

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Caribbean Women's Health Association**

May 13, 2010
Brooklyn, New York

IN ATTENDANCE

- Brenda Henderson – CHW Brookdale
- Karen Trench – CHW Brookdale
- Aeisha Minott – CHW Brookdale
- Dionn Durant – March of Dimes
- Agatha Hall
- Shoshana Brown – Caribbean Women’s Health Assoc. – sbrown@cwha.org
- Latonia Coryatt – Caribbean Women’s Health Assoc. – lcoryatt@cwha.org
- Marta Reid – Caribbean Women’s Health Assoc. – mreid@cwha.org
- Crystal Venable – Caribbean Women’s Health Assoc. – cmtv@verizon.net
- Cathleen Freemantle – Brooklyn Perinatal Network – cfreemantle@bpnetwork.org
- B. Elie – DOHMH Lead Poisoning
- S. Madyun – Brookdale Healthy Families
- M. Castro – Brookdale Healthy Families
- Natalie S. – Brookdale Hospital
- K. Viswanathe – Brookdale Hospital
- Erin White – Association of Perinatal Networks, Program Coordinator – ewhite@associationofperinatalnetworks.org

MEETING NOTES

Below is an overview of key messages and comments during the meeting.

- ***APN and New York State PIHN Presentation*** - Erin White, APN Program Coordinator
 - ∴ The Association of Perinatal Networks (APN) is an umbrella organization to the 18 regional perinatal networks. The APN focuses its efforts on statewide issues and supporting the week of each of the 18 individual Networks.
 - ∴ The local Networks strive to make positive change in health outcomes for women, infants and families. The Networks cover different areas of the state and programs vary, however the ultimate goal of improving maternal-child health is the same for all Networks.
 - ∴ The NYS Premature Infant Health Network (PIHN) began in 2007. Meetings were held in both Albany and New York City. In 2010, the PIHN transitioned to the Association of Perinatal Networks (APN). Over the next year, APN will hold 20 PIHN meetings throughout New York State.
 - ∴ The PIHN brings together community and health organizations, healthcare providers and parents to increase quality healthcare access and awareness around premature infant issues faced both in the NICU and when care begins at home.
 - ∴ The APN wants to be a sounding board to discuss issues of prematurity, we want to compare and contrast available services for families and caregivers of premature infants and we want to bring the issue of prematurity to the forefront in NYS.

∴ PIHN Objectives:

- Put a spotlight on the ongoing unique health and developmental issues premature infants and their caregivers face.
- Increase health care access for the ongoing care of premature infants.
- Raise awareness and create better standards for the ongoing care and needs of premature infants and their families/caregivers.

∴ 2010 PIHN Action Steps:

- Assess the needs of families with premature infants and children.
- Identify the availability (or lack) of medical providers and other services within local communities.
- Determine how NYS can better assist providers in serving families with premature infants and children.
- Create a NYS agenda to deal with issues that are faced by parents and caregivers of premature infants.

○ *Roundtable Discussion on Issues/Needs*

- It is important to encourage parents to talk to NICU doctors and ask questions.
- Educating parents on what to ask in the NICU, how to advocate for their child, health conditions, etc. is helpful in surviving the NICU journey.
- Breastfeeding should be encouraged in NICU's.
- Important for parents to interact with their baby while in the NICU: Talk to, read to, touch, feed, etc.
- Can be a challenge to receive coverage of RSV shot, particularly in the second year.
- Parents are unsure of how to access Early Intervention services; education on this in the NICU and by pediatricians is key.
- Support groups to link preemie parents with each other is a need that is not being met.
- Mothers go through an emotional rollercoaster: scared, feel guilt for not carrying baby full-term, overwhelmed, etc.
- Accessing transportation to get to and from the hospital and different appointments after discharge can be very costly to families.
- Parents need guidance on where to access services in their community.

○ *Next Steps*

- ∴ Conduct Premature Infant Health Network meetings throughout NYS and facilitate sharing and support for caregivers and parents of premature infants.
- ∴ Communicate resources and findings to meeting attendees.
- ∴ Use information gathered from meetings to create a report for prematurity issues throughout NYS.