



2021

Impact Report

DEAR FRIEND,

I hope you and your family are safe and well. We entered 2021 full of hope that we could put all the challenges of 2020 behind us and move forward with unrelenting determination to advocate for the needs of the SUDC community. We are delighted to be able to share some of the high points of the year with you now!

SUDC Awareness Month reached a new level of success in 2021 – including the incredible awareness event hosted by the Los Angeles Dodgers featured on the next page. We are humbled and grateful to the team and Major League Baseball for an afternoon that left us without words but with full hearts. We were incredibly touched to see our Stride for SUDC Challenge leaderboard filled with friends and extended family members from around the world supporting those affected by SUDC.

We are excited to see the safer return of in-person events. We are also glad to see that many of our hosts have continued to incorporate virtual options for their participants, expanding the opportunity for our global community to join.

We continue to represent a community with many stories but one shared voice. As we celebrate these successes, we continue to strive to meet the unique and evolving needs of the global community we serve in distinctive and innovative ways. Thank you so much for your support that allows this work to continue.

As always, I would love to hear from you and discuss the work being done at the SUDC Foundation.



In gratitude and peace,

Laura Gould
Laura Gould
Co-founder and President

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The mission of the SUDC Foundation
is to promote awareness, advocate for
research and support those affected by
sudden unexpected or unexplained death in
childhood.

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PROMOTING AWARENESS

March is SUDC Awareness Month!

- Our supporters participated in weekly activities to raise awareness throughout the month – shining a light on SUDC, wearing their hearts on their sleeves, spreading kindness and taking strides for awareness.
- We sent over 800 free awareness kits to our supporters all over the world to help mark the month.
- SUDC Awareness Month was honored through 44 U.S. state proclamations, one House resolution and one Executive proclamation.

From the bottom of our hearts, we offer our gratitude to everyone who helped us honor SUDC Awareness Month. Your efforts have helped us promote awareness, advocate for research and support those affected by sudden unexpected or unexplained death in childhood.

6,400+
miles for SUDC
Awareness Month!



To wrap up SUDC Awareness Month in 2021, the SUDC community accepted the Stride for SUDC Awareness Challenge – to walk, run, roll or ride 1,000 miles to raise awareness of SUDC and in honor of the over 1,000 families the SUDC Foundation supports worldwide. We were blown away when our supporters shattered that goal more than six times over, surpassing 6,400 miles! Thank you to everyone who participated!



Azure and Cody Kaasmann designed and sold SUDC awareness ribbons in memory of their daughter Adele to benefit the SUDC Foundation. Their fundraiser sold 250 ribbons! Thank you, Kaasmann family, for your support of the SUDC Foundation.

LA Dodgers Hit One Out of the Park for SUDC Awareness



Photo Courtesy Jessie Alceh/MLB

To recognize SUDC Awareness Month in March, the World Series Champion Los Angeles Dodgers and Major League Baseball (MLB) helped spread awareness of Sudden Unexplained Death in Childhood (SUDC) in a very big way. During their March 21st spring training game against the San Francisco Giants, the Dodgers wore specially designed SUDC

Foundation patches on their uniforms. During the sold-out game, announcers in the stadium and on the television broadcast shared information on SUDC and explained how the team was honoring the approximately 400 children lost to SUDC in the United States each year. We are so thankful to the Los Angeles Dodgers and MLB for their incredible efforts!

EVENT SPOTLIGHT

Jackson Walsh Foundation Chari-tee Golf Tournament

The Jackson Walsh Foundation hosted their Chari-tee Golf Tournament in Leesburg, Virginia in October of 2021. The event featured a golf outing, raffles, a silent auction and games throughout the day. The event raised funds specifically for SUDC research.

“We volunteer with the Foundation because we love to keep Jackson’s memory alive and bring awareness to this tragedy,” says Kelsey Walsh, “After losing our 17 month old son unexpectedly, we were eager to raise awareness and funds because of all the amazing things the SUDC Foundation has done in support of other parents like us.”



