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Press Release

October is SIDS Awareness Month

Why is changing SIDS to “Undetermined” on infant death certificates across Canada devastating for the SIDS community

Edmonton, AB, October 10, 2016: *“What has happened in the last 10 years is going back 50 years. The clock has been turned back,” Dr. Ernest Cutz M.D. FRCPC, Senior Staff Pathologist at Toronto’s Hospital for Sick Children and Chair, Medical Advisory Committee of Baby’s Breath.*

Historically, SIDS, or Sudden Infant Death Syndrome, has been associated with infants who died suddenly and unexpectedly with no cause(s) of death identified in spite of a detailed investigation. What we have seen in recent years is a trend by coroners and medical examiners across Canada to change how they label the cause of such deaths from “SIDS” to “undetermined.”

“They often look at these deaths as being nothing more than potential suffocations that can’t be proven, even when there are no signs of asphyxia [suffocation],” says Dr. Wendy Potter, Baby’s Breath Board Chair and SIDS parent. “This leaves affected families confused, despondent and stigmatized, and places an indefinite cloud of suspicion over grieving parents.”

Usage of the term “SIDS” provides parents some comfort with knowing that the death of their baby, while unexplainable, was not related to negligence or harm on their part but that it was likely a predisposition of the baby and out of their control. Also, the use of “SIDS” instead of “undetermined” legitimizes a real entity for which government and private funders can willingly support the research required to find medical causes of these tragic deaths.

Potter acknowledges the investigative approach is meant to rule out obvious cause(s) of death, but agrees with Cutz that even detailed investigation is needed.

“Because the coroners cannot find an actual cause that they can recognize by looking at the tissues with the naked eye or under a microscope – using the current techniques – they prefer to call it ‘undetermined,’ which leaves it open and (the cause) could be anything,” Cutz says.

“If you start to look for gene defects or other kinds of abnormalities using sophisticated technology, often you will find mutations,” Cutz says. “A lot of these sudden unexpected deaths are due to gene defects and in those cases, using the (current, standard) techniques, you will find nothing.”

Cutz notes that the amount of research that has gone into SIDS is miniscule compared to something like cancer research so it's not surprising that causes have yet to be found.

If "SIDS" disappears from coroner reports, it theoretically doesn't exist and therefore, funding and interest in research for the topic also disappears.

"Once the coroner or forensic pathologist closes the file, it remains closed," Cutz says. "If it's called SIDS as it was before, then people do research on it, but who's going to be interested in researching something called 'undetermined'?"

"The whole field has shifted in the direction away from trying to find the biological causes," Cutz says, adding that environmental risk factors (i.e. bumper pads in the crib) have been turned into causes rather than contributing factors. "SIDS is a pediatric disease, it's not an accidental death."

Baby's Breath is advocating for coroners and medical examiners across the country to re-instate the term SIDS to define the sudden and unexpected death of an infant less than one year of age that remains unexplained after full investigation, whether or not risk factors were present.

Research must be done and medical advances must be made if we have any hope of one day being able to screen, diagnose, treat and ultimately prevent these deaths. This cannot happen when these infant deaths are classified as "undetermined."

Baby's Breath advocates on behalf of Canadian families who have experienced the tragic loss of an infant.

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*If you would like more information about this topic, please contact **Emily Isaak**, Baby's Breath Executive Director, at 1-800-363-7437 or info@babysbreathcanada.ca, also see www.babysbreathcanada.ca*