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WHAT IS SUDC?

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 12 months and 18 years 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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The SUDC Foundation Launches Postmortem Genetic Testing Program in Partnership with GeneDx

Sudden Unexplained Death in Childhood (SUDC) refers to the unexplained death of a child over twelve months to eighteen years of age, even after a thorough investigation and autopsy. Recognizing the vital role of genetic testing in understanding these tragic losses, the SUDC Foundation has transitioned from its former DNA Banking Program to the Postmortem Genetic Testing (PMGT) Program. This shift reflects the rapid advancements in genetic testing technology and the growing acceptance of postmortem testing as an essential investigative tool to yield a comprehensive SUDC investigation.



In partnership with GeneDx, a leading provider of advanced genetic testing services, the SUDC Foundation is now offering postmortem genetic testing to medical examiners and coroners who are actively investigating SUDC cases. This service will be provided at no cost to eligible families and offices, removing financial and accessibility barriers.

The PMGT Program supports families in making informed decisions by potentially identifying specific genetic conditions that may have contributed to their child's death and allowing for further testing for family members if needed. Negative results provide peace of mind by alleviating concerns about hereditary risks, offering closure during an incredibly difficult time. GeneDx also provides high quality genetic counseling, helping families understand and navigate the implications of their test results to make informed choices about their health and care. The PMGT Program ensures equitable access to these essential diagnostic tools, supporting a continuum of care that includes medical management which is often covered by insurance.

Additionally, the PMGT Program has the potential to contribute genetic information to current and future research efforts, enhancing our understanding of SUDC and helping to prevent future tragedies.

The SUDC Foundation is deeply committed to supporting medical examiners and coroners with this essential program, ensuring that both professionals and families have access to the latest advanced tools and resources available for the most thorough investigation possible. This comprehensive approach not only aids in potentially determining the cause of death but also equips families with crucial information that can positively impact the health outcomes of surviving relatives providing clarity and hope for the future.

For more information about the SUDC Foundation's Postmortem Genetic Testing Program, please visit: sudc.org/post-mortem-genetic-testing/.

Peer Friends Connection Program

The Peer Friends Connection Program is a wonderful opportunity to connect with others in our community who are navigating similar experiences. This program offers a gentle and supportive way to find companionship and understanding.

Our Peer Friends are not a replacement for therapy, nor are they expected to provide professional counsel. Instead, they offer friendship, support, and a listening ear. Becoming a Peer Friend is a valuable experience for both the volunteer and the recipient, fostering mutual support and connection.

If you are looking for a way to make a meaningful impact or find support, apply today to join our Peer Friends Connection Program!

To learn more about the Peer Connections Program or to become a Peer Friend, please email us at support@sudc.org. Join us in making a meaningful difference!



BOARD of DIRECTORS

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- Amanda Brindle, LSW, Manager, Family Services
- Michelle Brodeur, Family Services Assistant
- Heather Maher, MSFS, Manager of Postmortem & Forensic Services
- Ghazala Siddiqui, Community Education and Outreach Coordinator
- Brittany Thompson, Content Creator and Communication Specialist
- Marissa Kambouris, Intern, Family Services
- Vivian Myers, Summer Intern

SUDC Foundation Aims to Raise \$125,000 Through Twin Cities 10 Mile and NYC Marathon

We are pleased to share that the SUDC Foundation has been selected as one of the charity partners for the Medtronic Twin Cities 10 Mile on October 6, 2024. This race features a beautiful scenic route that takes runners across the mighty Mississippi River, with a picturesque view of the State Capitol. If you live in the area, we hope you'll join us for brunch along the route to cheer on the twenty-five runners who have committed to raising a minimum of \$1,000 each.

Following the TC 10 Mile, on November 3, our board, staff, and supporters will be cheering on the eleven runners representing the SUDC Foundation in the TCS NYC Marathon. These incredible athletes have not only committed to run the 26.5 mile course throughout the five boroughs of New York City, they have committed to raise a minimum of \$5,000 each!

Our collective goal of \$125,000 for both of these events will directly fund SUDC Foundation partnerships toward SUDC research initiatives and make a profound difference in the lives of those affected by sudden unexplained death in childhood.

To learn more about joining us for one of these exciting events, please contact Director of Development, Liz Milliken, at elizabeth@sudc.org. To support one of our team members, please visit sudc.org/donate.



