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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

Raise awareness, fund research, and serve those affected by sudden unexplained death in childhood.

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Reflections from a Mom Who Returned to Fundraising

Run for Casey is the event we hosted for the first time this year in memory of our daughter Casey. It was an amazing experience. We had over 100 runners for the 5k, 30 children participating in the fun run, about 50 volunteers, and countless others who came to the event. Having so many involved, participating, and volunteering was overwhelming in the very best way. They were all there to celebrate Casey, support our family, and contribute to an important



Ellen Young with her daughters Jordan and Sydney

cause. In the beginning of the planning phase, I never expected the turnout we got! It gets me excited for the next run knowing that we can now reach more people who will know about Casey and our family’s story – more people to spread awareness, and more people to help raise money for research.

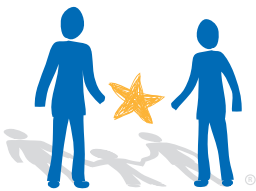
The first time I ever hosted an event for the SUDC Foundation was soon after Casey passed away. Less than a year after she died, we hosted Music for Casey. That was about 11 years ago, and to be honest, planning it happened in almost a haze of grief. I was already pregnant with my beautiful Sydney, and planning the event gave me an outlet and a place to focus my energy. I almost don’t remember many of the details of planning it now. I remember the support from family, friends, and the SUDC Foundation. No event is ever hosted without an incredible number of volunteers. At that time, SUDC was new to us, and everyone we knew. What happened to Casey was inconceivable, and all anyone wanted to do was help. That is still the case. My volunteers, my friends, and my family have been at the heart of all my events, then and now. What was different about that first event was that it was all-consuming for me. I spent all my time working on the event, seeking an outlet for my pain and grief. It was therapeutic for me and allowed me to talk about Casey and SUDC in a way that I wouldn’t have been able to before the event.

The challenges in planning Run for Casey have some overlap with my past events, but mostly the event presented its own unique challenges. The one constant challenge for me is a personal one – I struggle with asking for help. Fundraising events are a lot of work that cannot be done without a big support system. My friends, family, and even strangers lined up to help, but I have always had, and continue to have, a sense of guilt about asking for financial support and for people to give up their time. What I have come to know is that those who volunteer or donate are doing it for that same reason as I am – to make sense of a tragedy, and to do whatever they can to make that just a tiny bit less painful for me, and

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NAME and AAP Conferences

Members of the SUDC Foundation's staff are set to attend this year's National Association of Medical Examiners (NAME) and the American Academy of Pediatrics (AAP) conferences. The 57th annual NAME conference this year will be held in San Jose, CA October 13-17 focusing on the theme of Forensic Pathology - Prospering After a Pandemic. The SUDC Foundation will host a booth during the conference for attendees to meet our team and provide them with our informational resources. The national AAP conference and exhibition will be held in Washington DC October 20-24. This year's conference will include world-class education, an exhibit hall, special events, networking opportunities, a poster hall, and more. The SUDC Foundation will also host an exhibit for attendees to explore and learn more about our services.



BOARD of DIRECTORS

- Bobby Jenkins, President
- Erin Bowen, MD, Vice President
- Julia Burgess, Treasurer
- Laura Dozier, Secretary
- Lorri Caffrey
- Karla Elmberg, Esq.
- Carson McLean
- Steve Myers
- Deepa Suresh Roongta

STAFF

- Tina Yun Lee, Executive Director
- Elizabeth Milliken, Director of Development
- Amanda Brindle, LSW, Family Services Associate Manager
- Heather Maher, MSFS, Family Advocate
- Ghazala Siddiqui, LPN, Community Education and Outreach Coordinator
- Michelle Brodeur, Family Services Assistant
- Caitlin Anderson, Social Media Content Creator

Navigating the Unthinkable: 2023 Revised SUDC Family Resource Guide Offers Hope and Guidance

The SUDC Foundation Family Resource Guide has been a longstanding invaluable tool for those who have experienced the unimaginable loss of their child. It acts as a roadmap to empower and support families. Recently revised, the guide offers a comprehensive description of the SUDC Foundation's free and confidential services, expert information from professionals in research, and contributions from grief specialists on coping strategies to assist families in rebuilding their lives while honoring the memory of their child. The revised edition also includes personal narratives from those who have experienced this devastating loss firsthand. These stories of hope inspire and remind families that they are not alone on their grief journey.

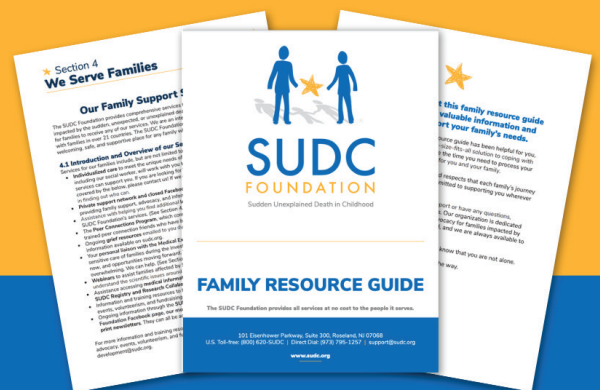
The Family Resource Guide represents the SUDC Foundation's commitment to continue to foster a compassionate and supportive community. This indispensable tool serves as a lifeline and a beacon of hope for our families seeking support and guidance.

