

SUDC
FOUNDATION

sudden unexplained death in childhood



THE SUDC FOUNDATION ANNUAL REPORT 2018

www.sudc.org

info@sudc.org

(800)620-SUDC

Our Vision, Mission and Value

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

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,

2018 was a monumental year for the SUDC Foundation and we are proud to share this summary with you. We are indebted to our community of supporters, who stay committed with us to reach a future free of SUDC.

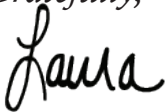
In 2018, we saw our family community surpass 900, and held our first ever SUDC Family Retreat in Naples, Florida. Witnessing the growing connections of people weighted with trauma be uplifted through the kindness of other bereaved families was an honor to witness and am so proud of our Foundation for making this happen.

Our research priorities continued with our funding to NYU Langone Health to support the SUDC Registry and Research Collaborative and completed our funding to the National Association of Medical Examiners to create national consensus standards for infant / child death investigations, research and family needs. The project will culminate in a book being published in November 2019.

Our awareness efforts took on amazing feats this past year. Through the continued growth of the SUDC Ambassador Program, the reintroduction of Scarlett's Sunshine Act in Congress, the first-ever Summer Podcast series, and successful SUDC Awareness month (March), we are so pleased with the accomplishments of our engaged community.

We are driven to continue our progress in 2019 and stay diligently committed to lead our community towards a world without SUDC.

Gratefully,



Laura Gould Crandall

Co-founder, President, and Executive Director



The SUDC Foundation Funds and Promotes Research

SUDC Registry and Research Collaborative (SUDCRRC)

In 2018, the SUDC Foundation provided a grant to New York University School of Medicine in the amount of \$160,000 to be used to fund the 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. To learn more visit [sudc.org>research & medical info>SUDC Research and Registry Collaborative](http://sudc.org/research&medicalinfo/SUDC%20Research%20and%20Registry%20Collaborative).

Recent publications from the SUDCRRC include:

- Crandall LG, Lee J, Stainman R, Friedman D, Devinsky O., Sudden Deaths in Children: Potential Role of Febrile Seizures and Other Risk Factors, JAMA Open Network, April 2019
- Hoch MJ, Bruno MT, Faustin A, Cruz N, Mogilner A, Crandall L, Wisniewski T, Devinsky O, Shepherd T. 3-T MRI Whole Brain Microscopy Discrimination of Subcortical Anatomy, Part 2: Basal Forebrain AJNR Am J Neurodiol. July 2019.
- Hoch MJ1, Bruno MT2, Faustin A3, Cruz N2, Crandall L4,5, Wisniewski T4,6, Devinsky O4,5, Shepherd TM7,8. 3T MRI Whole-Brain Microscopy Discrimination of Subcortical Anatomy, Part 1: Brain Stem. AJNR Am J Neuroradiol. 2019 Mar;40(3):401-407. doi: 10.3174/ajnr.A5956. Epub 2019 Jan 31.
- Gould Crandall, L. Inexplicable Child Deaths: Medicolegal Death Investigation Resources From the SUDC Foundation and the SUDC Registry and Research Collaborative Acad Forensic Pathol. 2017 7(2): xxiv-xxvi
- Crandall L, Devinsky O. Sudden Unexplained Death In Children. The Lancet Child and Adolescent Health, Vol 1, September 2017
- Halvorsen M, Petrovski S, Shellhaas R, Tang Y, Crandall L, Goldstein D, Devinsky O. Mosaic mutations in earlyonset genetic diseases Genet Med. 2016 Jul;18(7):746-9. doi: 10.1038/gim.2015.155. Epub 2015 Dec 30. PMID: 26716362

Sudden Death in Pediatrics: Consensus for Investigation, Certification, Research Direction and Family Needs

The SUDC Foundation awarded a grant of almost \$100,000 to the National Association of Medical Examiners (NAME) to work collaboratively with the American Academy of Pediatrics (AAP) to investigate and establish national practice guidelines surrounding the investigations, certification, research needs and the sensitive care of families in cases of sudden unexpected deaths in infants and young children.