MEDTRONIC TC 10 MILE





A NOTE TO OUR READERS...

Focused on the Future with Hope and Innovation

Dear SUDC Community,

As we reflect on another year of our journey together, I am filled with immense gratitude for the strength, resilience, and unwavering support that each of you brings to our mission. The past year has been marked by significant progress—new initiatives, growing partnerships, and a deepened commitment to our cause. These achievements are a testament to the dedication of our Board of Directors, staff, volunteers, and most importantly, the families and supporters who stand with us every day.

Looking ahead, I am inspired by the possibilities the future holds. Our strategic plan for 2024-2027 lays out a bold vision—one that builds on our successes and challenges us to dream bigger, reach further, and make an even greater impact. We are committed to expanding our research efforts, enhancing our support services, and raising awareness in new and innovative ways.

A key element of our future planning is ensuring financial agility to support our long-term goals. By fostering a sustainable and robust pipeline, we can continue to back groundbreaking research and extend the reach of our services, ensuring that our work endures and evolves to meet the needs of the SUDC community.

We are excited to announce the formation of our Scientific Grants Committee, a pivotal step in advancing our research strategy. This committee will guide our investment in research, directing funds to the most promising studies and fostering scientific discovery. We are pleased to welcome three new members to this committee, each bringing the expertise and acumen necessary to steer our research initiatives toward meaningful breakthroughs and work toward a future free from SUDC.

In addition, we are launching our Postmortem Genetic Testing Initiative, which will provide families with a continuum of care and improve investigative outcomes, ultimately enhancing our ability to understand and prevent SUDC.

In our ongoing commitment to support our families, we launched our SUDC Cares Program. This new initiative offers complimentary grief support and coaching led by our Licensed Social Worker (LSW), providing a compassionate environment for healing and equipping families with the tools they need to navigate their grief.

Additionally, we are thrilled to introduce our Teen Ambassador Program, a new initiative that represents the voice of our future. Our passionate young advocates will play a crucial role in raising awareness and ensuring that our message reaches every corner of our community. They embody the hope and inspiration that drives us forward, and we are eager to see the impact they will make.

We are also honored to welcome Rev. Kim Wildszewski as our first Poet Laureate. Kim's poignant and heartfelt poetry will add a unique and compassionate voice to our community, starting with a special poem at our upcoming Community Retreat Memorial Ceremony. Her contributions will enrich our events and provide a voice of comfort and reflection.

I would also like to take a moment to express our deep appreciation for our collaborative partnership with SUDC UK under the leadership of Nikki Speed, PhD, CEO. They have shown extraordinary dedication, and we celebrate their milestones with mutual enthusiasm. Their contributions have not only broadened the reach of our collective mission but have also underscored the importance of collaboration. Together, we are stronger.

As we move forward, we will continue to honor the lives of the children who inspire our work. Their memories guide us, and their stories fuel our determination to create a world where no family will have to endure the sudden and unexplained loss of their child. Together, I am confident our collective efforts will bring us closer to a future where SUDC will be understood and prevented.

Thank you for being a part of this incredible community. Your support, compassion, and dedication are the driving forces behind our progress. I look forward to all that we will accomplish together in the years ahead.

With hope and gratitude,



Tina Yun Lee, Executive Director

Announcing the SUDC Foundation's Cares Program!

We are excited to introduce the SUDC Cares Program, a dedicated initiative aimed at supporting the well-being of our SUDC families. This program offers a Complimentary Grief Support and Coaching service led by a Licensed Social Worker (LSW), providing specialized support and coaching to help families navigate the profound impact of sudden and unexplained loss.

The SUDC Cares Program is designed to create a compassionate environment where families can find solace and understanding. Our program objectives include providing tailored coaching support utilizing various therapeutic approaches, equipping families with effective



coping strategies to manage grief and stress, and promoting open emotional expression to facilitate healing. Additionally, we address family and relationship dynamics, helping families overcome potential challenges and fostering healthy, fulfilling relationships.

To be eligible for the SUDC Cares Program, families must be registered with the SUDC Foundation and have experienced the loss of a child due to SUDC. If you are interested in learning more or applying for the program, please visit: [sudc.org/sudc-cares-complimentary-](https://sudc.org/sudc-cares-complimentary-coaching-program/)

[coaching-program/](https://sudc.org/sudc-cares-complimentary-coaching-program/)

We are here to provide comfort, understanding, and guidance every step of the way.

