

Tayjon's story is featured in
Chapter 3 in new book

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WHAT IS SUDC?

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.



OUR MISSION

The SUDC Foundation envisions a world where no more children are lost to Sudden Unexplained Death in Childhood. The SUDC Foundation is the only organization worldwide whose purpose is to promote awareness, advocate for research and support those affected by SUDC.

CONTACT US

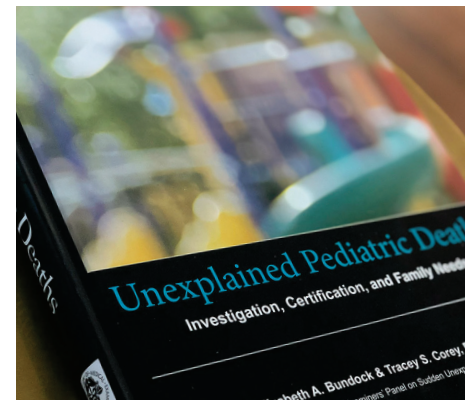
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Groundbreaking New Book Fills Dire Needs in Unexplained Pediatric Deaths

The SUDC Foundation's scientific grant award to the National Association of Medical Examiners (NAME) has now resulted in new U.S. national guidance to help determine why unexplained pediatric deaths happen and how to support families after these tragedies.

NAME led an effort in coordination with the American Academy of Pediatrics (AAP) to create a first-of-its-kind book, *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs*. The publication is a combined effort of a panel of over 30 medical examiners, pediatricians and federal agency representatives who represent the diverse interests of epidemiology, death investigation, autopsy performance, death certification, clinical subspecialties (neurology, cardiology, child abuse, injury prevention, infectious diseases, genetics and metabolic diseases), family needs, prevention and research.



"The devastating loss of a child is compounded when we cannot explain how that precious life ended," said Elizabeth Bundock, M.D., Ph.D., Deputy Chief Medical Examiner for the Office of the Chief Medical Examiner in Burlington, Vermont and one of the editors of the book. "While many of these unexplained deaths expose the limits of our collective medical knowledge, ideally, none should expose shortcomings in our effort to identify the cause of death."

Each year in the U.S., over 3,000 infants and children, who are otherwise apparently healthy, die suddenly and without explanation. These deaths not only have profound effects on families, but also serious implications for our public health system.

"This book draws on the experience and insight of dozens of experts from around the country," said Tracey Corey, M.D., Associate Medical Examiner for Florida Districts 5 & 24 and one of the editors of the 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."

Unexplained Pediatric Deaths 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.

To learn more about the book, please visit [SUDPeds.com](https://www.sudpeds.com).



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Dear Reader,

I hope this newsletter finds you and your family safe and well. Since our last newsletter, the world has become a different place – transformed by uncertainty and suffering, but also filled with opportunities for growth and compassion. The SUDC Foundation represents a community with many stories, but one shared voice. In this light, the SUDC Foundation reaffirms its commitment to support all those affected and improve the health of all children and their families.

We are proud to share some of the highlights of the recent months through this newsletter. After years of hard work and dedication by many, *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs*, a groundbreaking new book, is here! We are eternally grateful to the editors, Dr. Elizabeth Bundock and Dr. Tracey Corey, and the entire committee for their tireless work to bring this endeavor to fruition. We are so thankful for the generosity of our supporters, allowing us to publish the book and provide complimentary copies to more than 1,000 medical examiners across the U.S. and abroad!

It is through the vital support of our donors that we have been able to continue our support of the SUDC Registry and Research Collaborative at NYU Langone Health. The path to producing high-quality research is long and arduous, but we are making progress and have helped provide explanations for some previously unexplained deaths - each a new step closer to a future free of SUDC.

In addition, I hope you check out our improved website that features streamlined navigation, new features, updated resources and a remodeled online shop with brand-new SUDC gear!

As we celebrate these advances, we rise to meet the unique and evolving needs of the global community we serve in distinctive and innovative ways. We thank you for your vital support to allow 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,

Laura

Laura Gould Crandall, President and Co-founder

How Pediatricians Can Play an Important Role After a Child's Sudden Death

by Dr. Erin Bowen

After the sudden, unexpected death of a child, numerous professionals enter families' lives, including first responders, law enforcement, emergency department physicians and nurses, social workers and child protection agencies. Pediatricians can serve as a liaison between families and professionals during this overwhelming time, helping to explain the local medicolegal death investigation process, facilitating communication between the family and medical examiner or coroner, and offering a face-to-face meeting to address mental and physical health needs and appropriate referrals. Pediatricians can refer families to the SUDC Foundation and for research opportunities like the SUDC Registry and Research Collaborative.

