## **SUDConnections**

2019

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#### SUDC IS...

the sudden death of a child one year or older, which remains unexplained after a thorough case investigation, including review of the clinical history and circumstances of death, and performance of a complete autopsy with appropriate ancillary testing.

#### **OUR MISSION**

Promote awareness, advocate for research, and support those affected by sudden unexpected or unexplained death in childhood.

#### **CONTACT US**

SUDC Foundation 101 Eisenhower Parkway, Suite 300 Roseland, NJ 07068 800-620-SUDC(7832) info@sudc.org https://sudc.org











# **Celebrating Henry Ralph Chiaramonte Honoring His Legacy**

Henry Ralph Chiaramonte was a joyful little boy. His favorite things during his short life were dogs (affectionately called "woof woofs"), garbage trucks, airplanes, and Elmo. Henry was born on the 4th of July, an appropriate birthday for a boy whose parents had married in historic Philadelphia the year before.

Henry was a happy little boy. He woke up every morning and started his day with a high five, and he ended each day with a big kiss goodnight. He had fun wherever he went and brought joy to everyone he came across.

Henry's parents Colleen and Matthew Chiaramonte are committed to honoring his legacy and making Henry proud by hosting the annual Run for Henry 5K and 1 Mile Walk/Family Fun Run in Doylestown, PA, in memory of their beloved son to benefit the mission of the SUDC Foundation. The weather was so awful the first year of the event, yet that did not stop people from coming out to run and celebrate Henry. The amount of money raised to benefit the SUDC Foundation, over \$26,000, far surpassed their goal.

"I am not sure I can properly articulate how much the SUDC Foundation has helped guide my family through this unbearable journey," says Colleen. "Losing a child and not knowing why is beyond isolating. The Foundation has allowed my husband and I a safe place to grieve surrounded by strong families at all stages of grief. I have been incredibly inspired by so many families. It has motivated me to push forward and live my life honoring Henry."

This past June the Chiaramonte Family hosted the 2nd annual Run for Henry 5k and 1 Mile Walk/Family Fun Run in memory of Henry. Held at one of Henry's favorite parks, the event focused on spreading Henry's legacy of friendship and happiness while raising an additional \$27,000 to support the mission of the SUDC Foundation.

### Dear Reader,

Please enjoy our enclosed 2019 newsletter. For me, it is always a time of reflection as I look through the pages and revisit our accomplishments in the visual form. It reminds me of all the people responsible for the progress we are making - from our families, volunteers, and supportive donors to the medical professionals who share our passion to understand and prevent the tragedy of SUDC.

It never gets any easier to have that first phone call with a newly-bereaved family and express our deep regret that we have not yet reached a future free of SUDC. In fact, approximately 400 children, aged 1-18 years, still die every year in the U.S. without clear explanation.

The SUDC Foundation currently supports over 1,000 families affected by SUDC who reside in 18 countries. Because of this support, they know they are never alone. With our expanding services for families, we continue to reach to new levels to meet their needs while maintaining our goal of providing all care at no cost to the bereaved.

We have now granted approximately \$865,000 dollars to support SUDC research. The progress being made at the SUDC Registry and Research Collaborative, under the direction of Dr. Devinsky, is groundbreaking in areas including understanding the state of SUDC investigations, the merit of the case review process in uncovering previously-unrecognized diagnoses, neuroimaging techniques, neuropathology and the molecular origins of SUDC.

The pending publication of "Sudden Death In Pediatrics" is something that I have professionally (and personally) hoped for over the last two decades and ever since my own child died inexplicably. The work done by more than 30 volunteer researchers and clinicians to accomplish this cannot be underestimated. I thank each and every one of them, especially the editors, Dr. Bundock and Dr. Corey, for never giving up. Knowing that this book will finally provide national guidelines for investigations, focus research needs and set standards for the vital care of traumatized families in the aftermath of sudden deaths in infants and children is more than satisfying for a job well done. It is heartwarming to know the changes it will make in the lives of others.

I hope that each and every one of you reading this know the significant impact you have upon our collective efforts in SUDC. My cheers to you always.