We are excited to announce these guidelines will soon be published in a book. The SUDC Foundation will announce when it is available for purchase. We are grateful to all those involved who dedicated their time to volunteer for this important project, especially the Editors, Dr. Elizabeth Bundock and Dr. Tracey Corey, the National Association of Medical Examiners and the American Academy of Pediatrics. Learn more about the book, in press November 8, 2019, at sudpeds.com.

Bundock, E.A, and Corey, T. S (Eds). 2019. Unexplained Pediatric Deaths: Investigation, Certification and Family Needs. Academic Forensic Pathology International In Press.



Pictured left to right: Owen, Danielle, Andy and Emily holding a picture of Blake (3/26/15-9/3/16)

“The SUDC Foundation has provided our family a strong sense of close community and awareness for other families who’ve lost a child for a similar unapparent reason. The Foundation offers comprehensive services and support that have made a profound positive impact on our grief journey and has helped us hope and cope for the future.

Andy and Danielle Duffey

The SUDC Foundation Promotes Awareness of SUDC

☀️ SCARLETT'S SUNSHINE ACT ☀️

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) will authorize over \$49 million in new federal funding to strengthen efforts to better track, understand and prevent SUDC and SUID. Specifically, it would supply grants to help states and municipalities to improve data collection and death scene investigations related to unexpected infant and child deaths and ensure death reviews are completed for 100 percent of infant and child fatalities. 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.

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. To learn more and support Scarlett's Sunshine on Sudden Unexpected Death Act, please visit <https://sudc.org/scarlettssunshineact>.



SUDC Awareness Month

March 2018 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.

2018 Impact:

To date, the SUDC Foundation has provided support to 1,625 parents, 349 grandparents, 1,057 siblings and 101 extended family members who have lost a child to a sudden unexpected death.

**Staff hours
devoted to
Family Advocacy
efforts in 2018:
2,442**

**Staff hours
devoted to
Family Services
and helping our
families in 2018:
2,651**

Family Services

In 2018 the Foundation was a resource for over 900 families in 18 countries. The Foundation provided personalized, comprehensive care from licensed clinical social workers and cultivated a community of support for bereaved families, so no one grieves alone. The Foundation also helped approximately 86 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 Co-founders Nikki Speed, Helen Charalambous and Camilla Gooden

SUDC UK

Our affiliate **SUDC UK** was launched, enhancing the SUDC Foundation's efforts to support the needs of the SUDC community in the UK.

SUDC FOUNDATION FAMILY RETREAT

The first-ever **SUDC Foundation Family Retreat**, hosted in Naples, Florida, was a great success, bringing together 140 family members from three countries. The Retreat included guest speakers, news from the SUDC Foundation, restorative meditation, kids' programs, adult yoga, golf and a butterfly release, also enabled families to bond with one another.



Families at the 2018 SUDC Foundation Family Retreat in Naples, Florida

SUDC Foundation Ambassadors Promote Awareness



Dr. Erin Bowen meets with Dr. Colleen Kraft, President of the American Academy of Pediatrics to discuss SUDC and ways pediatricians can help support families after these tragic losses.

Members of the SUDC Foundation Ambassador Program continued to help the SUDC Foundation achieve its mission of promoting awareness, advocating for research, and supporting those affected by sudden unexpected or unexplained death in childhood.

SUDC Foundation Medical Ambassadors have spearheaded efforts to education fellow medical professionals about SUDC. Led by SUDC Foundation Board member Erin Bowen, M.D., their efforts have resulted in over 80,000 medical providers learning more about SUDC and improving care of families affected by SUDC.

Dr. Bowen also participated in presentations at Children's Hospital at Dartmouth-Hitchcock Medical Center, Yale New Haven Children's Hospital, and the National Conference of the American Academy of Pediatrics.





Fundraising supports the SUDC Foundation

In 2018, the SUDC Foundation applauded participants who supported members of the SUDC community by attending fundraising events.

