Newborn Coalition Announces 2014 Agenda

September 19, 2013

Washington, DC (RPRN) 09/19/13 — Harnessing Technology to Improve Outcomes and Reduce Disparities for the Youngest Patients

In coordination with National Health IT Week and the 50th Anniversary of Newborn Screening, and Infant Mortality Awareness Month, the Newborn Coalition today announced its 2014 policy priorities addressing immediate objectives for leveraging health IT, medtech and biotechnology in support of newborn health, including:

Early Detection + Intervention – secure reauthorization of the Newborn Screening Saves Lives Act (HR 1281), a vitally important law for early detection and treatment of newborns with critical health problems. Ensure the Act includes provisions for bolstering health IT infrastructure and hospital data interoperability between providers and public health departments. Continue to support provider and public health with educational and policy resources, particularly for the implementation of new tests and methods for early detection, diagnosis and follow-up, such as newborn heart screening using pulse oximetry.

Newborn Electronic Health Record – facilitate the implementation of the multi-center, multi-state "Growing Needs" project, where hospital newborn screening data serves as the foundational piece and first electronic birth notification and vital registration for state departments of health. The Newborn Electronic Health Record then serves as an organic hub of information for all reportable conditions, screening information, immunizations and disease/disorder surveillance.

Care Across Borders – advocate for bi-partisan policies and IT-enabled systems that allow physicians to use technology to collaborate across facilities, health networks, state lines and Medicaid borders in support of newborn health.

Foster Innovation, Technology + Interoperability – develop and advocate for policies and programs that facilitate timely and efficient regulation, encourage innovation, as well as safely bridge the gap between consumer technologies and medical devices that advance care for neonatal and pediatric patients.

The Newborn Foundation| Coalition will build upon the significant expansion of its state and federal advocacy efforts. In 2013 the Coalition took part in more than 150 briefings with Members of Congress and staff, as well as testified before the Energy & Commerce Committee significantly raising the visibility of newborn health issues on Capitol Hill.

"Babies continue to be among the most at-risk health populations. Connecting babies with the care they need is a critical demand, 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 continue to collaborate with the private sector, decision-makers here in Washington, D.C., as well as public health, provider, 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 industry, medical, academic, research, and public policy. The Newborn Foundation actively develops and implements pilots and demonstration projects that accelerate the adoption of health technologies and leverage the Newborn Coalition's policy efforts.

In 2013, the Newborn Foundation | Coalition focused on the continued policy and educational resource work required to implement newborn screening for the Critical Congenital Heart Disease (CCHD), the most common and deadly of all birth defects. The Newborn Coalition's cchdscreeningmap.org shows an additional 21 states enacted CCHD legislation or statutorily required screening in 2013, bringing the total number to 31. When the Newborn Coalition spearheaded efforts in 2010, the number of U.S. babies screened for heart defects was less than 1/3 of one percent. Today, nearly 1.2 million, or 30 percent are being screened in states, regions and institutions that have added the test, with that number anticipated to more than double in 2014, as additional states with recently enacted laws begin universal screening at their hospitals. The Newborn Foundation will continue it's current initiatives, including pilot project follow-up to the inaugural China Summit on Newborn Screening and Early Detection of CHD, in collaboration with the China Office for Maternal and Child Health Surveillance, international NGOs, numerous state departments of health, and all federal health agencies that touch the healthcare ecosystem.

About the Newborn Coalition

The Newborn Coalition 501(c)(4) (www.newborncoalition.org) and the Newborn Foundation (www.newborn-foundation.org) 501(c)(3) and are among the only multi-national organizations leveraging health IT, medtech and biotechnology innovation to improve outcomes and reduce disparities for newborns. The organizations have created a measurable footprint that supports increased understanding of newborn health issues and risk factors while helping improve access to quality care and resources for the newest, most vulnerable patients through vital research and pilot projects.

Newborn Foundation hosts

Inaugural China Summit on
Newborn Screening:

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