



Once Upon A Premie Inc.  
Black Maternal Health and Neonatal Equity  
Conference: Parents, Practitioners, Policies,  
and Solutions  
November 17, 2023

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## HOST



**Jenné Johns, MPH**, is a national health equity thought leader, author and advocate for reducing healthcare disparities. While advocating for the needs of her own son, Jenné wrote, “Once Upon a Premie”, the first of its kind children’s book written for parents of preemies while in the NICU. A graduate of the Disparities Leadership Program at Harvard University Medical School, Jenné has over a decade of experience advocating for policy, and community changes to improve health equity and health outcomes for low-income communities. She also led quality improvement and health equity transformation strategies with the nation's largest health insurance companies. Jenné is President of Once Upon A Premie, Inc. and Founder of Once Upon A Premie Academy, the first and only virtual training academy focused on delivering health and racial equity educational programs for perinatal and neonatal healthcare professionals.

# KEYNOTE SPEAKER



## **Charles Johnson, founder 4Kira4moms**

**A Family's Perspective**, has suffered an unimaginable tragedy that strikes too many families – and has made it his life's mission to save others from the same fate.

In April 2016 Charles' healthy and full-of-life wife, Kira, gave birth to their second beautiful child. But Kira immediately began struggling in ways that the hospital staff could not explain, even as Charles watched and implored the staff that something was horribly wrong. Kira died within hours.

Charles was understandably overcome by grief – grief that turned into outrage. He channeled his pain and his passion into founding a nonprofit, 4Kira4Moms, that is dedicated to changing systems to better prevent birth-related deaths. 4Kira4Moms advocates for improved maternal health policies and regulations; educates the public about the impact of maternal mortality in communities; provides peer support to victims' family and friends; and promotes discussion of maternal mortality as a human rights issue.

Charles has shared his story and advocated for change through countless live events and media appearances all over the country, including at the March for Moms rally in Washington, D.C., last year. Last September he testified before the U.S. House Energy and Commerce Subcommittee on Health about the need to pass the Preventing Maternal Deaths Act of 2017 – which, as you know, was indeed passed by Congress and signed into law.

When he is not advocating to improve maternal health practices, Charles is busy raising his two sons, Charles V and Langston.

## SPEAKER BIOS



**Dr. Ndidiamaka Amutah-Onukagha PhD, MPH, CHES** is the Julia A. Okoro Professor of Black Maternal Health in the Department of Public Health and Community Medicine at Tufts University School of Medicine. Founder and Director of the Center of Black Maternal Health and Reproductive Justice, and the Maternal Outcomes for Translational Health Equity Research (MOTHER) Lab, Dr. Amutah-Onukagha's research investigates maternal health disparities, reproductive health and social justice, and HIV/AIDS as experienced by Black women. Her work has been presented in 45 manuscripts, 5 book chapters, a best-selling book on Amazon, a textbook on culturally responsive evaluation, and has been featured across media platforms including The Lancet, TEDx, USA Today, and MSNBC. Currently, she is Principal Investigator of two multi-year studies on maternal mortality and morbidity, an R01 funded by National Institutes of Health and an interdisciplinary grant on health equity funded by the Robert Wood Johnson Foundation.

Dr. Amutah-Onukagha lives in Massachusetts with her husband and two sons.



**Alexia Doumbouya, Founder and President of Cocolife.black,** holds a Master's degree in Organizational Leadership and is certified in Mental Health Awareness and as a Postpartum Doula. Alexia has appeared on various domestic and international platforms like iHeart Media; and quoted by CNN and the CDC, to name a few. She is a change-maker and leading voice on social determinants of health. As a collaborator, Alexia communicates effectively across differences. She offers specialized training for birth workers, doulas, midwives, and medical practitioners. She is an unwavering advocate for healthy babies during the critical first months to five years of life. Alexia empowers mothers and plans healthy solutions with them, not for them. She also launched International Coco Mom Day, making her cause global.



**Dr. Angela M. Patterson, MD FAAP**, received her B.A. from Wake Forest University, her M.D. at Howard University College of Medicine, and completed her Pediatric Residency Training and Neonatal Fellowship at the University of Maryland Medical Systems. She is double board certified in Perinatal/Neonatal Medicine and General Pediatrics.

