SUDDEN UNEXPLAINED DEATH IN CHILDHOOD FOUNDATION

the Telescope

Navigating to a future free of SUDC 2026

IN THIS ISSUE

A New Era for SUDC Research 1
A Message from the Chief Executive Officer 3
A New Chapter in Family Services 4
The Impact of Early Professional Interactions 4
The Promise of Genomic Research 5
Postmortem Genetic Testing 5
Long-Read Genome Sequencing 5
A Community United in Purpose 6
From Family Experience to Systems Change 7

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

101 Eisenhower Parkway
Suite 300
Roseland, NJ 07068

Ph: 800.620.SUDC
Fax: 973.559.6191
Email: info@sudc.org

A New Era for SUDC Research

Landmark NIH Funding Expands the Search for Answers in Sudden Unexplained Pediatric Deaths

For families affected by Sudden Unexplained Death in Childhood (SUDC), the search for answers has too often taken place in a field with limited research and limited federal investment. A major new research award marks an important shift.

Researchers at Robert's Program on Sudden Unexpected Death in Pediatrics at Boston Children's Hospital, led by Dr. Richard Goldstein, have received a prestigious five-year R01 grant from the National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH).

The study, Multiomic Investigation of Sudden Unexplained Pediatric Deaths, represents one of the most significant federal investments to date in this field. Importantly, SUDC is specifically included within the broader investigation of sudden unexpected pediatric deaths spanning infancy through age 20.

Science at a New Scale

The study will draw on one of the largest collections of extensively investigated sudden unexplained pediatric death cases ever assembled. Through collaboration among Robert's Program, the NIH/CDC Sudden Death in the Young Registry, and the SUDC Foundation community, researchers anticipate studying more than 1,400 cases, including approximately 520 newly enrolled children and adolescents.

Led by Dr. Goldstein and colleagues Dr. Ingrid Holm and Dr. Monica Wojcik, the multidisciplinary team will combine detailed clinical information with advanced genomic and metabolomic technologies to investigate biological factors that may contribute to these deaths.

Researchers will examine single-gene causes through genome sequencing and advanced long-read sequencing; investigate how multiple genetic variants may collectively contribute to risk for conditions including epilepsy and cardiac disorders; and use metabolomic testing to identify biochemical signatures associated with previously unrecognized metabolic disorders and other biological pathways.

Bringing these different sources of information together is particularly important. Sudden unexplained pediatric deaths are unlikely to be explained by one biological pathway or one form of testing alone. A more comprehensive approach may reveal patterns and vulnerabilities that could not be identified through traditional investigations.

"Families affected by sudden unexplained pediatric deaths have long sought answers to questions that remain among the most challenging in pediatric medicine," said Dr. Richard Goldstein, Director of Robert's Program and Principal Investigator. "This award will allow us to apply powerful genomic and metabolomic technologies to better understand the biological mechanisms underlying these deaths."

What This Means for the SUDC Community

The significance of this award extends beyond the size of the study. R01 grants undergo rigorous scientific peer review and are among the NIH's principal mechanisms for supporting substantial, investigator-led research. In a field historically underfunded and understudied, this investment signals growing recognition that sudden unexplained pediatric deaths warrant sustained scientific investigation.

Continued on Pg. 2

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.



SUDC Foundation Board of Directors

Julia Burgess, CPA (retired) ★ President
Erin Bowen, MD ★ Vice President
Deepa Suresh Roongta, MBA ★ Treasurer
Laura Dozier, CNA ★ Secretary
David Cramer
Brian P. Ehret, F-ABMDI
Karla Elmberg, Esq.
Stephanie Gandomi, MS, MBA, LCGC
Carson McLean
Steve Myers

SUDC Foundation Scientific Advisory Board

Grace Hillyer, EdD, MPH ★ CHAIR
Geoffrey Balkman, PhD, CPO
Wendy Chung, MD, PhD
Heather C. Mefford, MD, PhD
Robert L. Nussbaum, MD, FACP, FACMG
Egondu Onuoha, MS, RDN, CDN, IBCLC, CDE/CDCES, GPC, FAND, FILCA
Lark J. Perez, PhD
Anne Slavotinek, MBBS, PhD, FRACP, FACMG

SUDC Foundation Staff

Tina Yun Lee ★ Chief Executive Officer
Anne Elizabeth Milliken ★ Chief Philanthropy Officer
Danielle Cristofano-Schwartz, LCSW ★ Director of Family Services
Heather Maher, MSFS ★ Manager of Postmortem & Forensic Services
Teri Kandel ★ Development Associate
Michelle Brodeur ★ Family Services Assistant
Elena Juliano ★ Family Services Intern

Continued from Pg. 1

"For the SUDC community, this grant represents more than a research award," said Tina Yun Lee, Chief Executive Officer of the SUDC Foundation. "It reflects growing momentum in a field that has historically been underfunded and understudied. By supporting one of the largest and most comprehensive studies to date to include Sudden Unexplained Death in Childhood, this investment strengthens the scientific foundation needed to advance discovery, improve risk assessment, and inform future prevention efforts."