To access the SUDC Foundation Family Resource Guide, please visit: <http://bit.ly/3slciny>



Updated

Family Resource Guide



sudc.org



A NOTE TO OUR READERS...

Dear Reader,

I hope this letter finds you all doing well. As we enter another year filled with promise and purpose, I am deeply honored to share with you the incredible continued progress and milestones we have achieved together at the SUDC Foundation.

With nearly a year and a half now at the Foundation, I have had the privilege of witnessing firsthand the tremendous growth within our Family Support Services to address the needs of our families reaching out for support and answers. Our team's commitment to prioritize our families first ensures that no one grieves alone. Our dedicated team continues to enhance our services by adding new programs such as our 8-week Grief & Loss Workshop and our SUDC Foundation Speaker Series. The workshop is designed to create a safe and supportive environment where our participants acquire therapeutic techniques and evidence based coping strategies to empower them to heal and find understanding among peers. Additionally, we have launched the SUDC Foundation Speaker Series where experts in the field share their insights and perspectives related to grief, trauma, and recovery. We believe that knowledge is power, and providing these platforms and welcoming spaces for learning, discussion, and community building will help us continue to empower and uplift individuals and families on their journey of healing and resilience and finding answers.

March 2023 was a particularly memorable month as our community rallied together to raise awareness during SUDC Awareness Month. Kits were distributed inviting the community to join the movement and share vital information about SUDC and the Foundation's free and confidential services. In a heartwarming display of solidarity, the Los Angeles Dodger's Major League Baseball team wore specially designed SUDC Foundation patches on their uniforms, during a spring training game. Participants in the Strides for SUDC Awareness Challenge walked, ran, rolled, and rode a combined distance of over 15,000 miles, demonstrating their unwavering support.

Our #ShineALightOnSUDC campaign was a resounding success, with 72 landmarks in the U.S. and from around the world illuminated in blue and yellow to raise awareness for SUDC. From the iconic Olympic Stadium in Montreal, Canada to Blackpool Tower in Lancashire, UK and landmarks in Australia, we united globally to shed a light on SUDC. It was a powerful display of unity and a testament to our collective dedication.

In addition to our awareness efforts, The SUDC Foundation continues to actively support groundbreaking research through our partnership with the SUDC Registry and Research Collaborative (SUDCRRC). This initiative brings together leading researchers, clinicians, and scientists to advance our understanding of SUDC and explore potential causes, risk

factors, and preventive measures. This research not only brings hope to affected families but also paves the way for potential breakthroughs in the future. We are committed to providing ongoing support to the SUDCRRC and their vital research efforts, as we believe that a comprehensive understanding of SUDC is crucial to finding effective interventions and ultimately preventing future tragedies.

Our Diversity Task Force met for the first time in June and has been diligently meeting and offering valuable recommendations. Their insights and perspectives shared during these meetings have been invaluable. We at the Foundation are committed to fostering an environment that embraces diversity, equality, and cultural sensitivity in everything we do.

Looking ahead, we are thrilled to announce that we have started to plan for our 2024 Family Retreat hosted at the Chateau On The Lake in Branson, Missouri, from Thursday, September 26 - Sunday, September 29, 2024. We are all looking forward to this opportunity for families to come together again, share their experiences, and find solace in the companionship of others who truly understand their journey. As always, the Family Retreat promises to be a transformative and an uplifting experience for all involved.

I am excited to announce the addition of two new board members who bring a wealth of expertise in strategy, finance, and relationship-building. Karla Elmberg, Esq. and Deepa Suresh Roongta will contribute invaluable insights and guidance to the Foundation, undoubtedly bolstering our organization and driving us further in our mission.

As we embark on another year of serving our community, I want to express my deepest gratitude for your unwavering support and commitment to our cause. It is through your dedication and generosity that we are able to continue making a difference in the lives of families affected by SUDC.

Your voice matters and your insights, suggestions, and feedback are invaluable to our mission. As always, please feel free to reach out to me at any time: tina.lee@sudc.org.

Together, our Board and staff are committed to continue to shine a light on SUDC, forge a path of hope and healing, and find answers so that we live in a future free of SUDC.