Dr. Patterson was also a pioneer in IV Catheter Simulation Training in 1998, where she provided the neonatal and pediatric expert content for the software. Dr. Patterson also developed a proprietary formula for her water beverage brand Saphia™, which was sold both in the US and internationally.

Dr. Patterson worked 10 years at MedStar Washington Hospital Center before leaving in 2010, to join her family and husband on an overseas appointment with the US government in Tunisia, North Africa. There, she provided medical services and consultation to the US Embassy in Tunis, even organizing a Tunisian NICU team to travel to the US for a 2-week training session on ECMO, only to be cancelled due to the Arab Spring revolution! Dr. Patterson additionally spent 2 years in Dubai UAE where she was involved in medical activities.

Dr. Angela M. Patterson, MD FAAP, is an Attending Neonatologist with MedStar Georgetown University Hospital (MGUH) and MedStar Montgomery Medical Center (MMMC), and an Assistant Professor with Georgetown University School of Medicine (GUSM).

She is involved in numerous committees at MGUH, MMMC, and GUSM, most notably Cura Personalis, MedStar Health Academic Affairs Working Group on Racial Justice - Wellness and Responsiveness Subcommittee, Pediatric Racial Injustice: Bias Committee, Pediatric 3rd Year Nursery Rotation Instructor, MedStar COVID Vaccine Ambassador, to name a few.

Dr. Patterson is named "Top Doctors 2023" Bethesda Magazine in Neonatal and Perinatal Medicine. She was nominated in 2022 and 2023 as Physician of the Year at MedStar Montgomery Medical Center.

Dr. Patterson serves on the Board of Directors for the National Perinatal Association, and an active member of Once Upon A Premie, National Medical Association, and American Academy of Pediatrics.

Recent publications include "Call to Action: RSV is a Serious Concern. A National Response is Urgently Needed" in the National Perinatal Association Newsletter Nov.2022 and Parents Magazine contributor "What Dealing With Fetal Growth Restriction Was Like" Jan 2023

Dr. Patterson is married with a daughter and a son. Her interests include travel, swimming, and Bollywood dancing.



**Aza Nedhari, LM, CPM, MS, Executive Director, Mamatoto Village Inc.** brings more than 18 years of experience in community organizing, reproductive justice, and program development. She is a mother, licensed Certified Professional Midwife, Family Counselor, and the Co-founding Executive Director of Mamatoto Village. Aza is a fiercely dedicated woman who believes that by promoting a framework of justice, the reduction of barriers in maternal and child health begins to dissipate; giving rise to healthy individuals, healthy families, and healthy communities. Aza is pursuing her Doctorate in Human Services with a concentration in Organizational Leadership and Management with an eye towards the sustainability of Black led-organizations and cultivating innovative models of perinatal care delivery and workforce development.



**Deb Discenza** is a huge advocate for all things patient families in and out of the NICU. As the mother to a 30-weeker, now 20 years old and multiply disabled, she sees the need to support families where they are at directly and equally. As the co-author of *The Premie Parent's Survival Guide to the NICU* and the Founder of PremieWorld, she sees equality in the form of patient education. In 2020, in Unity, she joined Ashley Randolph as a Co-Founder of the Alliance for Black NICU Families. The non-profit seeks racial and health equity in our space by breaking down barriers to access and equality through patient education, certifications and family assistance grants. Their inaugural program, a wearable breast pump program, is in its second year and extremely successful. Deb sits on boards and committees and writes for several publications in the space.



**Deborah A. Hoy, MD, MDIV** is an attending neonatologist and Associate Professor of Pediatrics in the Level IV NICU at MedStar Georgetown University Hospital. She cares for critically ill preterm and term newborns along with their parents. She also serves as the Medical Director for Neonatal Transport as well as the Neonatal Medical Director of MedStar Transport. Our mobile NICU includes the ability to offer all methods of respiratory support including high frequency ventilation as well as the ability to initiate whole body cooling for HIE.'

She also continues to follow the former neonatal patients in the Neonatal Follow up Clinic. The babies and their parents are supported during the transition from the NICU/SCN to home over the subsequent 12 to 18 months with their primary care providers. Their clinical and developmental status is closely monitored to allow for earlier intervention as necessary with the goal to maximize their long term potential and hopefully minimize re-hospitalization and emergency room visits. The follow up clinic also does collaborative care with all pediatric surgeons and subspecialists.

