

**NEW YORK PREMATURE INFANT  
HEALTH NETWORK**

**Association of Perinatal Networks  
The Bronx Health Link**

October 8, 2010  
Bronx, New York

## IN ATTENDANCE

- Jean Haris Persuad – Bronx Library System
- Colette Sturgis – Urban Health Plan
- Michele Downer – Urban Health Plan
- Lisa White – Bronx Lebanon Hospital
- Sandra Asanjarani – North Bronx Health Care Network/Jacobi Medical Center
- Rita Cordova – The Bronx Health Link – [rcordova@bronxhealthlink.org](mailto:rcordova@bronxhealthlink.org)
- Luisa Solis – The Bronx Health Link – [lsolis@bronxhealthlink.org](mailto:lsolis@bronxhealthlink.org)
- Erin White – Association of Perinatal Networks, Program Coordinator – [ewhite@associationofperinatalnetworks.org](mailto: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***
- ∴ *NICU Experience:*
- While in the NICU, the process is both emotional and overwhelming for parents.
  - It is important to encourage parent(s) to be involved in the care of their baby while in the NICU – Promote Attachment/Kangaroo Care.
  - Important for NICU's to promote breastfeeding both in the NICU and at home.
  - Difficult for parent(s) to balance home life and visiting NICU and also very difficult to leave baby in the NICU.
  - Important for NICU staff and parent(s) to celebrate achievements, even small ones, during stay.
  - Follow-up from NICU, i.e. phone call, would help parent(s) in transition to home.
  - Discharge planning should begin shortly after admittance in NICU takes place.
  - Additional costs such as transportation to get to and from NICU, parking, food and daycare can cause a major burden on NICU families.
- ∴ *Support For families:*
- Parents are unaware of what support services are available. A service directory would be helpful for both parents and providers. Something like this would also encourage collaboration between the different disciplines.
  - Support groups to connect parents with other parents going through similar situation would be useful. .
  - Increased communication between neonatologists, pediatricians and early intervention specialists would ensure premature infants and children received the services they needed to reduce and/or eliminate long term affects of premature birth.
  - Information on health care reform and its impact on premature infants and children would be helpful.
  - Information is needed on how to navigate the different systems, i.e. NICU, insurance, early intervention, education system, etc.

∴ *Care At Home:*

- Additional costs such as higher electric bills because of medical equipment or increasing cost of gas due to high number of doctors appointment can cause a major hardship on families.
  - Difficult to find medically sensitive daycare facilities that will accept/meet the needs of many premature infants and children.
- *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.