Health Equity Column: Four Featured Trainings

Jenné Johns, MPH, Mitchell Goldstein, MD

Once Upon a Premie Academy has four featured trainings coming up in the next several weeks. Jenné Johns, MPH has put in an extraordinary effort in coordinating speakers and putting together these trainings. As the nation grapples with disparities on so many different levels, we must confront those issues that affect the care of babies and their parents in the NICU with special attention to issues

of health and racial equity. In this interview, Dr. Goldstein discusses the upcoming four featured trainings with Jenné Johns, MPH.

“As the nation grapples with disparities on so many different levels, we must confront those issues that affect the care of babies and their parents in the NICU with special attention to issues of health and racial equity.”

Mitchell Goldstein: Tell me about this intro that you are going to be doing on what appears to be the fifth of November about health and racial equity in the NICU.

Jenne Johns: So, to kick the academy off, I thought it would be very important to make sure we level set with definitions and standards and expectations for the lens in which information will be presented under this academy. Dr. Joia A. Crear Perry is an internationally renowned birth equity thought leader, passionate advocate, and speaker around all things racial equity for African American moms and babies. She brings an incredible perspective as a physician as an OB-GYN who practiced during Hurricane Katrina Katrina and Rita in New Orleans and helped women to seek care in the middle of A catastrophic event and then, more importantly, meeting to find some creative and innovative solutions. To help to support these moms and babies post-delivery and what I am sure was a very new world in New Orleans at that time. And so she spent a good portion of her career laser-focused on quality improvement initiatives and strategies outside of the box, to eliminate racial and ethnic disparities with preterm birth and then more recently around the infant maternal and child health crisis. She is the founder and the leader behind the birth equity movement that we are now all starting to solution around to help keep black moms and babies healthy and alive pre during and post-delivery. And hopefully, hopefully, helping to spread some nuggets of information that will help reduce the disparities associated with the NICU admissions rates as well. I will be hanging out with her in a moderator capacity. I love listening to and leaning on and learning from her and everything that she does. Now offer some insights, if you will, from a preemie parent perspective or some of the things

we will talk about the role of institutional historical discrimination and racism and how that plays out in the black parents' body and how that is helping to shape the unfortunate experiences that we are having with the infant mortality crisis and the premature crisis.

Mitchell Goldstein: So, these, these that you touched on these desperate circumstances. Hurricanes and so forth. How do you see these affecting issues of disparity? Do you see them, in fact, further worsening these problems?

Jenne Johns: Absolutely. Unfortunately, some of these historical injuries continue to recycle them, so they continue to play out in our day to day current environment. It may look and feel very similar ten years from now when we go and analyze COVID disparities and COVID-related outcome and pairing that off with pregnancy and birth outcomes and NICU admissions rates. We do not know yet. We will see. But it is these kinds of systematic and routine injustices that continue to play out in the health and healthcare environment. That we just need to call a spade a spade and solution around and move us forward as a nation; our babies and our moms deserve equitable treatment and care at the end of the day.

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Mitchell Goldstein: I am going to go through the next one here. So we have talked about Dr. Perry. I know Michael Young, MD going way, way back. She is an absolute dynamo and absolutely advocate for the cause -- fantastic person; tell me your impressions about her because she is going to be talking about solutions for addressing and equities and implicit bias pre during and post NICU.

Jenne Johns: So that I couldn't agree with you more about Dr. Young is absolutely a dynamo she is newer to my radar, and I am sorry that I have not had an opportunity to work with her more closely when I was working in, you know, the insurance space, But she to me brings a unique perspective and that she is a neonatologist working in all black NICU, so she's got the secret sauce and ingredients of what her peers and counterparts may not have the opportunity to leverage or benefit from And some really leaning on her wisdom and her experiences and her thought leadership to help her peers and counterparts. Understand what may potentially be some blind spots that they can learn from her lessons if you will, and apply within their individual make you units paired off with Dr. Young will be Deirdre McDaniels; she was a NICU nurse, she doesn't have that in her bio, but she was once a NICU nurse.

She left the NICU and started to work inside the walls of the health insurance companies to influence perinatal neonatal outcomes. From a payers' lens and she had some really good experiences that she then took in applied with a few industry trade associations working on quality improvement and disparities reductions initiatives. She, too, has seen the NICU and the payer and the trade associations from three different lenses in her career and will offer us very invaluable information that we need to apply to disparities reduction and quality improvement as a marriage. All too often working in the payer space. I did not see a nice blend or a nice merge of what we are doing on the quality improvement side with what my lived experience, in reality, was on the NICU side personally or professionally, and there are some solutions. There are some tangible things. There are some low hanging fruit opportunities. There are some value-based incentive-based opportunities that I just feel are missing because the two worlds have not met in the middle yet so I'm hoping that with this do well. We'll get to some of those solutions.