Surviving siblings are often referred to as the "forgotten mourners" and pediatricians can advocate for these siblings and provide valuable support through age-appropriate resources, including recommendations for books, strategies for parents on how to discuss death with their children and referrals for sibling support groups and mental health specialists. Medical referrals for siblings will vary, but may include cardiology, genetics and neurology. Pediatricians should also approach the care of both surviving and subsequent siblings with sensitivity for the bereaved family's unique needs, recognizing that parents may fear that their surviving and subsequent children will die. It is important to balance the need for providing compassionate care with not overmedicalizing these children.

The loss of a child is devastating for all involved, including the family and the professionals involved in their care. The pediatrician is often one professional among the many involved that has an existing relationship with the family. They are in a unique position to advocate for families, and their role should not end with the child's death. The SUDC Foundation can assist pediatricians in ensuring families receive adequate support and are connected with appropriate resources after these tragedies.



the author, Dr. Erin Bowen, with her husband and two of her children



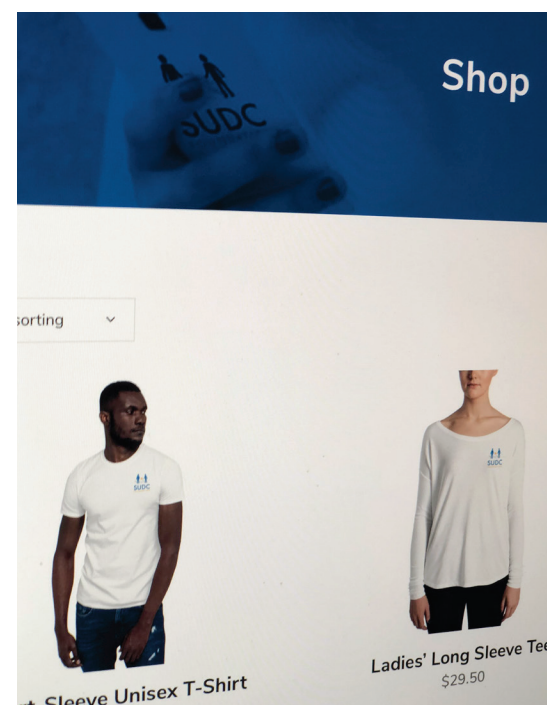
Check out our new look at [SUDC.org](https://www.sudc.org).

Our updated website has lots of new and improved information and resources!



Shop for SUDC

Check out our updated [Shop for SUDC](https://www.sudc.org/Shop) page that includes new styles of casual and polo-style shirts and brand-new products like children's sweatshirts and cell phone cases. 100% of the proceeds benefit the SUDC Foundation. Orders yours today at [SUDC.org](https://www.sudc.org) > [How to Help](#) > [Shop](#).





Meet the Newest Member of the SUDC Foundation Board of Directors: Laura Dozier

We are pleased to announce that Laura Dozier has been appointed to the SUDC Foundation Board of Directors. Laura is a Certified Registered Nurse Anesthetist, providing anesthesia care in the greater Charleston area for the last nine years. She received her Master of Science in Nurse Anesthesia from the Medical University of South Carolina after earning her bachelor's degree from the University of North Carolina, Chapel Hill.

Laura's son, Slade, died in his sleep at 18 months of age leaving behind his twin sister.

Along with her husband Tom, Laura founded the Slade Dozier Foundation in 2016. Its mission is to raise awareness of and facilitate research toward understanding and preventing SUDC. Laura serves on the Parent Advisory Committee for Mount Pleasant Presbyterian Learning Center and as a deacon at the church. Her hobbies include boating and traveling. She resides in Mount Pleasant, S.C. with her husband, two girls, two dogs and three chickens.

Providing Innovative Family Services During a Global Pandemic



The pandemic caused by the novel coronavirus has changed the lives of people around the world, including families affected by the sudden death of a child. As the world's response quickly evolved, so did the services the SUDC Foundation provides to meet the needs of our global community. The SUDC Foundation is always proud to provide a range of services at no cost to our families. And while many in-person services were forced to shut their doors, the SUDC Foundation expanded our services to those who needed it most.

