



**SUDC**  
FOUNDATION

**The SUDC Foundation**  
**Annual Report 2019**


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# Our Vision, Mission and Value

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

A photograph of three young children of diverse backgrounds. In the foreground, a young girl with dark skin and hair is smiling, resting her chin on her hands. Behind her, a young boy with light skin and curly hair is smiling. To the left, another young boy with light skin and short hair is smiling. They are all wearing bright, colorful clothing (red, green, and yellow).

We are the only organization worldwide whose purpose is to promote awareness, advocate for research, and support those affected by SUDC.

SUDC is the fifth 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.

## Why We Do It

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up. At this time, we do not know what causes SUDC, how to predict it or how to prevent it. SUDC is one of the most under-recognized medical tragedies of our time. **“Medicine has done a very poor job of identifying this disorder and studying it.”**-Dr. Orrin Devinsky.

## Dear Friend,

Thank you so much for your support in 2019. Through the generosity of our supporters, the SUDC Foundation continued to advance our mission of promoting awareness, advocating for research, and supporting those affected by sudden unexpected or unexplained death in childhood. I would love to share some of this year's highlights with you.

2019 was a pinnacle year for the Sudden Unexplained Death in Pediatrics Project. The project was made possible through a scientific grant from the SUDC Foundation to the National Association of Medical Examiners to work collaboratively with the American Academy of Pediatrics to create research-based national practice guidelines surrounding the investigations, certification, research needs and the sensitive care of families for sudden, unexpected deaths in infants and young children.

To further increase awareness of SUDC, we launched our medical education strategic initiative to provide direct medical education at academic medical centers and related medical conferences. We provided resources to help medical examiners, coroners, pediatricians and other doctors care for and communicate with families experiencing the sudden unexpected and unexplained loss of a child. We educated and advocated for the needs of the SUDC community through legislative efforts to ensure comprehensive and standardized death investigations. In November, we took our concerns directly to Washington, DC and educated our federal policymakers on current legislation under their review like Scarlett's Sunshine Act. The SUDC Foundation Ambassador volunteer program continues to grow and makes strides in awareness. We are so grateful for their coordinated efforts.

We also continued our critical role in advocating for SUDC research. We awarded a \$275,000 scientific grant to the SUDC Registry and Research Collaborative at New York University Langone Health, funding its efforts to increase our understanding of the deaths of children 11 months through 18 years who have died suddenly and unexpectedly, and, in some instances, without explanation to understand risk factors and causes and develop preventive measures. The registry is now the largest registry of SUDC cases in the world.

This year, we served more than 95 new families affected by the sudden death of a child and crossed the surreal landmark of serving our 1,000th family since our inception. This was a profound realization for me which I wrote out in our recent blog. We are now supporting families in 21 countries, with bereavement support services coordinated by our social worker. Our unique range of services ensure that no one grieves alone. We also hosted our second annual SUDC Family Retreat in Phoenix, Arizona. Over 200 family members attended the weekend of activities to restore, reconnect and renew. About 90 of the participants were children, who had lost a brother or sister to a sudden unexplained death.

Please read on to learn more about these amazing things you helped us to accomplish. We end 2019 in gratitude for everything we have been able to accomplish, and we reflect on the stories of precious children who have touched our hearts. We look forward with determination to attain our 2020 goals. We hope you will continue with us as we strive to achieve a future free of SUDC.

On behalf of the SUDC Foundation's Board of Directors and our staff, thank you so very much.

Gratefully,

A handwritten signature in cursive script that reads "Laura".

**Laura Gould (Crandall)**

Co-founder, President, and Executive Director

# The SUDC Foundation Funds and Promotes Research



In 2019, the SUDC Foundation provided a grant to Langone Health at New York University in the amount of \$275,000 to be used to fund the **SUDC Registry and Research Collaborative (SUDCRRC)**. The SUDCRRC's purpose is to increase the understanding of the characteristics, circumstances, medical histories and pathologies of children ages 11 months through 18 years who have died suddenly and unexpectedly, and, in some instances, without explanation, to understand risk factors and causes and develop preventive measures. The SUDCRRC provides families with a thorough case review, performed by a multidisciplinary panel, of a child's medical history and death, family history and information gathered during an interview with the child's family. It also includes additional testing, including (but not limited to) neuroimaging, neuropathology and genetic analysis on the child who died and his/her biological parents, all of which seeks to examine possible contributing factors and potential causes of death of the child they lost. There is no cost to participants or to medical examiner or coroner offices to refer participants.

