



SUDC Foundation

Teen Ambassador Orientation

Step 2: SUDC Foundation Information + Messaging

About Us

★ Our Vision

A world without Sudden Unexplained Death in Childhood (SUDC).

★ Our Mission

Raise awareness, fund research, and serve those affected by sudden unexpected or unexplained death in childhood.

★ Our Value

We are the only organization worldwide whose purpose is to raise awareness, fund research, and serve those affected by SUDC. SUDC is the **fourth** leading category of death in children ages one to four, yet SUDC receives no public funding. The SUDC Foundation provides all services at no cost to families.

★ Our History

- In 1999, a small group of parents affected by unexplained toddler death attended a presentation at the SIDS Alliance national convention in Atlanta, GA. The presentation by Dr Henry Krous was entitled "Post-Infancy SIDS-Is it on the rise?" Following the presentation, Dr. Krous agreed to review the children's records of the families in attendance to learn more about them. Over the following two years, more families who had experienced an unexplained childhood death were identified and Dr Henry Krous and Laura Gould cofounded the San Diego SUDC Research Project which studied cases of SUDC from 2001- 2012.
- Laura Gould, a Neurological Physical Therapist by training, and Chelsea Hilbert, an ER Social Worker by training, brainstormed together to create the mission of The Sudden Unexplained Death in Childhood Program. A proposal was submitted to the national

non-profit, the CJ Foundation for SIDS, to support this new program and it was created in the fall of 2001. The SUDC Program was created to be a centralized resource for Sudden Unexplained Death In Childhood providing information, support, advocacy and research.

With each year, the program grew to provide more services to more families with greater needs. In 2014, Laura Gould and Lorri Caffrey, both SUDC parents, along with Dr Orrin Devinsky and Jim Lintott founded the SUDC Foundation as an independent non-profit health organization. The SUDC Foundation was created to continue the mission of the Program, as well as meet the current needs of those touched by Sudden Unexplained Death in Childhood.

★ Planning Our Work and Priorities

- Our [team](#) and [board members](#) are part of the SUDC community, and we engage a variety of other professionals in our work.
- Our board of directors includes leaders across the U.S. and holds the organization accountable for achieving our initiatives and supporting professionals and families affected by SUDC
- Our SUDC Foundation Ambassador Program includes more than 100 committed and trained volunteers who support advocacy and outreach efforts.
- We consistently earn a platinum GuideStar rating – the highest honor from this group that reviews nonprofits and their operations, encourages charitable giving and helps donors make sound decisions.
- Our ratings, audit reports, annual reports and more details can be found [here](#).

Key Messages

These Key Messages provide an **overarching communications guide for the SUDC Foundation**. They provide the groundwork for all Foundation communications. Consistent messaging 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 serve as a guide outlining key concepts for all future communications. Communicators should use them in a way that feels most comfortable and is best suited for their audience.

These messages are also **intended to be flexible**. Each message point serves a specific and strategic purpose for the Foundation and is crafted succinctly for ease of communication. Additional data points are available to provide further support when needed, allowing for expansion as appropriate.

These Key Messages have four main points:

1. **The Need:** This message point explains the need that exists, the challenge that has to be overcome or a problem that must be solved.
2. **Why We Do What We Do:** This message point clarifies why the Foundation exists and the void it fills.
3. **How We Do It:** This message point describes how the organization works in its unique way to address the need, challenge or problem.
4. **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.

★ THE NEED

Every year, at least 500+ 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 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**.
- Due to variations in investigations and the way deaths are certified- **we do not know exactly how often SUDC occurs**. This is why the advocacy work the SUDC Foundation does, and the research it funds is so important. Consistency in recording unexplained deaths improves our understanding of the magnitude of SUDC and allows for appropriate allocation of resources.

★ 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 fourth 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 raise awareness, fund research, and serve those affected by SUDC. The SUDC Foundation provides all services at no cost to the people it serves.

- The SUDC Foundation currently supports over 1900+ families in 23 countries.
- The SUDC Foundation provides personalized care from licensed 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 obtaining post mortem autopsy reports and review and identifying SUDC research opportunities available to the family. Research can provide families with a thorough case review of a child's medical history and death, as well as additional testing to examine possible causes while also supporting research efforts.
- The SUDC Foundation is the primary funder of the Sudden Unexplained Death in Childhood Registry and Research Collaborative (SUDCRRC), at New York University. The [SUDCRRC](#) provides families with a comprehensive case review of 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.

★ What are the next steps?

Please continue to the next section of your Ambassador Program Training, which includes answers to frequently asked questions about the Foundation and the work we do.

Last Revised: 6.5.24