SUDDEN UNEXPLAINED DEATH IN CHILDHOOD FOUNDATION

# the Telescope

Navigating to a future free of SUDC 2025

IN THIS ISSUE



## WHAT IS SUDC?

Sudden Unexplained Death in Childhood (SUDC) is a category of death in a child 12 months of age or older that remains unexplained after a thorough investigation, including an autopsy. Most often, a seemingly healthy child goes to sleep and never wakes up.

SUDDEN UNEXPLAINED DEATH IN CHILDHOOD FOUNDATION

## OUR MISSION

Raise awareness, fund research, and serve those affected by Sudden Unexplained Death in Childhood.

## CONTACT US

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# The SUDC Foundation Explores New SUDC Research Partnership

## Advancing the Understanding of SIDS, SUID, and now SUDC at Seattle Children's

**By Dr. Jan-Marino Ramirez, PhD**
*Professor for Neurological Surgery and Pediatrics*
*University of Washington, School of Medicine*
*Director, Norcliffe Center for Integrative Brain Research*
*Seattle Children's Research Institute*


Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Infant Death (SUID) remain devastating tragedies with too many unanswered questions. Our research at Seattle Children's is dedicated to uncovering the underlying causes of these deaths through genetic and epidemiological studies, with the recent addition of multi-omics approaches. Recent findings from our genetic analyses suggest that the same genetic vulnerabilities contributing to SIDS and SUID may also play a role in Sudden Unexplained Death in Childhood (SUDC) or beyond. The prevailing hypothesis suggests that a vulnerable infant may succumb to SIDS/SUID when exposed to an external stressor during a critical developmental period. However, it's possible that in some cases, the infant survives infancy, carrying this vulnerability into childhood or even adulthood. When faced with additional stressors, such as vigorous exercise or illness, they may be overwhelmed and experience death. In light of this, we have expanded the focus of our genetic study to include children up to age 17, recognizing the need to better understand sudden unexplained deaths across a broader age range. To effectively pursue this effort, we are actively seeking to include affected children in this age group.

### Genetic and Multi-Omics Insights

Through the whole genome sequencing (WGS) of 339 infants, we identified genetic variants in genes linked to cardiomyopathies, arrhythmias, neurologic function, systemic disorders, and immunological function that may cause a susceptibility to these conditions putting the infant at risk of sudden death. Notably, we also discovered new variants in genes involved in the response to hypoxia and the regulation of reactive oxygen species (ROS), marking the first association of these genes with SUID. These findings have provided important clues about the biological mechanisms that may contribute to sudden death.

To gain a more comprehensive understanding, we are in the initial stages of integrating transcriptomics, metabolomics, and epigenomics, recognizing that WGS alone does not capture the full complexity of these biological mechanisms. By analyzing how gene expression and metabolic activity differ in affected individuals, we aim to build a more

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# Connect with Us on Social Media

***Connect with us on social media for updates and insights into our work toward a world free of SUDC.***

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comprehensive understanding of risk factors and potential biomarkers for early identification.

### Future Directions

Our next steps involve leveraging -advanced computational methods to uncover critical protein interactions, polygenic inheritance patterns, and gene modifiers that likely contribute to SUID and potentially SUDC—challenges that traditional methods struggle to address due to the vast number of implicated genes. We are actively expanding our collaborations to increase the number of infants and children sequenced. We particularly need samples from children up to age 17 to investigate our hypothesis that these vulnerabilities may persist beyond infancy.

One notable collaboration, still in the early phase, involves working with the SUDC Foundation to provide a full and thorough gene analysis to detect a wide range of genetic conditions or risks and those still unknown. This partnership will allow us to not only enhance our research but also provide families with valuable genetic insights, thereby improving our collective understanding of SUID and SUDC.

Our long-term goal is to develop newborn genetic screening to identify infants and children at increased risk, empowering parents and healthcare providers to make informed decisions and adjust care accordingly.

### Impact on Families and Professionals

In addition to families affected by SUID/SUDC, our work has significant implications for medical examiners, pediatricians, genetic counselors, grief specialists, and others who support those experiencing these tragedies. By improving risk assessment and advancing scientific understanding, we aim to not only inform prevention efforts but also enhance the support and care provided to families, ensuring that they receive accurate information, appropriate resources, and compassionate guidance during such difficult times.

We are grateful for the collaboration and support of this dedicated community, and we welcome ongoing discussions, data sharing, and participation in research efforts.

### Get Involved and Stay Informed

For more information about our ongoing genetic study or to discuss participating in this vital research, please email us at SUIDresearch@seattlechildrens.org or visit givetostopsids.org. To explore our latest genetic findings, read our publication in the American Journal of Medical Genetics, Part A: https://doi.org/10.1002/ajmg.a.63596

# A message from the CEO...

## Together We Rise. Together We Are Stronger.

**Dear SUDC Community,**

Each time we learn of another child gone too soon, we are reminded why our work matters. Every family we serve deepens our resolve to drive research forward, act with urgency, and expand support in ways that are meaningful and accessible. Over the past year, we have taken bold steps to advance our mission and have experienced tremendous growth-growth driven by your trust, your voices, and our shared determination to find answers for every family while ensuring they receive the compassionate care they deserve.