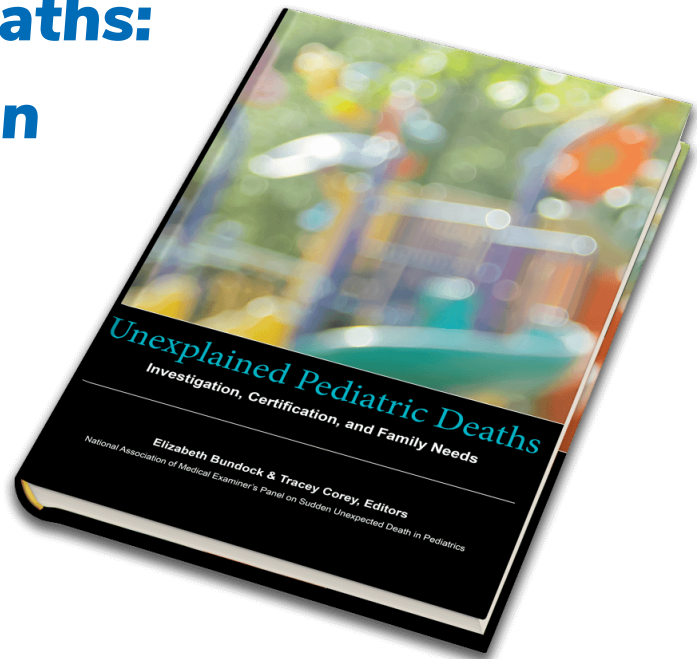
The registry is now the largest registry of SUDC cases in the world. We are privileged to support this multi-centered project with more than 25 multidisciplinary co-investigators.

To learn more visit <https://sudc.org/sudc-registry-research-collaborative/>

## Recent publications from the SUDC Foundation include:

- National Association of Medical Examiners Panel on Sudden Unexpected Death in Pediatrics. Unexplained Pediatric Deaths: Investigation, Certification, and Family Needs. Bundock E, Corey T, editors. San Diego: Academic Forensic Pathology International; c2019. 340 p.
- Phoon C, Halvorsen M, Goldstein D et al. Sudden unexpected death in asymptomatic infants due to PPA2 variants. *Mol Genet Genomic Med.* 2019;8(1). doi:10.1002/mgg3.1008
- OSAC, Proposed Standard Organizational and Foundational: Standard for Medicolegal Death Investigation, Prepared by Medicolegal Death Investigation Subcommittee Submitted to Standard Development Organization August 2019- Currently Under Review
- Crandall L, Lee J, Stainman R, Friedman D, Devinsky O. Potential Role of Febrile Seizures and Other Risk Factors Associated With Sudden Deaths in Children. *JAMA Netw Open.* 2019;2(4):e192739. doi:10.1001/jamanetworkopen.2019.2739
- Goldstein RD1, Blair PS2, Sens MA3, Shapiro-Mendoza CK4, Krous HF5, Rognum TO6, Moon RY7; 3rd International Congress on Sudden Infant and Child Death. Inconsistent classification of unexplained sudden deaths in infants and children hinders surveillance, prevention and research: recommendations from the 3rd International Congress on Sudden Infant and Child Death. *Forensic Sci Med Pathol.* 2019 Dec;15(4):622-628. doi: 10.1007/s12024-019-00156-9. Epub 2019 Sep 9. PMID: 31502215 PMCID: PMC6872710 [Available on 2020-12-01] DOI: 10.1007/s12024-019-00156-9
- Hoch M, Bruno M, Faustin A et al. 3T MRI Whole-Brain Microscopy Discrimination of Subcortical Anatomy, Part 2: Basal Forebrain. *American Journal of Neuroradiology.* 2019;40(7):1095-1105. doi:10.3174/ajnr.a6088 (SUDCRRC)
- Hoch M, Bruno M, Faustin A et al. 3T MRI Whole-Brain Microscopy Discrimination of Subcortical Anatomy, Part 1: Brain Stem. *American Journal of Neuroradiology.* 2019. doi:10.3174/ajnr.a5956 (SUDCRRC)

# Unexplained Pediatric Deaths: Investigation, Certification and Family Needs



The SUDC Foundation recently published a first-of-its kind book, *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs*, a collaboration led by the National Association of Medical Examiners (NAME) and the American Academy of Pediatrics (AAP), which establishes the first ever national consensus guidelines in the U.S. to fill crucial needs to determine why unexplained pediatric deaths happen and how to support families after these tragedies. It outlines procedural guidance for a comprehensive investigation and autopsy and provides guidance to promote consistent classification of unexplained pediatric deaths, which greatly impacts our ability to understand how often they occur. It also offers recommendations for the care of families after such tragedies. Adoption of these guidelines is critical to achieve a better understanding of these deaths, successful public health prevention strategies and appropriate care of the bereaved.

