



National Premature Infant Health Coalition Annual Meeting Summary

I was honored to be able to attend the inaugural meeting for the National Premature Infant Health Coalition this week. I went as a representative for the Mississippi Perinatal Association and for our nonprofit, the Zoe Rose Memorial Foundation. This is an effort to revitalize a coalition that was formed in 2005 by over two dozen stakeholders in maternal and child health. The original group was formed with a grant from MedImmune and was successful in doing a physician “gap” analysis to identify educational needs of parents affected by prematurity as well as producing a wonderful NICU journal for parents, now available for print. This NICU journal is far superior to any other I have seen personally up to this point. You can read more about their accomplishments on the [NPIHC](#) website.

The AAP originally handled the administrative duties of the coalition and thanks to a recent grant from the AAP, [National Healthy Mothers, Healthy Babies Coalition](#) is now leading the effort. The attendees at the meeting covered a wide array of professionals and parents working towards healthier pregnancies, better birthing outcomes, and support for families with premature babies. These organizations included, but were not limited to, the American College of Nurse-Midwives, [Mothers of Super Twins](#), Mothers & Babies Perinatal Network, March of Dimes, [PremieWorld LLC](#), MedImmune, US Dept of Health and Human Services, Premies Today, American Optometric Assoc., National Assoc of Pediatric Nurse Practitioners, National Perinatal Assoc., First Candle/SIDS Alliance, Infant Massage USA, and a number of hospitals and universities across the country. It was an educated, passionate group to say the least and I was thrilled to be a part of it.

As this was the Coalition’s first organizational meeting there was discussion about what the official name of the Coalition will be, and how we will organize and communicate. We also listened to a wonderful presentation by Mary Harris, PhD, RD of Colorado State University who specializes in Prematurity Prevention & Nutritional Science and whose current studies are showing how important the intake of Omega-3 fish oils are for decreasing the incidence of preterm birth. She also stated that there is accumulating evidence that Vitamin D may be protective against preeclampsia, the most common cause of preterm birth. Vitamin D is a very common deficiency among pregnant women, an estimated 50% of pregnant women in the US have such a deficiency. Very interesting research to say the least! She also discussed the importance of proper weight gain throughout pregnancy and how being underweight and overweight is associated with an increased risk of preterm birth.

We also heard from Sharon Chesna, MPA, of Mothers & Babies Perinatal Network in New York. Sharon is the past president of the National Perinatal Association and will be speaking at our MPA conference in July. She and Liz Shawen from the Florida Alliance for Healthy Babies shared strategies that have worked to make their regional networks successful both for parents and in affecting legislative change.



We also learned of a website developed by MedImmune, called [Premie Voices](#), which is a compilation of current legislation that impacts the care of premature infants. It also has a free advocacy tool kit that is in pdf form and can be downloaded. This tool kit is chock full of great information with everything from prematurity statistics in the US, to working with insurance companies, to advocating your cause through the media, and working with elected officials. This is a wonderful, "must have" resource for anyone who has anything to do with advocating for preemies and their parents.

Coming from the perspective of a parent I presented the following points to Judy Meehan, the Executive Director at Healthy Mothers, Healthy Babies. She noted that I will be receiving a survey to complete that would allow me to add my points to the general list of items the Coalition hopes to focus on. She also noted that the Coalition has limited funding and limited staff (don't we all!) and so the decision on whether or not the group would create original materials or simply endorse other materials is unclear at the moment. I will continue to update our Board on the progress of the Coalition and welcome anyone to contact me with additional ideas that would be pertinent on a national level.

My comments were as follows:

1. As a parent, I was encouraged to see such a diverse group of organizations that have been pulled together for the coalition. I would like to see more parents either as part of the coalition or maybe as an "advisory committee" of some sort. Since it is the parents who will ultimately be the "end user" of any education or materials the coalition produces, it makes sense that having input from parents on the front end would be beneficial.
2. Also, as a parent, one of the things I found most challenging was having access to resources. There are so many wonderful organizations doing wonderful things for families of premature infants and yet a recurring theme I here from other parents (and felt myself) is "I wish I would have known about that when I was in the NICU instead of afterwards." As you know, being in the NICU and then caring for a medically fragile infant at home is an intensely stressful situation and when you are as overwhelmed as many of these parents are (and possibly suffering from post traumatic stress or depression) it can be difficult to find the time to seek out the resources.
3. There are also a lot of small groups around the country, support groups for NICU parents created by former NICU parents. These groups are very grass roots, often having golf tournaments or silent auctions as their main source of fund raising. These parents are "in the trenches" if you will and I am wondering if there is a way to create a support system for these support group leaders? These parents have so much influence on the local families they support, in fact, most of the information that I got from parents I found to be the most useful (i.e. tips for feeding issues with infants, tips for dealing with sensory processing disorder, tips for organizing all our medical documents or charting feedings, etc.). Especially, when parents don't feel that their physicians are their partners they turn to other parents for support and advice. At the meeting it was said that we are stronger as a group than on our own and I think the same would hold true for these support groups as well if there was a way



to bring THEM together and have resources and information made available for them to disseminate.

4. End of life care - unfortunately, I am a parent who has lost a child while in the PICU. Being in that situation is surreal and there are so many things I wish I would have asked or known about as I spent my last hours with Zoe after she died. I have found in speaking with other parents across the country that there is a huge range in "standards of care" for parents when they lose a child. All I left the hospital with was a lock of hair, a couple of foot and hand prints, and an empty stroller. I had to ask to give Zoe a final bath. This was something that was suggested to me by a friend who was with me at the time, not something that was offered by the medical staff at the hospital, nor was it something in my shocked and grief stricken mind I would have thought to do. Whereas another friend of mine who lost a baby while in the PICU at a different hospital spent the entire day with her son after he died. They had pictures taken by a photographer from "Now I Lay Me Down to Sleep", they have molds of his hands and feet, they gave him a bath, and a host of other things. Her hospital followed up with her a week, two weeks, a month, three months, six months, nine months, a year, and so on to see how she was doing, to make sure she was receiving some sort of grief counseling, etc. Our hospital did none of that. So I'm wondering if our coalition can provide suggested guidelines for end of life care and support for the family after the child dies.

5. Transitioning home from the NICU - this is where our organization wants to focus our efforts because there is such a huge gap in services and support after you leave the bubble of the NICU. Maybe there is something being developed already, as I heard some discussion of discharge standards of care at the meeting. At any rate, this is an area I am very passionate about and would love to be a part of any kind of committee that may be working towards closing that gap.

Respectfully submitted,

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