New information, resources and opportunities to collaborate presented at the 2011 Premature Infant Health Summits

Born Too Soon
Each year, more than half a million babies are born prematurely in the United States\(^1\) -- roughly one in eight births. The toll prematurity takes on infant health and on families and society is profound. Babies born prematurely may be at risk of severe health problems. Some of the leading causes of infant death include low birth weight and prematurity.\(^2\)

As noted in an Institute of Medicine 2006 report, the societal cost of prematurity each year in the US is at least $26 billion.\(^3\) And yet, with all of these facts, the “voice” of premature patients and their families is often underrepresented compared to other chronic illnesses such as diabetes, cancer, etc.

2009 Collaborating for Preemies
In 2009, MedImmune Advocacy and 11 organizations hosted six state Premature Infant Health Summits across the country to shine a greater spotlight on the issues facing premature infants. The summits invigorated nearly 500 attendees to work together to formulate solutions to the growing needs of this population.

2011 Small Steps...Big Changes
Since that time, many stakeholders have developed programs and initiatives to improve the care of premature infants and the collective advocacy for them.

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*Three state-based networks are currently being sponsored and funded by MedImmune.*
With requests from the community, in 2011, MedImmune Advocacy and 23 organizations again hosted Premature Infant Health Summits in eight states.

459 attendees reviewed the four cornerstone issues of prematurity and discussed new data on rates of prematurity, national and community stakeholder engagement, new resources and the current policy landscape’s impact on prematurity.

**New Resources for Premature Infant Stakeholders**
Some of the resources presented included the website, toolkits and collaterals developed by MedImmune. They included

- Non-branded premature infant web site: [http://www.preemievoices.com](http://www.preemievoices.com) which houses information, resources, educational downloads and supportive links
- Toolkit for the Follow-up Care of the Premature Infant through the first year of life. Developed for healthcare providers in collaboration with the National Initiative for Children’s Healthcare Quality [http://www.preemietoolkit.com](http://www.preemietoolkit.com)
- Special Deliver Handle with Care: Easy-to-access information to help deliver quality educational pieces. [http://www.specialdeliveryhandlewithcare.com](http://www.specialdeliveryhandlewithcare.com)

**A Focus on Late-Preterm Infants**
Additionally, the National Perinatal Association (NPA) and Association of Women’s Health Obstetric and Neonatal Nurses (AWHONN) presented information specific to late-preterm infant care. Information from the NPA can be found at [http://www.nationalperinatal.org](http://www.nationalperinatal.org) and

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Information from AWHONN can be found at http://www.awhonn.org.

National & Community Stakeholders
Finally, a number of partners discussed the activities of premature infant coalitions and networks. Two national organizations now provide national forums for professionals and parents of preemies. The National Premature Infant Health Coalition is a network for those that care for children born too small and too soon and those who support affected families. The Preemie Parent Alliance is a network of parents of premature infants in the United States who lead support organizations for parents who have had a preemie or medically fragile child. Additionally, there are now 13 state-based premature infant health networks and coalitions* each of which define their own unique mission, activities and priorities specific to the state and community issues. A listing of networks can be found at http://www.preemievoices.com/news/-regional

Making a Difference
While big steps have been taken to support premature infants, there is still much to be done to protect this fragile and vulnerable population. Additional research on the short- and long-term health effects of prematurity is needed; policy to support continuity of care and early intervention services; and greater public/parent awareness and education are required.

Together, we will continue to drive focus on the issues and to create new initiatives while collaborating together to take full advantage of the resources that are currently available. Together, we can be the “voice” of this fragile population.

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