We have added virtual social hours for our community of families to connect - catch up, share coping skills, vent, discuss


their experiences in a safe place with others who understand and sometimes even laugh. We also host sessions tailored to newly bereaved families, fathers and grandparents. Some of our community members share their talents to offer unique programs. Recently, one of our SUDC parents, Holly Racine, shared her experience as a geologist and led an educational and engaging webinar on volcanoes that was fun for the whole family. Two of our SUDC parents, Genevieve and John Deely, led a virtual discussion on a book authored by Genevieve based on her journey as a grieving mother, which is now available for online viewing. And SUDC mother and master gardener Eleanor Wroath led a special education hour on gardening through grief. You can see a full calendar at SUDC.org.

The SUDC Foundation continues to share resources and tips for coping during times of trauma, stress and loss. Our volunteer Ambassadors have also stepped up to provide additional support to our newly bereaved families during this difficult time of social distancing. As always, the SUDC Foundation Family Services is forever listening and adapting to the needs of our community and will rise up to meet the challenges of today. To learn more about the SUDC Foundation Family Services, go to SUDC.org/services-for-bereaved-families.

Virtual Event Planning

The global pandemic due to the novel coronavirus has compelled many events that benefit the SUDC Foundation to shift to virtual events. Virtual events offer the opportunity for people from all over the world to participate while helping the host to raise money for a cause. Virtual events are also cost-effective, flexible and easy to plan!

Virtual events can include a physical challenge - like a walk, run or bike ride! We have created a "virtual event planning guide" to help supporters plan and execute a great event! This can be found at SUDC.org. We're here to assist you in any way you need!



Hosting a Successful Virtual Challenge Event

What is a Virtual Challenge Event?

Virtual challenge events are a great fundraising tool. They are flexible in design and easy to plan and execute because they are not as logistically complex as live challenge events. In addition, other than the cost of an online registration platform and prizes, there are very few expenses, which make these types of events the perfect fundraising option at any time.

A virtual challenge event is hosted online. Participants are able to join remotely from wherever they are, instead of gathering in person. Virtual events are most often organized around a fitness goal or group activity and, just like a live event, are hosted to raise funds for a charity or remembrance of a special person or to recognize a significant date. Anyone of any ability can participate at their own pace. It can be completed at any location in the time period set forth by the event organizers.

For instance, a virtual challenge event could be a physical challenge that participants can accomplish on their own, such as a 5K run, family fun walk or a long-distance bike ride. Participants who sign up for the challenge register online and choose a local course to follow, often within their neighborhood or community. They complete the required distance, upload their personal finishing time and receive acknowledgment from the host. The event can take place over a weekend or a few days, rather than on a single day, which can make it more convenient for a larger number of people to participate.

Planning a Virtual Challenge Event?


The SUDC Foundation can help you successfully plan and execute a virtual challenge event. Pick the type of challenge activity and the date(s) as soon as possible. This will allow all planning leading up to the event itself. Hostly the SUDC Foundation of the virtual event and the date as soon as possible so we can assist you in the planning process and provide additional resources to help ensure your success.

Select a small event committee, two or three people, to assist with planning. It is essential that one person (or co-chairs) oversees the entire event. If you are hosting an SUDC Foundation event, the chairperson must be a registered member of the SUDC Foundation and have given through the appropriate Ambassadors (volunteer) orientation. The chairperson should understand the mission and the work of the SUDC Foundation and be able to clearly communicate about the SUDC Foundation's mission.

When selecting the event planning committee, keep people's specific talents and connections in mind.

Key committee responsibilities:

- Managing timelines to ensure deadlines are met
- Being a liaison with the SUDC Foundation to ensure graphics and platform design meet standards and to access Foundation resources
- Selecting participants, online advertisements and sponsors
- Tracking all donations, registrations and sponsorships
- Communicating with participants, donors and sponsors throughout the event
- Purchasing custom event items, with any sponsor logos, to mail to event registrants in time for the day of the event

 [SUDC.ORG](https://SUDC.org)

Supporting Groundbreaking Research

The SUDC Foundation supports groundbreaking researchers working to improve our understanding of sudden unexpected and unexplained deaths in children. These are some of the recent works published with financial support from the SUDC Foundation. With the generous donations of our supporters, we are explaining the unexplained.

