stroke and 4x the risk of high blood pressure later in life.

A history of high blood pressure in pregnancy does not mean you will definitely develop cardiovascular problems, but that you should document your pregnancy experience and ask your current health care provider to monitor your current and future heart health.



My pregnancy was affected by:	My baby/babies experienced:
<input type="checkbox"/> Preeclampsia (___ prenatal ___ postpartum)	<input type="checkbox"/> Premature delivery
<input type="checkbox"/> Gestational Hypertension	<input type="checkbox"/> Stillbirth
<input type="checkbox"/> HELLP syndrome	<input type="checkbox"/> Infant loss after delivery
<input type="checkbox"/> Eclampsia	<input type="checkbox"/> Small for gestational age (SGA)
<input type="checkbox"/> Gestational Diabetes	<input type="checkbox"/> Intrauterine growth restriction (IUGR)
<input type="checkbox"/> Placental Abruption	<input type="checkbox"/> Neonatal Intensive Care Unit (NICU) stay
<input type="checkbox"/> Preterm Birth (<37 weeks)	<input type="checkbox"/> Unsure
<input type="checkbox"/> Twins, Triplets or other multiples	

**The Importance of Rest and Support** Recently delivered women, especially those who have experienced high blood pressure, may have a lot of physical and emotional recovery to do. Make sure you get enough sleep so your body can recover and rest, be in a place where you can feel safe and supported by those around you, and reach out for help for any food or housing concerns.



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SCAN ME

## MAKE A PLAN My Health Beyond Pregnancy

High blood pressure and weight can help your provider make a plan to manage your heart health risk after pregnancy.

Fill in your name and numbers on this sheet. Take it to discuss at your annual checkup.

Keep Track of Important Health Signs				
TIME SINCE DELIVERY	BLOOD PRESSURE (mmHg)	WEIGHT	BODY MASS INDEX	WAIST CIRCUMFERENCE
6 WEEKS Date: _____				
6 MONTHS Date: _____				
12 MONTHS Date: _____				

At Delivery 12 Month Goal

Weight: _____	BMI: _____	Weight: _____	BMI: _____
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## INCLUDES:

- Pregnancy history
- Co-morbidities (dyad)
- BP tracking
- Weight (BMI) tracking
- Serum labs tracking
- Ways to lower CVD risk

## MAKE A PLAN My Health Beyond Pregnancy

Your term health plan starts by understanding your risk factors, then modifying what you can.

So how can you lower your risk?

**Lower Your Heart Risk**

- Get moving for 20+ minutes per day
- See your primary care provider for regular check-ups
- Eat healthy - Lower your salt, fat, and sugar intake
- Live smoke-free - including a smoke-free environment
- Speak to your provider before your next pregnancy

Recently delivered women, especially those who have experienced hypertension, may have a lot of physical and emotional recovery to do. Try to take 1 or 2 of the above steps to begin your path to a healthier future.

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## MAKE A PLAN My Health Beyond Pregnancy

Your work can show how your heart, blood vessels, and kidneys are functioning after your pregnancy. Use this tracker to record your baseline numbers and discuss with your provider.

Parameter	My numbers	
	Date: _____	Date: _____
Cholesterol (mg/dL)		
Triglycerides (mg/dL)		
Hemoglobin (g/dL)		
Hemoglobin A1c (%)		
Blood Pressure (mmHg)		
Weight (lbs)		
BMI		

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# Patient Education Materials



Do your  
patients  
know about  
preeclampsia?

Brochures | Posters | Tearpads | Videos

Available in multiple languages

Order materials online at

[www.preeclampsia.org/store](http://www.preeclampsia.org/store)



PREECLAMPSIA™  
FOUNDATION



# What made my 2<sup>nd</sup> 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 patient-  
provider relationships and helps  
improve quality and safety.

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



# Get social with us!



@preeclampsia.foundation



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