



MoMMA's Voices



The Lived Experience Panel

Presented to

KS Perinatal Quality Collaborative

What is MoMMA's Voices?

Who We Are

MoMMA's (Maternal Mortality and Morbidity Advocates) Voices is the first-ever maternal health patient advocacy coalition established in 2018, to amplify the voices of those who have experienced pregnancy and childbirth complications or loss - especially those who have been historically marginalized - ensuring they are equipped and activated as partners with providers and researchers to improve maternal health outcomes.

Vision

Mommas' voices are integrated as partners wherever maternal health improvements are needed.



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What we do

Community of Learning

- The Lived Experience Integration into QI Community of Learning (COL) was an eight-week educational series created by MoMMA's Voices and funded by AIM. The program ran January to May 2022 and served three cohorts of 23 AIM state and jurisdiction-based teams, Indian Health Services facilities, and other healthcare entities.

Patient Family Partner Training

- Offering training for patient family partners on how to effectively work together to improve outcomes in maternal health in a self paced online platform.
- Provide direct coaching and mentoring to help our patient family partners heal from their birth experiences and learn how to use their voices to impact change.
- Connect with other patient family partners and build strong community.
- To date we have 57 Certified PFPs since May 2021, and have provided 41 “matchmaking” services to providers.
- We offer continued support and training to PFPs with continuing education training and providing coaching and support before/after engagements.

Provider Training coming soon!

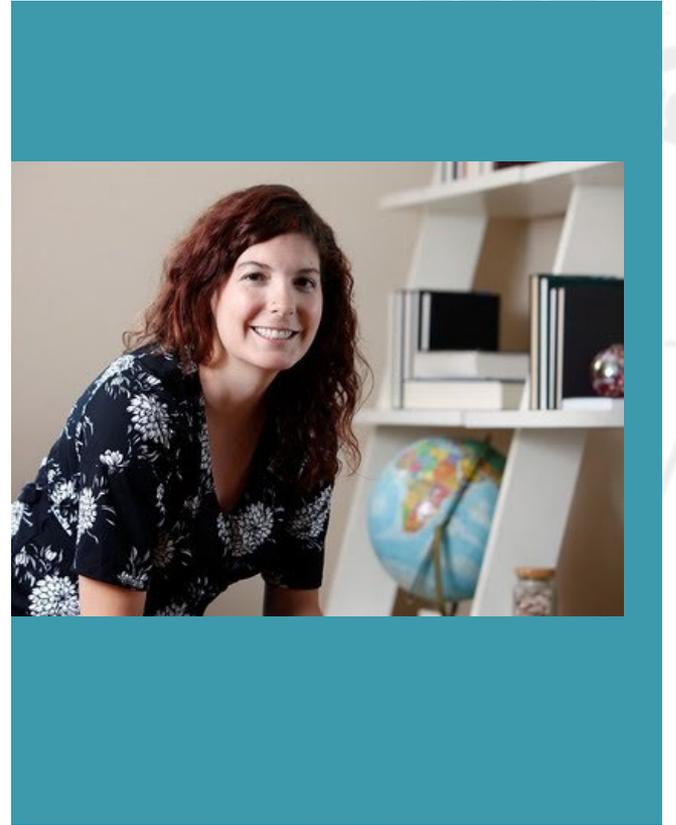
The **Lived Experience Integration™** is a framework designed to help organizations integrate patient perspectives into maternal healthcare practices and quality improvement initiatives. The **Lived Experience Integration™ Provider Training** is a self-paced online course designed to teach quality improvement teams how to listen and learn from patients and families. We believe that patient perspectives hold the key to unlocking new solutions and insights.



Emily Taylor

Provider Coordinator for MoMMA's Voices
Program Coordinator for AFE Foundation

Emily is a maternal health advocate and patient family partner in Cary, North Carolina. She is a survivor of an Amniotic Fluid Embolism. Emily is an advocate for diseases like pancreatitis and CDIFF which she also experienced after the birth of her daughter. She received her bachelor's degree in biological sciences from North Carolina State University. Her healthcare experience includes 6 years in the gastrointestinal field including the Rome Foundation and the International Foundation for Gastrointestinal disorders (IFFGD). She enjoys using her years of professional experience in patient-provider engagement to implement change.



Emily's story

- Easy pregnancy of first child
- Healthy, normal, “boring” pregnancy
- Induced at 37 weeks due to unknown cause of hypertension, tested negative for preeclampsia
- After 14 hours of labor my water broke
- Anaphylactic type reaction from my Amniotic Fluid
- DIC- 18 units of blood transfusions
- Cardiac arrest
- Heart Failure
- Kidney Failure
- Lung Collapse
- Induced Coma for 4 days
- Great care from healthcare providers
- Total of 11 days in the hospital
- CDI and pancreatitis developed after



Evelyn's story

- Evie's first picture
- Born at 37 weeks and got down to 4lbs
- Feeding tube and oxygen
- Took an ambulance to UNC for cooling therapy
- Diagnosed with HIE
- In the NICU for 10 days
- Unable to breastfeed
- Dealt with motor and speech delays
- Eye surgery at 10 months old
- I went through major mom guilt!
- PFP training helped understand how to process these experiences and use them to teach others
- If you want to work with patients you have to start with patients

