

**NEW YORK PREMATURE INFANT
HEALTH NETWORK**

**Association of Perinatal Networks
Buffalo Prenatal-Perinatal Network**

October 21, 2011
Buffalo, New York

IN ATTENDANCE

- Madeline Gathers – EPIC
- Emily Sheng – BPPN
- Barbara Boardway – BCBS WNY
- Cheryl Celotto – BCBS WNY
- Danielle Lancianu – BCBS WNY
- Tiara Clasablanca – BCBS WNY
- Christie Kosecki – Parent of Premature Twins
- Wanda Westmoreland – Mother of a premature infant
- Marcia Hixon – Monroe Plan, BCBS
- Heidi Lancher – Monroe Plan
- Linda Stockmeyer – Monroe Plan
- Caroline Crispin – Monroe Plan
- Cassandra Bridges – BPPN
- Cheryl Oliver – NCP
- Kathleen Rog – NICU at CHS Buffalo
- Connie Rivera Acevedo – BPPN
- Maria Ortiz – Parent of a premature infant
- Tanice Pendergrass – HMG WNY
- Vickie Rubin – Early Childhood Direction Center WNY
- Nuna Adhikari – Parent of a premature infant
- Cheryl Jordan – BPPN
- Rebecca Uribe Tilk – UCH
- Barbara Davis – UCH
- Judy Ricottone – Fidelis Care
- PAB – BPPN
- Debra Moore – BPPN
- Kimberly Manny – BPPN
- Millie Hall – BPPN
- Gwendolyn Hunt – BPPN
- Eunice Robinson – BPPN
- Rose Alexander – BPPN
- Carol Maclin – MSHC/CHS
- Bernice DeJesus – BPPN
- Venita McCullough – Parent of a premature infant
- 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 needs were identified:
 - ∴ Transportation
 - ∴ Many language and cultural barriers

- ∴ NICU service directory would be helpful for parents and providers.
 - ∴ Support groups
 - ∴ Medically sensitive daycare and overnight respite services
 - ∴ More pediatricians and specialists in rural counties
 - ∴ Marital support
- 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 continues to build a statewide network of parents and professionals through a set of meetings.
- Some Available Resources in the area:
 - Online Resources
 - Parent to Parent - Health Care Notebook
 - Hand to Hold
 - NPA Support Search
 - www.Prematurity.org
 - NICU Parent Advisory Committee
 - Email: nicumoms@yahoo.com.
 - Community Resources
 - Univera Community Health
 - Monroe Plan
 - Early Childhood Direction Center
 - Help Me Grow Western NY
 - Women and Children's Hospital of Buffalo (RPC)
 - Sisters of Charity Hospital (L3)
 - Mercy Hospital (L2)
 - Buffalo Prenatal Perinatal Network – Online Resource Directory
 - Kevin's House, Ronald McDonald House
 - ***Roundtable Discussion on Envisioning Changes in Resources and Support***
 - *Transportation.* Since Erie County is one of only two counties in Western New York that has a perinatal network or a Regional Perinatal Center, transportation over county lines is a significant issue. In brainstorming about this obstacle, participants brought up the American Cancer Society and its program “Road to Recovery”, whose staff includes a full time patient service coordinator and volunteers who use their own cars. In looking at setting up a transportation system for parents, looking at the way Road to Recovery is structured may help. It was also noted by an attendee that reaching out

to counties themselves to see what services exist and if they have suggestions would be a crucial step. Another attendee brought up the idea of contacting some churches in the surrounding counties to see if they would be interested in taking this on as a service project for helping families in their community.

○ ***Parent Stories***

- Parents Christie Kosicki, Nuna Adhikari and Venita McCullough each shared their unique stories about their journeys as mothers of children born prematurely. Although these mothers came from different backgrounds, they all shared in their emotional experiences in the NICU and beyond.
- **The APN would like to sincerely thank Christie, Nuna and Venita for sharing their personal experiences at our meeting.**

○ ***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.