With much appreciation and gratitude,



Tina Yun Lee, Executive Director

Collaborations with Partner Organizations Enhance Support

To honor our deep commitment to support families impacted by SUDC, the Foundation recently connected with bereavement support organizations to create and enhance our partnerships, provide resources, raise awareness, and foster collaboration. Those efforts include:

- Our collaborative efforts with the [SADS \(Sudden Arrhythmia Death Syndromes\) Foundation](#) strengthen support for families affected by SUDC and sudden arrhythmia deaths, combining the expertise of both foundations. This partnership ensures comprehensive support and information through shared resources and coordinated awareness campaigns to help families.

- Our connection with the [Southeast Wisconsin Grief Network \(SEWGN\)](#) ensures access to specialized support and information for bereaved families in the region while fostering knowledge sharing and laying the foundation for future collaborations.
- In discussions with [Wisconsin Children's Hospital](#), we seek to enhance care for SUDC families within the hospital setting focusing on resource sharing, support programs, and professional education opportunities.

By uniting with like-minded organizations, the SUDC Foundation expands its reach, raises awareness, and ensures families receive the necessary care and understanding they deserve.

Welcome New Board Members

The SUDC Foundation is pleased to introduce two new board members as they join the board. Karla ElMBERG, Esq. and Deepa Suresh Roongta both bring a wealth of expertise and passion to the Foundation's mission and will make invaluable contributions to benefit our organization and the SUDC community. Please join us in extending a warm welcome to Karla and Deepa.

Karla ElMBERG, Esq.

Karla understands deeply the challenges that SUDC families face after her daughter Tove (pronounced Tova) passed away at 16 and a half months while napping at daycare on February 2, 2022. Currently serving as the Head of Business Operations at Boston Scientific in Arden Hills, MN, she excels in developing strategic solutions to operational challenges faced by the company's legal and compliance department. Her leadership in complex projects has significantly improved the scope and quality of support provided. With previous managerial roles at KPMG and CPA Global Support Services, Karla has a proven track record of strategic thinking, operational excellence, and client-focused solutions. Karla's knowledge and insights will be instrumental in driving our mission forward.

Beyond her professional accomplishments, Karla is an active member of her community and deeply committed to making a positive impact on the lives of others dedicating her time to organizations such as Habitat for Humanity, Feed My Starving Children, and People Serving People. Her volunteer work reflects her compassionate nature and commitment to making a positive impact on the lives of others. Karla's dedication to service aligns with the SUDC Foundation's values of empathy, support, and advocacy.

Karla resides in Minneapolis, MN with her partner, Peder, and her 4-year-old son, Tor-Ole. Karla is so grateful to the SUDC Foundation for the connections that she has made and looks forward to providing help and support to the entire SUDC community.



Deepa Suresh Roongta

Deepa Roongta is Vice President of Finance at Ameriprise Financial and has over 25 years of experience in the financial services industry. Deepa received her undergraduate degree from Cornell College and has an MBA in Finance from the Carlson School of Management at the University of Minnesota. Throughout her career, Deepa has demonstrated her expertise in developing and executing effective strategies that drive business growth and operational excellence.

Her ability to translate strategic visions into actionable plans has consistently delivered exceptional results, making her a sought-after leader in the industry. In addition to her financial expertise, Deepa is known for her communication skills and her ability to build strong partnerships. She has been able to influence executives and senior leaders across organizations to align efforts and deliver on critical business objectives. With her collaborative leadership style, strategic mindset, and financial acumen, Deepa is poised to play a vital role in advancing the SUDC Foundation's mission.

Beyond her professional achievements, Deepa is actively involved in serving as a board member and through volunteer affiliations and is passionate about giving back to the community through leadership roles with mission-driven organizations that foster diversity and inclusion. She also serves on The Origins Program board and provides consultation to Vivienne's Joy Foundation.

Deepa was born in London to first generation immigrants from India and currently lives in Minneapolis, MN with her partner.



Workshop Provides Invaluable Strategies for Coping with Grief

The SUDC Foundation is offering an interactive and experiential workshop designed to address the long-term effects of grief on an individual's well-being. This 8-week workshop provides a valuable opportunity for participants to connect, share their experiences, and acquire new coping skills. It is free of charge for registered SUDC Foundation family members.

Participants have described the workshop as a transformative experience, providing a safe and inclusive environment for individuals from various backgrounds to come together and support one another. One participant shared, "I attended the last Coping with Grief and Loss session, and I felt completely included and identified with so many of the emotions, feelings, and perceptions that the parents commented on. At times it was difficult to confront the emotions, but so worthwhile. Everybody was so honest and open. I felt so honored to be included with these parents."

The workshop is conducted through the SUDCF Network, a private and secure social platform, with live sessions taking place virtually. Previous successful groups have demonstrated a remarkable 20% reduction in post-traumatic stress disorder (PTSD) symptoms.