In gratitude,

Laura Gould Crandall,

President and Executive Director



#### **Our Board of Directors**

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Lorri Caffrey
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# Join Us for the 2nd Annual SUDC Foundation Family Retreat! October 11-13, 2019 in Phoenix, AZ

It's hard to believe that 9 months have already passed since nearly 60 SUDC families gathered at the Naples Grand Beach Resort in Florida for the first-ever SUDC Family Retreat! Due to overwhelming positive feedback, the SUDC Foundation has committed to offer this experience annually. We look forward to building on our program

from last year, which included guest speakers, news from the SUDC Foundation, restorative meditation, kids' programs, adult yoga, golf, a butterfly release and most importantly- the time for families to be together with others who have had a shared experience.

This October, the SUDC Foundation staff, volunteers, and families will come together at the beautiful Wigwam Resort in Litchfield Park, AZ. This restorative weekend will again focus on self-care, information, education, and most importantly, the opportunities to bond with other families.

The weekend schedule is available online and plans to include mindfulness activities, SUDC Foundation advocacy trainings, research updates, offsite excursions to nearby cultural landmarks, age-appropriate activities for children and much more. Youth sessions will be

specifically designed for siblings and will be hosted by New Song Center for Grieving Children, a renowned local program through Hospice of the Valley.

SUDC parent Erin James, a 2018 attendee, enthusiastically shared, "The SUDC Foundation Family Retreat was

exactly that—a retreat to a safe place. A place surrounded by people who felt like family the moment we met them, and where we were free for the first time, in a very long time, to be completely who we are now after child loss. It's difficult to put into words all this retreat meant to us. It's an experience we will never forget."



The SUDC Foundation is grateful for the support of our lead sponsor, the Vivienne's Joy Foundation, for helping us make this retreat possible. If you are interested in attending the retreat or would like more information on how you can support the

retreat with a donation or sponsorship, please visit sudc. org/familyretreat.

REGISTER TODAY AT HTTPS://SUDC.ORG/FAMILYRETREAT

www.sudc.org 800.620.SUDC (7832) Direct 973.795.1257

### **Our Newest Services to Support Bereaved Families**

Grieving is an ongoing process, and those who experience it will benefit from learning the coping mechanisms that best help them on a daily basis. Due to the rarity of sudden child death, families can often feel isolated in their grief. With over 900 families now registered with the SUDC Foundation, our peer support community spans the globe providing easy access to other bereaved families. Cultivating these relationships allows the bereaved to connect with others whom they can identify with, gain coping strategies, insight into expectations in their grief journey and provide a safe place to share their feelings.

To further expand our peer support services, we are pleased to announce the addition of two new resources for bereaved families registered with the SUDC Foundation:

• The SUDC Parent Circle - A monthly virtual get-together, by online video conferencing, where parents from all over the world can connect in an

- open forum to share, ask questions and support each other in a new platform.
- SUDC Family Support Health & Science Information Facebook Group A group where family members can pose questions to discuss medical research, case investigations, and other topics related to the health and science available on SUDC. This group complements the Family Support Facebook group, which continues to provide emotional support to more than 300 members.

All groups are moderated by SUDC staff to ensure the security and safety of participants, as well as the accuracy of information. If you would like more information, or would like to register for services, please contact support@sudc.org or 800-620-SUDC.

# Give a Gift that Helps Secure the Future of the SUDC Foundation

Planned giving is the act of making a commitment to give a charitable organization a major gift, either over time, or as part of your overall financial or formal estate plans. The result is a mutually beneficial relationship between you and the organization. A planned gift to the SUDC Foundation will directly help sustain research initiatives to better understand 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. A lasting gift to the Foundation will also ensure that families affected by SUDC continue to receive all support services free of charge.

Suggested ways to make a planned gift to the SUDC Foundation include:

- Marketable securities. Publicly traded common or preferred stocks, mutual funds, exchange-traded funds, or corporate or municipal bonds.
- **Bequests and living trusts.** We encourage donors to make bequests to the SUDC Foundation in their wills and to name the SUDC Foundation as a beneficiary under living trusts.

