Newborn Foundation & Newborn Coalition Announce 2013 Agenda

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Washington, DC (RPRN) 09/13/12 — Celebrating Babies - Embracing Innovation Event Highlights Initiatives To Improve Outcomes and Reduce Disparities for the Youngest Patients

The Newborn Coalition and Newborn – Foundation today announced its 2013 policy priorities addressing immediate objectives for leveraging health IT, medtech and biotechnology in support of newborn health.

Held in coordination with National Health IT Week, Newborn Screening Awareness Month and Infant Mortality Awareness Month, today's event was an opportunity to also recognize the accomplishments of organizations, agencies and individuals in newborn health. Comments were provided by HRSA Administrator Mary Wakefield, PhD, RN and Canada Research Chair in Health Information, Carolyn McGregor, PhD, SMIEEE. Newborn and pediatric health pioneer, R. Rodney Howell received the first annual award in his name – the R. Rodney Howell "Aspire Award" for Excellence in Newborn Health, and the Hubert H. Humphrey "Dawn of Life" Award was presented by Hubert H. "Buck" Humphrey IV to Congresswoman Betty McCollum for her leadership in maternal and newborn health.

As part of the agenda, Newborn Foundation and Coalition announced 2013 policy priorities, including:

Early Detection - Reauthorization of the Newborn Screening Saves Lives Act, which is vitally important for early detection and treatment of newborns with critical health problems.

Focus on Infrastructure – Additional funds are required to expand further expand health programs for newborns that have been effective over time. These resources, however, must be deployed in a way that allows the programs to grow over time and evolve with the needs of a region's newborns. Moreover, we will pursue increased funding for technology grants for state departments of health to support these infrastructure needs, modernize antiquated record keeping systems, facilitate coordinated follow-up care, and reporting on patient health.

Interoperable Newborn Electronic Health Record - The Implementation of a multi-center, multi-state "Growing Needs" pilot project designed to implement a system where newborn screening data serves as the foundational piece and first electronic birth notification for state departments of health. The Newborn Electronic Health Record will then serve as hub for all reportable conditions and vital statistics, from screening information to immunizations.

Care Across Borders – advocate for policies that allow physicians to use technology to collaborate across state and Medicaid borders in support of newborn health.

Foster Innovation – advocate for policies that facilitate the timely and efficient process of FDA approval and deployment of medical technologies and devices for neonatal and pediatric patients.

Expand Health IT - in support of improved access and care for the youngest patients, asking for continued strong bi-partisan support of Health IT, Telehealth and Medical Technology Innovation funding.

During this National Health IT Week we join with HIMSS, the Health IT Now Coalition and other groups in supporting the nationwide adoption of EHRs and HIEs, a health IT-enabled transformation of American healthcare will enable greater patient engagement, facilitate major improvements in research, improve the quality of clinical care, and enhance the nation's population health management.

Laser-focused on these priorities, the Newborn Coalition and Newborn Foundation are working in collaboration with state and federal government, the private sector, healthcare institutions, NGOs, advocates and families to move these initiatives forward to improve outcomes and reduce disparities for newborns and their families.

"As a percentage, babies are among the most at-risk health populations – not just in the United States, but abroad. Connecting babies with the care they need is a critical need, and we believe Health IT, Telehealth and mHealth can enable that sort of access and improved care," said Jim Bialick, Executive Director, Newborn Coalition and Newborn Foundation. "Leveraging these priorities, we will continue to collaborate with the private sector, decision-makers here in Washington, DC, as well as public health, clinical, research, NGO and advocacy communities on key issues that impact the health and well-being of newborns and infants."

The priorities are compiled with input from the coalition's advisory board and expertise from the organization's numerous partners in the medical, academic, research, and public policy communities. The organization will also be working collaboratively with agencies, national associations and the private sector to initiate additional pilot and demonstration projects to support federal standards and projects aimed at increasing early detection of health conditions, improving care, and accelerating adoption of health technologies.

In 2011, the Newborn Coalition focused its efforts on the securing a federal recommendation from the U.S. Secretary of Health and Human Services that all newborns be screened for Critical Congenital Heart Disease (CCHD). Heart defects are the most common of all birth defects, impacting 1 of every 100 infants. The coalition and foundation has since worked with more than a dozen states and served on 6 workgroups helping accelerate hospital implementation of the screening across the country. The Newborn Foundation is also working internationally to support the introduction of newborn heart screening, expand existing public health programs for early

detection of diseases and disorders in babies, and work with health officials to establish electronically enabled health systems to support improved access and care.

More about the Newborn Coalition

The Newborn Coalition (www.newborncoalition.org) and Newborn Foundation (www.newborn-foundation.org) leverage health IT, medtech and biotechnology innovation to improve outcomes and reduce disparities for the newest, most vulnerable citizens. Co-founded by the mother of a baby diagnosed at 48 hours old with congenital heart disease, the Coalition has a national footprint that supports increased understanding of newborn health issues and risk factors while helping improve access to quality care and resources through vital research and pilot projects.

Newborn Coalition | Newborn Foundation - 750 9th Street NW, Suite 750, Washington DC 20001

Media Contact Name: Torin Kelly
Media E-mail: torin@ainsleyshea.com
Media Phone: 952-201-3483
Company Contact Name: New Born Coalition
Company Web Address: www.newborncoalition.org

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