In this issue, you'll read about our drive to foster innovation and accelerate scientific research, the expansion of our programming to support families, and the deliberate actions taken to grow institutional partnerships. These advancements are only possible because of the extraordinary commitment of our volunteers, the generosity of our donors, the strength of our community, and the expertise and support of our collaborators.

We enhanced our Scientific Advisory Board by bringing together a multidisciplinary team of experts, positioning us to diversify our research portfolio and strategically advance studies with greater collaboration, transparency, and long-term impact. Over the past decade, the SUDC Foundation has provided in excess of $2.5 million to support the SUDC Registry & Research Collaborative (SUDCRRC). In 2025, we further strengthened our commitment to research by deepening collaborations with leading institutions such as Boston Children's Robert's Program and Seattle Children's.

We also made measurable strides in professional education. Our Grand Rounds presentations continue to reach medical professionals across the country—raising awareness of SUDC and encouraging earlier referrals to vital resources. Soon, we will launch our first responder training, equipping emergency personnel with the tools and sensitivity needed to support families in the immediate aftermath of a sudden, unexpected child loss.

Our professional relationships have never been stronger, and we are deeply grateful to the medical examiner and coroner's offices whose excellence to the field is vital to our mission. Through our Postmortem Genetic Testing Program coordinated with GeneDx, we have removed financial barriers to testing, supporting thorough investigations while advancing scientific understanding of SUDC.

Together with our affiliates, SUDC UK and SUDC Australia, we are extending our global reach, reminding us that while grief knows no borders, neither does hope. Together with experts in forensics, grief, bereavement, and research, we are aligning the brightest minds and most compassionate hearts to advance our mission.

We made our voices heard through advocacy efforts, supporting bereavement leave legislation, MA Bill H. 2064 and a petition to reinstate full funding to the Paul Coverdell program in support with the National Association of Medical Examiners.

As we expand our reach, we've deepened our services. This year, we launched the complimentary grief coaching and strengthened clinical partnerships with Rutgers School of Social Work, Fordham University, and the Southern California University of Health Sciences Master of Science in Genetic Counseling Program, integrating advanced clinical interns into our work and expanding access to compassionate, specialized care at no cost to the Foundation. Additionally, we introduced sibling support, made possible through the generosity of the Jackson Walsh Foundation. We also onboarded a Spanish-speaking social worker, so language is never a barrier to care while all services remain at no cost to the communities we serve.

To our volunteers: your dedication is the force that keeps our mission in motion. To our donors: your generosity fuels every initiative. And to our partners who walk alongside us: together we are stronger. Your compassion, time, and trust are helping us build a more connected, informed, and supportive future for all families affected by SUDC.

We remain audacious in our goals and steadfast in our service. Our Board of Directors and team continue to forge ahead with urgency and purpose. We are not waiting for "someday." Together, we are acting boldly and decisively now. Our promise to our community is simple: together, we will take every step needed to understand and prevent SUDC and ensure that no one grieves alone. Thank you for being part of our mission. Your trust, support, and shared hope propel us forward every single day. We look forward to gathering in 2026 for our Community Retreat—a time to connect, remember, and strengthen the bonds that unite us.

With deep gratitude and unwavering commitment,

**Tina Yun Lee**
Chief Executive Officer
SUDC Foundation

## Strengthening the Foundation's Capacity to Serve Families Through Enhanced Clinical Expertise

The SUDC Foundation is proud to share that our Family Services Manager, Amanda Brindle, has earned her *LCSW certification*—a significant milestone for both Amanda and the Foundation's ability to serve families. For over six years, Amanda has led the Family Services program with compassion and dedication, guiding families through the sudden loss of a child. From counseling and peer connections to support groups, events, and coping skills workshops, she ensures families have access to high-quality, person-centered support. With this new credential, Amanda brings advanced clinical expertise that strengthens the Foundation's capacity to provide trauma-informed care and to help families find hope, healing, and connection. Please join us in congratulating Amanda on this outstanding achievement.

## Guiding the Future of SUDC Research by Harnessing Scientific Expertise

### The SUDC Foundation's Scientific Advisory Board is committed to finding answers for all families affected by SUDC.

The SUDC Foundation is proud to announce the continued expansion of its Scientific Advisory Board (SAB), a distinguished group of experts across medical, scientific, and academic fields dedicated to shaping the future of research into Sudden Unexplained Death in Childhood (SUDC).

SUDC remains one of the most under-researched pediatric public health issues, and the Foundation is committed to changing that by partnering with researchers, clinicians, and thought leaders determined to drive progress and meaningful discoveries.