The final group of the year is scheduled to begin on Wednesdays, from October 4 to November 22, 2023, 1:00 – 2:30 pm ET. If you're interested in participating, you can register by visiting: <https://www.surveymonkey.com/r/SUDC8Week>

Due to the positive response and impact, we will continue offering this group in 2024. To register for dates in 2024 go to: <https://www.surveymonkey.com/r/SUDCClosed2024>

Speakers Series Provides Insight to Community

The 2023 SUDC Foundation Speaker Series has been a resounding success, bringing valuable insights and support to the community. In February, SUDC mom Dr. Shan Gao shed light on Understanding EMDR. Another notable event, hosted in April, was the SUDC Parents Panel, where parents who have navigated life after the sudden loss of a child shared their experiences and insights. In June, Kelly Farley presented "Fathering Through Grief: Navigating the Challenges and Finding Strength in the Journey of Loss." And in August, Natalia Garcia, PhD, discussed Understanding Natural Recovery and Evidence-Based Treatments after Trauma and Loss. Each of these sessions were recorded and are available on the SUDC Foundation website for anyone who was unable to join.

Kelly Grosklags will be featured on October 22, 2023, for a "Conversation with Kelly about Coping with Holidays and Special Days." Bryan Piatt will present "The Art of Breathing" on December 3. To register for these upcoming events and ensure your participation, visit the following link: <https://www.surveymonkey.com/r/SpeakersSeries>

Don't miss out on the opportunity to learn from experts and gain valuable insights to support you on your journey of healing and growth.

The SUDC Foundation is already looking ahead to its 2024 Speaker Series, aiming to continue bringing valuable knowledge and support to the community. If you are interested in speaking at one of our events, we encourage you to reach out to us at support@sudc.org. We believe in the power of diverse perspectives and expertise, and we welcome individuals who can contribute valuable insights and experiences to our audience.

Mom Shines Light for Ronnie

After the sudden and tragic loss of her daughter, Ronnie, in 2017, Dahlia Guttman found herself grappling with profound grief and questions that seemed to have no answers. Determined to channel her pain into purpose, Dahlia embarked on a journey of healing and advocacy. In 2020, Dahlia and her family established the [Ronnie's Joy Foundation](#), a tribute to her daughter's memory, dedicated to bring joy and smiles to sick children and to support bereaved families. In that same year, Dahlia became an SUDC Foundation Ambassador, and through her medical background as a physician, Dahlia leveraged her connections to raise awareness about SUDC within the pediatric community, even delivering Grand Rounds at the [Montreal Children's Hospital](#). Her steadfast dedication has led to her latest accomplishment of spearheading a specialized "caring for grieving families" bereavement service at the Montreal's Children's Hospital to address a critical gap in care for grieving families. Dahlia's efforts reflect her enduring love for Ronnie, demonstrating that even in the face of unimaginable loss, she continues to "parent" Ronnie by creating a meaningful legacy and fostering positive change. Dahlia's story serves as a reminder to be patient and present in navigating the challenging journey of life after loss and that there's a life worth living.

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



Ronnie at age 23 months

SUDC Foundation Shines at the 2023 ACLP Conference



Amanda Brindle, LSW, SUDC Foundation Associate Family Services Manager

The 2023 Association of Child Life Professionals (ACLP) conference brought together professionals from around the world to share knowledge, exchange ideas, and collaborate on improving the lives of children and families. Amanda Brindle, LSW, Associate Family Services Manager, was able to connect with over 100 attendees, not only raising awareness about SUDC but also promoting our valuable resources and initiatives.

We were able to educate attendees on SUDC as well as the challenges families face when dealing with such tragedies, empowering professionals to enhance their support to families. Our booth provided essential information about SUDC, drawing attention from conference participants who were previously unaware of its existence.

The conference also provided the opportunity to showcase *Unexplained Pediatric Deaths: Investigation, Certification, and Family Needs*, a vital resource for medical professionals, death investigators, and researchers highlighting the importance of proper investigation and certification. In addition to the text, we promoted our [ongoing webinar series](#), which delves deeper into the multifaceted aspects of SUDC.

We also encouraged attendees to add our custom [“Help for Families” brochure](#) to their available resources. This brochure serves as a valuable tool to provide information and support to grieving families, ensuring they never leave the hospital empty-handed.

Through our participation in the conference, we played a crucial role in ensuring that families affected by SUDC receive the support and understanding they need during their difficult journey.

Reflections from a Mom Who Returned to Fundraising (continued...)

any other family who goes through this.

Prior to hosting Run for Casey, I had not hosted an event since 2015. Since that event, Cocktails for Casey, I have moved from Brooklyn to New Jersey. I have a whole new community, work-place, friends, and a life where no one really knew about Casey. Navigating this has been difficult, and starting over to let people know that Casey did, in fact, live, and that her memory and life are important and meaningful, is hard. You have to go out of your way to share this information, and sometimes that can be really difficult. I have shared Casey’s story and information about SUDC with this new community over time but recently felt more disconnected from her than I have in the past. These events allow me to do something for her. They help me to share her story. I have found that the same amazing support system that I had a year after her death is still there to support me 12 years later. I also have a whole new group in New Jersey who were all there to help!

