

**From:** [Fed Is Best.org](http://FedIsBest.org) [<mailto:christie@fedisbest.org>]

**Sent:** Wednesday, February 07, 2018 2:15 PM

**To:** Kaeser, Lisa (NIH/NICHD) [E] <[kaeserl@mail.nih.gov](mailto:kaeserl@mail.nih.gov)>

**Subject:** Letter of Intent to Speak at the Task Force Meeting on February 26

Dear Ms. Kaeser,

I am writing to request the opportunity to speak at the Task Force meeting on February 26, 2017 at the NIH. I am writing as one of the Co-Founders of the Fed is Best Foundation whose mission is to research and provide education to parents and health professionals on safe infant feeding and safe breastfeeding to prevent the complications of jaundice, dehydration and hypoglycemia and the related brain injury caused by insufficient infant feeding. We would like to provide the U.S. Task Force important information that we have gathered regarding the prevalence of these complications, their pathogenesis, the preventable health care costs and the irreversible long-term consequences to newborns who sustain brain injury from these complications. We wish to address gaps in scientific knowledge, research and public awareness of these preventable complications that is costing the U.S. healthcare system billions of dollars a year. In addition, we wish to raise awareness on the ethical and legal gaps in informed consent and patient education on these feeding complications that occur on a daily basis.

Jaundice from insufficient feeding and dehydration are among the leading causes of newborn extended and repeat hospitalization in the U.S. and across the globe.[1-4] Among the leading risk factors for jaundice and dehydration, a entity called starvation jaundice, is exclusive breastfeeding of a newborn before full breast milk production.[5] This most commonly results from insufficient breast milk supply and secondly, from ineffective latch. According to the Academy of Breastfeeding Medicine, starvation jaundice occurs to 10-18% of U.S. exclusively breastfed newborns in the first month of life.[6] The increased risk of this brain-threatening complication associated with early exclusive breastfeeding and the important role of supplementation to prevent and treat jaundice is not currently shared with mothers. This serious gap in patient education results in approximately 228,000 phototherapy admissions every year in addition to preventable admissions for hypoglycemia (low blood sugar), hypernatremia (high sodium), dehydration and failure to thrive, all known causes of perinatal brain injury and disability. Phototherapy admissions cost the U.S approximately \$3.2 - 4.5 billion dollars annually, the majority of which (approximately 86%) are caused by starvation jaundice (i.e. non-hemolytic jaundice).[7,8] Previously healthy newborns who sustain brain injury from feeding complications can develop subtle to severe declines in attention, motor, sensory, language, behavioral and cognitive development leading to lower academic achievement and even frank global developmental disability and cerebral palsy.[9] The long-term consequences of brain injury from feeding complications can result in millions of dollars in health care costs over the lifetime of a child. A recent malpractice case of jaundice resulting in brain injury of a breastfed newborn resulted in an award of \$46.5 million dollars to a family in Arkansas. The cost to society and the emotional and psychological toll of these injuries are immeasurable.

We need publicly available statistics on the incidence of infant feeding complications in hospitals, a requirement that on its own will drive rates of feeding complications down by encouraging hospitals aggressively prevent complications. While decades of scientific evidence has shown the neurological consequences of jaundice, dehydration and hypoglycemia, we need more data to show the prevalence and the range of specific developmental disabilities in newborns who develop feeding complications. We also need research on the best ways to ensure infant patient safety and prevent feeding complications while supporting a mother's personal infant feeding goals.

Our organization has reviewed almost the entire scientific literature on infant feeding complications and has received thousands of breastfeeding complication stories from mothers directly. We believe that there are major gaps in breastfeeding education, public policy and health professional training regarding safe infant feeding, newborn caloric and fluid requirements and recognition of feeding complications. Given the financial and societal costs of infant feeding complications and their devastating consequences, we believe safe infant feeding is the most pressing issue in maternal-infant health. We would be grateful for the opportunity to assist the Task Force committee to address these issues in order to improve patient care while saving the U.S. healthcare system billions of dollars in preventable costs. In addition to speaking at the meeting, we plan to provide a written submission before the posted deadline in order to give the committee a more complete picture of the issues I have discussed above. We would also like to inquire as to how we can be involved in your Task Force committee as members or advisors beyond the upcoming meeting. We are currently involved in quality improvement research aimed at reducing neonatal feeding complication admissions at a large hospital and would be able to pass on the knowledge and insight gained from our involvement to your committee.

I thank you for this opportunity to participate in the Task Force's meeting.

Sincerely,

Christie del Castillo-Hegy, M.D.

1. Young PC, Korgenski K, Buchi KF. Early readmission of newborns in a large health care system. *Pediatrics*. 2013 May;131(5):e1538-44.
2. Janet H. Muri, Nancy Crawford, Bonnie Connors Jellen, Director Maternal and Child Health American Hospital Association, Washington, DC. Reducing Avoidable Obstetrical and Neonatal Readmissions. [https://drive.google.com/open?id=1TSlyICxBIt3BFbM\\_pzVcsu4ednleF5Ai](https://drive.google.com/open?id=1TSlyICxBIt3BFbM_pzVcsu4ednleF5Ai)
3. *Neonatology*. 2016;110(3):172-80. Neonatal Jaundice in Low-and Middle-Income Countries: Lessons and Future Directions
4. Olusanya, B. Et al Niger J Clin Pract. 2016 Jan-Feb;19(1):1-17. The burden and management of neonatal jaundice in Nigeria
5. Bertini G, Dani C, Tronchin M, Rubaltelli FF. Is breastfeeding really favoring early neonatal jaundice? *Pediatrics*. 2001 Mar;107(3):E41.
6. Bhutani VK, Maisels MJ, Stark AR, Buonocore G; Expert Committee for Severe Neonatal Hyperbilirubinemia; European Society for Pediatric Research; American Academy of Pediatrics. Management of jaundice and prevention of severe neonatal hyperbilirubinemia in infants  $\geq 35$  weeks gestation. *Neonatology*. 2008;94(1):63-7.
7. C. Del Castillo-Hegy; Calculation of annual phototherapy admissions
8. Lee BK, Le Ray I, Sun JY, Wikman A, Reilly M, Johansson S. Haemolytic and nonhaemolytic neonatal jaundice have different risk factor profiles. *Acta Paediatr*. 2016 Dec;105(12):1444-1450.
9. Bhutani VK, Johnson-Hammerman L. The clinical syndrome of bilirubin-induced neurologic dysfunction. *Semin Fetal Neonatal Med*. 2015 Feb;20(1):6-13. doi: 10.1016/j.siny.2014.12.008. Epub 2015 Jan 7. Review

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