The SAB guides the Foundation's scientific strategy, evaluates research proposals, and ensures responsible funding of innovative studies. With this strong foundation, the SUDC Foundation is poised not only to accelerate impactful research, but also to foster global collaboration with scientists, institutions, and community stakeholders.

Dr. Grace Hillyer, an accomplished epidemiologist whose career spans more than 45 years in public health, epidemiology, and health promotion, serves as Madam Chair of the SAB. Following her retirement from Columbia University Mailman School of Public Health, Dr. Hillyer continues to advance research as a Special Researcher at Columbia and Adjunct Professor of Public Health at William Paterson University. Dr. Hillyer shares, "The SAB represents a milestone in the Foundation's mission. We are laying the groundwork for a more integrated and data-driven future. It is an opportunity to channel our collective expertise into advancing innovative research that brings hope and answers to families affected by SUDC."

The SAB signals a powerful step forward: we are no longer willing to accept "unexplained" as the final word. With their expertise—and the support of our community—we are building the foundation for scientific understanding that will one day prevent these tragedies and honor every child gone too soon.

Learn more about the SAB: sudc.org/about-us/scientific-advisory-board

## Breaking Down Barriers: Expanding Support for Spanish-Speaking Families

Sudden Unexplained Death in Childhood (SUDC) affects families across all backgrounds, cultures, and languages. The SUDC Foundation is committed to providing compassionate, culturally sensitive care to every family we serve.

To strengthen support for Spanish-speaking families, we welcome Lorraine M. Kransdorf, LCSW-R, to our team. A bilingual social worker with over 30 years of experience, Lorraine brings deep expertise in grief counseling and a dedication to helping families navigate loss. She shares, "I have dedicated my life to supporting others through their most vulnerable moments. As a certified death doula, I am deeply committed to providing compassionate, informed guidance to families navigating grief and loss."

By expanding our services to include bilingual care, we are creating a more inclusive and supportive space for all families affected by SUDC.

## Guidestar Platinum Certified

**GuideStar, the world's largest source of information on nonprofit organizations, has consistently awarded the SUDC Foundation its highest honor, the Platinum rating. GuideStar uses its rating system to advance transparency, help donors make better decisions, and encourage charitable giving. To read our most current financial statement please visit sudc.org/about-us/financial-overview/**

## Investing in the Future: Internship Partnerships with Leading Universities Shaping a New Generation of Compassionate Professionals

The SUDC Foundation partners with academic institutions nationwide to offer meaningful internships that support our mission and the professional growth of emerging leaders. Through partnerships with Fordham University's Center for Community Engaged Learning (CCEL), Rutgers School of Social Work, and the Southern California University of Health Sciences Master of Science in Genetic Counseling program (SCU MSGC), we are building a pipeline of trauma-informed, grief-aware professionals dedicated to serving families impacted by Sudden Unexplained Death in Childhood (SUDC).

These internships provide students with hands-on experience in family support, outreach, advocacy, and clinical learning—deepening their understanding of grief, trauma, and loss. Stephanie Gandomi, Program Director of SCU MSGC, notes: "This partnership empowers future genetic counselors to make a meaningful impact in the lives of families through compassion, science, and advocacy."

Jamie Hakim, LCSW, clinical supervisor at the SUDC Foundation, adds: "Integrating advanced clinical interns allows the Foundation to expand services at no cost to families or to the Foundation- offering more support, more often, to those who need it most."

This model strengthens the Foundation's reach and responsiveness while training a grief-literate, trauma-informed workforce. Stephanie Gandomi emphasizes: "Our students gain invaluable experience while contributing to a cause that exemplifies the transformative power of genetics in public health."

The SUDC Foundation is honored to work alongside these emerging leaders and grateful to our academic partners. Together, we are investing in a future where every family affected by SUDC receives knowledge, empathy, and compasionate support.

If your academic program is interested in partnering with the SUDC Foundation, please email info@sudc.org.

## Board Finance Committee

The SUDC Foundation is pleased to welcome three new members to the Board Finance Committee:

- Colin Watters CFP, SUDC dad to Finn
- David Cramer, SUDC grandfather to Christopher
- Will Carrington, SUDC dad to Maria
- Jesse Bergland CFP, RICP, ChFC, CLU, CAP,

Each new member brings extensive financial expertise and a shared commitment to our mission. The Finance Committee, led by SUDC Foundation Board Treasurer Deepa Roongta Suresh, President Julia Burgess, and Board Member Carson McClean, plays a critical role in safeguarding the Foundation's financial health. Its responsibilities include overseeing financial and tax compliance, internal controls, risk management, investment policies, and ensuring the organization's overall long-term sustainability.

We are deeply grateful to these dedicated volunteers for their time, expertise, and unwavering support in advancing our mission.

# How your support makes a difference:

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

**$150**

Helps educate medical professionals and first responders about SUDC, fostering a well-informed healthcare community to improve outcomes and support affected families.