Run for Casey was different from any other fundraiser I had planned. I had never done this before and knew nothing about hosting a race. Fitness and running are now a huge part of my life, and I realized I wanted to blend that with honoring Casey. On day one, I lacked confidence that I could do it, and was thinking of backing out. After speaking with Liz Milliken, the SUDC Foundation’s Development Director, I realized that the SUDC Foundation was not just going to be the recipient of the funds, but they would be my partner in hosting the event. I left our first meeting with a renewed energy and anticipation for the challenge ahead. Every part of the planning process was challenging, but in a wonderful way. I was learning new things and working very hard, but this brought me back to that same feeling of purpose, love, and grief. I was doing it for Casey. Each challenge I overcame was an accomplishment for her. Each new runner who signed up was one more person who knew about Casey and SUDC. That was an amazing feeling that I had been missing, and turned out it was one that I needed.

The SUDC Foundation has been an invaluable resource for me and my family. I would not be where I am in life without them. To be a part of a group that no one wants to belong to is powerful.



Ellen and Jonathan Young, Casey’s Parents

In the early days, even the first few years after Casey's death, the Foundation supported us in our grief. We took advantage of the support services as a lifeline – the meetings, phone calls, online resources, and community building. When the fundraising started, SUDC Foundation staff was a constant support network. Even now, events where we meet new families are very special to me and oddly comforting. My advice for other families is to lean on this community to help get you through. If you're thinking about hosting an event, you can do it. The SUDC Foundation will be your guide and partner, and, as always, you will not be alone. Hosting these events makes me feel closer to Casey, and I could not have done that without the support from the SUDC Foundation.

Even though the SUDC Foundation and community has always been there for us and knowing that has brought me peace, I didn't always need it, and at times I did need a break. Stepping back into being involved with the SUDC community was the easy part. It's like the friend who has your back when you need them but is happy for you to be independent. Hosting a fundraiser after an

eight-year break felt great! I would encourage any family to jump into hosting an event. Sometimes coming back to it, after a prolonged time, gives you a new perspective. In my case, it gave me purpose and drive that I think I had been missing for quite some time. I have gotten so much positive response about the event that I am already planning for next year! This time I think it will be a bit easier, since there was a steep learning curve in organizing my first race. I know now that the support the Foundation gave me in planning the event will be there, and I have learned that people really do want to help, so don't be afraid to ask!

Having my family by my side at this event was important. That includes my daughter Jordan, who misses her little sister every day, and Sydney, who has never met her big sister. I think that it does the same for them as it does for me. It is a way to connect with Casey, to do something FOR her, to honor her, and remember her. It also allows us to share her with others and share our story.

—Ellen Young

Reflections of Two Moms After Fundraising Event Year Two

So much of our relationship as a couple has been shaped by running and running together. We decided to get married after running a half marathon. We often ran with the kids as they encouraged, "Go, Mama, go!" Tara has a shirt that says, "Stroller miles count double!"

We want Malcolm's legacy to be one of joy and community. It was an obvious decision to organize a race in his honor. And while the last two years have been remarkable in the ways our many communities have shown up for us, Malcolm, and the SUDC community, having an in-person event in 2022 and 2023 has been deeply healing, too. Malcolm died in the height of the pandemic; we couldn't gather with loved ones.

Neither of us had ever hosted an event of any kind and the questions seemed endless – would it rain? What if no one showed up? What if too many people showed up? Where will people park? Who will create our signs or our T-shirts? The list went on. These questions at times felt like they clouded the purpose of our efforts – to remember Malcolm, to celebrate him, and to support the SUDC Foundation and families like ours.

Tara kept Kim calm by making spreadsheets showing things like weather trends from the last five years. Liz Milliken from the SUDC Foundation took on administrative tasks that felt too challenging even two years after Malcolm's death. Our team of friends rallied the community, created our logo, made sure there was food, and, most importantly, secured a considerable number of sponsors. It was our story, but we weren't forced to retell it repeatedly to make the event a success. We weren't the only ones carrying the impact of Malcolm's death. The support we received while hosting our event was a gift that reminded us that we weren't the only ones carrying his legacy.

We've had one year of gorgeous weather and another of freezing rain and we will have more years with more sur-



Kim and Tara Wildszewski, Malcolm's Parents

prises. If we have any wisdom to share from our experiences it would be not to try to do it alone. We only realized after we were in the planning stages that we were choosing to do something that triggered feelings of being out of control. Every unexpected change or surprise reactivated a grief-response in Kim's body. Planning an event in memory of your loved one is too stressful, and it's too important to think that you can do it alone. But hold onto the fact that it's also an opportunity for the people who love us to offer their continued care, and for us to receive that care.