Mitchell Goldstein: Have you seen the interaction between what you're doing and potentially some of the professional organizations like the NMA and the NBMA. Have you seen them have an interest in getting involved even reached up from at this point in time? I know Dr. Young has been very much involved in NMA politics, and they again seem like a likely supporter in terms of the emphasis of your initiatives.

Jenne Johns: I have not had an opportunity to reach out to NMA yet. They are on our radar; we will be continuing conversations with NBNA. NBNA again is the National Black Nurses Association, and here you have an organization that's full of black nurses. Unfortunately, there isn't a huge preponderance of those black nurses who land in the neonatal space. And so while I can have theoretical conversations within NBNA and we are, and we will continue to have those conversations, we need some of that diversity to transfer over into the neonatal space, and so it will be our continue our conversation can progress.

Mitchell Goldstein: Do you know Millicent Gorham?

Jenne Johns: Yes

Mitchell Goldstein: She is amazing.

Jenne Johns: She is another dynamo. She's another dynamo whom I look forward to engaging with the expansion of the academy in the future. We are starting to put some ideas together now.

Mitchell Goldstein: I think she could be a very, very potent advocate. She has been involved in the National Coalition for health issues, previously when we were engaged with a lot of the battles around RSV, RSV advocacy, breast milk, breast milk advocacy.

Jenne Johns: Right. She is great.

Mitchell Goldstein: Wonderful, wonderful collaborator just fantastic really on point on-spot. She is incredible -- Excellent.

Jenne Johns: Absolutely, thank you for confirming and assuring me that, you know, these two leaders, in particular, are leaders that I don't want to miss the window of opportunity to continue to engage as we expand the again.

Mitchell Goldstein: Let's go to your next PDF, and here you're bringing in Dr. Patterson and Shante Nixon to talk more about

black NICU mother's mental and emotional health pre during and post NICU. Tell me a little bit more about that particular activity.

Jenne Johns: This topic is I think, probably one of the most timely topics that we could talk about right now in our nation's current state. We are faced with two global pandemics and both that are impacting Black NICU families' experiences pre during and post NICU, and so we shouldn't shy away from the emotional and mental needs of this community. All too often, when I meet other African American NICU moms. They, like myself, did not show up with the emotional issues during that NICU stay because we were too busy trying to be strong for our babies. And some of the depression or post-traumatic stress disorder thing did not show up until a year or two years later. It is important for me to introduce this topic or further expand the knowledge that clinicians have on this topic so that they can understand how black women may or may not show up needing help during this very traumatic time in their babies lives and to not be offended if the help that's offered isn't accepted or it is not received in the way in which we, you know, clinicians think that it should be. But it is really just time again to roll up our sleeves and be transparent about what the issues are, you know, some of the stigma and some of the shame and some of the fear around just being honest, that there may be a mental and emotional issue that needs to be addressed in the African American community, let alone in the African American NICU parent community, I should say. And so we're really going to lean on some of the lived experiences and observations of Chavis at CHOP, one of the nation's largest Children's Hospital here in my hometown of Philadelphia, to unpack and uncover some of the racial differences he may see you know that he's seeing and observing and experiencing delivering psychosocial services and care to NICU families. And then Shante is going to bring them real-world experience. Unfortunately, she experienced infant loss during the NICU. And she had a bit of a traumatic journey as a black woman who lost her baby, and it was all race-based, and it was all avoidable and preventable. So we just wanted to provide some tools and some skills to help prevent and avoid other clinicians leaving thorns so that we can have more clinicians leaving families with roses because these things carry with us for a lifetime - For a lifetime.

Mitchell Goldstein: Do you have any thoughts about how to have people re-engage staff if they feel that the interventions or, for that matter, the interactions are inappropriate. And again, a lot of people talk the talk but they don't necessarily, walk the walk, and they say that they're sensitive and they say that they have measures in place. But in terms of calling that out in terms of saying, hey, you know, I am not being treated the way I should be. There is something wrong with the way you are interacting with me. How do you do that? How does a family engage that way?

Jenne Johns: Unfortunately, we do not have that making mechanism created yet, which is part of the chasm here, which is part of the challenge. A lot of families may or may not know that the patient satisfaction surveys that they have received during their stay and post-stay home hold value, but to what end I am unclear what happens with the results of those surveys, is it shows a grievance that will file based on discrimination or based on race, within the hospital. I know what happens at the payer level. I am not sure what happened at the hospital level and who's holding the hospital accountable for addressing some of those grievances or some of those issues with the staff; hopefully, with the expansion of the

academy, we can get some quality improvement collaborative going around the country where we look at ways to hold one another accountable for ensuring that the information and the tools and resources that they learn at the academy isn't a checkbox opportunity. This is not what this is really an opportunity to help move us forward with holding ourselves accountable individually and collectively as neonatology, as a neonatal community to deliver better care different here that's more sensitive and more equitable and more targeted based on the needs of the populations we are serving

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Mitchell Goldstein: I agree, moving forward. It is just so important in terms of getting to a better place.