**$250**

Provides a Pathway to Healing workshop, a six-week evidence based coping skills workshop designed specifically for bereaved families to heal.

**$500**

Supports the Unity Fund, ensuring that more members of the SUDC Foundation Community can take part in the SUDC Community Retreat to restore, reconnect, and renew.

**$1,000**

Provides Help for Family brochures to five Medical Examiner/Coroner Offices.

**$1,800**

Helps one family receive postmortem genetic testing for their child in an effort to provide key insights about their child's passing.

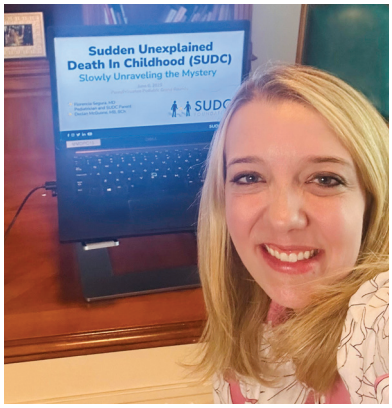
# Advancing SUDC Literacy Awareness and Compassionate Care in the Medical Community through Grand Rounds

This year, the SUDC Foundation had the privilege of presenting "Sudden Unexplained Death in Childhood: Slowly Unraveling the Mystery" at Grand Rounds across multiple medical institutions. We are deeply grateful to the hospitals and institutions that welcomed us into their learning environments. These sessions offered invaluable opportunities to educate professionals about SUDC, highlight emerging research, and provide resources to better support families affected by child loss.

A special thank you to Dr. Florencia Segura, pediatrician and SUDC Foundation Ambassador, who brought both her clinical expertise and the profound courage to share her experience of losing her daughter, Rosalie. We are also grateful to Matt and Aimee MacDowall, parents of Macy, and Meaghan Barakett, SUDC Foundation Ambassador and mother of Lincoln, for sharing stories that honored their children's lives and legacies. Additionally, Dr. Erin Bowen, SUDC Foundation Vice President, pediatrician, and mother of Conor, along with Dr. Maurine Neiman, mother of JJ, delivered a well-received Grand Rounds presentation at the University of Iowa.

Together, their reflections deepened the medical community's understanding, fostered empathy, and reinforced the importance of advancing SUDC research and compassionate care.

SUDC Foundation Grand Rounds are more than educational sessions—they are catalysts for change. To schedule or learn more, please visit: [sudc.org/request-a-sudc-foundation-grand-rounds-presentation-today](sudc.org/request-a-sudc-foundation-grand-rounds-presentation-today)




*Florencia Segura, MD*


*Matt and Aimee MacDowall*

## Advancing Research Through Collaboration

On April 29th, Chief Executive Officer, Tina Yun Lee and Chief Philanthropy Officer Liz Milliken represented the SUDC Foundation at the 2025 Pediatric Rare Disease Summit: *Bridging Science & Care* in Boston, MA.

Hosted by Boston Children's Hospital, this event brought together national leaders in genomics, precision medicine, and rare disease research, providing an important opportunity to ensure SUDC remains part of the national research dialogue.

With approximately 80% of rare diseases involving a genetic component, the Foundation's presence underscored the importance of genetically informed, cross-disciplinary collaboration. Strategic partnerships like those fostered at the Summit are critical to improving diagnostics and uncovering insights that may one day help explain and prevent SUDC.

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## Building Stronger Partnerships with Medical Examiners and Coroners

The SUDC Foundation recognizes and deeply values the vital role that Medical Examiner and Coroner (ME/C) offices play in supporting families affected by Sudden Unexplained Death in Childhood (SUDC). Our customizable Help for Families brochure and professional resource library are designed to complement their work, offering additional tools to help deliver trauma and grief-informed care.

As a liaison between families and ME/C offices, the SUDC Foundation helps bridge communication, offers guidance, and ensures that no family faces this journey alone. These partnerships are part of our broader advocacy to enhance investigative processes and ensure that every family receives compassionate, informed support during the most difficult time of their lives.

**"The SUDC Foundation has been an invaluable resource to the Charleston County Coroner's Office...to provide compassionate support, resources, and understanding has made the difficult process a little easier for both our team and the families we serve. Their expertise and approach to bridging gaps unique to each ME/C office continues to make a meaningful difference in our work. Thank you, SUDC Foundation, for all you have provided to our families."**

*— Alison E. Garbarini, MPH, D-ABMDI,*
*Child Death Review Coordinator,*
*Charleston County Coroner's Office, SC*

This October, the SUDC Foundation will once again exhibit at the 2025 National Association of Medical Examiners (NAME) Annual Meeting in Louisville, KY—furthering our commitment to supporting the ME/C community, sharing resources, and fostering partnerships that enhance care for families.

All services and resources are provided at no cost to families or professionals.

Learn more: [sudc.org/medical-professionals](sudc.org/medical-professionals).