—Kim and Tara Wildszewski

Guiding Families Through Loss: The Vital Role of the SUDC Foundation Family Advocate

Finding the SUDC Foundation is often a pivotal moment for families experiencing the sudden and unexpected death of a child, as it offers them a much-needed lifeline to face the confusing world of medical jargon, legal procedures, and emotional turmoil along with a myriad of unanswered questions. At the heart of the Foundation's dedicated Family Services team, is the Family Advocate, who not only assists families but also the professionals involved. Acting as a liaison between the family and the professional, the Family Advocate encourages a collaborative, multidisciplinary approach that fosters collaboration and communication, ensuring informed decision making and improved outcomes for all those involved.

One of the key roles of the Family Advocate is to prepare families for what to expect during the death investigation process, conveying information in simple and compassionate terms. This guidance helps alleviate some of the uncertainty and anxiety families may experience. The Family Advocate offers information about the investigation timeline, additional community resources, and available options, such as DNA banking and research initiatives. By equipping families with knowledge and empowering them to make informed decisions, the Family Advocate helps ease their burden and provides a sense of direction during a tumultuous time. The



**Heather Maher, M.S.F.S.,
Family Advocate**

Family Advocate also plays a vital role in reviewing final autopsy reports. This comprehensive review helps families gain a deeper understanding of the investigation's findings, bringing them a sense of closure and facilitating any further medical consultations or decision-making that may be required.

In addition to supporting families, the Family Advocate also extends their reach to the professional community. The Family Advocate can provide additional support networks they may not be aware of, provide additional information to the family's medical professional(s) if needed, and ensure that families' voices are heard throughout the investigation process. This collaborative and holistic exchange of communication helps professionals expand their toolkit and provide more comprehensive

patient centered care to families affected by SUDC.

The Family Advocate at the SUDC Foundation plays a vital role in establishing trust and understanding between families and professionals. By offering comfort, clarity, and hope to families, and utilizing their expertise to connect with the professional community; the Family Advocate serves as a testament to the Foundation's commitment to providing comprehensive support and ensures that no one affected by SUDC has to navigate this difficult journey alone. For more information on our Family Advocacy Services, please email: support@sudc.org.

Heather Maher, M.S.F.S., Family Advocate, earned her undergraduate degree from Quinnipiac University in Hamden, CT with a concentration in Biomedical Sciences with minors in Chemistry and Psychology. She earned a Master of Science in Forensic Science from Pace University in New York, NY with a concentration in genetic testing.

Prior to joining the SUDC Foundation, Heather worked for the Armed Forces DNA Identification Laboratory as a Forensic Scientist for six years. At AFDIL, she participated in many missions, including the identification of the remains of soldiers from past wars. Heather's work at AFDIL allowed her to develop extensive expertise in DNA analysis and genetic testing techniques, solidifying her skills in this crucial field.

Heather joined the SUDC Foundation in 2015. Her work within the SUDC Foundation DNA Banking program was presented at the National Association of Medical Examiners Conference in 2018.



Sunflowers for Frank

In memory of their beloved son, Frank, and in honor of his 6th birthday, the [Frank McLean Forever Foundation](#) concluded another impactful annual sunflower sale for the 4th year in a row. This year's sunflower sale raised funds to advance research into sudden unexplained pediatric deaths and bereaved family services in partnership with the SUDC Foundation and [Novant Hemby Children's Hospital](#). The SUDC Foundation extends our deepest gratitude to the Frank McLean Forever Foundation and to all the fundraising hosts who organized an event this year, in memory of their beloved child. All our funding comes from private donations, and fundraising events are essential to helping us raise awareness and donations to support SUDC Foundation initiatives.

News from the UK

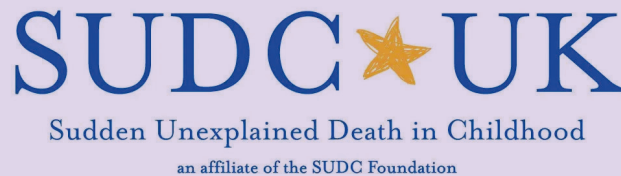
As awareness of SUDC increases in the UK, our affiliate organization continues to expand in impact and size. SUDC UK is thrilled to have hired two wonderful new members of staff, Hannah Johnston, and Mandy Rooke, to support their communications and administration, respectively.

The improvement in UK awareness means that more families are accessing support and connecting with SUDC UK and the SUDC Foundation earlier in their journey. Activities so far in 2023 are sure to continue this hopeful trend so that no family grieves alone. For example, Paediatrician Peter Flemming CBE, SUDC UK scientific advisor and SIDS/SUDC expert, recently presented a keynote talk entitled "Understanding Sudden Unexpected Death in Children over 1 Year of Age" at the Royal College of Paediatrics and Child Health (RCPCH) conference in May. This talk shared a national report which was co-authored by SUDC UK and reviews national population data on unexpected child death for the first time.