Kelsey and Peter Walsh, with their daughters, Harper and Blake



Vivienne’s Joy Foundation Starry Night Gala

The Vivienne’s Joy Foundation hosted their 2nd annual Starry Night Gala in May of 2021. The event featured a silent and live auction and a special performance by Cloud Cult. It also featured bestselling author and podcast host Nora McInerny as the Mistress of Ceremonies. The virtual evening raised funds to help make the 2022 SUDC Foundation retreat accessible to as many families as possible!

“After canceling last year’s event, we hosted our first ever virtual gala this year,” Julia Burgess, one of the event chairs shared. “We are beyond grateful for all our generous donors who made the event a huge success and helped us raise \$60,000 to support the annual SUDC Foundation Family Retreat.”

The Vivienne’s Joy Foundation Starry Night Gala is held in memory of Vivienne, who passed away unexpectedly in her sleep in 2016 when she was just 3 years old. Vivie’s parents, Julia and Wade Burgess, describe her as a joyful child who loved books, spending time with her big sister, Elianna, and playing with her friends at school.



ADVOCATING FOR RESEARCH

The SUDC Foundation is proud to support the work of the SUDC Registry and Research Collaborative (SUDCRRC), led by Dr. Orrin Devinsky at the NYU Grossman School of Medicine through our scientific grants. With over 300 SUDC families enrolled, it is now considered to be the largest centralized registry of SUDC cases in the world. Our growing understanding has allowed the SUDCRRC to explain some deaths that were previously unexplained, but we have a long way to go. Our continued support is vital to reaching a future free of SUDC. In 2021, scientific advancements by the SUDCRRC include the following publications:

Blinded Review of Hippocampal Neuropathology in Sudden Unexplained Death in Childhood Reveals Inconsistent Observations and Similarities to Explained Pediatric Deaths.

Leitner DF, McGuone D, William C, Faustin A, Askenazi M, Snuderl M, Guzzetta M, Jarrell HS, Maloney K, Reichard R, Smith C, Weedn V, Wisniewski T, Gould L, Devinsky O.

Researchers at the SUDCRRC utilized hippocampal H&E slides (n=67; 36 SUDC, 31 controls) and evaluated them across 9 blinded reviewers. Results identified a lack of an association of hippocampal findings in SUDC and controls. Inconsistent observations call for larger studies to standardize the evaluation of hippocampal findings and better understand its normal variation.

Seizure-related deaths in children: The expanding spectrum.

Harowitz J, Crandall L, McGuone D, Devinsky O.

This literature review provides a current analysis of the shared epidemiological features of SUDC, SUDEP and SUID as they relate to seizures and recognizes the crucial need for improved recognition, surveillance and research to better understand and address these tragedies.

For a full list of publications from the SUDCRRC, visit sudc.org/published-research-articles

SUDCRRC

SUDC Registry and Research Collaborative

First Genetic Risk Factors Identified for Sudden Unexplained Death in Children After Age 1

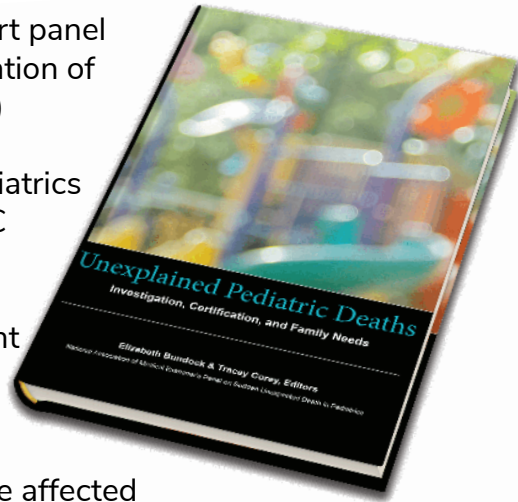
A study by the SUDCRRC found that changes in specific genes contribute to the approximate 400 children lost to SUDC each year. The study, which was published in December of 2021, is the first to identify genetic differences present in a large group of SUDC cases, the majority of which occurred in children between ages 1 and 4. Researchers at the NYU Grossman School of Medicine, including SUDC Foundation Co-founder and President Laura Gould, analyzed the DNA codes of 124 sets of parents and of their child who died suddenly. They found that “nearly 9 percent—or 11 of the 124 children—had DNA code changes in genes that regulate calcium function. Calcium-based signals are important for brain cell and heart muscle function. When such signals are abnormal, they may cause arrhythmias (abnormal heart rhythms) or seizures, both of which increase the risk of sudden death” (NYU Langone News Hub).