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The Summit featured thought leaders including Dr. Wendy Chung, Chief of Pediatrics at Boston Children's Hospital and a member of the Foundation's Scientific Advisory Board, who urged the rare disease community to "be audacious" in aligning research with families' urgent needs. Dr. Annapurna Poduri, Deputy Director at NINDS, closed the event by emphasizing the role of collaboration in driving meaningful progress.

We are grateful to Boston Children's Hospital for creating a space where bold science and compassionate care converge, and where the SUDC Foundation continues to amplify its voice for all the families we serve, and the children gone too soon.

## Caring Through Crisis: New Training Prepares Professionals to Support Families After SUDC

The SUDC Foundation is proud to launch *Caring Through Crisis: Supporting Families After Sudden Unexplained Death in Childhood (SUDC)*—a new training designed for first responders, hospital personnel, and professionals who may encounter families facing sudden child loss.

This training is the result of the Foundation's ongoing commitment to increasing SUDC literacy among the professional community and recognizing the unique challenges medical and emergency personnel face when supporting families through such devastating loss. Developed and led by a multidisciplinary team of clinical experts, many with lived experience, this training explores the impact of child loss on both families and professionals. Participants will increase their knowledge regarding sudden unexplained death in childhood, learn about the medicolegal death investigation process, and discover their role in providing trauma-informed, compassionate care. The presentation also offers guidance on supporting grieving families and emphasizes the value of collaboration and self-care.

Presenters and contributors include Amanda Brindle, LCSW, Manager of Family Services, SUDC Foundation; Kristen Dillon, PsyD, ABPP, Clinical Psychologist, mother to Junie; Natalia Garcia, PhD, Clinical Psychologist, mother to Jackson; Jordan Klekamp, LMHC, RPT-S, mother to Rory; and Elisabeth T. Schneider, LMFT at Bridgeport Hospital, CT. Available virtually, in person, or on-demand. For more information, contact info@sudc.org.

## Postmortem Genetic Testing

### Removing Financial Barriers and Enhancing Investigations

Postmortem genetic testing can play an essential role in identifying potential cause(s) of death when a child dies suddenly and unexpectedly. The SUDC Foundation's Postmortem Genetic Testing (PMGT) program, offered in partnership with GeneDx—a leader in advanced genetic testing—provides families and Medical Examiner and Coroner (ME/C) offices with access to testing that may help to identify potential genetic causes of death and assessing whether blood relatives may be at risk for related genetic conditions. In addition, GeneDx offers the expertise of a highly trained genetic counseling team to guide families through their results with clarity and compassion and to consult with pathologists on the interpretation of any genetic findings.

By removing financial barriers and working closely with ME/C offices nationwide, the PMGT program ensures that vital genetic insights are available when they are needed most. This initiative supports families in their grief, aids in thorough investigations, and contributes to critical genetic data to current and future research efforts, aimed at advancing our understanding of SUDC and potentially preventing future tragedies.

**"The SUDC Foundation is a highly focused and dedicated team trained to evaluate cases of SUDC. For a forensic pathologist, the education and irreplaceable support the SUDC Foundation provides is invaluable. The staff at the Foundation have provided extensive support and resources to our medical examiner's office in both a timely and considerate manner. They have gone above and beyond to assist our office with questions and resources. In addition, the SUDC Foundation provides access to the Postmortem Genetic Testing program which would not otherwise be available to many families. This genetic testing access by the SUDC Foundation provides even more resources for families at the most difficult times in their lives and is irreplaceable not only for grieving but for future family planning."**

*— Dr. Kia Newman, Chief Medical Examiner, Rensselaer County, NY*

The PMGT program is offered at no cost to families or professionals, ensuring equitable access and providing the resources needed for a thorough, comprehensive investigation.

Learn more: sudc.org/post-mortem-genetic-testing

## The SUDC Foundation Driving Policy Changes & Advocating for SUDC Families

At the SUDC Foundation, advocacy is integral to our mission. We are committed to advancing policies that strengthen systems of investigation, promote compassionate care, and recognize the unique needs of families affected by Sudden Unexplained Death in Childhood (SUDC). From federal funding that supports forensic science, to state legislation offering workplace protections for grieving parents, our advocacy efforts are driven by one goal: ensuring every child gone too soon is honored, parents are met with care, dignity and understanding, and every family is supported.

### Advocating for Stronger Investigations and Support for Families

The SUDC Foundation proudly joins the National Association of Medical Examiners (NAME) in opposing a proposed 70% cut to the Paul Coverdell Forensic Science Improvement Grant Program in the FY2026 federal budget.

As the only federal funding source dedicated to improving forensic science services, including those of medical examiners and coroners vital to investigating Sudden Unexplained Death in Childhood (SUDC), its reduction would compromise investigations, deny families answers, and hinder critical research.

Restoring full funding is essential to strengthen death investigations and support families impacted by SUDC. Sign our petition at sudc.org/legislation-and-policy/the-paul-coverdell-grants-program/ to urge Congress to fully restore this critical funding because every family and child gone too soon deserves answers.