The SUDC Foundation's longstanding partnership with Robert's Program includes direct investment in specialized neuropathology expertise through its Supporting Neuropathological Assessment in Robert's Program study. This commitment, distinct from the NIH-funded research, reflects the Foundation's sustained efforts to strengthen scientific investigation and deepen understanding of SUDC.

Families remain central to this progress. Their willingness to share their children's medical histories, samples, experiences, and unanswered questions makes investigations of this scale possible. Equally essential is collaboration among clinicians, medical examiners, coroners, death investigators, neuropathologists, geneticists, and researchers whose collective expertise advances the search for answers.

No single study can promise an answer for every family. Yet research of this magnitude creates opportunities to investigate biological vulnerabilities, identify potential biomarkers, and inform future approaches to risk assessment, earlier detection, and ultimately prevention.

The scale and depth of this research mark an important shift, from investigating individual findings toward understanding the biological mechanisms that may connect them. For the SUDC community, this represents a significant advancement in the pursuit of answers.

LEARN MORE

Read the full press release:

Scan or click the QR code.

A message from the CEO...

A Year of Progress. Redefining What's Possible.

Dear Friends,

When I reflect on this past year, what stands out most is not any single accomplishment, but how significantly the SUDC Foundation has grown in its capacity to advance research, strengthen professional practices, and expand the resources and support available to families.

Our mission remains steadfast: to serve families following the sudden, unexpected, and unexplained death of a child and to advance our understanding of why these deaths occur. What has evolved is the breadth of our work, the strength of our partnerships, and our growing ability to influence the field of SUDC.

For too long, SUDC has received limited scientific attention and investment. Today, we are seeing meaningful shifts in that landscape.

A landmark five-year National Institutes of Health research award to Robert's Program at Boston Children's Hospital represents a significant advancement in the investigation of sudden unexplained pediatric deaths. Through our longstanding partnership, the SUDC Foundation continues to invest in specialized neuropathology expertise that contributes to this important research. At the same time, our collaboration with the University of Washington and Seattle Children's Hospital is expanding opportunities to apply emerging genomic technologies to the search for answers.

These developments represent more than individual research initiatives. They signal growing scientific recognition, stronger multidisciplinary collaboration, and new possibilities for understanding the biological mechanisms underlying SUDC.

Equally important is our expanding role in strengthening the systems families encounter following a child's death.

Through our Postmortem & Forensic Services program and complimentary Postmortem Genetic Testing Program, we are helping bridge gaps between advanced scientific capabilities, medicolegal investigations, and access to critical resources for families.

Our inaugural multidisciplinary training in Fairfax County, Virginia brought together 100+ first responders and medicolegal professionals to strengthen investigative practices, communication, and family-centered care. Informed by our newly accepted peer-reviewed research examining the relationship between early professional interactions and long-term psychological distress among bereaved caregivers, this initiative demonstrates how family experiences can drive research and how research can translate into meaningful changes in professional practice.

Within Family Services, we are strengthening individualized support, expanding peer connections, and developing resources that respond to families' evolving needs. Our 2026 Community Retreat brought together families from across the United States and Canada, reinforcing the importance of community, shared understanding, and access to professional expertise and peer support.

While these initiatives span different areas of our mission, they are intentionally interconnected. Stronger investigations contribute to better research. Scientific advances create new opportunities for answers. Professional education strengthens how families are supported. And families' experiences remain central to shaping each of these efforts.

This interconnected approach reflects how the SUDC Foundation has evolved—not simply by expanding programs, but by strengthening our ability to connect scientific discovery, professional practice, and family care in ways that advance the entire field.

As we develop our 2027–2029 Strategic Plan, we are building upon this momentum with clear priorities: accelerating scientific discovery, transforming systems of care and investigation, strengthening family services, and ensuring the organizational capacity to sustain this work.

I also want to express my sincere gratitude to SUDC UK, under the leadership of its CEO, Nikki Speed, PhD, for their valued partnership and shared commitment to families affected by SUDC. Our collaboration is an important part of expanding our global reach, strengthening international awareness, and advancing a more coordinated approach to supporting families and pursuing answers.

