

Newborn Coalition Testifies Before Congress on Making More Technology Available to Improve Newborn and Infant Health

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Executive Director Jim Bialick appeared Wednesday before the House Energy & Commerce Health Subcommittee to discuss a framework that would make consumer technologies such as mobile apps more available to

parents and families caring for babies' medical issues, including congenital heart defects (CHD), the most common and deadly birth defect, affecting one in every 100 newborns.

"Babies may be sent to several hospitals, be seen by a myriad of doctors, and given a number of medications which, in today's less-than-interoperable health care system, means parents and caregivers will be responsible for managing and reconciling most of this information on their own. Very often they rely on the same smartphone or tablet they use at home to manage all of their other important information," Bialick said in his oral testimony.

Bialick spoke about the increasing integration between consumer technologies, such as smartphones and tablets, and more traditional medical devices – and how these technologies are working together to support

families and caregivers.

He continued: "We estimate that since our efforts began in 2010, the number of babies screened for heart defects in the U.S. has increased nearly 4500 percent. We are very proud of these numbers, but we have learned it is not enough just to screen. We also have an obligation to accommodate the life-long needs of those children diagnosed and living with health issues – and consumer technologies such as mobile apps play an important role in fulfilling that responsibility."

In his testimony, Bialick laid out a three-tiered, risk-based framework to promote patient safety and ensure that patients and families have continued access to life-saving technologies such as mobile apps, remote monitoring, and telemedicine. He called on Congress to convene appropriate stakeholders to develop suitable regulations for mobile apps and other technologies providers and families use to care for newborns with congenital heart disease and other serious health conditions. Bialick and the Newborn Coalition will continue to work with Congress in a bipartisan manner to address this very important issue.

Video of today's hearing and a transcript of the Newborn Coalition's testimony are available on the House Energy & Commerce website:

www.energycommerce.house.gov

About the Newborn Coalition

The Newborn Coalition (www.newborncoalition.org), a 501(c)(4) shapes policies and advances a federal agenda by leveraging health IT, medtech, and biotechnology innovation to improve outcomes and reduce disparities for our newest, most vulnerable citizens. Co-founded by the mother of a baby diagnosed at 40 hours old with congenital heart disease, the Coalition works in conjunction with the Newborn Foundation (www.newborn-foundation.org), a 501(c)(3) which has a national and international footprint that supports increased understanding of newborn health issues and risk factors while improving access to quality care, resources, and technologies through vital

research and pilot projects.

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