### Massachusetts Committee Hears Testimony in Support of Bereavement Leave for Families After the Loss of a Child

On July 22, the Massachusetts Joint Committee on Labor and Workforce Development heard testimony supporting Bill H.2064—An Act Relative to Bereavement Leave for the Loss of a Child. The bill would provide employees 10 days of paid, job-protected leave within one year of a child's death.

Filed by State Representative James Arciero with the SUDC Foundation and Junie's Place, the bill recognizes the profound impact of child loss. Testimony was shared by Rep. Arciero and SUDC Foundation Ambassadors: Dr. Kristen Dillon, Junie's Place founder, and Lynne Sallet, mother of Carson, and SUDC Foundation leaders. Partner organizations, including Evermore, First Candle, Robert's Program at Boston Children's Hospital, and Samaritans, Inc., also voiced support.

We are grateful to all who spoke out and hope this legislation passes in Massachusetts and inspires similar efforts nationwide. Learn more at sudc.org/ma-bereavement-leave-bill

## The Power of Purpose: How Volunteering for the SUDC Foundation Helps Honor, Connect, and Advocate

For many bereaved families, finding a path forward after the sudden, unexplained death of a child can feel overwhelming. At the SUDC Foundation, volunteerism offers a meaningful way to stay connected, create impact, and honor a child's legacy through action.

We are deeply grateful to our volunteers whose compassion and commitment fuel our mission. Sydney Meeks, Isabella Crossman, and Kaori Kabata embody the strength and spirit of service that define our community. We thank them and all our volunteers for bringing comfort, connection, and hope to families affected by SUDC.

Sydney Meeks, whose son Lincoln passed away seven years ago, channels her love into action. "One of the ways I have chosen to remember Lincoln is through support of the SUDC Foundation. We spread awareness every year for Lincoln's birthday. I am also an SUDC Ambassador and Peer Connection Friends volunteer. I have dubbed our yearly awareness projects 'Love, from Lincoln' because it is my desire to manifest our love for Lincoln in tangible

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ways that affect our community and the world. That is one reason why the work of the SUDC Foundation is so important. I am grateful for their initial and ongoing support, even years later."

Sydney's commitment extends to her whole family, her brother, Drew Toland, will run the 2025 TCS New York City Marathon in Lincoln's memory, raising visibility and critical research funds.

Isabella Crossman, a Teen Ambassador from Kentucky, shows you are never too young to make a difference. In memory of her nephew Sullivan Reece, who passed in 2022, Isabella created a #ShineALightOnSUDC bulletin board at her high school during SUDC Awareness Month. She invited classmates to learn about SUDC and take Kindness Cards to inspire acts of kindness in Sullivan's memory and in honor of all children gone too soon.

Kaori Kabata, mother of Kohtaro who passed in 2023, is helping bring SUDC awareness worldwide. She raised awareness at work, where a colleague dedicated a charity bike ride to SUDC. Kaori also partnered with the Foundation to create Japanese-language resources, which she shared with Japan's Children and Families Agency. That meeting sparked interest in improving the nation's Child Death Review process, a powerful step forward in prevention and understanding. "I want to share my journey of advocacy with the SUDC Foundation in memory of my beloved son, Kohtaro. Through this work, I hope to honor his life and ensure more families, researchers, and policymakers become aware of SUDC. The Foundation is helping me navigate this cruel reality and find meaning in life again."

Whether offering support, raising awareness, or advocating for change, volunteers like Sydney, Isabella, and Kaori carry the Foundation's mission forward, transforming loss into connection, compassion, and purpose.

Please consider joining our volunteer community. To learn more, email info@sudc.org

## SUDC Australia Dedicated to Helping SUDC Families

A new charity, SUDC Australia, has been established to support families bereaved by Sudden Unexplained Death in Childhood (SUDC). Founded by four bereaved families from different states, the organization was created in response to limited awareness of SUDC in Australia and inconsistent support for families, particularly during the coronial investigation process.

Through their own experiences and conversations with other bereaved families, the founders identified the urgent need for clearer guidance, consistent bereavement support, and opportunities to connect with research that may help prevent future tragedies.

Under the leadership of SUDC Mum Brooke Prately, SUDC Australia is laying its foundation. The charity recently completed a national survey of coronial and forensic services to better understand how families are supported and where the biggest gaps lie. Survey findings will inform recommendations to ensure all families bereaved by SUDC receive high-quality care, regardless of location.

SUDC Australia is also working collaboratively with bereavement support agencies across the country to establish relationships and cross-referral pathways. Recognizing how difficult it can be for acutely bereaved families to navigate services, the organization aims to provide practical, accessible support. A key project in development is an Australian-based Family Resource Guide, offering tailored information and guidance for families.