Dr. Hoy participates with the Pediatric DEI committee at Medstar Georgetown. She has presented Racism in the NICU to the Division on Neonatal-Perinatal Medicine and the Department of Pediatrics. She is working with Neonatal Fellow to evaluate the effectiveness of DEI training in the NICU among all staff evaluate any significant changes after the education through use of Simulation.

She participates in teaching medical and nursing students, residents, and fellows. Simulation is an absolute interest of hers. She works with teams to help keep them ready to respond to emergencies, and keep their skills honed for providing even better and equitable care. She is an Instructor Mentor for NRP, a lead Instructor for STABLE and part of MedStar Neonatal Simulation Training team.



**Dr. Diana Montoya Williams** is a neonatologist at the Children’s Hospital of Philadelphia (CHOP), a physician scientist in CHOP’s PolicyLab and an assistant professor of Pediatrics in the University of Pennsylvania’s Perelman School of Medicine. In addition to taking care of infants in the ICU, Dr. Montoya-Williams researches racial and ethnic inequities in maternal and infant health outcomes, including a focus on immigrant birth outcomes. She also has a special interest in promoting anti-racism efforts in medicine.



**State Representative Gina H. Curry** was elected in a November 2021 special election to represent the 164th Legislative District in Delaware County. Representative Curry serves on several committees & Caucuses including but not limited to: Appropriations, Children & Youth, Education, Transportation, Pennsylvania Legislative Black Caucus, Southeast Delegation, PA Women’s Commission and, Co-Chair of the Women’s Health Caucus.

Prior to being elected state representative, Gina worked as a Diversity Equity and Inclusion/Racial Equity consultant and trainer, as a small business owner of Coach Your Vision LLC, and diligently served in many community-based roles including serving as vice president of the Upper Darby School Board. She brings to Harrisburg a strong understanding of community needs, fairness and grassroots advocacy in education, women’s health, and real estate/housing.

She received her bachelor’s and master’s degrees in Criminal Justice with a concentration on Sociology from St. Joseph’s University. She also has experience in the behavioral health field as a clinical supervisor, behavioral specialist, and therapeutic consultant to children and families.



**Jatesha "Jaye" Madden-Wilson** is a Black Woman, Mom, Social Entrepreneur, Social Impact Speaker, Maternal Health Advocate, Published Author and Self-sufficiency Coach. Jaye has created big strides in advocacy for women of color most notably with the First Lady and Governor of New Jersey as a public speaker and maternal health advocate for Nurture NJ with the Black Maternal Health crisis. In her professional career as a Community Health Nurse, she provided clinical care and moved into clinical operations as the Nursing Operational Manager for Callen-Lorde Community Health Center, a Federally-Qualified Health Center (FQHC) that specializes in providing care for the LGBTQ+ community.

Jaye received her first opportunity in advocacy while at Callen Lorde and began lobbying in Washington DC, Albany NY and Trenton, NJ as a community advocate for the LGBTQ+ community. While in these positions, she saw the importance of how community advocacy and engagement created better physical, emotional and mental health outcomes for its people.

After 10+ years at Callen-Lorde, Jaye went through several transitions, both personally and professionally, which sparked the idea of creating a community of support that changed the narrative of motherhood, sisterhood and womanhood. Starting as a small mommy meetup group, Melinated Moms quickly grew into a health equity-focused women empowerment organization that changed the way community engagement related to maternal health. As her organization has grown, she has incorporated the additional titles of published author, and she was recently appointed by the Governor of New Jersey as a Special State Officer for the New Jersey Maternal Health Quality Collaborative.





**Joanne Craig, MS, Chief Impact Officer for The Foundation for Delaware County**, has many years' experience developing and administering supportive family health programs. She has been recognized with a range of distinctions for her work, the Athena Leadership Award, and March of Dimes, Woman of Achievement for Health Equity, among others.

Joanne founded the women and children's services for the former Crozer-Keystone Health System. She acquired a highly competitive and prestigious federal Healthy Start grant. Since the Healthy Start program in Delaware County began, the infant mortality and morbidity (IMMR) rate in the service area declined from 23 infant deaths per 1000 live births, to the current rate of 14/1000.

