



IN THIS ISSUE

- Letter to Our Readers 2
- Community Connection..... 2
- New Board Member 3
- New Research 3
- Ambassador Spotlight..... 3
- Medical Education 4
- Supporting Research 4
- Grandparent Spotlight..... 5
- Stride for Awareness..... 6
- SUDC Events..... 6
- Event Spotlight..... 7

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's mission is to promote awareness, advocate for research and support those affected by SUDC.

CONTACT US

101 Eisenhower Parkway
Suite 300
Roseland, NJ 07068

Ph: 973.795.1257
Fax: 973.559.6191
info@sudc.org

LA Dodgers Hit One Out of the Park for SUDC Awareness

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!



Photo Courtesy Jessie Alchen/MLB

Honoring Jackson Walsh

Jackson Walsh was generous with his hugs and kisses. His mom describes him as a "lover boy," charming everyone with his big, beautiful brown eyes, sweet voice and infectious laugh. His life exuded love - he loved his pacifier, food, golf, his scooter, lions, leopards, his train set and playing with the buttons on the dishwasher. He also loved his big sister, Harper, hanging on her every word and following her every instruction. Jackson's love of life ended on February 28th, 2020, when he went to sleep and never woke up. Shortly after his death, the Walsh family found the SUDC Foundation, and with it, a way to carry on Jackson's legacy and love of life.

"It's really difficult to find purpose after your child passes away," Kelsey, Jackson's mom, said. "By starting The Jackson Walsh Foundation, we have been able to carry on Jackson's legacy while raising awareness of what happened to him. The funds we receive from our events go to the SUDC Foundation."

The Walsh family held their first event, The Jackson Walsh ChariTee Golf Tournament, only



Continued on Pg. 3



342

unexplained child deaths
ages 1-18 years in U.S. in 2019



2x Black/African American
vs. White children



Statistics above are based on ICD-10 Codes R95-R99 from CDC Wonder Database



BOARD of DIRECTORS

- Bobby Jenkins, Chairman
- Laura Gould, M.A., President
- Erin Bowen, M.D., Vice President
- James Lintott, Treasurer
- Julia Burgess, Secretary
- Lorri Caffrey
- Laura Dozier
- Carson McLean
- Steve Myers
- Matthew Polenzani

STAFF

- Amanda Brindle, L.S.W., Family Services Coordinator
- Michelle Brodeur, Family Services Assistant
- Lily Crandall, Volunteer Program & Digital Marketing Coordinator
- Heather Maher, M.S.F.S., Family Advocate
- Elizabeth Milliken, Director of Development
- Sarah Morrison, Business Office Manager
- Amber Velayudham, Grant Writer

Dear Reader,

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 recent months in this newsletter.

SUDC Awareness Month reached a new level of success this year – including the incredible awareness event hosted by the Los Angeles Dodgers featured on the front 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 safe 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. And we look forward to hopefully seeing many faces, both returning and new, at our 2021 SUDC Family Retreat in San Antonio, Texas in September!

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,

Laura

Laura Gould, President and Co-Founder

New Ways for Community Connection

This summer, the SUDC Foundation is launching the SUDC Foundation Network, a private and secure online platform for sharing ideas and information, fostering conversations and providing a network of community support. The network will be hosted on the Mighty Networks platform and will allow the SUDC community to participate in virtual support groups and access a variety of informational resources that we have curated just for the SUDC community.



Honoring Jackson Walsh (continued...)

a few short months after losing Jackson, raising over \$40,000. Earlier this year, they also hosted their first virtual race, Jogging for Jackson, raising another \$6,500.

In addition to wanting to honor Jackson, it was important to the Walsh family to support the SUDC Foundation because of the services the organization provided to their family including helping them to enroll in the SUDC Registry and Research Collaborative (SUDCRRC) at New York University Langone Health, and navigate the difficult and confusing process of Jackson's death investigation and autopsy.

The generosity of the Walsh family has helped the SUDC Foundation financially support the groundbreaking research at the SUDCRRC. "SUDC research is so important to us because no family should have to experience unexpected child loss without an explanation as to why they passed away," Kelsey added.

