Healthcare Organization Commitment

Contact Details

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Commitment Details

Commitment Name
Preventing Deadly Delays: Newborn Screening Culture of Safety

Participants
Dr. Rahul Gupta, MD, MPH, MBA, FACP

What Patient Safety Challenge does your Commitment address?
Challenge 1 - Culture of Safety

How Many Hospitals Will This Commitment Represent
**Action Plan**

1) Convene the NBS QI WG and encourage the member organizations to look beyond the transit delays identified by the MJS and develop a “culture of safety” approach. a. At least two meetings in 2014, including in-person meeting(s) and conference call(s).  
2) Continue to advocate for the passage to the Newborn Screening Saves Lives Reauthorization Act. a. Passage by the Congress will be a key milestone.  
3) Continue the evaluation of vulnerabilities related to Deadly Delays in the newborn screening system a. Dr. McCabe is a member of a subcommittee of the SDACHDNC that was tasked with working on specific timeline recommendations at the April 9 meeting of the NBS QI WG.  
4) Develop March of Dimes Newborn Screening Leadership Awards a. Announce the inaugural awardees at the Patient Safety Summit in January 2015.  5) Continue to raise awareness of a need for the Culture of Safety in Newborn Screening. a. Publicize the March of Dimes Newborn Screening Leadership Awards described above and determine awardees by December 15, 2014 to be announced in January 2015 at the Patient Safety Summit in honor of Birth Defects Awareness Month. We can work with the 51 March of Dimes Chapters covering all 50 states, the District of Columbia and Puerto Rico, as well as ASTHO and our additional NBS QI WG partners, to publicize these awards b. Addition of this material to grand rounds and other presentations by Dr. McCabe in 2014. c. Update the Patient Safety Movement on this topic by Drs. McCabe and Howse in the 2015 Patient Safety Summit.

**Commitment Timeline**

By August 1, 2014, determine the status of the Newborn Screening Saves Lives Act; if not passed by that time it will not pass in this congressional session because of mid-term elections By September 1, 2014, establish the March of Dimes Newborn Screening Leadership Awards and begin call for nominations By October 1, 2014, working with the SDACHDNC, identify best practices to prevent the errors resulting from Deadly Delays in newborn screening By November 30, 2014, receive nominations for the March of Dimes Newborn Screening Leadership Awards By December 15, 2014, notify the winners of the March of Dimes Newborn Screening Leadership Awards By December 31, 2014, March of Dimes will have completed at least 5 opportunities for outreach to news media, professional audiences and other venues in presentations, interviews and print about the culture of safety in newborn screening In January 2015, update the Patient Safety Summit on progress made in this Commitment and announce the March of Dimes Newborn Screening Leadership Awards This Commitment will not be completed, since the culture of safety requires ongoing maintenance and continuous quality improvement

**Impact Details**

**Lives Lost in Last Calendar Year** 0

**How many lives do you expect to spare from harm in the next calendar year?**
Methodology for Determining Lives Saved
In the absence of data collection on misses and near misses in newborn screening, then we must rely on the literature for projections. The best source for modeling the impact of this initiative is the paper from the CDC (Holtzman et al. Descriptive epidemiology of missed cases of phenylketonuria and congenital hypothyroidism. Pediatrics 1986;78(4):553-558). They estimated 1.5 missed cases for every 100,000 babies screened in the best programs with many missed patients going undetected and unreported. However, the incidence of the two disorders they studied is 1/20,000 for PKU and 1/2,500 for congenital hypothyroidism, compared to the incidence in general of 1/100,000 or less for many of the additional 27 disorders in the RUSP identified by dried blood spot testing; therefore, the overall incidence of these 27 added disorders can be estimated at 1/3,700-1/7,500, given an average incidence of 1/100,000 of 1/200,000 each. Therefore, we would estimate a total error rate of 2.0-3.0/100,000. With this range of errors and approximately 4,000,000 babies born and tested each year, we would estimate a minimum of 80-120 babies missed per year resulting in unnecessary morbidity and mortality for these babies. These estimates do not include the functional testing for hearing loss and critical congenital heart disease, about which there is considerable concern because of lack of integration of the functional testing in the dried blood spot newborn screening infrastructure.