

**NEW YORK PREMATURE INFANT  
HEALTH NETWORK**

**Association of Perinatal Networks  
Northern Manhattan Perinatal Partnership**  
September 21, 2010  
New York, New York

## IN ATTENDANCE

- Segrid Renne – N. Manhattan Perinatal Partnership
- Peggy Regensburg – SIDS Risk Reduction
- Kayla York – SIDS Risk Reduction
- Sabrina Brown – N. Manhattan Perinatal Partnership – [sbrbrw@aol.com](mailto:sbrbrw@aol.com)
- Ekua Ansah – Samuel – N. Manhattan Perinatal Partnership – [ekuaansahsamuels@yahoo.com](mailto:ekuaansahsamuels@yahoo.com)
- Joan Edwards – Women in Need
- DC Livers – Parent of a Premie
- 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.

- ***New York State PIHN Presentation*** - Erin White, APN Program Coordinator
  - ∴ 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 for NICU staff to listen to the parents' perspective.
  - NICU's should collect narrative of parents to share with current NICU parents.
  - It is difficult for staff to know when to switch from medical care to preparing parents to go home.
  - Discharge planning should begin as soon as possible and not on the day of discharge.
  - It is important to encourage parents to be at NICU as much as possible and engage them in their baby's care.
  - Breastfeeding should be encouraged in the NICU.
  - Parents need to learn to advocate for their baby.
  - Training for parents on how to handle medical equipment, disperse medications, etc. should be done before discharge.
  - Parents are overwhelmed, scared and inundated with information – Important to repeat information.
  - When parents are discharged it is scaring for them when their baby is taken off the monitors.
  - It takes major planning, money and time for parents to make follow-up appointments.
  - It would be helpful to have someone in the NICU to do follow-up calls, take calls from parents, etc.
  - NICU's should consider family centered rounds.
  - Parent support groups are needed to connect parents to other parents with the same experiences.
  - It is very difficult to balance home life with NICU life.
  - It is very difficult to find childcare that can meet the needs of a premature infant.
  - A resource directory of available services in the community would be helpful to parents.
  
- ***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.