

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Lower Hudson Valley Perinatal Network**
October 12, 2011
Valhalla, New York

IN ATTENDANCE

- Ellen Whittlemore – Westchester County Department of Health
- Flora Walsh – WCMC
- Susan Marchwinski – WCMC
- Carolyn Graham – Early Intervention
- Anita Henderson
- Rajan Nair – Westchester County Department of Health
- Debra Nodiff – Planned Parenthood
- Linda Rosso Lopez – Lower Hudson Valley Perinatal Network – lopezli@wcmc.com
- Leila Blackman – Lower Hudson Valley Perinatal Network – blackmanl@lhvpn.net
- Julie Larkin – WCMC NICU
- Gene Rose – March of Dimes
- Cheryl Hunter-Grant – Lower Hudson Valley Perinatal Network – hunter-grant@lhvpn.net
- Kaitlin Drouin – Association of Perinatal Networks, Program Coordinator – kdrouin@associationofperinatalnetworks.org

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 your area, the following support needs were identified:
 - ∴ Limited network of providers with experience
 - ∴ Transportation
 - ∴ Social workers for preemies in NYC do not know what resources to connect families to when moved
 - ∴ An online resource directory
 - ∴ Language barriers can be a challenge
 - ∴ Finding childcare
 - ∴ Pediatricians to know when to make referrals

∴ 2011 PIHN Actions

- ∴ A Preemie 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.

○ ***Roundtable Discussion on Envisioning Changes in Resources and Support***

- ∴ **Dr. Jordan Kase** spoke on his experience with premature infants, the discharge process, and follow-up. He went into detail about services available at the WCMC and where gaps in services exist. There also was a Q&A for the attendees.
- ∴ *Transportation.* It was made clear that transportation is a huge obstacle for many families. Ideas concerning breast milk carriers and driving volunteers were mentioned and discussed.
- ∴ *Prenatal Awareness.* One attendee mentioned that a series of Lamaze classes she used to teach a while ago used to include a class on what early labor feels like and what to expect if your child is born prematurely. It was agreed by several attendees that this should be included in Lamaze classes.
- ∴ *Population Gaps.* Several attendees mentioned that certain populations in particular are being left behind when it comes to services – one being non-English-speaking families, and the other being the “new poor”, or middle class families who are losing their jobs. Families who cannot understand English fully have an even more difficult time decoding all of the NICU terminology. Where any parent would be confused, those who cannot understand English are truly left behind. Also, the middle class families who are losing their income are often unaware that they are now within the range of poverty, and are also unaware of what assistance services are available to them. The attendees attempted to find a solution to these problems, but they are complicated and wide-spread.
- **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 Preemie 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.

