

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

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

August 12, 2010
Plattsburgh, New York

IN ATTENDANCE

- Maria Hayes – CVPH
- Lisa Papp – CVPH
- Cassie Belzer – CVPH
- Susan Allott – CVPH
- Peg Contwell – FCPHS
- Heather & Art Carter – Parents of Premie Twins
- Alicia Sirk – CCHD
- Gloria Garami – CCHD
- Gennie Roussell – CCHD
- Tim Kramer – Parent of a Premie
- M. Betters – FCPH
- Tara Ellis – FCPH
- Dianne Harvish – ACAP –EHS/HS
- Mary Summers, RN – ACAP-EHS
- 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*
- The day your preemie is born is both the best and worst day of your life – Emotional Rollercoaster.
 - The extra costs, i.e. transportation, parking, food, daycare can be a major financial burden for NICU parents beyond the medical costs.
 - Parents are afraid to leave the comfort of the NICU.
 - It is important to start discharge planning as soon as possible so parents have the knowledge and comfort to care for their baby once they leave the NICU.
 - For many preemie parents in the Plattsburgh area their baby was in the NICU in Vermont – Since they are a New York State resident they are not eligible for their follow-up programs.
 - With proper discharge planning, parents come home not knowing what to expect – breathing, coughing, body temp, clothing, developmental milestones, etc.
 - Many moms of preemies feel guilty because there is no explanation as to why premature birth took place.
 - There is no rest/respite for families with a preemie.
 - Support groups are needed to link parents with one another so additional support can be provided.
- *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.