

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
North Country Prenatal/Perinatal Council**
July 14, 2010
Watertown, New York

IN ATTENDANCE

- Carol Bennett – Fort Drum New Parent Support Program
- Terry Herzog – Fort Drum New Parent Support Program
- Bernice Zehr – JCPHNS
- Patricia Esford – JCPHNS
- Bethany Duflo – Parent of a preemie
- Cathleen Dowe – JCC
- Amber Meyers – Parent of a preemie
- Shannon Nevin – Parent
- Kay Peck – JCDSS
- Liz Quencer – From Assemblywoman Addie Russell’s office
- Lynn Reichert – Parent of a preemie
- Kari Chavoustie – North Country Prenatal/Perinatal Council – kchavoustie@ncppc.org
- Anne Beevers – North Country Prenatal/Perinatal Council – abeevers@ncppc.org
- Penny Ingahm – North Country Prenatal/Perinatal Council – pingham@ncppc.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*

- Many new moms do not know what pregnancy feels like so they are unsure if going into preterm labor – May delay going to hospital.
- Mom's are forced to split up their maternity leave so they have time off when their baby comes home from the NICU – Have to work during the day and visit their baby before and after work hours.
- After being discharged it is nerve racking to lose that support from the NICU and provide care at home.
- Many preemie babies are unable to be put in daycare because they cannot be exposed to germs or have medical needs – No medically sensitive daycares – Families have to have a parent stay at home or rely on family and friends to watch.
- Making connections with other parents in the NICU helps to be able to cope with all that is happening – Need Support Groups.
- It is hard for some moms not to feel envious of “healthy” babies.
- Preemie families become isolated because of the fear of being exposed to harmful germs.
- It would be nice to have a follow-up from NICU staff after discharge.
- Support for military moms is needed because in many cases that family support is not there.
- Cost and access to transportation can be a major burden for families – Travel to Syracuse is needed to see specialists.
- It is difficult to balance one's home life and NICU life.
- It would be nice to have materials, quality websites, etc. with clear, simple information.
- It would be nice if doctors made house visits when there is a preemie.
- Parents are afraid to touch their child – Afraid they will hurt them.
- The NICU experience is a rollercoaster ride – Never know what to expect.
- Parents can experience post traumatic stress.

- *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.