Marianne Tiemensma recently joined the advisory board. A senior forensic pathologist in South Australia, Marianne has extensive experience across Australia's forensic units and has collaborated with SUDI/C researcher Roger Byard.

## SUDC UK Update: Growing Awareness, Expanding Support, and Strengthening Our Mission

Message from Nikki Speed, PhD, CEO, SUDC UK

The continued improvement in national and local awareness of Sudden Unexplained Death in Childhood (SUDC) means more families are accessing support sooner—with the hope that no family grieves alone.

SUDC UK remains committed to championing and funding vital research. We are proud to support the recent publication of "Febrile Seizures and Sudden Death Risk: A Case-Controlled Analysis", a key step forward in understanding potential risk factors in SUDC cases.

Attending national and local conferences continues to be central to our awareness strategy. A notable recent event at The Francis Crick Institute featured SUDC UK on an expert panel discussing genetic testing, child bereavement, and grief.

This year's National SUDC Awareness Day (18th March) was particularly impactful, with over 1,000 professionals, families, and supporters joining our online webinar to learn more about SUDC and how to advocate for affected families.

We are pleased to have expanded our family support services. In addition to our two annual family events and the Stars for Our Children remembrance, we introduced a winter virtual pebble painting session in 2025, providing families and siblings a creative space to connect. Looking ahead to the end of September, 20 bereaved parents will take part in a peer support weekend, including a trek up one of the UK's highest peaks in memory of their children.

SUDC UK is growing, and we are delighted to welcome three new staff members: Vanessa Grzywacz, Graphic Designer; Catherine Matson, Trusts Manager; and Lorna de Bourg, Family Support Nurse whose skills and passion will further our work to raise awareness, support families, and advance research into SUDC.

Thank you for your continued support as we work together to raise awareness, support families, and further research into SUDC.

# Marching Toward Awareness: Highlights from SUDC Awareness Month 2025

March is SUDC Awareness Month—a time to honor, educate, and advocate.

Each March, the SUDC Foundation leads a national effort to raise awareness of Sudden Unexplained Death in Childhood (SUDC) and remember the children gone too soon. In 2025, our community demonstrated extraordinary unity, compassion, and advocacy.

As part of our #ShineALightOnSUDC initiative, 154 landmarks across the globe were illuminated in blue and gold, the official colors of the SUDC Foundation, serving as beacons of remembrance and raising public awareness of SUDC. These illuminations reminded families that their children are not forgotten—and helped spark important conversations in communities nationwide.

Advocacy efforts gained momentum with 43 state and 4 local proclamations declaring March as SUDC Awareness Month, an intiative started by Christina Grantham, friends of Devron and Georgia Boswell, who lost their son Drew in 2014.

Legislative outreach was another major milestone. SUDC Foundation Ambassadors Dr. Kristen Dillon, mother of Junie and Lynne Sallet, mother of Carson, in partnership with Representative James Arciero, supported the filing of Bill H.2064 in Massachusetts.

In Minnesota, members of our community participated in the RDAC Legislative Action Day, and 50 individuals completed legislative advocacy training through the National Organization for Rare Disease (NORD)—strengthening our national voice for change.

Over 800 awareness kits and thousands of Acts of Kindness cards were distributed, offering accessible tools to educate, engage, and raise awareness.

SUDC Awareness Month continues to be a vital opportunity to advance our mission through education, advocacy, and remembrance. We extend our heartfelt gratitude to all who participated in 2025, and we invite you to join us again—March 2026 is just around the corner.

## SUDC Cares: Complimentary Coaching Program

The SUDC Cares Complimentary Coaching Program offers no-cost, one-on-one support to families navigating the sudden and unexpected loss of a child.

Families are connected with a mental health professional for weekly 50-minute sessions, tailored to meet each person's individual needs. This trauma-informed, short-term model focuses on emotional regulation, coping tools, and navigating life after loss all while providing a compassionate space to be heard, supported, and guided through this complex journey.

This year, we've expanded access by incorporating advanced clinical social work interns under supervision, ensuring families receive timely, high-quality care while also strengthening future professionals in grief-informed practice.

For more information, please contact support@sudc.org.

## SUDC Foundation Sibling Uses Her Voice to Help Young Children


For her senior high school capstone project, Madison Day is helping young children navigate big emotions through her children's book, *The Worry Game*, illustrated by Allison Droege. The story is inspired by her brother JJ, who passed away suddenly and unexpectedly at the age of 9 in 2021.

"I wrote *The Worry Game* after losing my brother because I wanted children to know that their feelings matter. Even when worries feel overwhelming, there are ways to name them, face them, and remember you're not alone," Madison shares.

Inspired by her own journey and the deep empathy that comes from loss, Madison chose to use her voice to make the world a little kinder and a little gentler for others. Her work is a beautiful reminder that young people have the power to create meaningful change, one story, one heart, and one helping hand at a time.

You can find Madison's book here: amazon.com/Worry-Game-Madison-Rose-Day/dp/B0FJ51WK7D. All profits from the book will be donated to the SUDC Foundation to support families, fund research, and raise awareness in honor of JJ.

