Healthcare Organization Commitment

Contact Details

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Position
Deputy Medical Officer, Senior Vice President Maternal and Child Health & NICU Innovation

Organization Name
March of Dimes

Commitment Details

How many hospitals are represented in this commitment?

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<th>Last Report</th>
<th>Current</th>
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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. The Newborn Screening Saves Lives Reauthorization Act was passed by Congress and signed into law on December 18, 2014, successfully completing this commitment. March of Dimes is now championing the next 5-year reauthorization of this law (see below.) 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 Update
Since 2016, March of Dimes has championed a wide range of advocacy initiatives related to newborn screening. In 2017 and 2018 alone, March of Dimes advocated successfully for the addition of new conditions to the screening panels in numerous states: • Severe Combined Immunodeficiency (SCID) screening in Arizona, Indiana and Louisiana; Patient Safety Movement Foundation | patientsafetymovement.org • Mucopolysaccharidosis I screening in 7 states, including Nebraska, New Hampshire, and North Carolina; • Pompe disease screening in 7 states, including California, Florida and Georgia; • X-linked adrenoleukodystrophy in 7 states, including Texas and Washington; and • Critical congenital heart disease screening in Kansas. In addition, March of Dimes is a leader in advocating state budget allocations and fees to support newborn screening programs. In 2017 and 2018, March of Dimes led the charge for such funding and fees in a dozen states, including major proposals to overhaul vital newborn screening laboratory systems in Oklahoma and Texas. In states like Colorado, March of Dimes played a central role in comprehensive efforts to update and modernize state newborn screening systems and laws. In 2018, March of Dimes brought together a broad coalition of organizations to align interests in support of the required five-year renewal of the federal programs that support the state-based newborn screening system, which is due to be taken up by Congress in 2019. We worked closely with the past sponsors of this legislation to renew their commitment and recruit strong new Senate champions for the bill. March of Dimes also led a dialogue in the advocacy community to discuss potential changes to the bill, provide a forum for discussion, and rally groups behind a single, unified proposal. By the end of 2018, a solid framework had been laid to support the introduction and passage of the legislation in the 116th Congress. In 2019, March of Dimes is leading the drive in the U.S. Congress for passage of the Newborn Screening Saves Lives Reauthorization Act (NBSSLRA). NBSSLRA will reauthorize and increase funding for programs at the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and the National Institutes of Health, and well as making important updates to the Secretary’s Advisory Committee on Heritable Disorders. Throughout the year, March of Dimes and the coalition will lead educational efforts in Congress, recruit cosponsors, and work with the committees of
jurisdiction to promote consideration and passage of this important legislation.

Other
Challenge 1 - Culture of Safety

Please describe any best practices your organization has learned through your commitment and share valuable lessons or challenges that were overcome

Impact Details

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<tr>
<th>Initial Commitment</th>
<th>Commitment Update</th>
<th>Project Next Year</th>
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<td>Actual Lives Spared Harm in last 12 months</td>
<td>Lives Spared Harm Target for following calendar year</td>
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<td>Projected Target of Lives Saved for following calendar to try to finish commitment</td>
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<td>New Lives Lost (lives lost – actual lives saved)</td>
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Acknowledgement

Yes, I acknowledge that this commitment may be used for external communication and publicly announced at the World Patient Safety, Science & Technology Summit. Furthermore, I agree that this commitment may appear on the website of The Patient Safety Movement Foundation or the Masimo Foundation. I also give permission for my commitment to be used in support of the promotion of the World Patient Safety, Science & Technology Summit as well as The Patient Safety Movement initiative.