- **IRA** and retirement plans. Donors may name the SUDC Foundation as the beneficiary or partial beneficiary of retirement plan assets.
- **Charitable remainder trusts.** The SUDC Foundation will accept designation as a remainder beneficiary of a charitable remainder trust.
- Charitable lead trusts. The SUDC Foundation will accept designation as an income beneficiary of a charitable lead trust.
- **Life insurance.** The SUDC Foundation will accept gifts of life insurance where the SUDC Foundation is named the beneficiary.
- **Donor advised funds.** The SUDC Foundation will accept grants from a donor advised fund when such gifts are designated by the owner of the fund.

Have you already remembered the SUDC Foundation in your estate plans? Do you plan to make a major gift in the future? Please let us recognize your generosity. For more information, please contact SUDC Foundation Director of Development, Elizabeth Milliken at (973) 795-1268 or elizabeth@sudc.org.

### **Board of Directors Announcement**

We are pleased to announce the appointments of Erin Bowen, MD, and Julia Burgess to the SUDC Foundation's Board of Directors.



Frin Rowen

Erin graduated from medical school at University College Cork in Cork, Ireland, and received her bachelor's degree in English from Boston College. Erin is currently a pediatrician at Children's Medical Associates in Ansonia, CT, and has over 10 years of experience in the medical field.

Erin lost her son Conor in 2016 when he was just 17 months



Julia Burgess

Julia, a former CPA, received her undergraduate degree from the Wharton School of Business at the University of Pennsylvania. Julia is also a SUDC mom.

Her daughter Vivienne died 3 days after her 3rd birthday. Julia has been an active member of the SUDC

Foundation's community and is focused on raising awareness of SUDC and supporting other bereaved parents. She is the founder and executive director of Vivienne's Joy Foundation and lives in Minnesota with her husband and Vivienne's older sister. Vivienne's Joy Foundation is the lead sponsor of the SUDC Foundation 2019 Family Retreat.

### **U.S Federal Legislation Reintroduced: Support Scarlett's Sunshine Act**

SUDC, once again, gained national attention this spring with the reintroductions of "Scarlett's Sunshine on Sudden Unexpected Death Act." (S.1130/H.R.2271) And you can help it become law!

old. She is an active member of the SUDC Foundation

community through her work with "Kisses for Conor" to spread kindness in Conor's memory. Erin also manages the

SUDC Foundation's medical education initiatives through

the SUDC Medical Ambassador Program.

If passed, Scarlett's Sunshine Act would supply grants to states and municipalities to improve data collection and death scene investigations related to unexpected infant and child deaths, promote safe sleep practices, and ensure death reviews are completed for 100 percent of infant and child fatalities. Currently, there are no nationwide standards in the United States for investigating and collecting data following an infant or child death. This often makes it impossible to determine the causes of these deaths and to develop strategies to prevent these tragedies.

Scarlett's Sunshine Act is bipartisan, bicameral federal legislation that was first introduced in the U.S. in the fall of 2018 but was reintroduced this spring when it did not pass in the previous congressional session. It was introduced by U.S. Senators Bob Casey (D-PA), Johnny Isakson (R-GA), Sherrod Brown (D-OH), Doug Jones (D-AL) in the U.S. Senate and by Representatives Gwen Moore (WI-04), Tom Cole (OK-04) and Jaime Herrera Beutler (WA-03) in the U.S. House of Representatives.

Scarlett's Sunshine Act has already received support from several national organizations, including the American Academy of Pediatrics, March of Dimes, Children's Hospital Association, Cribs for Kids, First Candle, Kids in Danger (KID), Aaron Matthew SIDS Research Guild of Seattle Children's Hospital, and Safe Kids Worldwide. Please visit https://sudc.org/scarlettssunshineact to see a current list of co-sponsors and endorsements. The legislation was introduced in honor of Scarlett Pauley, who was lost to SUDC in January 2017 when she was just 16 months old.

#### **Take Action With Us!**

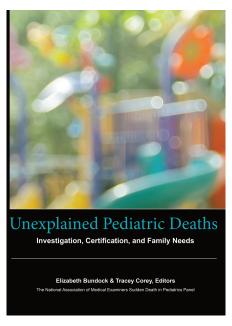


Use our new platform that allows you to contact lawmakers directly in support of SUDC research and make your voice heard.