“This book draws on the experience and insight of dozens of experts from around the country,” says Tracey Corey, M.D., Associate Medical Examiner for Florida Districts 5 & 24 and one of the editors for this book. “Each guideline was developed based on extensive research, historical context, and sound rationale. Implementing them will advance the way we investigate these deaths, arming us with a system that will help us better determine why these deaths happen and support those we serve.”





**“The SUDC Foundation has put us in touch with others who know our pain and they have given us hope that we can find an answer, whether it be now or in the future.”**

*– The Zachara Family*

# The SUDC Foundation Promotes Awareness of SUDC



The SUDC Foundation supports Scarlett's Sunshine on Sudden Unexpected Death Act, legislation introduced in honor of Scarlett Pauley, who was lost to SUDC in January

2017 when she was just 16 months old. If passed into law, Scarlett's Sunshine Act (H.R. 2271/ S. 1130) would strengthen efforts to better understand SUID and SUDC, facilitate data collection and analysis to improve prevention efforts, and support children and families. Currently, there are no nationwide standards for investigating and collecting data following an infant or child death. This makes it nearly impossible to determine the causes of these deaths and what strategies our country can implement to prevent these tragedies.

In November, we took our support directly to Washington, DC and educated our federal policymakers on current legislation under their review like Scarlett's Sunshine Act.

This bill has also been endorsed by the American Academy of Pediatrics, Children's Hospital Association, Cribs for Kids, First Candle, March of Dimes, Kids in Danger, Within Our Reach and the Aaron Matthew SIDS Guild of Seattle Children's Hospital.

## SUDC Awareness Month

March 2019 marked the third year of SUDC Awareness Month activities. Forty-three states joined our nationwide effort and proclaimed March as SUDC Awareness Month. In addition, 3,000 people changed their Facebook profile pictures to spotlight SUDC awareness. Each week, the SUDC Foundation's public Facebook, Twitter, and Instagram pages announced a new activity and encouraged the SUDC community to share their stories of participation on social media with #SUDCawareness. We had very high participation in our month-long activities, which included wearing SUDC memorabilia, performing random acts of kindness, sharing information about SUDC, and posting videos on social media about why SUDC Awareness Month is so important.



# 2019 Impact

To date, the SUDC Foundation has provided support to:

**1,900** parents,

**403** grandparents,

**1,104** siblings,

and **124** extended family members

who have lost a child to a sudden unexpected death.

Staff hours devoted to Family  
Advocacy efforts in 2019:

**2,686**

Staff hours devoted to Family  
Services and helping our  
families in 2019:

**3,048**



# Family Services

In 2019, the SUDC Foundation served its 1,000th family. While we are sorry for the reason, we are honored for the opportunity to help so many families. The Foundation provided personalized, unique services and cultivated a community of support for bereaved families, so no one grieves alone. The Foundation also helped approximately 95 newly registered 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. In addition, the Foundation assisted 40% of those newly registered families in accessing research and DNA banking services which could lead to answers on what may have happened to their child.



## Connecting the SUDC Community



**SUDC UK:** Our affiliate, SUDC UK, which launched in 2017 has been successfully fundraising for research and was able to provide \$50,000 to the SUDC Foundation to further support our research grant efforts.



**SUDC Family Retreat:** We held our second annual SUDC Family Retreat in Phoenix, Arizona. Over 200 family members attended the weekend of activities to restore, reconnect and renew. About 90 of the participants were children, who had lost a brother or sister to a sudden unexplained death. SUDC Foundation



**Ambassador Program:** The SUDC Foundation Ambassador Volunteer program continues to grow and makes strides in awareness. We are so grateful for their coordinated efforts. We now have 109 members, who have completed 118 awareness activities in 2019 alone! We launched our medical education strategic initiative at Dartmouth University in September, led by Dr. Erin Bowen. Erin is an SUDC parent, pediatrician and member of the SUDC Foundation's Board of Directors and our team of SUDC Medical Ambassadors. The initiative will provide direct medical education at academic medical centers and related medical conferences.

