

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Perinatal Network of Monroe County**

August 24, 2011
Rochester, New York

IN ATTENDANCE

- Jacqueline Procope-Isaacs – Perinatal Network of Monroe County – jisaacs@perinatalnetwork.net
- Jennifer Cowans – EMOMS Rochester
- Chaakaa Collalto – Monroe Ambulance
- Cynthia Childs – University of Rochester, Vitamin D Research
- Yolanda Sayres – Outreach Coordinator, Perinatal Network of Monroe County – ysayres@perinatalnetwork.net
- Nicole Smith – CPPSN Program Manager, Perinatal Network of Monroe County – nsmith@perinatalnetwork.net
- Deb Peartree – Monroe Plan
- Michelle Dixon – Action for a Better Community
- 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: 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 week 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 to identify gaps, and to bring premature infants to the forefront. Our ultimate goal is to eventually help establish resources for support where they are needed most.
 - ∴ 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 Rochester, the following issues were identified: lack of follow-up support, transportation, hospital separation, need for a support group or network, and incomplete insurance coverage for medications and vaccines.

∴ 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 Monroe County

- Some preliminary research on the county revealed that several resources are available at the Golisano Children's Hospital, including a parent to parent support group, a NICU cuddler program, a follow-up program, and Ronald McDonald Houses.
- The Perinatal Network of Monroe County's Mood Disorder Coalition is currently in the process of setting up a parent to parent support group for grieving families who have lost an infant. The PNMC also has an online database of local resources which they are willing to expand upon to include resources for premature infants and their families.

- The Monroe County Child and Family Health Services have two programs that are relevant to premature infant health – the Children with Special Healthcare Needs Program, and Family Bereavement for those who have lost an infant.
- ***Roundtable Discussion on Envisioning Changes in Resources and Support***
- ∴ *Resource Database:*
- In lieu of the PNMC’s offer to expand their resource database, meeting attendees gave a few ideas on what local resources should be included. The list included: the support services mentioned above provided by Golisano Children’s Hospital, the services mentioned above provided by the Monroe County Child and Family Health Services, Monroe Ambulance, March of Dimes – Rochester, Rochester Hearing and Speech, the Children’s Institute, the Rochester Child First Network, Early Head Start, Day Star, EMOMS Rochester, Monroe Plan, Action for a Better Community, Nurse Family Partnership.
- ∴ *Gaps in Support and Resources:*
- A main concern was identified that, while hospitals like Golisano are providing in-house social workers to connect women to resources in the community, premie moms have no case management in the community once they are discharged.
 - The benefits of mandatory counseling for parents of premature infants were discussed. Attendees thought it would be useful to have follow-up appointments months after the move home in addition to an initial assessment for PPD and PTSD. Just as premature infants differ in their needs from full term infants, mothers of premature infants differ in their needs from moms of full term infants. Specialized steps should be taken.
 - The group of attendees was unsure of whether there was a general “NICU orientation” service provided to parents at hospitals. The group discussed including a video and the March of Dimes “NICU Journal”. Again, it is unknown what orientation if any is given at hospitals for the NICU, perhaps the NICU survey will reveal the details of this.
 - Since levels of prematurity and induction are on the rise in the U.S. and in NYS, the group discussed the benefits of including education on the risks and consequences associated with a premature birth in the OB office for all pregnant women.
- ***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.
- ***Questions and Comments taken on Recent Updates***
 - ∴ One attendee mentioned that there had been recent legislation passed in Massachusetts that prevented professionals from intervening with a delivery if the infant's lungs were not yet fully formed. The attendee stated that this has caused suffering among women who go into labor before full term. The group discussed how this is an example of how legislation can be far removed from the realities and necessities of birth.
- ***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.