Joanne's success in delivering supportive services toward reducing the disparity in Black infant mortality and morbidity rates and improving maternal and birth outcomes in the Chester community, led to establishing Nurse-Family Partnership in Delaware County. Joanne has built on this mission by adding numerous programs, such as, Medical-Legal Partnership, the Housing Opportunities Program for Equity (HOPE), Cribs for Kids, Storks Nest, and El Centro.

Joanne's leadership has led work that has impacted tens of thousands of families in Delaware County. She is considered a thought leader and actively advocates for maternal and child health services, racial equity, policy changes and funding across Pennsylvania. Joanne is serving a second term on the Pennsylvania Maternal Mortality Review Committee; she has been appointed a co-chair. She participates in local, statewide, and national coalitions. Joanne is an active member of area advisory committees and boards.



**Julian Nixon** is an award-winning STEM educator, speaker, diversity leader, thought leader, and NICU dad. He has engaged listeners and learners through TEDx stages, radio shows, national conferences, universities, and more. His impressive years of experience have allowed him to walk in the shoes of a college professor, community leader, children's hospital council member, diversity leader, author, and advocate. His hard work doesn't stop there. Mr. Nixon spends his off-hours writing his dissertation and enjoying time with his wife and daughter. He is currently the Director of Diversity & Inclusion for the College of Agriculture, Forestry & Life Sciences at Clemson University.



**Kanika Harris, PhD, MPH** currently serves as the senior director of maternal health for the Black Women's Health Imperative. She is a behavioral health scientist, with a special focus on health equity, maternal health and women's health. She is a mother of 3, near miss survivor, doula, and birth justice advocate. She also serves as the Maternal Health Equity Advisor for the State of Maryland and the public health expert for the lactation commission in Washington DC.

She received her master's degree in public health and international development from Morehouse School of Medicine and her PhD in Health Behavior and Health Education from the University of Michigan.



**Nastassia K. Harris DNP, MSN, RNC-MNN, IBCLC** is a registered nurse, International board certified lactation consultant (IBCLC), and a mother of 4. New Jersey. She has over 19 years of experience working with birthing & lactating families. Nastassia is passionate about improving access to qualified lactation professionals and improving breastfeeding rates in the Black community.

Nastassia founded The Perinatal Health Equity Initiative in 2018, a non-profit advocacy and support organization dedicated to eliminating racial disparities in Black infant and maternal health using a reproductive Justice lens.. Her most recent venture, Ignite Maternal Health is a consulting and education firm focused on postpartum and newborn nursing and care where she will use her background in academia to provide education at the community level.

A lifelong learner, Nastassia has a BSN, MSN-ED, a DNP in educational leadership, and is certified in maternal newborn nursing. Nastassia is an instructor in the Gold Lactation 90 hour breastfeeding course. Additionally, She is active in several committees and organizations including the Jegna council with the Robert Wood Johnson Foundation, The Association of Women's Health Obstetrics and Neonatal Nursing, the Black Mamas Matter Alliance and Black Breastfeeding Week.

Nastassia's research and clinical interest include implicit bias/racism in healthcare, breastfeeding in the black community, obstetrical violence, high risk OB, and reproductive justice.



**Niesha D. Darden** is a multi-faceted individual, embodying a range of expertise in her various roles as a mother, clinical research coordinator, postpartum doula, maternal-child health research consultant, and perinatal health advocate. Her experiences as a mother have deepened her understanding and compassion in her professional roles, guiding her commitment to supporting families throughout their unique journeys.

Professionally, Niesha plays a pivotal role managing and contributing to grant funded research studies in the Intensive Care Nursery (ICN) at the Hospital of the University of Pennsylvania and in the Neonatal Intensive Care Unit (NICU) at the Children's Hospital of Philadelphia. As a clinical research coordinator and professionally trained postpartum doula, she facilitates and manages research projects focused on advancing maternal health in neonatal spaces and improving outcomes for premature infants and their families. Her compassionate and knowledgeable approach offers much-needed comfort and guidance to families navigating the complexities of premature birth and postpartum health.

Beyond her work in the NICU, Niesha is recognized for her expertise as a maternal-child health research consultant and perinatal health advocate. Through her consultation services, she provides invaluable insights and evidence-based solutions to various projects and initiatives, with a focus to improve maternal and child health outcomes. Her research and advocacy work involves raising awareness about important issues and championing policies within healthcare systems that support the well-being of families in Philadelphia.