Jenne Johns: And together we spend together, we can do this. I do not think this is as difficult to work as people think it is. I mean, I have lived in this space for about a decade of my career a little longer and have a starting place, and I am hoping that if any professional shows up to train people without knowing where to start. They can at least count this training as their official [training].

Mitchell Goldstein: Let me talk to you about the last PDF in the collection. I think it's the last one, and this is the black preemie parents as partners in preemie care. And this one I think, is most compelling. It really gets down to what is important.

Jenne Johns: Thank you. Thank you. I think this is gonna be a pretty compelling training session as well. I'm excited to have her. Oh, my goodness. Another dynamo is Dr. Terry Major Kincaid. She is a neonatologist and board-certified pediatrician practicing in two NICUs in two states, and she sees a lot. She is experienced a lot, and most importantly, she does the hard work right at the unit and the patient at the unit and practice level to ensure that patients are not isolated. That the parents have been making families and babies are integrated and included in the delivery of the care for the baby. By doing so, she is helping to remove and reduce stigma and fear, and other issues surrounding black families in the NICU. Partnered off with Dr. Major Kincaid is Ashley Randolph of Glo preemies, who is an up and coming, you know, rising leader -- a preemie parent leader in the preemie parents space. She has developed a host of programs and support resources and services to equip and empower parents to be their child's best advocate. And to be a part of planning and decision making tables with new strategies with new programs when new services are being delivered to roll out in the NICU. And so, I am really thankful and appreciative to have both of them because they sit, of course, in two different spaces and then the NICU but to have valid tools and

resources and experiences to leave our population with and all too often, I think for us as professionals. We want to create solutions, right. We want to do what's best for the population that is struggling and the population that is vulnerable whose outcomes are just not moving at all. But we have to ask ourselves as professionals. How often do we simply stop and ask the population that we're attempting to serve what their recommendation or solutions are? And this is what I hope to accomplish with this training session.

Mitchell Goldstein: This sounds amazing. These are all wonderful symposia. I just want to emphasize and underscore the fact that we're really excited about having this collaboration with NT, and I think that it is going to really pay off dividends in terms of getting people to hear your message and to draw people to what you are trying to do because I think it is definitely going in the right direction, and definitely, something that we need so much more of to get to a better place.

Jenne Johns: Thank you. Thank you. This has been on my heart and in my mind for four years now. And although I didn't see it happening virtually, you know, I really saw this being a big major national conference. I'm excited about the opportunity, and I cannot thank you enough, Dr. Goldstein, for taking a chance on me. I'm not a clinician, you know, don't have an MD or in my name, and will never, but I think in acknowledging appreciate you for taking a chance on me

Mitchell Goldstein: What you have is a lot more; it is passion: the passion for doing something. And for making something right and for really showing us, you know what it is that we need to do to get to that better place; It means more than just about any degree. So you should be proud of what you do, never feel that you have to apologize for not having the right initials after your name. It does not matter to me. You are eloquent; you have an extremely devoted cause. And again, anything that I, or we, can do as Neonatology Today, we will always be in your corner.

Jenne Johns: [hears babies, crying in the background at Dr. Goldstein's NICU] Oh, I hear cries in the background, my goodness, I just got a tickle in my belly. We thank you so much, Dr. Goldstein, we have about we have 147 people registered already. I was hoping for 25

Mitchell Goldstein: So let's double that. Let's hope we get to 300.

Jenne Johns: Let's do it.

Mitchell Goldstein: And then we'll do a post symposia afterward, but again, I am really devoted to trying to get this to be a monthly because I want this in front of people all the time. I want to make sure that they see it that they understand it and they know where you're coming from and that they recognize the importance of it.

Jenne Johns: We will have four powerful articles out of the training, definitely.

Jenne Johns: A kind of end of year reflection of it all is what I'm hoping to get for you for the December issue, but thank you again. Dr. Goldstein. I really appreciate your hand in partnership.

Mitchell Goldstein: Pleasure is mine. And we will be in touch, of course.

Jenne Johns: Thank you.

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Respiratory Syncytial Virus:

How you can advocate for babies this RSV season

Track national data and trends at the CDC's website
www.cdc.gov/rsv

Identify babies at greatest risk

including those with CLD, BPD, CF, and heart conditions

Teach families how to protect

their babies from respiratory infections

Advocate for insurance coverage for palivizumab prophylaxis so more babies can be protected *

Use your best clinical judgement

when prescribing RSV prophylaxis

Tell insurers what families need

and provide the supporting evidence

National Perinatal Association

*See the NPA's evidence-based guidelines at
www.nationalperinatal.org/rsv