MW



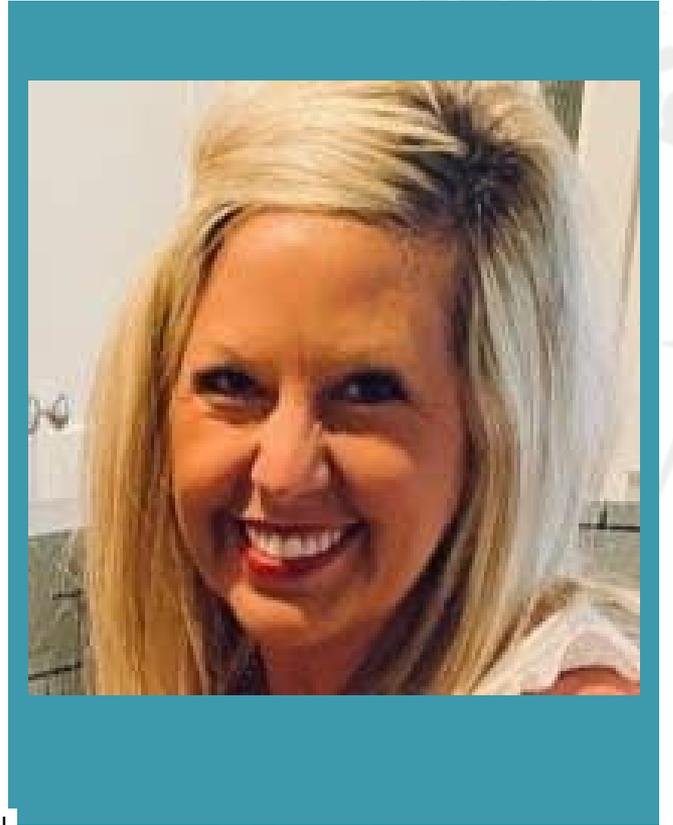
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Bekah Bischoff

Bekah Bischoff serves as the Patient Family Partner Coordinator for the MoMMA's Voices Coalition, assisting patients and family members going through the online training to prepare them for working with individual providers or organizations on maternal health process improvement.

Following her own near-death experience and postpartum recovery with the birth of her second child due to severe preeclampsia and HELLP syndrome, Bekah is passionate about helping moms identify and heal from their traumatic birth experiences. She recognizes the importance of sitting beside each hurting mother in the isolation that comes with pregnancy trauma. Her work centers on helping empower these women to transform their pain to purpose.

In 2018, she collaborated with the Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN) for legislative policy work, where she learned how much she loved meeting with policymakers to advocate for maternal health legislation and to ensure mothers are given a seat at the table. She specializes in storytelling for advocacy. She enjoys using her years of professional experience as an educator to help teach mothers how to effectively share their story to implement change through the MoMMA's Voices Lived Experience Integration™ framework.



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The Scariest Day of My Life

Bekah Bischoff



Bekah's Story

- Debilitating heartburn
- Excessive weight gain, despite not eating
- Upper right quadrant pain
- Extreme Fatigue
- Headaches
- Fluid loss
- Seeing stars
- Summary: Dismissal. I was almost a statistic
I never knew was a possibility



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Learning to Live with a Lived Experience

- Learned this wasn't rare after USA Today's Investigation "Deadly Deliveries" in 2018
- Sharing with legislators
- Found my voice and passion for the pain
- Hearing from mothers every day helping them identify and heal
- [Merck for Mothers "Reverse" on Vimeo](#)



References

Creigh, S. (Director), & Salamone, R. (Producer). (2019). Merck for Mothers: "Reverse" [Film]. Florence fka Whitelist.



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Quantrilla Ard

Quantrilla is an author, speaker, maternal health advocate and patient family partner based in the Atlanta area. She holds a PhD in Health Psychology and a Masters in Public Health. She uses her platform to educate and inform non-minority groups of all sizes and in various media outlets on the perils of negative birth outcomes for Black women and their infants who suffer mortality rates 3 to 4 times their White counterparts. She specifically advocates for women of color to be empowered to advocate for themselves and gain bodily autonomy before, during, and after pregnancy. Her passion comes out of her own personal birth experience in which she developed severe preeclampsia during her first pregnancy. During an emergency cesarean, she felt herself being cut open after repeated complaints of discomfort had been dismissed. This trauma coupled with a life-threatening illness proved to be a significant challenge to overcome, but in doing so it became a source of motivation and purpose. It is her goal to empower Black and Brown mamas to speak up and speak out during and about their birthing experiences. She believes that every mother deserves to be heard and treated with equitable care.



My Survival Story

A Journey of Missed Opportunities and Near Misses

MV



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My Birth Experience

- Feeling of dread/unease
- No typical signs for concern (no swelling, vision disturbances, headaches, etc.)
- High blood pressure detected at prenatal visit almost 2 weeks later
- Drove from doctor's office to the hospital *after* preeclampsia diagnosis
- Induction, stalled delivery, epidural resulting in emergency cesarean
- Teased for “sensitivity” told it was just pressure not pain
- Insufficient communication and dismissal of pain, c-section incision felt like searing hot knife
- Traumatizing recovery with subsequent hospital and NICU stays



Why is this Important?

- Black mamas and birthing people need platforms to have their voices heard platforms such as Momma's Voices allow for our stories to be told, front and center
- Black women are disproportionately affected by adverse perinatal events, morbidity, and mortality
- Patient-centered care respects individual nuances often overlooked due to cultural differences and provider bias
- Political agendas drive and influence budgets and dollars allocated. Eliminating disparities in perinatal outcomes and systems change involves budgetary support.
- Storytelling can be used as a means of resistance to racist stereotypes and medical narratives that drive negative birth outcomes.



Thank you!

Any questions?

MV



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