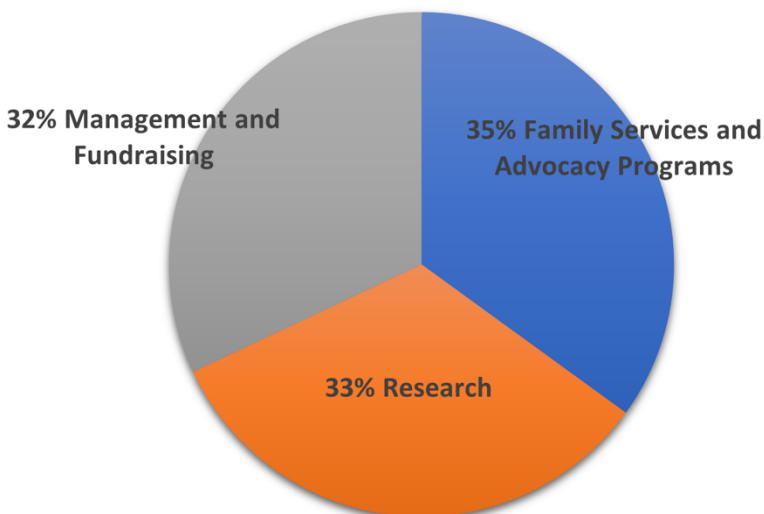


**Fundraising in support of the SUDC Foundation:** In 2019, the SUDC Foundation applauded participants who supported members of the SUDC community by attending fundraising events. A total of 60 fundraising events were hosted to raise awareness of SUDC and fund the critical work of the SUDC Foundation. Events for SUDC included run/walk races, challenge events, T-shirt sales, golf outings, gala receptions, community gatherings and a fishing tournament hosted among 16 U.S. states and four countries, raising collectively over \$634,000.

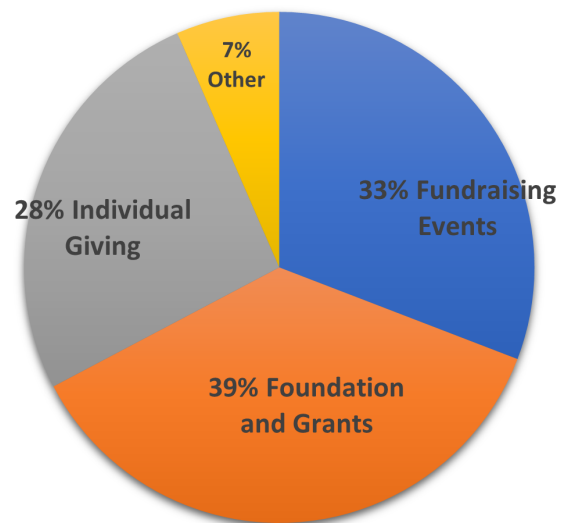
**THE SUDC FOUNDATION**  
**STATEMENTS OF ACTIVITIES**  
*For the Years Ended December 31, 2019 and 2018*

	2019			2018		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
	<b>REVENUES</b>					
Private foundation contributions	\$ 513,619	\$ -	\$ 513,619	\$ 497,662	\$ 75,000	\$ 572,662
Special events, net of expenses of \$53,451 and \$48,205 for the years ended December 31, 2019 and 2018, respectively	186,292	-	186,292	214,246	-	214,246
Memorial gifts	104,323	-	104,323	89,192	-	89,192
Interest income	4,320	-	4,320	-	-	-
Other income	4,731	-	4,731	32,942	-	32,942
Net assets released from restriction: Satisfaction of purpose restrictions	50,759	(50,759)	-	11,714	(11,714)	-
<b>Total revenues</b>	<u>864,044</u>	<u>(50,759)</u>	<u>813,285</u>	<u>845,756</u>	<u>63,286</u>	<u>909,042</u>
<b>EXPENSES</b>						
Program services - research and family services	622,430	-	622,430	349,352	-	349,352
Management and general	280,148	-	280,148	206,542	-	206,542
Fundraising	12,581	-	12,581	13,318	-	13,318
<b>Total expenses</b>	<u>915,159</u>	<u>-</u>	<u>915,159</u>	<u>569,212</u>	<u>-</u>	<u>569,212</u>
<b>CHANGES IN NET ASSETS</b>	(51,115)	(50,759)	(101,874)	276,544	63,286	339,830
<b>NET ASSETS - Beginning of year</b>	<u>1,321,145</u>	<u>77,019</u>	<u>1,398,164</u>	<u>1,044,601</u>	<u>13,733</u>	<u>1,058,334</u>
<b>NET ASSETS - End of year</b>	<u>\$ 1,270,030</u>	<u>\$ 26,260</u>	<u>\$ 1,296,290</u>	<u>\$ 1,321,145</u>	<u>\$ 77,019</u>	<u>\$ 1,398,164</u>

**Expenses**



**Revenue Sources**



# Board of Directors and Staff

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