

**NEW YORK PREMATURE INFANT  
HEALTH NETWORK**

**Association of Perinatal Networks  
Queens Health Coalition**

October 7, 2010  
Queens, New York

## IN ATTENDANCE

- Tamara Bell – New York Hospital Queens
- Kathleen Finn – New York University, College of Nursing
- Billie Jean Sheridan – New York University, College of Nursing
- Kayla York – Office of Chief Medical Examiner, SIDS Department
- Moe Takagi – SIDS Program
- Annie Cummings – Community Healthcare Network: Long Island City Health Center
- Li Li Karina Feng – Bilinguals, Inc.
- Edgar Santana – Bilinguals, Inc.
- Edwina Nunez-Gordon – Mental Health Association of NYC
- Cathy Warkala – Queens Early Childhood Direction Center
- Doreen Kosowski, LCSW – Cohen Children’s Medical Center of New York, NICU Social Worker
- Sarina Jean-Louis – Public Health Solutions – Asian/Jamaican Nurse Family Partnership
- Letricia Johnson – Forestdale, TASA
- Donna Downes – Forestdale, IMR Project
- William Molette – Comprehensive Genetics Cohen Children’s Medical Center of NYC, NSLIJ Health System
- Phyllis Shafran – Queens Health Coalition – [pshafron@qhcnyc.org](mailto:pshafron@qhcnyc.org)
- Gina Porras – Queens Health Coalition – [gporras@qhcnyc.org](mailto:gporras@qhcnyc.org)
- Lorena Flores – Queens Health Coalition – [lflores@qhcnyc.org](mailto:lflores@qhcnyc.org)
- Pamela Davis – Queens Comprehensive Perinatal Council – [qcpcorg@aol.com](mailto:qcpcorg@aol.com)
- 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 (Manhattan). 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***
  - Difficult for many families to find/pay for transportation to get to and from the NICU as well as to get to and from different medical appointments after discharge. This is an added cost that insurance does not pay for.
  - Discharge planning should begin as soon as possible after admittance into the NICU.
  - A parent information kit providing information on what to expect in the NICU and what to expect at home would be helpful for parents to cope with experience.
  - It is important to involve parent(s) in care of their baby in the NICU to promote bonding.
  - Essential that NICU staff meets parents where they are at. Parents are overwhelmed, confused and scared. Important to hear and listen to parents.
  - NICU staff should be culturally competent/sensitive to meet the needs of all families in the NICU. Many NICU families experience language and cultural barriers.
  - There should be increased education on what parents can expect in the school setting if there are long term affects of a premature birth. Many services stop once a child reaches the age of 5 and enters the school setting.

- Support groups to connect parents with other parents going through similar situation would be useful.
  - Parents, NICU staff and pediatricians should be educated on what services are available in their given communities. NICU staff and pediatricians should encourage families to fully utilize these services.
- *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.