The opportunities before us are greater than they were just a few years ago. Our responsibility is to translate that momentum into lasting progress.

The questions haven't changed. The possibilities have.

To the families, researchers, medical and medicolegal professionals, donors, volunteers, Board members, and partners who continue to make this work possible, thank you for your commitment and contributions.

Families First. Research Always.

With deep gratitude,





Tina Yun Lee
Chief Executive Officer
SUDC Foundation

A Personal Connection, A New Chapter in Family Services

By Danielle Cristofano-Schwartz, LCSW, Director of Family Services

My connection to the SUDC Foundation began long before I joined as Director of Family Services.

When my daughter Lydia died unexpectedly in 2022, our family was left without an explanation. Like so many families who turn to the Foundation, I was searching for answers while navigating an unimaginable loss. Although a cause of death was eventually identified, the SUDC Foundation remained a place where I felt welcomed, understood, and supported.

That experience, together with my background as a licensed clinical social worker, shapes my approach to supporting families. Since joining this past March as the Director of Family Services, I have focused on building upon our established programs and strengthening our commitment to trauma-informed, family-centered care.

One of our most significant developments has been expanding peer-led support groups. Connecting with someone who has experienced child loss can provide a powerful sense of understanding and belonging. Today, our groups are facilitated by bereaved individuals, some of whom also bring clinical expertise. We have expanded our Newly Bereaved Parents Support Group while continuing to offer specialized groups for grandparents, dads, parents of older children, and bereaved parents. These connections complement the professional guidance, advocacy, and individualized support central to the Foundation's work. We are especially grateful to our volunteer peer facilitators, whose dedication makes these opportunities possible.

We are also transforming our Peer Connections Program based on family feedback. Through enhanced volunteer training and more comprehensive and individualized matching, we are strengthening relationships that reflect each family's circumstances, preferences, and needs.

Looking ahead, we are developing a **Growing Families After Loss** initiative for parents considering expanding their families following the death of a child. This work is especially personal to me. After Lydia's death, I struggled to find resources as I considered having another child, eventually establishing my own pregnancy-after-young-child-loss support group. Drawing on that lived experience, my clinical background, and additional training with renowned grief expert David Kessler, I am helping develop an initiative that provides families with evidence-based information, peer connections, and resources for informed decision-making.

Grief does not follow a timeline, and families' needs change over time. By combining professional expertise, peer connections, and family perspectives, we are strengthening a more responsive approach to bereavement care.

Having once turned to the SUDC Foundation for support myself, I am grateful for the opportunity to help shape its next chapter. Guided by our Families First philosophy, we are committed to ensuring families have the knowledge, resources, and support to make informed decisions and remain at the center of every decision about their care.

New SUDC Foundation Research Highlights the Impact of Early Professional Interactions

A new SUDC Foundation study, "The Psychological Impact of Sudden Unexplained Death in Childhood: Associations Between Early Professional Interactions and Long-Term Distress Among Bereaved Caregivers," has been published in *OMEGA – Journal of Death and Dying*.

Drawing on responses from 174 bereaved caregivers, the study identified significant psychological distress, including anxiety, depression, prolonged grief, and probable post-traumatic stress disorder (PTSD). Nearly half of respondents described their interactions with emergency medical services or emergency department professionals as neutral or negative. These experiences were significantly associated with prolonged grief and probable PTSD.

While the findings do not establish causation, they highlight the importance of compassionate communication and trauma-informed, family-centered care during the earliest encounters following a child's death.

By bringing families' experiences into bereavement research, the study provides valuable insights that can help shape professional education and practice. These findings also inform the SUDC Foundation's expanding first responder training initiative, which equips professionals with practical strategies to better support families during these critical moments.

The SUDC Foundation gratefully acknowledges the Vivienne's Joy Foundation for its generous support of this research.

READ THE FULL STUDY

Scan the QR code to access the complete research article in *OMEGA – Journal of Death and Dying.*

Scan or click the QR code.

Expanding the Search for Answers: The Promise of Genomic Research

Advances in genomic technologies are creating new opportunities to investigate Sudden Unexplained Death in Childhood (SUDC) and uncover biological factors that may previously have gone undetected.

At the SUDC Foundation's 2026 Community Retreat, renowned medical geneticist and Scientific Advisory Board member Dr. Robert L. Nussbaum explored these developments during his keynote presentation, "Expanding the Search for Answers: The Critical Role of Genomics in Advancing SUDC Research."

Central to his presentation was whole genome sequencing, which allows researchers to examine nearly the entirety of a person's DNA, offering a more comprehensive view of genetic variation than traditional targeted testing.

