

**NEW YORK PREMATURE INFANT  
HEALTH NETWORK**

**Association of Perinatal Networks  
Mohawk Valley Perinatal Network**

October 7, 2011  
Utica, New York

## IN ATTENDANCE

- Sindy Lyman – Oneida County Health Department
- Rosanne Clemente – Oneida County Health Department, MCH
- Maureen Bruce – Oneida County Health Department
- Irene Willett – Oneida County Health Department
- April Miller – Mohawk Valley Perinatal Network
- Cheri Elefante – Mohawk Valley Perinatal Network
- Colleen Cavallo – The Family Nurturing Center
- Katie Painter – Rome Memorial Hospital
- Cathe Bullwinkle – Oneida County Health Department
- Patricia Meyer – Oneida County Health Department, Early Intervention
- Stacy Farrell – Oneida County Health Department
- Susan Niedzielski – Early Intervention
- Diana Haldenwang – Mohawk Valley Perinatal Network
- Kaitlin Drouin – Association of Perinatal Networks of NY

## MEETING NOTES

Below is an overview of key messages and comments during the meeting.

- ***APN and New York State PIHN Presentation*** – Kaitlin Drouin, APN Program Coordinator
  - ∴ The Association of Perinatal Networks (APN) is an umbrella organization to the 17 regional perinatal networks. The APN focuses its efforts on statewide issues and supporting the work of each of the 17 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).
  - ∴ 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 issues premature infants and their caregivers face.
    - Increase access to resources and support for the ongoing care of premature infants and their families.

- Raise awareness and create better standards for the ongoing care and needs of premature infants and their families/caregivers.

∴ 2010 PIHN Meeting Details

- Last year, the PIHN meetings brought together parents and caregivers of premature infants to share their experiences and concerns, and to give recommendations to improve services.
- 18 total meetings were held, at which statistics, and financial and health implications were discussed.
- Statewide obstacles included not knowing how to advocate for preemies, difficulty balancing the NICU with home life, preparing for discharge, emotional distress, financial burden, losing the support of NICU staff when moving the baby home, transportation to the hospital or doctors appointments, lack of community support, and a need for a directory of available services.
- Suggestions to aid these problems included making more resources available in the NICU, providing family rooms, creating a NICU report card, making breast pumps available, and providing things like food vouchers or parking passes.
- In Utica, the following needs were identified: transportation, cultural competency training, experienced parent volunteers, follow-up support, support groups, directory of services, financial hardship, public health nurse home visits

∴ 2011 PIHN Actions

- A Premie E-memo has been created to inform participants on recent developments, legislation, resources and experiences related to premature infant health. This will also allow participants to keep in touch with the APN for questions, concerns, or requests.
- As a first step in establishing parent support, a NICU survey has been created and will be distributed this year to all hospitals with a NICU in New York State. The results of this survey will be used to identify target areas with incomplete support and give the PIHN direction in their future plans to establish a support model.
- The PIHN will continue to build a statewide network of parents and professionals through a set of meetings.

∴ Available Resources in the area:

- Oneida County Health Dept
  - Maternal Child Health (MCH) nursing
  - Community Health Worker program
  - Child Find
  - Early Intervention
  - MOMS program
  - Physically Handicapped Children's Program
- Herkimer County Public Health Programs