Meet Our New Board Members!

The SUDC Foundation welcomes our two new Board of Directors each bringing a wealth of experience and dedication to our mission. Stephanie and Brian's expertise will complement our current board's strengths as we work together to advance our understanding of SUDC and provide vital support to our families.

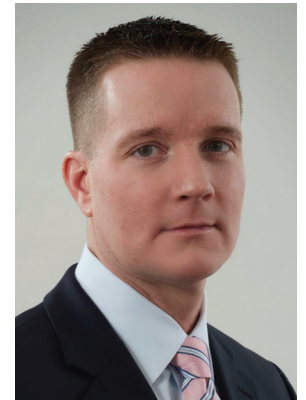
Stephanie Gandomi, MS, MBA, LCGC

Stephanie Gandomi brings over 18 years of expertise in genetic counseling, healthcare policy, and precision medicine. She currently serves as a professor and Program Director for the Master of Science in Genetic Counseling at Southern California University of Health Sciences. Stephanie co-founded the Lucile Packard Children's Hospital Maternal-Fetal Medicine Clinic at Stanford Perinatal Diagnostic Center in Salinas in 2006 and has held leadership roles at Ambry Genetics, Invitae, and UnitedHealthcare. Her deep experience in clinical genomics and healthcare policy has been instrumental in guiding our Postmortem Genetic Testing Initiative, ensuring we provide the best support and care for families. With her formal training in pre-and-perinatal psychology, somatic-based therapy, marriage and family therapy, and trauma-based counseling, Stephanie brings a unique and invaluable perspective to our efforts as we continue advancing research and providing compassionate support to families.



Brian P. Ehret, F-ABMDI

Brian Ehret is the Chief Forensic Investigator at the Center for Forensic Sciences in Syracuse, New York and has over 32 years of experience in medicolegal death investigation. As an adjunct professor at Syracuse University and a respected leader in the field, Brian has served as Immediate Past President of the American Board of Medicolegal Death Investigators. Brian is involved with numerous prestigious organizations in the field of forensic science and medicolegal death investigation to include the American Board of Medicolegal Death Investigators (ABMDI), the National Institute of Standards and Technology (NIST), Organization of Scientific Area Committees for Forensic Science (OSAC), and the Forensic Technology Center of Excellence (FT-CoE). Additionally, Brian is a contributing member to the National Association of Medical Examiners (NAME), the International Association of Coroners and Medical Examiners (IACME), and the New York State Association of County Coroners and Medical Examiners (NAME). He has been a leader in raising SUDC awareness and sharing the Foundation's resources with professionals during his lectures at the state, national, and international levels, where he emphasizes the importance of legally defensible death scene investigations and the need for standardized procedures. In 2023, Brian was honored by the International Association of Coroners and Medical Examiners as "Investigator of the Year."



Heather Maher, MSFS, Steps Into Expanded Role as Manager of Postmortem & Forensic Services

We are pleased to announce that Heather Maher, MSFS, formerly our Family Advocate, has transitioned to the role of **Manager of Postmortem & Forensic Services**. This change reflects the SUDC Foundation's commitment to providing high-quality support for families, guiding them through death investigations, reviewing autopsy reports and medical records, coordinating biospecimen and genetic testing, and facilitating research referrals. As part of this transition, our Advocacy Services program has been renamed as the Postmortem & Forensic Services. Heather will continue to act as a liaison, establishing collaborative partnerships with medical examiners, coroners, and other professionals to ensure comprehensive autopsies and follow-up care when appropriate. In her expanded role, Heather will also oversee the Postmortem Genetic Testing Program, continuing to guide families with the same dedication and compassionate care.

Finding Purpose Through Loss: An SUDC Sibling's Journey



Hil! I'm Vivian Myers, a junior in high school, living in San Francisco, California. My days revolve around spending time with family and friends, participating in volleyball and track, and giving back to the community through volunteering at Saint Anthony's and the Compass Family Shelter. I am also an SUDC sibling; and my dad, Steve Myers, is a current board member. This summer, I've had the honor of interning at the SUDC Foundation, where I've been working on the launch of the Teen Ambassador Program, helping plan for the upcoming Community Retreat, and promoting the SUDC Foundation's runners in the New York City Marathon.