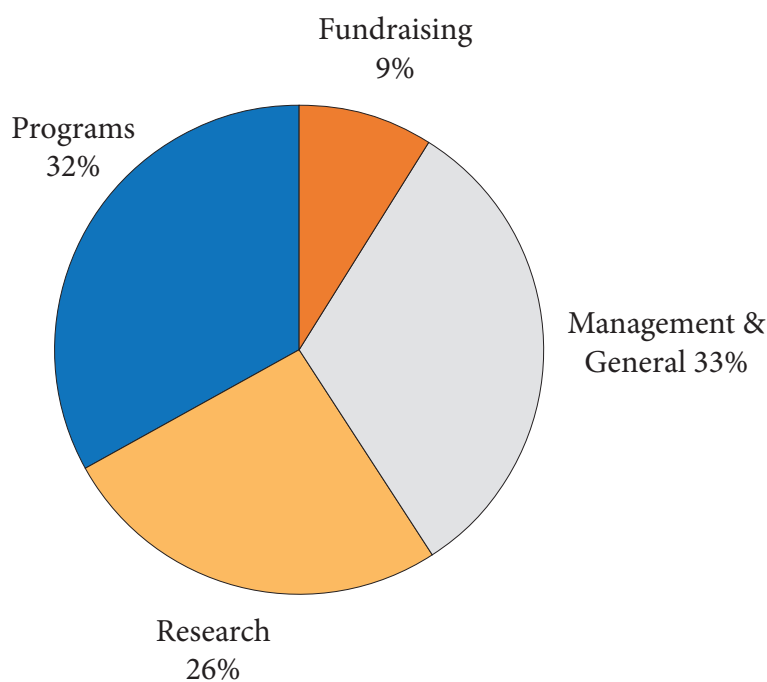
A total of 64 fundraising events were hosted to raise awareness of SUDC and fund the critical work of the SUDC Foundation.

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 4 countries, raising collectively over \$634,000.



THE SUDC FOUNDATION
STATEMENTS OF ACTIVITIES
For the Years Ended December 31, 2018 and 2017

	2018			2017		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
REVENUES						
Private foundation contributions	\$ 497,662	\$ 75,000	\$ 572,662	\$ 713,755	\$ -	\$ 713,755
Special events	262,451	-	262,451	249,542	-	249,542
Memorial gifts	89,192	-	89,192	92,921	-	92,921
Other Income	32,942	-	32,942	11,437	-	11,437
Net assets released from restriction:						
Satisfaction of purpose restrictions	11,714	(11,714)	-	16,000	(16,000)	-
Total revenues	893,961	63,286	957,247	1,083,655	(16,000)	1,067,655
EXPENSES						
Program Services	356,203	-	356,206	518,574	-	518,574
Management and General	206,542	-	206,542	235,637	-	235,637
Fundraising	54,672	-	54,672	40,743	-	40,743
Total expenses	617,417	-	617,417	794,954	-	794,954
CHANGE IN NET ASSETS	276,544	63,286	339,830	288,701	(16,000)	272,701
NET ASSETS - Beginning of year	1,044,601	13,733	1,058,334	755,900	29,733	785,633
NET ASSETS - End of year	\$ 1,321,145	77,019	1,398,164	1,044,601	13,733	1,058,334



SUDDEN UNEXPLAINED DEATH IN CHILDHOOD (SUDC) FOUNDATION 2018-2022 STRATEGY

2018 was a pivotal year for the Foundation as we achieved significant progress toward implementation of our five-year strategic plan. In April 2018, we asked foundation stakeholders to rank direct family services and community services offered. The results are helping us to strategically drive resources for the best impact for our community. 336 respondents represented various sectors of SUDC Foundation community including the National Association of Medical Examiners, American Board of Medicolegal Death Investigators and the International Association of Coroners and Medical Examiners. We learned that the most valued direct family services provided are those centered around family advocacy, sudc.org and the LCSW support of families. The most valued community services we provide are assisting ME/C offices with investigation resources, providing SUDC medical research grants and assisting ME/C offices as a family liaison. To learn more about how respondents ranked the SUDC Foundation visit <https://sudc.org/about-us/our-vision-mission-and-value>.

Officers and Founding Members:

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Lorri Caffrey, Vice President & Secretary
Jim Lintott, Esq., Treasurer

Members:

Erin Bowen, MD **Julia Burgess**
Bobby Jenkins **Steve Myers**
Matthew Polenzani

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& STAFF**

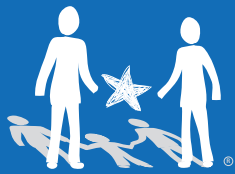


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THE SUDC FOUNDATION
101 EISENHOWER PARKWAY, SUITE 300
ROSELAND, NJ 07068
973.795.1257
WWW.SUDC.ORG