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

The authors examine genetic variants in the PPA2 gene responsible for the sudden death of two asymptomatic siblings who were 10 and 12 months old. These variants led to lethal cardiomyopathies. Authors conclude these findings provide further information on clinical and molecular features of PPA2 variants.

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

Authors analyzed neuroimaging data from SUDC cases of the brain stem which contains life-sustaining sensorimotor and autonomic structures. They concluded that "possible structure-function asymmetries in these pathways will require further study—that is, the cross-sectional area of the left corticospinal tract in the midpons appeared 20% larger ($n = 13$ brains, $P < .10$)."

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

Authors analyzed neuroimaging data of the basal forebrain in SUDC cases and authors conclude findings "better define individual variations relevant to functional neurosurgical targeting and validate/complement advanced MR imaging methods."

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 Network Open*. 2019;2(4):e192739. doi:10.1001/jamanetworkopen.2019.2739

Authors examined 391 cases of both SUDC and sudden, explained deaths in children between the ages of 1 and 6 years from 2001-2017 in 18 different countries. Data for this study was collected from 622 family members of children who died suddenly and unexpectedly and voluntarily registered with the SUDC Foundation. The family members provided the data evaluated through a comprehensive interview on medical and social histories and circumstances of death and forensic evaluations revealed an explained or unexplained cause of death (SUDC). "This analysis of the largest SUDC cohort confirmed an increased febrile seizure (FS) rate and found significantly increased rates of FS among sudden explained deaths in children. This study suggests that seizures may contribute to some SUDC and sudden, explained deaths in children. The risk of sudden death in a sibling was low. To develop and assess preventive strategies, population-based studies are needed to define the epidemiology and spectrum of risk factors and identify biomarkers of patients with FS at high risk of sudden death."

McGuone D, Leitner D, William C et al. Neuropathologic Changes in Sudden Unexplained Death in Childhood. *Journal of Neuropathology & Experimental Neurology*. 2020;79(3):336-346. doi:10.1093/jnen/nl136

Authors performed systematic neuropathologic investigation in 20 SUDC cases and found hippocampal alterations were the most common finding on histological review, but were also found in possibly explained deaths. They concluded the "significance and specificity of hippocampal findings is unclear as they may result from seizures, contribute to seizure pathogenesis, or be an unrelated phenomenon."

our partner in research

SUDCRRC
SUDC Registry and Research Collaborative



Learn more about ways the SUDC Foundation fulfills its mission to advocate for research by watching our enlightening new video at [SUDC.org/advocate-for-research](https://www.sudc.org/advocate-for-research).

“ The generosity of the supporters of the Taylor McKeen Shelton Foundation has allowed us to invest in cutting edge and innovative research funded by the SUDC Foundation. One project we are particularly proud of investigates neuroimaging techniques to better understand the brain in SUDC. This research was featured on the cover of the *American Journal of Neuroradiology* in March 2019. Together with the SUDC Foundation, we will continue to find answers. ”

- Wes and Ella Shelton

How You Can Help: Planned and Monthly Giving

Planned and monthly giving help ensure the future of the SUDC Foundation, allowing us to invest in critical research into the causes of Sudden Unexplained Death in Childhood and ensuring families affected by SUDC continue to receive support services free of charge.

Planned Giving:

Thoughtful gift planning can help meet your overall financial goals while leaving an enduring legacy that supports program areas that are most meaningful to you. And it helps us endow a brighter future for all children.

One way to do this is leaving a gift to the Foundation in your will, through a specific dollar amount, a percentage of the residual estate or a specific asset, such as a marketable property.

The SUDC Foundation could also be named as a charity beneficiary of your IRA or retirement plan, life insurance, charitable remainder or lead trust account. In addition, Qualified Charitable Distributions (QCD) allow individuals over 70½ years old to donate up to \$100,000 in IRA assets directly to a charity annually, without taking the distribution into taxable income. These are easy ways to support our mission without altering your existing estate plans.

The SUDC Foundation is also able to accept grants from a donor advised fund when such gifts are designated by the owner of the fund.

If you have already remembered the SUDC Foundation in your estate plans or are planning to do so in the future, please let us recognize your generosity by including you in the SUDC Foundation Legacy Society.

Monthly Giving:

For as little as a gift of \$20.00 per month, you can help the SUDC Foundation support cutting edge research! The process is easy – your payment will be automatically charged each month in the amount of your choosing.

Monthly gifts may be cancelled or changed at any time. Your monthly gift may also be eligible for a match by your employer, doubling the amount donated each month. Please let us know if you need assistance with establishing a monthly gift or learning more about your employer’s matching gift program.

