

Using a Community Approach to Address Sudden Unexplained Infant Death

Alison Jacobson



Saving babies. Supporting families.

First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.

"The introduction in 1994 of the Safe Sleep Guidelines developed by the American Academy of Pediatrics (AAP) led to a 50% reduction in SIDS rates, which remain level while SUID rates have increased, with rates twice as high among Black and Native American infants than white."

Approximately 3,500 infants in the U.S. die annually within the first year of life from Sudden Unexplained Infant Death (SUID) and Sudden Infant Death Syndrome (SIDS), making it the leading cause of infant mortality. The introduction in 1994 of the Safe Sleep Guidelines developed by the American Academy of Pediatrics (AAP) led to a 50% reduction in SIDS rates, which remain level while SUID rates have increased, with rates twice as high

among Black and Native American infants than white.

In the years since our involvement in the Safe Sleep campaign launch, we have come to learn anecdotally that compliance with the guidelines is not a given, even when the evidence indicates this reduces sleep-related infant mortality. In 2020 and 2021, First Candle commissioned online focus groups in Michigan, Connecticut, and Georgia to understand this issue better to explore what parents, extended family members, and caregivers thought about the guidelines and their feelings about following them. (1)

We learned that context and trust matter – who is giving the advice and how it is being given -- and that families often feel there is a gap between the health care universe and the realities of daily life they face.

We came to realize that education would be far more effective if it reflected the realities of lived experiences, helped by communication that is clear, positive, sensitive to literacy levels and language needs, and included outreach that involves local communities.

"Straight Talk will continue its train-the-trainer work to help health care providers counsel families on safer sleep practices in constructive and culturally sensitive ways, and the Let's Talk Community Chat will offer families the chance to receive education and support around safer sleep and breastfeeding every month at a convenient and accessible location."

With that in mind, we decided to expand our [Straight Talk for Infant Safe Sleep](#) training program and also introduce the Let's Talk Community Chat initiative, which launches this month. (2) Straight Talk will continue its train-the-trainer work to help health care providers counsel families on safer sleep practices in constructive and culturally sensitive ways, and the Let's Talk Community Chat will offer families the chance to receive education and support



To every NICU nurse who has cared for these precious babies we say.....
"Thank you."

Did you know that premature and low birth weight babies have a 4x greater risk for SIDS?

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org

around safer sleep and breastfeeding every month at a convenient and accessible location.

These community events will bring together new parents with doulas, lactation consultants, fathers, and grandparents from the community who have gone through Straight Talk and become trained facilitators. This program addresses the issue that not all families may have the opportunity to talk in-depth with health care providers about safer sleep best practices or receive support around breastfeeding or get to well-baby visits. It also recognizes that the information they may have received could have come across as a directive rather than a conversation.

Safer sleep messaging is not a one-size-fits-all scenario and should meet families where they are “at” so they are receptive to it. We also know that fathers want to speak with other fathers or male figures, which holds true for grandparents.

The goal is to provide everyone in the family – parents, siblings, relatives, and other caregivers – clear information about safer sleep practices, the reasoning behind the AAP Safe Sleep guidelines and talk with them about the challenges, obstacles, and choices they make about where and how their baby sleeps. Supplies such as diapers, sleep sacks, and other items will also be offered, and connections to agencies and other resources families may need.

“The first Let’s Talk Community Chat is being held in Harlem in New York City, with subsequent sessions held once a month. This session is in partnership with Hope Center Harlem and the Northern Manhattan Perinatal Partnership and with support from the Ryan Wolfe Kossar Foundation.”

The first Let’s Talk Community Chat is being held in Harlem in New York City, with subsequent sessions held once a month. This session is in partnership with Hope Center Harlem and the Northern Manhattan Perinatal Partnership and with support from the Ryan Wolfe Kossar Foundation. The program will also be introduced in Brooklyn, Queens, and the Bronx, New York.

By expanding our reach to include families and healthcare providers, we can deepen our understanding of what works and does not work in advancing infant safer sleep and breastfeeding and help both professionals and consumers approach each other in partnership and community.

References:

1. Himes, B., Jacobson, A. *Understanding the Obstacles and Influences in Adopting Infant Safe Sleep Practices. Neonatology Today, Volume 16, Issue 10. October 2021, pp 63-66.*
2. <https://firstcandle.org/straight-talk-for-infant-safe-sleep/>

Disclosure: The author is the Director of Education and Bereavement Services for First Candle, a 501c (3) non-profit organization.

NT

Corresponding Author



Alison Jacobson
Executive Director
Chief Executive Officer
First Candle
49 Locust Avenue, Suite 104
New Canaan, CT 06840
Telephone: 1-203-966-1300
For Grief Support: 1-800-221-7437
Email: Alison@firstcandle.org
www.firstcandle.org

About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Infant Death Syndrome and other sleep-related infant deaths while providing bereavement support for families who have suffered a loss. Sudden unexpected infant death (SUID), which includes SIDS and accidental suffocation and strangulation in bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,600 infant deaths nationwide per year.