Matthew Halvorsen, Laura Gould, Xiaohan Wang, Gariel Grant, Raquel Moya, Rachel Rabin, Michael J. Ackerman, David J. Tester, Peter T. Lin, John G. Pappas, Matthew T. Maurano, David B. Goldstein, Richard W. Tsien, Orrin Devinsky [De novo mutations in childhood cases of sudden unexplained death that disrupt intracellular Ca²⁺ regulation](https://doi.org/10.1073/pnas.2115140118), *Proceedings of the National Academy of Sciences*, Dec 2021, 118 (52) e2115140118; DOI: 10.1073/pnas.2115140118 www.pnas.org/content/118/52/e2115140118

Groundbreaking Book

Unexplained Pediatric Deaths: Investigation, Certification and Family Needs offers the first national consensus guidelines to fill crucial needs to help identify why these deaths happen and support families after these tragedies.

It is the product of an expert panel led by the National Association of Medical Examiners (NAME) in collaboration with the American Academy of Pediatrics (AAP) funded by the SUDC Foundation. The SUDC Foundation donated over 600 copies of this important resource in 2021 to medical examiners, coroners, physicians, and other professionals who are affected by SUDC.



The full text is available for free online at tinyurl.com/upd-book. To request a free copy, reach out to info@sudc.org while supplies last.



SUDC★UK

Sudden Unexplained Death in Childhood

an affiliate of the SUDC Foundation

Did you know?

SUDC UK is an affiliate of the SUDC Foundation that is dedicated to raising awareness, funding research and supporting families affected by Sudden Unexplained Death in Childhood (SUDC) in the United Kingdom.

SUDC UK aims to help make SUDC predictable and preventable by raising awareness and funding crucial research, as well as supporting those affected by SUDC by connecting them with expert professional and peer support through collaboration with the SUDC Foundation.

For more information on SUDC UK, visit sudc.org.uk

“The SUDC Foundation has been a vital source of support for us as we continue to navigate life without Shaiden.”

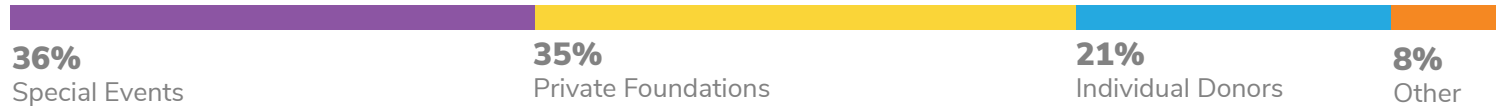
“It has helped us to find purpose in our pain by providing an opportunity for us to contribute to the work of understanding unexplained deaths as well as a community of support among other families that have experienced the devastating, untimely loss of a child. We are grateful that we do not have to experience the depths of grief alone.”

