

SENATE HEALTH, HUMAN SERVICES AND AGING COMMITTEE

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Testimony by Lisa Carroll, R.N., B.S.N.

Good afternoon Chairman Coughlin and members of the Senate Health, Human Services and Aging Committee. Thank you for the opportunity to offer testimony today in support of Senate Bill 144. My name is Lisa Carroll. I am a registered nurse and I have been advocating for and working to help train and support Shaken Baby Syndrome (SBS) prevention programs in the State of Ohio for several years. Today, I'd like to speak as to why Senate Bill 144 is needed in our state.

First, I think it is essential to define SBS.

- SBS is a term used to describe the constellation of signs and symptoms resulting from the violent shaking of an infant or small child up to age 5.
- Ninety percent of the time it results from the momentary lapse of control of a caregiver in response to persistent inconsolable crying.
- Symptoms usually include subdural hematoma (brain bleeding), brain swelling, and 75-90% of the time, retinal hemorrhages.
- SBS is the most violent form of child abuse for children under one year of age and accounts for 20-30% of deaths. Those children that survive will be left with disabilities ranging from learning difficulties, blindness, seizures, paralysis and mental retardation.

- One-third of the time SBS is missed when the child first presents to a health care provider. Initial symptoms can be flu-like and include vomiting, lethargy and irritability.
- Physicians are still not always coding an SBS case as SBS. Cases are also coded as inflated brain trauma and subdural hematoma. We have no effective tracking system in place in Ohio or nationwide.
- Males, including typically those who are fathers, stepfathers and mother's boyfriends account for 60-70% of the perpetrators of SBS. Most of the perpetrators are between the ages of 18-25. In-home day care providers account for 21% of perpetrators, and mothers make up 13% of perpetrators.
- Most caregivers are not given information on crying, including information that healthy infants can cry 2-4 hours for the first few months of life in 20-40 minute bouts. The average 6-week-old baby cries for approximately 3 and ½ hours.

A successful prevention message will inform parents and SBS and teach infant soothing techniques. This successful message will also give parents permission, after ruling out illness and after having made efforts to soothe, to lay a baby down in a safe place (such as a crib) on his or her back (to prevent Sudden Infant Death Syndrome) and to walk away for 10-15 minutes to regain control. The American Academy of Medicine endorses this message.

This prevention model involves minimal resources because it can be done via trainings, a teaching card used by the educator as a mental prompt, and health care professionals providing direct patient care and only three to five

minutes of their time. An additional element that can be used is a brochure so that the visual learners are reached in addition to the auditory learners.

Now, I'd like to tell you how this model was actually put into place by a project in Central Ohio.

In 2001, a small group of community volunteers from a Jewish organization in Columbus, myself included, heard a woman named Emily Fisher give a presentation on SBS at Columbus Children's Hospital. Emily told us how her baby, Elijah, was shaken to death by his biological father. Nobody in our group, including a nurse, a teacher and an attorney, had ever heard of shaken baby syndrome or had ever imagined that a tragedy could result from leaving your baby with another person that you trust or even love. I had been a practicing nurse for over 25 years at that time and was a mother of three, but I had never been taught about SBS aside from hearing or reading the obvious media message, "don't shake a baby." I began questioning my colleagues as I attended trainings all over the state, and I found that none of them really understood SBS or were talking to new mothers about normal infant crying patterns, coping with a newborn, the dangers of shaking or how to soothe a newborn baby.

After hearing Emily Fisher's story and realizing through research that there was a need for enhanced prevention efforts, our small group worked in tandem with other partners in Central Ohio to craft the Love Me, Never Shake Me Project. We looked to Dr. Mark Dias who had a successful hospital-based project in upstate New York as a guide in developing our project. We also spoke

with the Council on Child Abuse in Cincinnati and Prevention Specialists in Cleveland to learn about their prevention initiatives.

Our project involves direct, in-person prevention education through the sharing of information about SBS with new mothers and hopefully, with new fathers and others who will be significant in the baby's life. The parents are educated about normal infant crying patterns, coping methods and soothing techniques. The educator also discusses SBS. The whole process for new parents takes under five minutes, and the parents are typically given a brochure after the presentation. The project has also reached out to educate child-care workers, high school students, physicians, home visitation participants and inmates.

The world has changed some since 2001. Physicians are recognizing SBS as a differential diagnosis, coding for SBS has been established to diagnosis SBS, and I have personally trained over 50,000 people in settings as varied as hospitals, physician's offices, home visitation programs, prisons, schools and social service agencies. The training has reached far beyond Central Ohio to touch other Ohio counties in both rural and urban settings.

However, just like a domino game, when you remove one critical player in any of the participating educational settings- a critical nurse-manager on a mother infant unit leaves the participating hospital and the new nurse-manager arrives and doesn't know anything about the program- it makes it very difficult to sustain the prevention activities that this bill would make mandatory instead of voluntary.

The prevention effort has started, and it is working. Statistics show that to be effective, a prevention message must be heard three times. Research coming out of the upstate New York project run by Dr. Mark Dias is showing a 46% reduction in SBS cases since their prevention project was instituted.

I realize that this project is not without cost, but the cost is marginal in comparison to lost lives, lost futures, and lost families, as well as costly trials and incarceration and lost productivity for the perpetrator. New York statistics show that nearly half of all SBS survivors are dependent on Medicaid. The cost to institute this program ranges from approximately 15 cents per brochure to approximately \$1.00 per education subject if including nurse time, videos and trainings.

On behalf of advocates for SBS prevention and on behalf of families across the state who have been affected by SBS, I thank you for your time and urge you to support Senate Bill 144. SBS is 100% preventable!