The SUDC Foundation is grateful to the Walsh family and all the SUDC supporters who donate their time and energy to make events which benefit the SUDC Foundation such a success. For more information on this year's The Jackson Walsh Chari-Tee Golf Tournament, Foundation, please visit sudc.org/events.

Embarking on New Research

The SUDC Foundation is embarking on another groundbreaking research project examining grief responses and coping strategies of families affected by the sudden and unexpected death of a child. The study, entitled "Coping Mechanisms, Grief Responses and Experiences with Professionals Following the Sudden Unexpected Death of a Child," will fill a glaring gap in current bereavement research, which until now has only focused on parents who have lost an infant or child under the age of 1. The study was approved by the Institutional Review Board of Integreview, an independent institutional review board dedicated to providing unsurpassed ethical review services for research conducted in the United States.

Meet the Newest Member of the SUDC Foundation Board of Directors: Carson McLean

We are delighted to announce that Carson McLean has been appointed to the SUDC Foundation Board of Directors.



Carson has over a decade of experience in financial services and a passion for industry practices that better serve end investors. He currently works at Dimensional Fund Advisors as a Regional Director assisting independent financial planning fiduciaries evaluate their investment models, client education programs and practice management efficiencies. He holds a bachelor's degree in Finance from Loyola University Chicago, an MBA from the University of Wisconsin Whitewater and is currently pursuing the Certified Financial Planner (CFP)® designation through Wake Forest University.

Carson's son, Frank, died from sudden and unexplained causes at 23 months old. Along with his wife Ellen, he founded Frank McLean Forever in 2019, a nonprofit dedicated to advancing SUDC research, awareness and supporting families in grief.

Originally from Southeastern Michigan, Carson currently resides in Charlotte, North Carolina with Ellen and surviving children Davy and Lewis.

Welcome, Carson!



Ambassador Program Spotlight



SUDC Ambassador and mom, Melissa Pompa, hosted an information table in June to spread awareness of SUDC at the Build Up the Block event, a monthly block party hosted by Lindsay School of The Arts in Fort Pierce, Florida. Lindsay School of The Arts hosts the Gabriella Art Start Program in memory of Melissa's daughter, Gabriella, who was lost to SUDC last year. Approximately 100 people attended the event and learned about SUDC and Gabriella's story. Thank you, Melissa! To learn more about our Ambassador Program and apply, please visit sudc.org/ambassador-program.

SUDC Foundation Leads the Way in Medical Education on SUDC

Many medical professionals have never heard of Sudden Unexplained Death in Childhood – it is not part of the standardized medical curriculum, and many professionals may only see an affected child or family once in their careers, if at all. This can profoundly and negatively impact their ability to provide optimal care to affected families.

In order to address this gap in medical education, the SUDC Foundation began an initiative to educate medical professionals about SUDC, discuss how to best care for families in its aftermath and inform professionals about research opportunities available to SUDC families. The effort is led by Dr. Erin Bowen, pediatrician and SUDC Foundation Vice President. Erin knows firsthand the havoc SUDC can wreak on a family and medical professional. She lost her son Conor to SUDC when he was just 17 months old.

The initiative began in 2018, and since then, Dr. Bowen has had the opportunity to speak at many distinguished medical education institutions and conferences, including seven presentations in the last year alone. Some of the presentations included perspectives from New York City Medical Examiner Kristen Landi, M.D. and New York Medical Examiner Katherine Maloney, M.D. SUDC moms and Ambassadors Kristi Kelley and Julia Burgess participated with presentations to professionals in Minnesota and Texas. SUDC Foundation President and research scientist Laura Gould joined Dr. Bowen to present at the American Academy of Pediatrics (AAP) National Conference in October. This conference is typically attended by over 10,000 pediatric professionals

globally, but last year's virtual format enabled an even wider audience.

The SUDC Foundation offers a wealth of resources to assist medical professionals, as well as an easy way to refer families for our support. To learn more, please visit sudc.org. If you are a medical professional, and are interested in a presentation, please email us at info@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.