#### **How to Take Action Today**

- •Grab your phone
- •Text SUDC to 52886
- •You'll receive an auto-response asking you to take action on Scarlett's Sunshine Act. Click the provided link to contact your elected officials.
- •If you don't have your phone handy, you can participate by visiting https://p2a.co/bGMMxbw?





# 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.

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

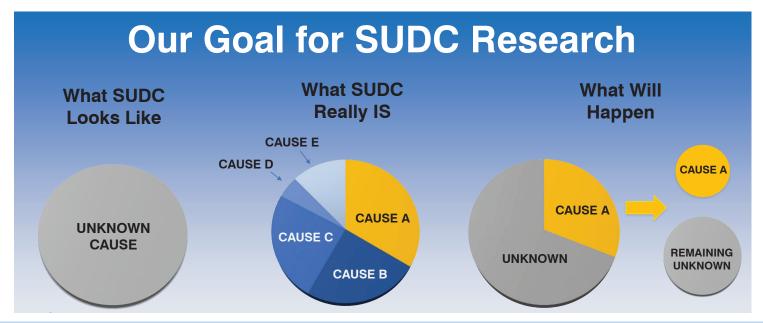
### **Investigating Risk Factors of SUDC**

JAMA Network Open recently published an analysis of 16 years of data gathered through family interviews with the SUDC Foundation.

"In this case series of 391 children from 18 countries, febrile seizure rates were increased among both sudden explained and sudden unexplained deaths compared with the general population, suggesting that seizures contributed to some of these deaths. No sudden deaths occurred in more than 3100 life-years among siblings of children with sudden unexplained death. Meaning: Patients with febrile seizures are at increased risk for sudden death, but the risk is small; identifying clinical features or biomarkers of high risk is essential to develop and assess preventive strategies."

The article is now available online go to sudc.org> research & medical information> published research. Thank you to all who made this possible.

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



# SUDCRRC

SUDC Registry and Research Collaborative

# At New York University's Langone Health Principal Investigator: Orrin Devinsky, MD

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) nueroimaging, 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: sudc.org> research & medical information> SUDCRRC

Recent publications from the SUDCRRC include (in addition to JAMA Network Open article noted above):

- 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 early-onset genetic diseases Genet Med. 2016 Jul;18(7):746-9. doi: 10.1038/gim.2015.155. Epub 2015 Dec 30. PMID: 26716362

### **SUDC Professional Resource Corner**

Private donations to the SUDC Foundation allow us to provide all services at no cost to professionals and families affected by the sudden, unexpected, and often unexplained, death of a child. These services include:

**Communication with families:** SUDC Foundation staff will act as a liaison during the investigation and after, providing families with bereavement support and assistance navigating the investigation process with realistic expectations.

**DNA banking:** The SUDC Foundation advocates and supports DNA banking to ensure opportunities for future genetic analyses. The Foundation provides logistical support for medical examiner and coroner offices to obtain DNA banking for the families they serve. Financial support may also be available.

**Educational resources:** Through our website (sudc.org), newsletters and social media platforms, we provide up-to-date information about SUDC, including the latest publications on sudden death in children, news and trainings.

**Customized "Help for Families" brochure:** This brochure for medical examiner and coroner offices helps investigators communicate with families during the initial investigation of all sudden pediatric deaths. The brochure explains the death investigation process, the professionals involved and bereavement services available. It is designed to meet the needs of each office and free printing is available upon request.

**No-cost comprehensive family services:** Support is available for families affected by the sudden, and unexpected, death of children older than 12 months.

#### **Upcoming Events**

Keep up-to-date on all events at www.sudc.org.



Smiles for Owen
July 20, 2019–Niagara Falls, NY



Corey's Run for a Reason July 27, 2019–Willoughby Hills, OH



Checking for Charity

August 9, 2019–Voorhees, NJ



Team Wesley
August 24, 2019–Virtual

For information on how the SUDC Foundation staff can help with event planning, please contact Liz Milliken at elizabeth@sudc.org.

