

SUDC FOUNDATION KEY MESSAGES

These Key Messages provide an **overarching communications guide for the SUDC Foundation**. They provide the groundwork for all Foundation communications. Message consistency is essential to the success of any organization. All future communications about and for the Foundation should include these messages in some manner.

These messages are **not a script and do not need to be memorized verbatim**. Instead, they should serve as a **guide outlining key concepts for all future communications**. Key words or phrases are bolded to emphasize those key concepts as well as accurate terminology preferred by the Foundation. But each communicator should use them in a manner that is most comfortable for him/her and best suited for the audience s/he is communicating with.

These messages are also **not intended to be limiting**. Each message point serves a specific and strategic purpose for the Foundation and are written succinctly and concisely for ease of communication. Each message point has additional data points to be incorporated when additional support is needed. Additional support can be added or expanded upon as needed as well.

These Key Messages have four main points:

- **The Need:** This message point explains the need that exists, the challenge that has to be overcome or a problem that must be solved.
- **Why We Do What We Do:** This message point clarifies why the Foundation exists and the void it fills.
- **How We Do It:** This message point describes how the organization works in its unique way to address the need, challenge or problem.
- **Vision:** This message point describes the world the organization hopes to create once it has accomplished its mission and the end result of its efforts after the needs are met, the challenges are overcome and the problem is solved.

SUDC Foundation's Key Messages

The Need: Every year, **at least 400 children** die for no known reason. Even after a **thorough investigation and autopsy**, families, medical professionals and death investigators have no answers on why a healthy and thriving child passes away



The SUDC Foundation
800-620-SUDC (973-239-4849)
www.sudc.org

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suddenly and unexpectedly. The only answer we have currently is Sudden Unexplained Death in Childhood (SUDC).

- **Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 which remains unexplained after a thorough investigation and autopsy.**
- Most often, SUDC occurs in seemingly healthy children during sleep.
- At this time, **we do not know what causes SUDC, how to predict it or how to prevent it.**
- SUDC is believed to be rare; occurring in about **one in every 100,000 children.**
- **We do not know exactly how often SUDC occurs.** Because of inconsistencies in death certification practices and because the World Health Organization (WHO) lacks a specific way to record sudden and unexplained deaths in children that have been thoroughly investigated, it is impossible to know how widespread the problem is.

Why We Do It: SUDC is one of the most under-recognized medical tragedies of our time. The medical community and our society have failed these children and their families. **We have done far too little for far too long, and we have to change that.** Research is crucial to uncovering cause(s) of and ways to prevent SUDC deaths. Families not only need emotional support, but also medical guidance, assistance navigating the difficult and often confusing process of searching for what may have happened to their child and how to live their lives after loss. Medical professionals need help providing the best medical care and emotional support for the families they care for.

- **While it is the fifth leading category of death among children ages 1 to 4, SUDC has received no public funding to date.**
- SUDC families often grieve in isolation, without information, resources or awareness that other families exist with a similar loss.
- Due to a lack of consistency and standards in death investigations, coroners and medical examiners don't always have the resources to perform all the testing needed to thoroughly investigate each child's death or give the support families need.
- The lack of consistency and standards leads to a lack of data, further exhausting the medical community's ability to find overarching connections and trends in SUDC deaths.



How We Do It: The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC. The SUDC Foundation provides all services at no cost to the people it serves.

- The SUDC Foundation currently supports **over 800 families in 18 countries.**
- The SUDC Foundation provides personalized, comprehensive care from licensed clinical social workers with a variety of programs and cultivates a community of support for bereaved families so no one grieves alone.
- The SUDC Foundation helps families navigate the difficult and often confusing investigation into their child's death by being a liaison between families and the medical examiner or coroner.
- The Foundation assists families in accessing DNA banking services and SUDC research, including the Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC), at New York University. The SUDCRRC provides families with a thorough case review of a child's medical history and death, as well as additional testing to examine possible causes and ways to diagnose and prevent SUDC.
- The SUDC Foundation helps doctors, medical examiners and coroners to care for and communicate with families experiencing the sudden, unexpected and/or unexplained loss of a child.
- The SUDC Foundation supports efforts, including legislative, to ensure comprehensive and standardized death investigations, fair treatment of and appropriate medical care for families and thorough data collection to improve our understanding of SUDC.

Vision: The SUDC Foundation envisions a world where no more children are lost to Sudden Unexplained Death in Childhood.



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