

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

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

July 26, 2010

Suffolk County, New York

IN ATTENDANCE

- Gail Burrus – Suffolk Perinatal Coalition – gburrus@suffolkperinatalcoalition.org
- Dolores Gordon – Suffolk Perinatal Coalition – dolores@spcbabies.org
- Janis Hurley – Suffolk County Department of Health
- Maureen Karpilovsky – Suffolk Perinatal Coalition – maureen@scpcbabies.org
- Debora Rippel – Suffolk County Department of Health
- Ellen Roisman – Suffolk County DOH
- Eden Solomon – Consortium Coordinator of Downstate Healthy Start
- Sinead Suszcynski, RN – St. Catherine of Siena Medical Center
- Julianna Villafane – Suffolk Perinatal Coalition – julianna@spcbabies.org
- Regina Palmer-Spencer – SCDOHS Neighborhood Aide
- Linda Velicka – SCDOHS Neighborhood Aide
- 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***

- Parents need to advocate for their child while in the NICU – Need to learn the system, what questions to ask, medical terms, etc.
- Support groups to link parents with one another would be beneficial for parents to help them cope with their situation.
- Parents are afraid the leave the support of the NICU and its staff.
- Medically sensitive daycares are not available.
- Parents need to be encouraged to utilize Early Intervention services – Sometimes wait until delay is evident.
- Maternity/family leave is not conducive to preemie parents.
- Difficult to balance family life, work life and NICU life.
- It can be a challenge/financial burden to access and use transportation to get to and from the hospital and doctors visits.
- It would be nice to have a follow-up phone call from the NICU after discharge.
- It would be nice to have educational materials available to NICU parents – picture directions and palm card with essential phone numbers.
- Stony Brook has a parking pass waiver and childcare for NICU 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.