— Shedrick and Danica Brown (right), with their son Shaiden, who was lost to SUDC in 2019



2021 FINANCIALS

INCOME



EXPENSES



	2021			2020		
	Without Donor Restrictions	With Donor Restrictions	Total	Without Donor Restrictions	With Donor Restrictions	Total
Private foundation contributions	\$ 385,768	\$ 21,502	\$ 407,270	\$ 495,589	\$ 8,000	\$ 503,589
Special events, net of expenses of \$54,344 and \$13,252 for the years ended December 31, 2021 and 2020, respectively	397,582	-	397,582	219,691	-	219,691
Memorial gifts	224,926	-	224,926	181,061	-	181,061
Investment income	6,328	-	6,328	23,561	-	23,561
Other income	9,349	-	9,349	8,758	-	8,758
Loan forgiveness	95,279	-	95,279	-	-	-
Net assets released from restriction:						
Satisfaction of purpose restrictions	-	-	-	24,641	(24,641)	-
Total revenues	<u>1,119,232</u>	<u>21,502</u>	<u>1,140,734</u>	<u>953,301</u>	<u>(16,641)</u>	<u>936,660</u>
Program services - research and family services	525,865	-	525,865	575,972	-	575,972
Management and general	273,141	-	273,141	175,654	-	175,654
Fundraising	82,666	-	82,666	48,235	-	48,235
Total expenses	<u>881,672</u>	<u>-</u>	<u>881,672</u>	<u>799,861</u>	<u>-</u>	<u>799,861</u>
CHANGES IN NET ASSETS	237,560	21,502	259,062	153,440	(16,641)	136,799
NET ASSETS - Beginning of year	<u>1,423,470</u>	<u>9,619</u>	<u>1,433,089</u>	<u>1,270,030</u>	<u>26,260</u>	<u>1,296,290</u>
NET ASSETS - End of year	<u>\$ 1,661,030</u>	<u>\$ 31,121</u>	<u>\$ 1,692,151</u>	<u>\$ 1,423,470</u>	<u>\$ 9,619</u>	<u>\$ 1,433,089</u>



Guidestar, the world's largest source of information on nonprofit organizations, has **consistently awarded the SUDC Foundation its highest honor**, the Platinum rating. Guidestar uses its rating system to advance transparency, help donors make better decisions and encourage charitable giving.

OUR 2021 IMPACT — THANKS TO YOUR SUPPORT

1,491

families served in

22

countries



7

presentations to educate medical professionals on SUDC, how to care for families and SUDC research opportunities



\$285,000

donated to support cutting edge SUDC research

3

NEW research publications helping bring us closer to solving these medical mysteries



633

copies of unexplained death investigation guidelines distributed to support medical death investigators and medical professionals



GET INVOLVED

GIVE

Donate now
at sudc.org

Become a monthly donor
even \$10 a month can make
a difference

Join our Starlight Society
by remembering the SUDC
Foundation in your estate
planning



Support the SUDC Foundation at work through your employer's giving program. Find out if your employer includes the SUDC Foundation in their employee giving program on our website.

Visit sudc.org/workplace-giving for more information

"Through my work at Comcast, I have the opportunity for my yearly charitable contributions to be matched via the Comcast NBCUniversal Matching Gift Program, and it was an easy choice for me to have those funds go to the SUDC Foundation. The Comcast NBC Universal Foundation provided a two-for-one match of my donation this past year, effectively tripling our family's support of this incredible organization, which has given us so much."

—Ron Zachara (left), SUDC Parent

SHARE

Follow us on our social media and share the stories of the beautiful children lost to SUDC and the work we are doing to create a world free of SUDC.



@sudcfoundation



@sudc



/sudcfoundation



/company-sudcfoundation

VOLUNTEER

Join the SUDC Foundation Ambassador Program to promote awareness of SUDC and support the mission of the SUDC Foundation.

"There's a quote I found really helpful that says, 'Nothing good can come from my daughter's death, but good can come from my response to it.' That's why I wanted to become an SUDC Foundation Ambassador, to honor Lucy's legacy, and to try to have a positive impact on others."

— Samantha Willis (right), SUDC Foundation Ambassador; daughter Lucy pictured above



For more information, visit sudc.org/ambassador-program

JOIN

Attend an event near you held in memory of an SUDC child to support the SUDC Foundation.

For a full list of upcoming events, visit sudc.org/events

Right: PAC MAN Party 5K,
hosted in memory of Paxton Shaw