“Seizure-related deaths in children: The expanding spectrum” This research examines the similarities in sudden unexpected infant deaths, sudden unexplained death in childhood and sudden unexpected death in epilepsy, including “clinical, neuropathological, and genetic features, including male predominance, unwitnessed deaths, death during sleep, discovery in the prone position, hippocampal abnormalities, and variants in genes regulating cardiac and neuronal excitability.” The publication notes that while common in children, seizures “can be fatal in children with or without an epilepsy diagnosis and may go unrecognized by parents or physicians.” The researchers

concluded that improved recognition, surveillance and research is critical to better understand and address these tragedies.

– Harowitz J, Crandall L, McGuone D, Devinsky O. Seizure-related deaths in children: The expanding spectrum. *Epilepsia*. 2021 Feb 14. doi: 10.1111/epi.16833. Epub ahead of print. PMID: 33586153.

“Evaluation of Concordance Between Original Death Certifications and an Expert Panel Process in the Determination of Sudden Unexplained Death in Childhood” While blindly reviewing 100 cases included in the SUDC Registry and Research Collaborative, forensic pathologists disagreed with 40% of the causes of death determined in the original certification. This includes 28 children whose deaths were initially determined to be accidents or “natural” causes. This research supports the longstanding belief that SUDC is likely underreported, and that the true incidence of SUDC could be veiled by the lack of standards in the U.S. for investigating, certifying and reporting sudden,

unexplained deaths in children.

– Crandall LG, Lee JH, Friedman D, et al. Evaluation of Concordance Between Original Death Certifications and an Expert Panel Process in the Determination of Sudden Unexplained Death in Childhood. *JAMA Netw Open*. 2020;3(10):e2023262. doi:10.1001/jamanetworkopen.2020.23262

“Sudden Unexplained Death in Childhood: A Neuropathology Review”

This article provides an in-depth review of the neuropathology of SUDC, the knowledge gaps that exist and research needed. The researchers concluded that more research is needed to help identify the causes as well as ways to help predict and one day prevent SUDC.

– McGuone D, Gould Crandall L, Devinsky O. Sudden Unexplained Death in Childhood: A Neuropathology Review, *Frontiers in Neurology*, Vol 11 2020 DOI=10.3389/fneur.2020.582051

To view a full list of published research, please visit sudc.org/published-research-articles.

SUDC Grandparent Spotlight

Kevin and Peg Wilcutt know a few things about living through trying times and overcoming challenges. Kevin is a retired Marine, who served as a Commanding Officer of an Aviation Combat Element in Kuwait during his service. While Kevin was in Kuwait, Peg managed a volunteer program that served over 300 wives and children of deployed marines throughout the United States. Kevin was trusted to fly former president George W. Bush, which was both an honor and a huge responsibility, keeping his thoughts on his brother's wellbeing as he served as an astronaut and Commander of two shuttle flights.

But nothing could have prepared them for March 17th, 2017. That's when their 2-year-old granddaughter, Nora, went down for a nap and never woke up.

Nora's loss left the entire family struggling to figure out to how carry on in the aftermath of the tragedy. "It is like stretching a slinky all the way out, letting go and then trying to unravel the tangle," Peg said of navigating life in the aftermath.

Not only were Kevin and Peg devastated to lose their granddaughter, but they also grappled with the best ways to support their daughter Maggie and son-in-law Andrew through their pain and confusion.

While researching online, Peg found the SUDC Foundation, on what would end up being the same day Maggie and Andrew learned Nora's death had been ruled SUDC. Before long, Maggie and Andrew connected with the SUDC Foundation. "The SUDC Foundation has helped them to survive," Kevin said.

Kevin and Peg saw a noticeable difference after Maggie and Andrew returned from the 2018 SUDC Foundation Family Retreat. "They returned home like a breath of fresh air, renewed by the friendships they found meeting other families who shared their unique grief," Peg said. They noted their grandson, Dylan, also made some new friends during the trip.

The difference they saw in their loved ones inspired Kevin and Peg to become regular donors to the SUDC Foundation. They want to make sure that same support is available to other families who will have to walk the journey in the future. They also invest in SUDC research, hoping it will one day provide answers on what happened to Nora and other SUDC children.



