

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Greater Adirondack Perinatal Network**

August 11, 2010
Glens Falls, New York

IN ATTENDANCE

- Suzanne DelSignore – Washington County Public Health
- Traci Boerem – Saratoga County EOC Headstart, Region Health Coordinator
- Sara Quartiers – Parent
- Patty Myhrberg – Warren County Public Health
- Karen Doering – Glens Falls Hospital
- Cathy LaMay – Greater Adirondack Perinatal Network, Program Director – clamay@medserv.net
- Jackie Avignon – Greater Adirondack Perinatal Network, Program Coordinator - javignon@medserv.net
- 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.

- ***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***
 - Discharge should not happen on a Friday evening or be left to the last minute. Discharge planning should begin as soon as possible after being admitted to the NICU.
 - NICU's should have their own breast pumps for mothers to use.
 - Parents need to be encouraged to advocate for themselves and their babies, follow-up with NICU staff, know what questions to ask, etc.
 - Support groups are needed to connect current NICU parents with past NICU parents.
 - It is difficult to balance home life, work and visiting NICU.
 - In rural area's transportation can be expensive due to having to drive a long distance to visit hospital and visit specialists or public transportation is very limited and expensive.
 - Parents need to feel empowered in the NICU – Encourage parents to touch, hold, feed, change, talk and read to their baby.
 - Parents are afraid to hold their baby or expose them to harmful germs.
 - A Care Map Booklet would be a great resource to provide NICU parents – Plan of what they might see – What is going to happen while in the NICU, different medical terms, what questions to ask, etc.
 - NICU's, particularly RPC's need to know what services are available outside of their immediate area.
 - Maternity leave is not conducive to a premie mom – Has to decide between taking time off to be with baby while in the NICU or taking time off when baby comes home.
 - Difficult to get coverage for RSV shot, particularly in the second year of life.
 - Families are very isolated during RSV season – Extended family does not understand why they can't come visit.

- ***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.