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Celebrating Healing Through Words: Introducing Rev. Kim Wildszewski as the SUDC Foundation's First Poet Laureate

Rev. Kim Wildszewski, mother of Malcolm, has been appointed as the SUDC Foundation's first Poet Laureate. Kim's poignant poetry will add a heartfelt touch to our events, starting with a special poem for the 2024 Community Retreat Memorial Ceremony. Kim will act as our literary ambassador and play a vital role in raising SUDC awareness, supporting those experiencing grief and loss, and enriching communities through the power of poetry. Kim's responsibilities will include composing original poems for key SUDC Foundation events and communications, bringing a unique and compassionate voice to our community.

Kim and her wife, Tara, are parents to their beloved sons, Malcolm, Otis, and Tobias. They have relied on their community for essential support throughout their grief journey after losing Malcolm at just two years old.

Kim leads our Lectio Divina sessions, a contemplative poetry practice involving thoughtful reading and reflection to deepen connections and provide solace. These 30-minute sessions offer a meaningful space for reflection and unity, helping families navigate their grief together.

Join us in congratulating Kim on this meaningful journey. Her contributions will undoubtedly inspire and uplift many. Additionally, we encourage you to participate in her Lectio Divina sessions, fostering a sense of community and healing. Contact support@sudc.org or visit the [SUDC Network Events Calendar](#) and join upcoming sessions.



Rev. Kim Wildszewski, mother of Malcolm

Finding Purpose Through Loss: An SUDC Sibling's Journey

My connection to the SUDC Foundation began after my family experienced the devastating loss of my younger brother, Jacob. He passed away at the age of two in 2012, when I was only four years old. His passing not only changed our family dynamic but also led me to spend a few formative years as an only child. Without siblings and surrounded by adults, I found myself gaining understanding and independence at a young age. I was often described as “8 going on 18.” Despite his short time here, Jacob's journey brought my family to the SUDC Foundation, where we found purpose in sharing his story.

While losing my brother was, and still is, a profound tragedy, it has shaped the person I am today. His memory inspires my leadership and determination—qualities that have guided me in my roles both at school and within the SUDC Foundation. As I prepare for my next chapter—college—these gifts continue to motivate me to make an impact, just as Jacob's memory has made

an impact on me.

Through my journey, I've learned that time alone doesn't heal; it's living through life that heals. I believe in the power of moving forward, even though we may never fully move on. One phrase that resonates deeply with me, especially as I reflect on the loss of loved ones, is this: “One is able to move forward without moving on.” It reminds me that healing doesn't mean forgetting; instead, it's about carrying the memories and lessons with us as we continue to grow and live.

I'm excited to be part of the Teen Ambassador Program and to connect with others who have been affected by SUDC. Sharing our stories, supporting each other, and honoring the memories of those we've lost are what make this community so special. I'm grateful for the chance to give back to the organization that has been such an important part of my family's journey, and I look forward to continuing this work in the years to come.

Finding Peace and Living a Meaningful Life While Honoring Alex's Memory

On February 5, 2006, our lives changed forever. Our adorable, healthy, almost 2-year-old daughter, Alex, did not wake up.

The SUDC Foundation was a lifeline for us. My husband and I, as well as our parents, Alex's grandparents, received amazing support from the Foundation for our newfound grief. We also registered Alex in the SUDC Research Project, which at that time was under the direction of Henry Krous at San Diego's Children's Hospital.

In October 2006, with the help and guidance of the SUDC Foundation, we hosted our first “Alex's Run for A Reason.” Our run became an annual community event each October for the next 10 years, and raised over \$600,000 for the SUDC Foundation.

Over the years, I have enjoyed continuing to be involved with the SUDC Foundation speaking on panels, participating in the [Unexplained Pediatric Death publication](#), and most recently becoming a SUDC Ambassador.

But it is important to note that as my family grew, my involvement with the SUDC Foundation had to sometimes take a back seat. With the addition of Brandon and Carly to our family, I found myself having less time to volunteer. And even though being busy with my kids afforded me less time to be involved with the SUDC Foundation, it did not mean Alex was forgotten. We continued to honor her and remember her as a family.

As Brandon and Carly have gotten older (and more self-reliant), I have found myself aching to get more involved with the Foundation again, although in a different capacity.

A simple email to Elizabeth Milliken, Director of Development at SUDC, allowed me the opportunity to get back involved with an organization that is near and dear to me. I am looking forward to my role as an SUDC Ambassador and I am excited to explore other ways in which I can be effective for the Foundation in the future.