# **SUDC Foundation Ambassadors Promote SUDC Awareness**

The members of the SUDC Foundation Ambassador Program continue to do amazing work 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.

Since the inception of this program, SUDC Foundation Ambassadors have educated their communities about SUDC and the SUDC Foundation by:



- Representing the SUDC Foundation at fundraising events
- Sharing their personal stories to help improve the death investigation process and care of families affected by SUDC
- Leading efforts for a highly successful SUDC Awareness Month in March
- Working to have the SUDC Foundation recognized as an official charity for its first major marathon, Dick's Sporting Goods Pittsburgh Marathon
- Participating in media interviews to give personal insights into SUDC
- Advocating for legislation to support SUDC families in the United States and Canada
- Hosting SUDC information tables
- Organizing regional SUDC family gatherings
- Leading presentations on SUDC and the SUDC Foundation for medical and childcare professionals
- Hosting over 50 fundraising events to benefit SUDC this year alone!

SUDC Foundation Medical Ambassadors have spearheaded efforts to educate fellow medical professionals about SUDC. Led by SUDC Foundation Board member Erin Bowen, MD, their efforts have resulted in in over 80,000 medical providers learning more about SUDC and improving care for families affected by SUDC. Dr. Bowen will also participate in medical 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 later this year.

To learn more about the SUDC Foundation Ambassador Program, please visit https://sudc.org/get-involved/ambassador-program.

Pictured below, SUDC Foundation Ambassador, Karen Hescher, hosts an information table at the 2018 Labor of Love Infant Mortality Conference in Indianapolis, IN.



# Celebrating Henry Ralph Chiaramonte (continued from cover)

"I refuse to allow Henry's 'story' to just be a sad one," explains Colleen. "He was the most incredible little boy who brought a smile to everyone that met him. He deserves to be celebrated. A 5K is a great way to get all of Henry's favorite people together to honor him while raising awareness for SUDC."

"I also want to show our community the power of grief," adds Colleen. "I want people to see that even during the hardest times we can channel our grief and do good in Henry's name as a way to honor his memory."

The Chiaramonte family is hoping that Henry's 5K can become bigger than just Doylestown, PA. The power of social media and the virtual runner option make it possible for participation all over the country!

The SUDC Foundation is tremendously grateful to the Chiaramonte Family and all of the dedicated volunteers, who contribute time and energy each year to help make the event a success. For more information on the annual "Run for Henry 5k and 1 Mile Walk/Family Fun Run," please visit, www.sudc.org/henry.



### **SHOP FOR SUDC**



100% of the net proceeds benefit SUDC Foundation Family Services which provides personalized, comprehensive care and cultivates a community of support so no one grieves alone.

ORDER YOUR SUDC MERCHANDISE TODAY https://sudc.org/get-involved/shop-for-sudc

#### **Upcoming Events**

Keep up-to-date on all events at www.sudc.org.



Drew's Tunes Bowl-A-Thon August 24, 2019–New Orleans



Nate's Great Ride August 24, 2019–Ontario, Canada



Scramble for Scarlett
August 24, 2019–Bridgeville, PA



Run and Play for Ariana Mae September 7, 2019-Grand Ledge, MI



Jackson's Flower Walk September 21, 2019–Seattle, WA

#### **Upcoming Events**

Keep up-to-date on all events at www.sudc.org.



Livy's Legacy Horseballs Tournament September 24, 2019–Kenosha, WI



Golfing for Olivia September 28, 2019–Novi, MI



Slade Dozier Memorial Fishing Tournament October 19, 2019–Mt. Pleasant, SC



Adeline's Angels
October 20, 2019–Allison Park, PA



Ava and Emmett's Harvest of Hope November 2, 2019–Maple Park, IL

For information on how the SUDC Foundation staff can help with event planning, please contact Liz Milliken at elizabeth@sudc.org.

# **SUDC Awareness Month in March is a Great Success**



This past March, the SUDC Foundation once again honored SUDC Awareness Month to raise awareness of one of the most under-recognized medical tragedies. During the month-long campaign, we hosted weekly activities for SUDC supporters all over the world.