Thank you for helping us invest in a future free of SUDC. We are deeply grateful for your generosity and continued support.

For more information on planned or monthly gifts, please contact Director of Development, Elizabeth Milliken.



the CARES ACT

includes new tax incentives to benefit charitable giving

The Coronavirus Aid, Relief and Economic Security (CARES) Act, enacted on March 27, 2020 allows individual taxpayers to deduct donations to a qualified charity of up to \$300 on their 2020 federal tax return (\$600 if filing jointly with a spouse), even if they take the standard deduction.

For U.S. citizens who itemize their annual deductions, the CARES Act increases the maximum of Adjusted Gross Income for charitable contributions to qualified charities from 60 to 100% through the end of this year.

For further information on how personal charitable giving may be impacted by the CARES Act, please speak with your personal financial advisor.

How your support makes a difference:

Every dollar you give to support the SUDC Foundation brings us one step closer to fulfilling our mission!

\$50	\$75	\$100	\$200	\$500	\$1000
helps one bereaved family bank their child's DNA	provides our customized "Help for Families" brochures to a medical examiner or coroners' office	provides online group support sessions for the newly bereaved	gives a lifeline of unique resources and information through our Family Resource Guide	assists advocacy efforts for the fair treatment and appropriate medical care of families	can support critical research to better investigate the genetic characteristics of SUDC

event SPOTLIGHT

SUDC supporters continue to amaze us with the fundraising events they host in memory of their loved ones to support the SUDC Foundation!



GOLFING for OLIVIA

Novi, MI, USA



The Butash family hosted their 2nd annual Golfing for Olivia event this past September. The event featured a golf outing, dinner and raffles, spreading awareness to approximately 200 people and raising over \$22,000 for the SUDC Foundation, bringing the event's two-year total to over \$40,000!

"Hosting Golfing for Olivia in memory of Olivia meant the world to Ryan, myself and our family," said Erika, Olivia's mom. "The event provided us a great opportunity to celebrate Olivia's life with those we love the most. We were able to share memories of Olivia as well as raise awareness and funds for the SUDC Foundation. These types of events are a great avenue to educate those who have not heard of SUDC and generate critical funds to support the great work of the Foundation. The overwhelming support we have had for Golfing with Olivia has far surpassed what we imagined when we first decided to create the event."

Golfing for Olivia is held in memory of Olivia Butash, who passed away unexpectedly in her sleep in September 2015 when she was just 17 months old. Olivia's parents describe her as a happy girl who loved books and her Minnie Mouse stuffed animal.



LEVI'S RUN for A REASON

Rensselaer, IN, USA



The Hitchings family hosted their first annual Levi's Run for a Reason in March. The event featured a 5K run, 3K family fun walk and cornhole tournament. Levi's Run for a Reason hosted 300 people and raised over \$25,000 for the SUDC Foundation!

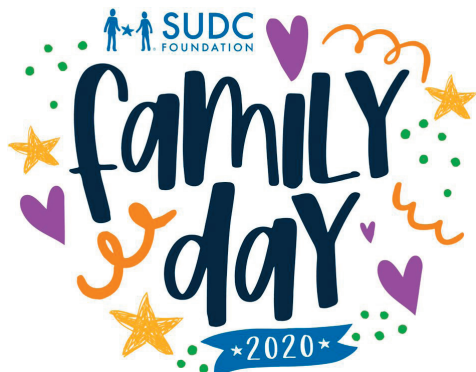
"We were so honored to host this event in honor of our son Levi," Danielle, Levi's mom said of hosting the fundraiser. "The support we received from the SUDC Foundation, our family, friends and community was overwhelming."

Levi's Run for a Reason was held in memory of Levi Hitchings who passed away when he was just 2 years old in March of 2019. Levi's family describes him as a fearless little boy who loved superheroes, singing and his family.

The SUDC Foundation is grateful to the Butash and Hitchings families, and all our supporters, who host and attend events to benefit the SUDC Foundation and enable the services and grants we provide. To see a list of upcoming events, please visit: [SUDC.org](https://www.sudc.org) > Calendar.



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We are pleased to announce our inaugural SUDC Foundation
FAMILY DAY SEPTEMBER 26, 2020
Connect with our community from all over the world!
Registration is open at [SUDC.org](https://www.sudc.org)