—Danna Richardson, SUDC Mom to Alex



Alex age 19 months



Brian, Danna, Brandon, and Carly Richardson 2024

Empowering the Next Generation: Announcing The SUDC Foundation Teen Ambassador Program

The SUDC Foundation is excited to introduce the Teen Ambassador Program, a dynamic initiative designed to engage young people aged 13-17 in raising awareness and supporting our mission. As an extension of our broader Ambassador Program, this program will inspire a new generation of advocates who are passionate about making a difference in their communities.

The Teen Ambassador Program offers participants an opportunity to create meaningful impact while developing valuable leadership and citizenship skills as well as acquiring volunteer community service hours. By joining, teens will have access to educational resources and opportunities that not only deepen their understanding of SUDC but also empower them to lead awareness efforts among their peers.

Through this program, teens will:

- **Inspire Change:** Become a voice for SUDC awareness and help spread the message to new audiences.
- **Develop Leadership Skills:** Engage in activities that foster leadership and community involvement, preparing them to be a strong advocate in any setting.
- **Expand Awareness:** Participate in youth-driven initiatives that broaden the reach of SUDC awareness efforts, ensuring that our mission resonates with more people.

The SUDC Foundation is committed to building a diverse and inclusive network of advocates. By involving teens from all backgrounds, we will ensure that the message of SUDC awareness touches every corner of the community.

We would like to welcome our first cohort of Teen Ambassadors: Emily Kirrane, Vivian Myers, and Sofia Lee-Verovic. Each brings a unique perspective and dedication to supporting our mission.

Emily

Emily is a rising junior at Storm King School in New Jersey. Honoring her cousin Conor, who passed away at 18 months in 2016, Emily has organized several impactful events, such as "Kisses for Conor Week". Emily is passionate about law and justice and attended the Advanced Law and Justice Reform Program where she contributed to legal reform efforts and has used these skills to make an impact in the lives of others. As a Teen Ambassador, Emily hopes to continue her work to raise awareness for SUDC, honoring the children and families that have been affected while continuing to spread kindness as she strives to be the change she wishes to see in the world.



Vivian

Vivian is a dedicated and compassionate rising junior attending high school in San Francisco, California. As an SUDC sibling who lost her brother Jacob in 2012 at the age of two, Vivian is taking an active role as our Summer Intern, orienting the Teen Ambassador candidates, and helping with the upcoming Community Retreat. She hopes to empower and unite teenagers who have experienced similar losses. In addition to her commitment to the SUDC Foundation, Vivian is deeply involved in her San Francisco community, volunteering at the Compass Family Shelter. She is also a talented athlete who enjoys playing volleyball and participating in track.



Sofia

Sofia is an incoming junior at Bronx Science High School in New York City. She founded NoteWorthy, a student-led organization that promotes citizenship, volunteerism, and mental health advocacy among high school student musicians. Sofia created several successful social media posts for our March is SUDC Awareness Month campaign and contributed to the soundtrack for our Awareness Month Highlights video which garnered over 7,000+ views and likes. Although Sofia does not have lived experience with SUDC, she believes that it is important to increase grief literacy in the community and recognizes that every child's life and the impact of their loss should be recognized and honored. Sofia views supporting causes like the SUDC Foundation as a collective social responsibility.



We look forward to the incredible contributions of our new Teen Ambassadors as they help support our mission and unite our community.

If you know of a passionate teen ages 13-17 years old who would like to make a difference, we encourage them to apply to become a Teen Ambassador and join us in this meaningful and impactful work. For more information, please visit: sudc.org/ambassador-program/. Or email: AmbassadorProgram@sudc.org.

Advancing Our Mission: Introducing the SUDC Foundation's Scientific Grants Review Committee and Our Newest Members

The SUDC Foundation is proud to announce the formation of the Scientific Grants Review Committee, a vital step in our ongoing mission to drive groundbreaking research to better understand, predict, and ultimately prevent Sudden Unexplained Death in Childhood (SUDC).

The Scientific Grants Review Committee will play a pivotal role in guiding the Foundation's research strategy and shaping the future of SUDC research. Comprising of experts from diverse scientific disciplines and extensive experience in grants management, the Committee will be responsible for reviewing grant applications and advising on research priorities. Their collective expertise will ensure that our research investments are directed toward the most promising and impactful studies.

