

**NEW YORK PREMATURE INFANT  
HEALTH NETWORK**

**Association of Perinatal Networks  
Suffolk County Perinatal Coalition**

July 27, 2010

Nassau County, New York

## 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***

- The NICU can be a frightening, confusing and overwhelming place for parents – Parents don't know what is going on, what questions to ask, etc.
- It is hard for families and friends to understand what parents of a preemie go through.
- Premature births create a lot of question marks – Families are nervous something bad is going to happen for a long time.
- It is important to celebrate milestones in the NICU, even the small ones.
- NICU's should be family oriented – Provide activities such as a photographer coming in to take photographs.
- It is important to promote breastfeeding and skin-to-skin care in the NICU.
- Current parents need support from past NICU parents – It is nice to hear stories of hope and success and pictures of preemies when they are older and thriving.
- It would be nice to have help for utility bills – Machines increase these bills, expensive formulas, etc.
- Once discharged, families are isolated – Unable to go out because infants are so fragile and can't be exposed to harmful germs.
- Discharge planning is essential and should not happen just on the day of discharge, should begin as soon as possible.
- It is difficult to balance one's home life and NICU life.
- It would be nice to have a follow-up phone call from the NICU after discharge.
- Important for NICU's to encourage parents to utilize Early Intervention services and to make referrals.
- Since medically sensitive daycares rarely exist, many mothers are forced to quit their job and stay at home with their preemie.

○ ***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.