Kevin and Peg's home is full of pictures of Nora, and their hearts are full of memories of her love of puffs, cupcakes and donuts. They built a memorial garden in their yard so they could have a peaceful space to meditate and remember her. And they make sure to incorporate Nora into their family celebrations – holding a picture of her when they pose for family photos and helping the rest of their grandchildren know who she was.

They channel their love for her into their devotion for advancing the cause of SUDC so someday, no other family has to experience what theirs has – no more children die, no more parents have to bury them and no more families have to walk this terrible path.

And they continue to share a very important, but hard-learned, lesson. "You can love someone one day and they may be gone the next," Kevin advises. "Never take a moment for granted."

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

gives a lifeline of unique resources and information through our Family Resource Guide

\$100

provides online group support sessions for the newly bereaved

\$200

helps one bereaved family bank their child's DNA

\$500

assists advocacy efforts for the fair treatment and appropriate medical care of families

\$1,000

helps a family attend our Family Retreat to connect with others who have experienced a similar loss

\$1,500

supports critical research to better investigate the genetic characteristics of SUDC

Making Strides for SUDC Awareness!

SUDC Awareness Month 2021 was an astounding success!

- 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.



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



Azure's parents

Support SUDC This Summer and Fall

Thank you to the families for hosting these amazing events to benefit the SUDC Foundation! Please consider joining us at an upcoming event near you!



June 21st-25th Wild Timber Team Extreme Week, Sugar Hill, GA, United States



August 13-15th Checking for Charity, Voorhees, NJ, United States



October 2nd Answers FORE Adele, Johnson, NY, United States



June 26th 7th Annual Tee Off for Taylor Golf Tournament, Rogers, AR, United States



August 21st Nate's Great Ride 2021, Poplar London, ON, Canada



October 16th 8th Annual Adeline's Angels 5K Run & 1 Mile Walk, Pittsburgh, PA, United States



July 4th Run for a Reason California 2021, Virtual and Orinda, CA, United States



September 11th Tri-State Tough Mudder, Englishtown, NJ, United States



October 23rd 6th Annual Slade Dozier Memorial Fishing Tournament, Mt. Pleasant, SC, United States



July 31st First Annual Declan's Day Dive, Lawrence Township, NJ, United States



October 1st The Jackson Walsh Char-i-tee, Leesburg, VA, United States



November 13th The Cairo Brown Foundation Charity Dinner & Toy Drive, Killeen, TX, United States

To learn more about these and future events, please visit sudc.org/events.

We'd like to give special thanks to all of our supporters who hosted Facebook and T-shirt fundraisers!

SPOTLIGHT

STARRY NIGHT GALA

St. Paul, MN, USA

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



PAC MAN PARTY 5K

Dacula, GA, USA

Friends and family of the Shaw family hosted their 1st annual PAC MAN Party 5K in June. The event raised over \$16,000 in support of the SUDC Foundation!

"We have struggled to find a balance between honoring and celebrating Paxton and this race allowed us to feel a true celebration," Paxton's mom Natalie said. "It was such a welcomed feeling that we have not felt in such a long time and seeing all of those who came together to celebrate our baby boy's birthday was the most heartfelt experience. It was a beautiful sea of 'lellow,' his favorite color, and we look forward to being able to celebrate his birthday annually with the PAC MAN Party 5K with all those near and far who continue to stand by our side in support, prayer, love and encouragement."

The PAC MAN Party 5K was held in memory of Paxton and in honor of what would have been his 4th birthday. Paxton passed away in 2019 at the age of 28 months. Paxton's family describe him as an energetic, adventure-seeking boy who loved tractors, fire trucks, large machinery, dinosaurs and the color yellow.



The SUDC Foundation is grateful to the Burgess and Shaw 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/events.



101 Eisenhower Parkway, Suite 300
Roseland, New Jersey 07068



SEPTEMBER 24-26, SAN ANTONIO, TX

Registration is now open!

SUDC FOUNDATION FAMILY RETREAT 2021

Scheduled for **SEPTEMBER 24-26** in **SAN ANTONIO, TEXAS.**

For more information or to register, visit sudc.org/family-retreat-2021.

**Thank you to the Vivienne's Joy Foundation for
being the Lead Sponsor of the 2021 Retreat!**