

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Mothers & Babies Perinatal Network**

June 8, 2010
Oneonta, New York

IN ATTENDANCE

- Treena Halstead – Building Healthy Families, Opportunities for Otsego
- Cali Riese – Building Healthy Families, Opportunities for Otsego
- Terri Butts – Planned Parenthood
- Elba Ahrens – Early Intervention
- Jean Lilja – Otsego County Department of Health
- Mary Taylor – Otsego County Department of Health
- Grace St. John, RN – Bassett Birthing Center
- Demetra Alberti – Healthy Families of Delaware Opportunities
- Yvonne Stepp – EHS
- Jackie Vandervort – Delaware County Early Intervention
- Heather Warner – DCPH
- Heather Tranvaag – DCPH
- Karen Fabian – UHS, Wilson Hospital NICU
- Ashley Knetchel – UHS, Wilson Hospital NICU
- Christie Finch – Mothers & Babies Perinatal Network – cfinch@mothersandbabies.org
- 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***

- It is important to get parents involved in the care of their baby while in the NICU and to not be afraid to touch their child: Holding, changing diapers, feedings, talking/reading to, etc.
- It is important to work on developmental care while babies are in the NICU.
- It would be beneficial to parents if there was a NICU support group so parents could connect with other parents.
- It is difficult to find a car seat that properly fits a preemie.
- It is difficult to find preemie friendly daycares that can meet the medical needs of these infants.
- There is a backlog of Early Intervention services in rural counties.
- There is a lack of providers/specialist in rural counties.
- Parents need to be encouraged to advocate for their child: Parents need to voice their questions, concerns and opinions.
- It is important for nurses and parents to build relationships in the NICU.
- When discharge happens only on the day of discharge you lose the planning opportunities.
- WIC does bases thing on chronological age, so parents have to get an extension to get approved for services.
- Being in the NICU can be traumatizing for babies.
- There is a major financial strain that families experience, both because of medical expenses and additional expenses like travel, parking, food, daycare, electricity bills, etc.
- It would be nice to have the NICU conduct a follow-up call to see how families are doing.
- It would be nice to have a lactation consultant for NICU moms.
- It is important to have services in place in the NICU for those families that do not speak English.

- *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.