These advances are helping researchers investigate rare genetic conditions and identify potential biological contributors to unexplained childhood deaths. By expanding the application of genomic technologies, researchers are opening new pathways toward understanding SUDC and identifying opportunities for future discovery.



Dr. Robert L. Nussbaum discusses advances in genomic research at the 2026 Community Retreat.

Advancing Answers Through Postmortem Genetic Testing

Launched in late 2024 in partnership with GeneDx, the SUDC Foundation's Postmortem Genetic Testing (PMGT) Program provides complimentary testing for eligible cases undergoing medical examiner or coroner investigations, removing financial barriers to advanced genetic testing.

For Melissa Carlton's family, the program provided critical information following the deaths of her daughters, Abigail and Molly. Postmortem genetic testing for Molly identified a pathogenic variant in the PPA2 gene associated with PPA2 deficiency, a rare inherited metabolic condition. This finding provided insight into a genetic contribution to the deaths of both daughters and highlighted potential implications for surviving family members.

Dr. Rebecca Graziano, forensic pathologist with the Maricopa County Medical Examiner's Office, emphasized the program's importance, explaining that testing identified a rare genetic finding that would not have been detected through autopsy alone.

Melissa's experience demonstrates how access to postmortem genetic testing can strengthen death investigations, provide families with important information, and identify inherited conditions that may affect other family members.

Through partnerships with medical examiners, coroners, and genetic specialists, the Foundation continues to expand access to advanced testing and support families in their pursuit of answers.

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

Advancing Discovery Through Long-Read Genome Sequencing

Through a research partnership with the SUDC Foundation, Dr. Danny Miller and Dr. Alexandra Keefe at the University of Washington are using advanced long-read genome sequencing to investigate genetic changes that may be missed by traditional testing.

Unlike conventional sequencing, which examines DNA in smaller fragments, long-read technology analyzes longer stretches of DNA, helping researchers identify complex genetic variations that may otherwise go undetected.

"When a child dies suddenly and the autopsy offers no explanation, families are left with a huge amount of uncertainty, and questions no one can answer. By offering the most comprehensive research genomic testing available, we feel we are offering SUDC families the best possible chance at finding answers," says Dr. Keefe.

Although not every case will yield an explanation, this research may identify previously undetected genetic factors, inform future postmortem testing guidelines, and strengthen death investigations.

The Foundation's investment in this innovative research reflects its commitment to expanding scientific understanding and pursuing answers for families.

Families First. Research Always. A Community United in Purpose

2026 SUDC Foundation Community Retreat | September 17–20 | Bloomington, Minnesota



For families navigating the sudden, unexpected death of a child, finding others who understand their experience can be profoundly meaningful. The SUDC Foundation's 2026 Community Retreat brought together families, researchers, professionals, and community partners around a shared commitment: **Families First. Research Always.**

Held September 17–20 in Bloomington, Minnesota, the Retreat welcomed 60 families who traveled from 29 states and Canada.

Guided by the theme *Restore. Renew. Reconnect. Remember.*, the Retreat offered therapeutic programming, educational sessions, and opportunities for meaningful connection. Specialized activities for parents, siblings, and grandparents recognized that every family member experiences grief differently.

A highlight of the weekend was the presentation of the **Families First Award** to Dr. Andrew M. Baker, Chief Medical Examiner of Hennepin County, recognizing his excellence in the field of forensic pathology and his commitment to compassionate, family-centered practices. The award honors professionals whose leadership and dedication make a meaningful difference for families following the sudden death of a child.

Scientific education was another important component of the Retreat, featuring presentations by two members of the SUDC Foundation's Scientific Advisory Board. Renowned medical geneticist Dr. Robert L. Nussbaum delivered the keynote, "Expanding the Search for Answers: The Critical Role of Genomics in Advancing SUDC Research." Dr. Lark J. Perez, professor and Chair of the Department of Chemistry and Biology at Rowan University and SUDC parent to Atley, presented "Research, Advocacy, and the Pursuit of Answers," bringing both scientific expertise and personal experience to the discussion.



Heather Maher, MSFS, Postmortem & Forensic Services Manager and Dr. Andrew M. Baker, 2026 Families First Award Recipient



2026 TMI Project Storytellers & Workshop Leaders

One of the weekend's most powerful experiences came through the Foundation's collaboration with **TMI Project**, a nonprofit organization that uses true storytelling to foster connection and understanding. Eight SUDC Community members participated in a guided storytelling experience, sharing deeply personal narratives about their children, their grief, and the ways their experiences have shaped their lives. Their stories offered moments of reflection, recognition, and connection for those gathered.

