

February 2009

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National *preemie* Network News

sharing ideas across the nation's preemie networks

Best Practices *story*

IPIHN leverages its membership for survey development

The Illinois Chapter, American Academy of Pediatrics (ICAAP), one of the Network's most active and critical members, was able to call upon the relationships built through the Network to develop its survey of NICU follow-up programs in Illinois. Once the survey is completed, ICAAP will share the results with the Network, helping to develop future initiatives improving access to care for Illinois premature infants and their families. Read more about the survey [here](#).

National News

U.S. Gets a 'D' for Preterm Birth Rates

November 12, 2008
Washington Post

When it comes to premature birth rates, the United States rates a "D," and 18 states plus Puerto Rico and the District of Columbia get failing grades. [Click here](#) for full story.

21-year study of children set to begin

October 27, 2008
New York Times

After nearly a decade of planning, researchers will begin recruiting pregnant women in January for

Network News

Seven Networks Act to Increase Quality Healthcare Access for Premies

In 2007, seven premature infant health networks located in Florida, Illinois, Maryland, Minnesota, New York, Ohio and Pennsylvania, were formed to increase quality healthcare access and awareness related to premature infant health issues. Key state leaders involved in each network include community and health organizations, faith-based groups, healthcare providers, and parents.

The networks have all chosen to focus on four priority areas: continuity of care, access to healthcare, family support and education, and policy. In addition to these areas, other networks are concentrating on areas such as safety and injury prevention, immunizations and vaccinations, oral health, car safety seats, and the impact of secondhand smoke.

Current action steps being initiated by several of the networks include:

- Coordinating legislator NICU tours;
- Identifying consistent resources and materials;
- Developing a best practices document;
- Drafting template letters to legislators related to premature infant issues; and
- Training more community health workers to help high-risk women and parents of premature infants.

All networks are sponsored and funded by MedImmune, LLC.

To read more about each individual network, please click on the respective link below.

[Florida Alliance for Healthy Babies](#)
[Illinois Premature Infant Health Network](#)
[Maryland Premature Infant Health Network](#)
[Minnesota Premature Infant Health Network](#)
[New York Premature Infant Health Network](#)
[Premature Infant Health Network of Ohio](#)
[Pennsylvania Premature Infant Health Network](#)

Florida Alliance for Healthy Babies

As the state of Florida looks toward the start of the 2009 legislative session, the Florida Alliance for Healthy Babies is implementing a communications campaign aimed at educating new and returning legislators about the Alliance. Although the Alliance does not have a specific legislative agenda, many of its member organizations will be facing budget cuts. We anticipate the cuts will be deep and threaten

an ambitious nationwide study that will follow more than 100,000 children from before birth until age 21.

The goal of the federally financed project, the National Children's Study, is to gain a better understanding of the effects of a wide array of factors on children's health. [Click here](#) for full story.

MedImmune, LLC strives to cultivate long-term sustainable relationships with national and state organizations to optimize health outcomes for premature babies and their families. That's why MedImmune supports regional prematurity networks. These networks bring together interested parties focused on the health and well-being of premature babies.

For more details regarding your state's network, please use the contact information below. All networks are funded and supported by MedImmune.

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the already limited dollars that are allocated to services for Florida's most vulnerable babies. At the beginning of session, each member of the House of Representatives and Senate will receive a hand-delivered information kit on behalf of the Alliance that includes information about the network, its 10 areas of concern and position as a clearinghouse of information related to premature infant health in the state of Florida.

Illinois Premature Infant Health Network

Currently, the Network is driving its initiatives through two committees, Continuity of Care and State Policy. The Continuity of Care committee is currently supporting efforts of the Illinois Chapter, American Academy of Pediatrics that focus on follow-up services provided by Level III NICUs in Illinois and the unique issues encountered in primary care management of the NICU graduate. The State Policy committee is primarily interested in improving data collection on premature infants in Illinois and is considering potential legislative opportunities for the 2009 Illinois legislative session, as well as planning to organize in legislative districts and to connect with state agencies. State Policy member March of Dimes recently hosted a NICU tour for legislators in the state capital, and the committee will support future NICU tours in other locations next year.

Maryland Premature Infant Health Network

The Maryland Premature Infant Health Network met in December 2008, where the members finalized the network's mission statement and identified the following committee work groups: Advocacy, Education and Coordination. **Advocacy:** Under this committee, the network is working to introduce premature infant legislation in the upcoming 2009 legislative session. The purpose of the legislation is to improve healthcare quality and outcomes for infants born preterm through enhanced hospital discharge, follow-up care and management processes and reduced re-hospitalization; and reduce infant morbidity and mortality associated with prematurity.

Education: The network will focus on the following categories: peers/professionals, patients/families and media/policymakers. The group has committed to expanding the educational resources Web site provided by the Maryland Department of Health and Mental Hygiene Office for Genetics and Children with Special Health Care Needs. **Coordination:** This group is focused on developing a needs assessment around the coordination of care for children from pre-birth to age three and will work to provide recommendations to maintain a standard of care.

Minnesota Premature Infant Health Network

At the Minnesota Premature Infant Health Network meeting in May 2008, network members mobilized on the issues they determined to be the most pressing for premature infants in Minnesota. The network formed four sub-groups around these issues: Resources, Best Practices, Public Policy and Community Health Workers. Since May, the four sub-groups have participated in conference calls and have met individually to delegate action steps to accomplish their goals. Please [click here](#) for more information regarding the sub-groups activities.

New York Premature Infant Health Network

The goal of the New York Premature Infant Health Network is to dedicate efforts to increase communication and education to medical professionals, policy makers and communities of available services and programs for families affected by prematurity, and the opportunity to centralize expertise to create a statewide advocate.

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National Preemie Network News, funded and sponsored by MedImmune, LLC, is a quarterly resource for sharing information about advocacy efforts across the nation focused on increasing quality health care access for premature infants.



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To advance this goal, Network member Maureen Doolan Boyle, executive director, MOST and PreemieCare, coordinated a press statement announcing the Network to members of the media, legislature and the premature infant community in December 2008. The press statement articulated that one of the biggest challenges caregivers and families face in New York is the continuum of care from the NICU to the community.

Network members will continue advocating to policy makers and insurers about the importance of maintaining existing policies and standards of care.

Premature Infant Health Network of Ohio

At the network's last meeting in September 2008, members decided that the network's role should be to help improve processes that already exist. To achieve this objective, the network developed a quarterly eNewsletter to share best practices, materials and information. The newsletter will serve as an avenue to look at consistencies and duplications across organizations so that network members can make better use of time and funds.

Additionally, in November, the network coordinated a legislator NICU tour in honor of National Prematurity Awareness Month. The network is currently reaching out to members of the Ohio Prematurity Caucus to engage them in the network.

Pennsylvania Premature Infant Health Network

The Pennsylvania Premature Infant Health Network held a group conference call in November 2008 to bring Harrisburg and Philadelphia area group members together to identify next steps for the network. The network is working to develop a state action plan and committee sub-groups around three contributing factors for prematurity as identified by the March of Dimes state report cards: uninsured women, smoking and late preterm births. Network members were also invited to participate in a NICU tour with state legislators at the Children's Hospital of Philadelphia.