In total, 43 U.S. states joined our effort, issuing proclimations in awareness of SUDC. People changed their Facebook Profile picture to spotlight SUDC and remember the children

gone far too soon. They also shared memorabilia and acts of kindness performed in the names of those lost to SUDC. This year, our medical community partners participated by sharing our posts and providing poignant insights on why SUDC awareness is important to them.

We also reached new audiences. The Chicago Tribune published a front-page feature article on SUDC families, and the American Academy of Pediatrics featured a story by Dr. Erin Bowen, a pediatrician and SUDC Foundation Board Member. Matt Iseman, host of American Ninja Warrior interviewed the Foundation's President, Laura Gould Crandall on his *Warrior Wednesdays* program.

Thank you to everyone who supported SUDC Awareness Month. You helped us raise awareness of SUDC around the world, and we couldn't have done it without you!

# HOST AN APPAREL FUNDRAISER



### An Easy Way to Support the SUDC Foundation

The SUDC Foundation is pleased to announce a new partnership with Bonfire Custom Designs. Together, we have created an efficient, stressfree, streamlined process to host apparel fundraisers.

Launching this summer, we will offer a centralized platform to all SUDC Foundation–registered members who wish to host a personalized fundraising campaign to support the mission of the SUDC Foundation.

To learn more please visit www.sudc.org

## **Shout Out to Recent Fundraising Events**

A Mile for Maddie

Adalyn Rose Reverse Raffle

Cassidy's Sparkle Gala Event

**Designer Pocketbook Bingo & Mini Tricky Tray** 

**Dicks Pittsburgh Marathon and Participants** 

**Easton Keith Webb Memorial Tournament** 

Glitter Cups for Ariella

Jacob's Joy



Kaden's Dance **Light Up the Night for Norah** Lily Jo Candle for SUDC Livy's Legacy Scotch **Doubles Tournament** Love for Luke Golf **Tournament** 

LuLaRoe for SUDC

Mary's Magical Maps

**Mason James Foundation** 

**Golf Tournament** 

Max's 7th Annual Track Dash

**MossFest** 

Nate's Clicks for Six

**Orangetheory Fitness 5k** 

Read for a Reason Challenge

Reading for Magnolia

Run for a Reason California

**Tee Off for Taylor Golf Tournament** 

The Bushcraft Auction

The Patel Law Group and Fidelity National

han

Title Rib Cook Off

### 2018 Highlights: We Couldn't Have Done It Without You!

- Provided personalized, comprehensive and compassionate care from licensed clinical social workers to over 900 families affected by Sudden Unexplained Death in Childhood.
- Hosted the SUDC Summer Podcast Club with Natalia Garcia, M.S., who combined her experience as both an SUDC parent and her experience as a therapist to help support the SUDC community with innovative ways to cope with their grief.
- Gathered 140 SUDC family members as a community by hosting a family retreat in Naples, Florida.
- Funded the SUDCRRC, a multi-site research collaborative of NYU Langone Medical Center, Columbia University, Mayo Clinic and more than 30 clinical and forensic collaborators.
- Funded the Sudden Unexpected Death in Pediatrics (SUDP) Project to create and implement national investigation guidelines to improve data collection and treatment of families who have lost a child suddenly and unexpectedly.
- Supported Scarlett's Sunshine Act into Congress, a bill directed toward efforts to understand SUDC on a national level, introduced by Senator Bob Casey from Pennsylvania in honor of Scarlett Lillian Pauley who was lost to SUDC in 2017.
- Advocated and attained proclamations from 43 U.S. states declaring March as SUDC Awareness Month.

Trained 58 SUDC Ambassadors to promote global outreach and awareness efforts of 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. We provide all services at no cost to the people we serve due to the generosity of dedicated donors and supporters like you. Donations to the SUDC Foundation can be made online at sudc.org or by mailing a check to The SUDC Foundation 101 Eisenhower Pkwy, Suite 300, Roseland, NJ 07068.



The SUDC Foundation 101 Eisenhower Parkway, Suite 300 Roseland, New Jersey 07068