The **Celebration of Light** provided a meaningful opportunity for families to honor and remember their children together. An original poem, **Beachgoers Form a Human Chain to Save a Family Trapped in a Rip Current, Panama City, 2017**, written by the Foundation's Poet Laureate, Rev. Kim Wildszewski, was read during the ceremony, offering words of remembrance and reflection as families gathered in community.

Beyond the scheduled programming, conversations over shared meals, parent gatherings, and children's activities created space for new friendships and renewed connections.

Throughout the weekend, families were surrounded by people who understood the significance of their children's lives, professionals committed to supporting them, and researchers working toward answers.

Families First. Research Always. The Retreat brought these commitments together in a community grounded in remembrance, connection, and a shared determination to advance understanding of SUDC.

From Family Experience to Systems Change

Inaugural Fairfax County Training Creates a New Model for Responding to Sudden Unexpected Child Deaths

When a child dies suddenly and unexpectedly, the first hours that follow can have a lasting impact on a family. The thoroughness of the investigation, the way professionals communicate, and the coordination between agencies can influence both the information available about a child's death and the family's experience.



Presenters and partners at the inaugural Fairfax County first responder training.

On August 14, the SUDC Foundation took an important step toward strengthening that response.

In partnership with the Fairfax County Police Department and the Virginia Office of the Chief Medical Examiner, the Foundation convened its inaugural multidisciplinary workshop, "Responding to Sudden Unexpected Child Death Scenes: Investigation, Communication, and Family-Centered Care."

More than 100 first responders and medicolegal professionals participated in the half-day training, which emphasized comprehensive investigations, effective communication, interdisciplinary collaboration, and family-centered practices.

Spearheaded by Fairfax County Police Department Investigator Mary T. A. Weldon, MS, F-ABMDI, the workshop featured Investigator Weldon; Investigators Paige Bakatsias, F-ABMDI and Paola Cruz Maldonado, F-ABMDI of the Virginia Office of the Chief Medical Examiner; and Florencia Segura, MD, FAAP, a board-certified pediatrician and SUDC mother to Rosalie.

Central to the training were the voices of bereaved parents. Dr. Segura shared her perspective as both a physician and Rosalie's mother. Miranda Magdangal, SUDC mother to Ezra, contributed a recorded presentation, while Matthew White, SUDC father to Preston, spoke directly with participants.

Their participation reinforced a fundamental principle: a thorough investigation is essential, but the words, actions, and interactions families encounter during those first hours also matter. Hearing directly from parents helped participants understand how their professional responses can affect families long after an investigation concludes.

The Fairfax initiative grew from the Foundation's commitment to listening to families and translating their experiences into meaningful change. Previous research examining families' interactions with first responders identified significant associations between early professional experiences and long-term psychological distress. These findings were recently published in *OMEGA – Journal of Death and Dying*.

The workshop put that knowledge into practice, equipping professionals with strategies to strengthen their response while recognizing the distinct responsibilities of law enforcement, death investigators, medical examiners, and healthcare providers. Expanding this work offers an opportunity to increase SUDC literacy among professionals, strengthen investigative practices, and establish more consistent approaches to supporting families.

Importantly, Fairfax was designed as the beginning of a broader initiative. The Foundation is evaluating participant feedback, refining the curriculum, and exploring opportunities to replicate this multidisciplinary training model in communities nationwide.

The Fairfax initiative marks a significant evolution of the SUDC Foundation's work—extending our impact beyond direct family support to helping shape the investigative practices, professional responses, and systems of care that families encounter in the immediate aftermath of a child's sudden death.

The inaugural Fairfax County workshop was made possible with generous support from Love Like Rosie.

How Your Support Keeps Families at the Center of Our Work

Your generosity makes specialized family programs possible today while advancing the research needed to bring us closer to answers tomorrow.

Scan or click to donate.

$150
Educate first responders about SUDC

$250
Provide personalized, trauma-informed bereavement care to families

$500
Connect families with SUDC research opportunities

$1,000
Ensure grieving families have access to essential resources

$1,800
Fund postmortem genetic testing for one SUDC child

SUDC FOUNDATION

101 Eisenhower Parkway, Suite 300
Roseland, New Jersey 07068

DONATE
www.sudc.org
TODAY!

GIVING TUESDAY | DECEMBER 1, 2026

One Gift. Twice the Impact.

Your generosity goes twice as far this Giving Tuesday. Gifts made on December 1 will be matched, up to $50,000. Make your gift count.

Families First. Research Always. Together, We Fund the Future.

Scan or click the QR code.