Alongside this national report, the stories of many



Nikki Speed, PhD
CEO, SUDC UK



SUDC-bereaved families were shared in January at the first ever UK Parliamentary debate on SUDC. Since this milestone event, SUDC UK has been in discussion with the UK Department of Health and Social Care (DHSC) who are engaged in making tangible changes to benefit bereaved families and SUDC research.

We are excited to share that the DHSC and their National Health Service colleagues recently hosted a roundtable meeting in London, where senior representatives from 20 national organizations met as a follow up to the SUDC debate. Awareness, education, research, and care were all discussed. SUDC had the national attention and engagement it deserves, and we will collaborate to deliver

commitments that were made, working towards improvements in all areas.

SUDC UK has had the privilege of hosting two family days this year as well as our annual virtual event "Stars For Our Children" as a positive act of remembrance and community.

SUDC UK and the SUDC Foundation would like to thank everyone who supports the mission of SUDC UK. We are proud to collaborate every day to support registered families and encourage research to save lives in the future.

SUDC on the Global Stage

The Sudden Infant Death and Pediatric Forensic Medicine conference held May 3-5 in Oslo, Norway, brought together dedicated researchers, clinicians, and investigators to share progress in research efforts around the world and support crucial collaborations to understand and prevent sudden deaths in the young.

The SUDC Foundation and SUDC UK were proud to support Laura Gould, MSc, MA, PT, Research Scientist at the SUDC Registry and Research Collaborative (SUDCRRRC), NYU Langone Grossman School of Medicine; and Declan McGuone M B, BCh, Assistant Professor Pathology, Yale School of Medicine, to travel and present the many areas of progress at the SUDCRRRC at this special meeting. Nikki Speed, PhD, CEO of SUDC UK also attended and together, they engaged in dynamic discussions across many countries, cultures, and investigation systems. In addition to the genetic, neuropathology, and proteomic advances presented from the SUDCRRRC, presentations were diverse and included topics such as algorithms to predict higher risks of infant deaths, research priorities across ethnic minorities, difficult case discussions, updated UK guidelines for postmortem investigations, barriers to research, classification systems, neurotransmitters, research of the hippocampus, dynamic breathing control in SIDS, cardiac arrhythmias in sudden infant deaths, head trauma, and neuroradiology.

The meeting was large enough to bring together an incredible group of professionals, but also small enough to foster new exciting engagements to benefit the health of all children.



Laura Gould, MSc, MA, PT, presenting in Oslo, Norway

The SUDCRRC: Growing our Understanding of SUDC Everyday

The SUDC Registry and Research Collaborative at NYU Langone Health, created in 2014, is the largest registry of SUDC cases in the world inclusive of full medical records, biospecimens, trio (child and both parents) whole exome sequencing and enables novel research which is growing our understanding of SUDC. Learning from each and every tragedy, the SUDCRRC team, led by Dr Orrin Devinsky and Laura Gould (Cofounder and Past President of the SUDC Foundation), are dedicated to finding answers and preventing SUDC.

The SUDCRRC team of more than 30 members continues to grow. In the last year, the registry welcomed collaborators from the Children's Hospital of Philadelphia, PA, (USA) and University of Monash (AUS) to add their unique expertise to investigate SUDC. The team has explained some cases of SUDC, but many still elude us.

At this time, the Registry is studying more than 300 children and more than 700 family members who donated their information to support discoveries. While the study enrolls unexplained deaths up to 18 years, about 80% of the children enrolled were between 1 and 4 years of age. This is consistent with national data from the US Centers for Disease Control and Prevention (CDC). Slightly more than half were boys (~60%) and the majority were sleep related. While most children had no significant medical history prior to their deaths, the Registry continues to see ~30% association with febrile seizures which is 10X higher than we see in the general population. Utilizing whole exome se-

SUDCRRC

SUDC Registry and Research Collaborative

quencing, about 9% of cases are identified with significant gene changes associated with the heart and brain function.

Among the Registry's 15 publications thus far, it recently published the first study of proteomics in SUDC brain tissue. Molecular signaling pathways associated with protein differences were identified in SUDC compared to explained deaths. These surprising discoveries warrant larger studies in other brain regions to help us understand their meaning and relationship to the causes of SUDC. The most recent publication from the Registry is a systematic review of febrile seizure (["Are brief febrile seizures benign? A systematic review and narrative synthesis"](#)) which found that while mortality associated with febrile seizures are very low, data from sudden death registries do support that simple febrile seizures can sometimes increase risk.

The SUDC Foundation is a proud sponsor of the SUDCRRC, breaking new ground to understand SUDC and achieve our common - "world without SUDC".

If you would like to support the SUDCRRC, please visit sudc.org/sudc-registry-research-collaborative.

For more information on the SUDCRRC at NYU Langone Health, visit sudcrrc.org.

Diversity Task Force Created to Improve Support to Diverse Communities

According to the Centers for Disease Control and Prevention (CDC), Black or African Americans in the U.S. are twice as likely to succumb to SUDC compared to White Americans.