The creation of the Scientific Grants Review Committee also underscores the Foundation's commitment to fostering collaboration and innovation within the scientific community as we work toward a future free of SUDC.

To learn more about the Scientific Grants Advisory Committee, please visit: sudc.org/about-us/scientific-grants-review-committee. For those interested in applying, please submit a cover letter and CV/resume. Please direct your submissions and inquiries to Tina Lee, Executive Director at tina.lee@sudc.org.



Geoffrey Balkman, PhD, CPO

Geoffrey Balkman, PhD, CPO, is a Certified Prosthetist-Orthotist and Assistant Professor in the Department of Rehabilitation Medicine at the University of Washington. He conducts research at the University of Washington Center on Outcomes Research in Rehabilitation and teaches in the Master of Prosthetics and Orthotics clinical education program. He has served as principal investigator on grant awards funded by the American Orthotic and Prosthetic Association and The Orthotics and Prosthetics Foundation. His research efforts have primarily focused on measuring health outcomes of people who use orthotic braces or prosthetic limbs. He has training and expertise in research study design, survey development, and outcomes assessment. He also has experience serving as a research committee member and grant reviewer for professional organizations. Since his 7-year-old son, Carson, died in his sleep in 2022, Dr. Balkman has been eager to contribute his skills to SUDC research and looks forward to serving on the SUDC Foundation's Scientific Grants Review Committee.



Grace Hillyer, EdD, MPH

Grace Hillyer brings a wealth of expertise and dedication to the SUDC Foundation Scientific Grants Committee. With a career spanning nearly 45 years, Grace has focused on health and healthcare, with a specific emphasis on public health, epidemiology, and health promotion. After retiring from her full-time role as an Assistant Professor of Epidemiology at Columbia University's Mailman School of Public Health, she continues her impactful work as a Special Researcher at Columbia and an Adjunct Professor of Public Health at William Paterson University. Grace's research centers on improving health outcomes for minority and underserved populations, with a particular focus on health behaviors, cultural determinants, and educational interventions. Her prolific career includes mentoring numerous students and professionals and authoring over 110 peer-reviewed papers. She has also secured sustained grant funding from prestigious organizations, including the Department of Defense, National Cancer Institute, and Stand Up to Cancer.



Egondy Onuoha, MS, RDN, CDN, IBCLC, CDE/CDCES, GPC, FAND, FILCA

Egondy is the Vice President for Real Estate and Special Programs at the Brooklyn Hospital Center in NYC, where she oversees maternal and child programs, including the WIC program serving over 20,000 individuals monthly. She previously directed several key programs, including Prenatal Care Assistance and diabetes management.

Egondy has secured over \$300 million in grants, expanded services for underserved communities, and improved performance through innovation. She holds credentials as a Registered Dietitian, International Board Certified Lactation Consultant, Certified Diabetes Educator, and Grant Professional Certified. She is a Fellow of the Academy of Nutrition and Dietetics and the International Lactation Consultant Association.

With over 20 years of board experience, Egondy is the Board President for the Grant Professional Certification Institute and serves as a federal grant reviewer. She resides in New York City.

Together with the expertise and dedication of our new members, the Scientific Grants Review Committee is poised to accelerate progress and empower the SUDC Foundation's mission to advance research that brings us closer to living in a world without SUDC.

SUDC UK 2023-2024: A Year of Milestones and Momentum, Updates from Nikki Speed, PhD, CEO

In February 2024, SUDC UK gained unprecedented national attention through comprehensive BBC coverage, including a primetime Panorama program, *Sudden Child Deaths: The Search for Answers*. This program, supported by SUDC UK, explored key issues like research, awareness, and family support, following a family's journey after losing a child. This exposure significantly increased SUDC awareness, helping more families find support, and educating professionals. We extend our heartfelt thanks to everyone involved. A special thanks to Jodie and Gavin Dacres, Addy's parents. To learn more: www.bbc.co.uk/news/uk-68154904.

On March 18, 2024, SUDC UK launched National SUDC Awareness Day with a Parliamentary Reception at the House of Commons. The event, supported by SUDC UK Ambassador Julia Rogers, brought together 130 professionals, members of Parliament, and SUDC UK Ambassador families to celebrate progress and inspire further action. For more details: sudc.org.uk/sudc-in-parliament-and-policy/.