With her diverse skill set and unwavering dedication, Niesha exemplifies a passion for making a positive impact both in the world of clinical research and in her community. Her holistic approach to her roles reflects a deep commitment to creating an equitable, more supportive environment that extends far beyond the realms of her expertise, leaving a lasting and positive influence on the lives of many.



**Shirley Smith**, Business Owner, Founder of a Non-profit, Author, Speaker, Mentor, Life Coach, Teacher and wife to NBA Two-Time Champion, JR Smith is a native of Newark, NJ where she was raised and had to overcome the adversities in the inner city with her single mom and two brothers.

Shirley is the proud mom of Dakota, also known as, Kota Bear, who was born a micro-premature baby (at 22 weeks & zero days. Out of this unexpected experience, My Kota Bear, Inc., a 501c3 non-profit was born, where they cater to families of the NICU (Neonatal Intensive Care Unit).

With Shirley's experiences of being raised in the inner city of Newark, work in Early Childhood Education and with her mother passing away when Shirley was 21 years old, a flame was ignited in her to uplift and give back to those around her. This created a passion within her that would center around empowering and uplifting women and girls, which allowed her to develop Dropping Jewels. This includes mentoring young girls and women, faced with adversity, guiding them to set life goals and providing them with assistance and the tools to do so, which will ultimately guide them to their life's purpose.

Despite her adversities, Shirley received her Associates Degree from Union County College in Liberal Arts and attended Cleveland State University, majoring in Urban Studies with a minor in Organizational Leadership while she resided in Cleveland, Ohio.

Shirley is, also, an active mother to Demi (11), Peyton (11), (Dakota-4) and Denver (2) Smith as well as her extended family. She continues to push herself in other avenues, such as real estate and other business ventures to come.

It is her hope to use her platform in a constructive light by making a positive impact in the world, today by continuing to serve the community and by the publishing of her new book "Mama Bear", which was released on September 14, 2021.



**Theresa Pettaway** is the Founder and Executive Director of Pettaway Pursuit Foundation. As a mother of three premature babies who experienced trauma during her pregnancies, Theresa was inspired to become a maternal and child health advocate.

In 2001, Theresa founded Pettaway Pursuit Foundation, Inc. (PPF), a non profit organization serving members in Pennsylvania, Massachusetts, and Rhode Island. Through PPF, Theresa pioneered and developed a collaboration between doulas and managed care agencies to provide doula services to the Medicaid population.

Theresa has participated in various initiatives such as Doula Town Halls and Surveys, the Pennsylvania House Democratic Policy Committee Hearing on Meaningful Solutions to Maternal Mortality - Doula Care and Coverage, and the Maternal Mortality Public Hearing as a Maternal Health stakeholder. In 2021, Theresa joined the PA Doula & Perinatal CHW Advisory Group working to create equitable access to Doulas and develop a statewide infrastructure to support the work of Doulas, Community-Based Doulas, and Perinatal CHWs.

Theresa then became a founding mother of the Pennsylvania Doula Commission (PADC) whose mission is to promote equitable access to doula services.

In 2022, Theresa was featured on 6abc Philly proud, received the HerStory Award, and testified at the House Democratic Policy Committee Hearing on the Maternity Desert in Delaware County, and answered the call on her life and started serving as a Minister at Victory Christian Center.

While her boundless love and support for her family, friends, and the maternal health community is shown through her actions, humbly she would say, "I'm just Theresa."

## EMCEE



**Lydia Seymour, B.S.** works in Philadelphia Department of Public Health's division of Maternal Child and Family Health as the Community Action Network (CAN) Coordinator. Prior to joining the health department, she worked in health management at Einstein Medical Center for over a decade. During that time, she was blessed to become a NICU mom, spawning a great passion for motherhood and advocacy around the importance of black maternal health. This passion ignited; she joined the Philadelphia CAN community as a way to share her vision for change within black maternal and infant health. She began her journey with CAN as a lived experience expert in June 2020 later becoming one of the co chairs of the CAN Chronic Conditions workgroup before assuming her current role as coordinator. When Lydia is not working, her greatest joys in life include cooking, being outdoors and spending time with her husband and two children.