- Medicaid Prenatal Services (formerly Prenatal Care Assistance Program (PCAP))
  - Child Find
  - Early Intervention
  - Pre-school Special Education
  - Children with Special Health Care Needs
- ***Roundtable Discussion on Envisioning Changes in Resources and Support***
  - ∴ *Transportation.* Since the local RPC is in Syracuse, families have difficulty with visiting their premature infant. While the Ronald McDonald house and Sarah’s House provide some aid, parents often have to leave their children at home, live part-time away from their families, or become detached from their preemie because of the obstacle of visiting. An attendee mentioned that in some places, volunteer transportation exists. One such organization is the RSVP, or the Retired Senior Volunteer Program. Referring families to such services may help reduce the stress of arranging transportation. Additionally, moms with preemies who have been transported to Syracuse experience an obstacle to their breastfeeding efforts. An attendee mentioned that having a similar transport system for mothers who pump would eliminate part of that obstacle. A discussion developed over the details of working out such an arrangement. The breast milk could be stored and shipped in a similar manner to blood/urine samples when they are transported between the local hospital and the RPC in Syracuse. This would preserve sterility, chain of custody, and allow the preemie access to its mother’s milk on a regular basis.
  - ∴ *Web-access Check-in.* Another solution to the barrier created by transportation and distance was mentioned by an attendee: a web-based system for parents to check in on their premature infant. Parents or family could be given an access code to an online account, detailing the medical procedures, developmental progress, medication changes, weight gain, and information on doctors and nurses. The preemie could have their picture taken (without flash) regularly, and the photos could be posted on their baby’s informational account. This service would help parents who are unable to make regular visits to check in on their preemie and maintain an emotional bond by seeing their picture, but can also help any parent keep track of changes in their baby’s health or care.
  - ∴ *Counseling.* It was identified that family counseling is an essential next-step in NICU care – when caring for a premature infant, you must also care for their family. If the family is healthy, the infant will be discharged into a better environment (and may even have fewer hospitalizations). It was mentioned by an attendee that Krauss has a DVD for parents entering the NICU, which would be a useful resource for other hospitals.
- ***APN: New York State PIHN Presentation*** – Kaitlin Drouin, APN Program Coordinator
  - Recent State Legislation
    - The Public Health Law in NYS was amended as of January of 2011 by adding a new section to S2803-t. This amendment includes the following:

- Any hospital providing birthing services must provide written, educational material about the complications, care and support involved in having a premature infant (before 37 weeks). The information will include:
  - Unique health issues to preemies (developmental issues, nutritional challenges, infection, chronic lung disease, vision and hearing impairment, breathing problems, feeding, body temperature, jaundice, hyperactivity, infant mortality, and long-term learning complications)
  - Care needs of premature infants including screenings and monitoring, and what healthcare services are available
  - Education on infectious disease and preventative measures for common infections in premature infants
  - Community resources to help families care for and support their preemie
- Bill Number S4219 was passed in 2010 in order to prevent the NYS Department of Health from reducing the reimbursement rates for providers who provide services under the Early Intervention Program.
- Recent Federal Legislation
  - In September 2010, the PREEMIE Act was introduced for reauthorization to continue and enhance federal support for research into the causes and prevention of premature birth and to reduce infant mortality caused by prematurity.
    - Expands the scope of work supported by the National Institutes of Health, the Centers for Disease Control and Prevention, and Health Resources and Services Administration to include new initiatives. This bill was last acted upon when it was referred to the committee of Senate Health, Education, Labor and Pensions.
  - In July of 2009, the Nationally Enhancing the Wellbeing of Babies through Outreach and Research Now Act was introduced.
    - Its purpose is to authorize funding for the creation and implementation of infant mortality pilot programs in standard metropolitan areas with high rates of infant mortality. This bill has passed the House and is entering the Senate as of Sept. 2010.
  - In June 2011, the Maximizing Optimal Maternity Services for the 21st Century Bill was introduced.
    - It promotes optimal maternity outcomes by making evidence-based maternity care a national priority.
- Late Preterm Infant Guidelines
  - Late preterm infants are premature infants born between 34 and 37 weeks, and account for 75% of all prematurity in the U.S.
  - The National Perinatal Association held a summit in 2010, bringing together leaders of prominent nation-wide organizations to create a set of evidence-

based guidelines to be used in the care of late preterm infants across disciplines and across the nation.

- A steering committee was formed, and the guidelines are currently in the process of being published.
- The APN hopes to partner with the NPA once these guidelines are released to help universalize these guidelines.

○ *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.
- ∴ Signing up attendees for the Premie E-memo.
- ∴ Sending out the powerpoint and notes from the meeting.
- ∴ Collaborating with the NPA to promote late preterm infant guidelines.
- ∴ Sending out the NICU survey to identify gaps in support services.