SUDC UK continues to host family events, including family days, a *Stars for Our Children* event, a weekend retreat hosted by trained counselors, and our annual SUDC dads' meal to remember our much-loved children. In 2024, the SUDC UK is adding a winter virtual event to support families and siblings.

With the start of the school year, the SUDC UK introduced a new UK-specific guide for schools, created in collaboration



Nikki Speed, PhD
CEO, SUDC UK

with families and professionals and led by SUDC sibling and teacher Amy Haynes, who based her master's thesis on this crucial topic.

We're excited to welcome Lorna McKay as our Events and Fundraising Manager, and new trustees Madeleine Finn and Chris Bingham, who bring valuable expertise in education and finance.

SUDC UK continues to advocate globally. CEO Dr. Nikki Speed, now co-chair of the global SUDC working group, and Dr. Emily Cooper, presented research at the ISPID conference in Florence and a forensic pathology conference in Oslo. We also financially supported three professionals to attend and chaired an SUDC session.

SUDC UK is very proud that its advocacy work

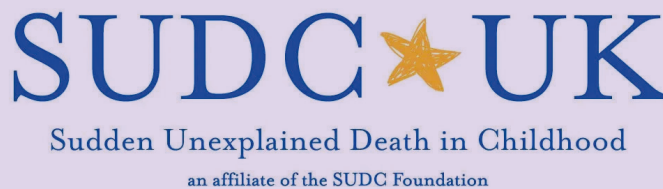
has supported a change in the genetic sequencing and analysis available for families in England as part of the standardized NHS pathway. In addition, Ambassador Brian Topping's medical

education program has been shared nationally, inspiring local training. Ambassador Daisy McKenzie has advanced SUDC awareness in Scotland with awareness presentations already in the diary.

In July 2023, SUDC UK launched materials for more compassionate child death reviews across England, supported by our Communications Manager, Hannah Johnston.

We are grateful for your continued support of SUDC UK and the SUDC Foundation's partnership as we work together to support families and advance research.

For more information, visit www.sudc.org.uk.



Welcome Family Services Intern

We're thrilled to welcome Marissa Kambouris, a Rutgers University Masters of Social Work candidate, to our Family Services team as an intern. With over a decade of experience in business operations and client relations, Marissa brings valuable expertise and a strong commitment to growth. Since joining us, she has eagerly trained in group facilitation and family member registration, and she is preparing to become more involved with our SUDC Cares program.

During her first semester, Marissa played a key role in expanding our Peer Connection Program, significantly increasing meaningful connections. Her background in psychology from Fordham University and her ongoing studies at Rutgers provide her with a deep understanding of human behavior, which she applies effectively in her role.

As Marissa heads into the fall semester, we are excited about the continued impact she will make and grateful for her contributions to our mission.



Charting the Future: The SUDC Foundation's Strategic Plan Overview 2024-2027



The SUDC Foundation's mission is to raise awareness, fund research, and serve those affected by Sudden Unexplained Death in Childhood (SUDC). With a vision of a world without SUDC, we are continually looking towards the future and evolving to meet the needs of our community. Our 2024-2027 Strategic Plan marks a pivotal step forward in this journey, reflecting our deep commitment to expanding our impact, and creating lasting change.

Building a Strong Foundation

The Foundation made crucial advances by engaging in a Diversity, Equity, and Inclusion (DEI) workshop prior to developing our strategic plan. Led by Agnes Meneses and Carol Xu of Meneses Consulting, our Board of Directors and staff engaged in a workshop that identified and reinforced the core values that underpin our work.

With these principles of equity and inclusion at the core of our strategy, Greg Talley with Talley Management led the Board and senior staff to identify the five strategic priorities that will shape our efforts in the years moving forward.

Families First is at the center of all the SUDC Foundation's work, and at the heart of our strategic plan. In response to our family needs, over the next three years, the SUDC Foundations is committed to expand and deepen our impact on those we serve. All board and staff will contribute to our shared effort to deliver that impact. Success in any one of these priorities is deeply interconnected with the other priorities.

Our Strategic Priorities

Over the next three years, we will focus on five key priorities that will drive our mission forward.

Priority 1: Strive for Organizational Excellence

★ We will strengthen our governance and operations to ensure alignment with our culture and values to enhance transparency, accountability, and operational efficiency.