Recognizing that our registered families only represent a portion of those grieving the sudden, unexplained loss of a child, the SUDC Foundation's Board of Directors is taking intentional steps to address the effectiveness in accessing, engaging, and retaining all families affected by SUDC.

The SUDC Foundation distributed surveys to families and medical professionals in the SUDC community in the fall of 2021. In April 2022, the Foundation hired Dr. LaShonine Gandy-Smith, a diversity and inclusion consultant with experience in community mental health to assess the survey and help establish the SUDC Foundation Diversity Task Force to provide recommendations for improving access and services to diverse communities with cultural responsiveness.

In a letter to the Diversity Task Force candidates, Laura Gould, Co-Founder and President (ret.) wrote:

The work of the SUDC Diversity Task Force will undoubtedly push our organization forward, and I hope their recommendations can serve as a model for other bereavement focused organizations who share in these same systemic struggles.

Launched in June 2023, the SUDC Foundation Diversity Task Force consists of 17 members, including bereaved families, medical examiners, community organizers, law enforcement, board members, and staff representing diverse perspectives from Canada, the United Kingdom, and the United States.

Under the guidance of Agnes Meneses of AGMeneses Consulting, LLC, and Carol Xu, PhD, both with extensive experience in diversity and inclusion work, the Task Force met bimonthly with a goal of creating a list of recommendations based on their collective experiences and insights. These recommendations will undergo review by the Foundation's Board of Directors and become a crucial component of the organization's strategic planning, policies, practices, and programs.

The SUDC Ambassador Program

The SUDC Foundation Ambassador program serves as a vital platform that empowers passionate advocates to actively promote awareness and understanding of Sudden Unexplained Death in Childhood (SUDC). By leveraging the collective strength of our growing global community, the program seeks to create a dedicated army of Ambassadors committed to supporting the organization's mission and vision. These advocates come from diverse backgrounds, including families directly affected by SUDC and medical professionals who lend their voices and support to SUDC awareness and advocacy.

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



Create a Lasting Legacy of Hope: Include the SUDC Foundation in Your Estate Plans

Bobby and Jan Jenkins have a deep connection to the SUDC Foundation which began after the loss of their grandson Moss in 2014. Bobby serves as President of the Board of Directors and is a passionate fundraiser for the Foundation. As generous donors, Bobby and Jan



Bobby, SUDC Foundation Board President, and Jan Jenkins

are determined to fund innovative research through the SUDCRRRC at NYU Langone Health. Setting up a legacy gift to the SUDC Foundation to ensure SUDC research at NYU Langone Health continues is profoundly important to them.

Your enduring legacy of Hope can also have profound impact by remembering the SUDC Foundation in your estate plans. By doing so, you play a pivotal role in shaping the future of our foundation and driving vital research into the causes of Sudden Unexplained Death in Childhood. Your contribution ensures that families affected by SUDC receive critical services without any financial burden.

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. A simple 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 marketable property.

To learn more, please visit sudc.org/legacy-planned-giving/. If you have already remembered the SUDC Foundation in your estate plans or are planning to do so in the future, please contact, Elizabeth Milliken, Director of Development, at Elizabeth@sudc.org so that we can recognize your generosity. Thank you for helping us invest in a future free of SUDC. We are deeply grateful for your generosity and continued support.

Welcome, Ghazala Siddiqui!

The SUDC Foundation would like to welcome Ghazala Siddiqui, LPN, our Community Education and Outreach Coordinator. With over 20 years of experience in healthcare management, Ghazala brings a diverse skill set including marketing, patient and community education, and effective advocacy.

In previous roles, Ghazala has demonstrated exceptional leadership skills, success in bridging communities, and supporting families in hospice. Ghazala's ability to organize and coordinate marketing events, nurture relationships with community organizations and healthcare professionals, and spearhead initiatives to educate and advocate for community well-being will be invaluable to the Foundation. Ghazala will oversee the SUDC Ambassador Program and looks forward to working with our Ambassadors to promote the Foundation's mission and establish strong relationships within diverse communities.

Ghazala holds a BA in Sociology, along with being a Professional Licensed Nurse. She is also multilingual in English, Arabic, Urdu, Punjabi, and Hindi.

She lives in Plainfield, New Jersey, with her husband and daughter who is soon to be college bound.

Please join the SUDC Foundation in extending a warm welcome to Ghazala. We are confident that her expertise, dedication, and passion for community wellness will make a meaningful and positive impact on both the Foundation and the communities we serve.

To reach out to Ghazala and learn more about our SUDC Ambassador program, please email: ghazala@sudc.org.





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Support our 15 Marathoners for SUDC this Fall!

The TCS New York City Marathon is on Sunday, November 5!

Tune in to ABC starting at 9am to watch and cheer on the 15 runners supporting the SUDC Foundation. Show your support for their incredible efforts by donating to the team or to an individual runner at tinyurl.com/sudc-runners.