## Expanding Compassionate Care: The Power of Peer Facilitation at the SUDC Foundation

The SUDC Foundation is taking the next step in strengthening its support services by expanding peer support through facilitated group programs. In November 2025, the SUDC Foundation will be attending the three-day Robert's Program International Bereavement Peer Support Virtual Training Course, Boston Children's Hospital to become certified peer support facilitators. This training will allow us to bring this powerful model of care to the SUDC community.

As a Silver Sponsor, the SUDC Foundation is also offering scholarships to support

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other peers in the grief community interested in attending the training.

Peer support plays a vital role in processing grief. Research shows that connecting with others who have experienced similar loss can reduce isolation, foster understanding, and promote hope. Once trained, peer facilitators will lead small groups designed specifically for those impacted by SUDC.

This new offering will complement our existing Peer Connection Friends Program, which pairs trained peers to provide individualized emotional support. Together, these programs will broaden our support network and ensure that every family can find meaningful connection—whether one-on-one or in a group setting.

By investing in peer facilitation, we are expanding our reach and honoring the wisdom of those who have lived through the unimaginable—transforming shared sorrow into shared strength.

## SUDC Sibling Circle

### In partnership with the Jackson Walsh Foundation and Kids Grief Support

This year, we were honored to launch the SUDC Sibling Circle, a supportive space designed especially for children grieving the loss of a sibling. With groups for both younger children (ages 4–8) and older children/teens (ages 9–15), the program provides age-appropriate ways for kids to express their feelings, connect with peers, and find comfort in knowing they are not alone.

Since its launch, the Sibling Circle has hosted four successful sessions, each offering meaningful opportunities for children to share openly, reflect on their grief, and connect with peers through activities like read-aloud stories, art projects, memory bead bracelets, imaginative games, and grounding exercises. The groups have created spaces for both playfulness and healing, helping participants feel understood and supported.

We are grateful to the Jackson Walsh Foundation for their generous support in making this program possible and to Kids Grief Support for their partnership in bringing thoughtful, developmentally sensitive care to our community's youngest grievers.

For more information about the Sibling Circle, please contact support@sudc.org.

## Partner Spotlight: Meaghan Barakett and One Girl

We are honored to partner with Meaghan Barakett, Founder & CEO of One Girl, a NYC-based nonprofit empowering women to lead with purpose and impact. Meaghan is also an SUDC Foundation Ambassador and mother to Lincoln, who passed away suddenly and without explanation in 2020.

In June, One Girl hosted its first-ever Icon Awards Luncheon at The Harvard Club of NYC, celebrating women who embody compassion, leadership, and diversity.

Through her leadership, the Foundation was introduced to Fordham University's Center for Community Engaged Learning (CCEL), opening the door to a new internship partnership. This collaboration will expand our reach in areas such as social media, marketing, grantmaking, and social work—while mentoring the next generation of professionals dedicated to supporting families and raising awareness of SUDC.

We are grateful for Meaghan's courage, leadership, and commitment to shining a light on SUDC. As she shared at the event: "Even one voice can make a difference."

If you or your organization are interested in partnering with the SUDC Foundation, please contact us at info@sudc.org. Every connection brings us closer to greater understanding, knowledge, comfort, and hope.

## Perhaps Tomorrow

It was overcast, and the days before
another one of those storms that took
out small sedans too low to the ground
on valley roads. I spent the morning,
again, picking up tree branches from
the old pine and offered a small
blessing for the butterfly bush that split
in two: We give thanks for what you are
and were. May you grow strong and – you
get the gist. The rain was done but it had
been here and the sky hadn't yet finished
reminding us of this, which is all to say,
the water in the community pool was cold
and the child was pent up after one whole
day of summer without too hot sun. Why
is it so easy for me to refuse him? Why
can't I will myself to play as he plays, to
love the repetition of his jokes, the speed
and volume at which he greets the day?
I did not want to ease the soft and tender
parts of me into the cold water. I did not
want to get used to it in time. But here I
am, shoulders under a weighted blanket of
chlorine and chemical and his delight.
Is it enough? His joy in my eventual yes.
My surrender. Is it enough to forgive my
first refusal? And each one each day before?
If there is to be a blessing made of these
storms I pray they are to gentle him to me,
to remember that I loved him louder
than his laughter, quicker than his chase
but rarely with the frivolity that I would have
liked. That we would have liked. Perhaps
tomorrow when the sun is too hot again.
And if not then, perhaps another day.

*— Kim Wildszewski, Rev.*
*SUDC Foundation Poet Laureate*

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OFFICIAL CHARITY PARTNER

tcs NEW YORK CITY MARATHON

## Support our 11 Marathoners for SUDC this Fall!

**The TCS New York City Marathon is on Sunday, November 2!**
Tune in to ABC starting at 9am EST 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/4glGutr**.