Priority 2: Achieve Financial Endurance

★ To secure our future, we will establish long-term financial stability to effectively serve the evolving needs of our families as well as the professional and research communities, both in the present and into the future. We will build a robust and enduring financial pipeline, aggressively pursue grants and unrestricted revenue streams, as well as expand our staff, ensuring we can continue to meet the needs of families and researchers alike.

Priority 3: Accelerating Innovation & Partnerships in SUDC Research

★ As a global leader in SUDC research, we will enhance accessibility and funding opportunities to accelerate SUDC research. By establishing a Scientific Grants Review Committee, we will bring together multidisciplinary experts to guide an intentional research agenda and ensure that SUDC remains at the forefront of scientific discovery. Our commitment to excellence and innovation will be reinforced by our dedication to building strong, collaborative relationships with academic institutions, medical professionals, and other research organizations to accelerate the pace of discovery, moving us closer to a future where SUDC is fully understood and preventable.

Priority 4: Enhance & Expand Support & Advocacy Services

★ Enhancing the quality of support services for the community we serve, is a top priority. We are committed to providing exceptional care that fosters a sense of belonging and empower individuals with the skills to thrive both mentally and physically. We will continue to expand our offerings, ensuring lower-barrier, trauma-informed, person-centered care is available at no cost to our families. A new initiative is the Postmortem Genetic Testing Program, which not only provides families with a continuum of care and opportunities to participate in research, but also offers significant benefits to medical examiners, coroners, and other medical professionals. By removing barriers to accessing postmortem genetic testing, the initiative ensures

that both professionals and families have the necessary resources for thorough and comprehensive investigations. This initiative strengthens collaboration between the SUDC Foundation and the medical community, ultimately enhancing the quality of care and investigation outcomes. Read more about this initiative on page 1.

Priority 5: Advance Advocacy & Awareness

★ Building awareness and advocacy are essential to our mission. We will advance public policy on SUDC to ensure that the needs of affected families are heard and addressed at all levels. This includes advocating for increased research funding, public education, and the inclusion of SUDC in local, state, and national health priorities. We aim to equip healthcare providers with the knowledge and tools to address SUDC in their practices while striving for standardized protocols to better investigate and understand these tragedies. Our comprehensive advocacy efforts will combine grassroots mobilization, strategic alliances, and targeted campaigns to drive meaningful awareness and policy change.

Looking Ahead

The SUDC Foundation’s strategic plan for 2024-2027 is a comprehensive roadmap and a promise to our community. We are taking deliberate and meaningful steps toward a world where no family has to endure the tragic loss of their child. With the collective dedication of our Board of Directors, staff, and community partners; we are confident that we will continue to make a significant impact bringing us closer to a future free of SUDC.

MAJOR GOALS

- ★ **ESTABLISH A SCIENTIFIC GRANTS REVIEW COMMITTEE** to guide research priorities; build partnerships with academic institutions, medical professionals, and research organizations to drive discovery and innovation.
- ★ **LAUNCH THE POSTMORTEM GENETIC TESTING PROGRAM** to provide comprehensive care and research opportunities; enhance collaboration with medical professionals and to access the latest advanced tools and resources for the most thorough investigation possible.
- ★ **SECURE FUNDING FROM EXTERNAL SOURCES** to financially support 50% of Family Services programs and general operating funds.
- ★ **PROVIDE PRO BONO CLINICAL SERVICES** to ensure that every registered SUDC Foundation Family Member receives access to high-quality, compassionate, person-centered, trauma informed grief support services at no cost.
- ★ **IDENTIFY AND IMPLEMENT LEGISLATIVE ACTION PLAN** to influence public policy to address the needs of affected families; advocate for increased research funding and public education; promote standardized protocols for investigating SUDC; engage in grassroots mobilization and strategic campaigns to drive policy change.



Compassion



Integrity



Innovation



**SUDDEN UNEXPLAINED
DEATH IN CHILDHOOD
FOUNDATION**

Our Core Values



Collaboration



Inclusion & Equity



Hope



Empowerment



101 Eisenhower Parkway, Suite 300
Roseland, New Jersey 07068



OFFICIAL CHARITY PARTNER



Support our 11 Marathoners for SUDC this Fall!

The TCS New York City Marathon is on Sunday, November 3!

Tune in to ABC starting at 9am to watch and cheer on the 11 runners supporting the SUDC Foundation. Show your support for their dedication and commitment by donating to the team or to an individual runner at bit.ly/SUDC2024.