Federal Research Investment Marks Historic Milestone for Sudden Unexplained Death in Childhood and Sudden Unexpected Death in Pediatrics Research

The SUDC Foundation is pleased to share that researchers at Boston Children's Hospital's Robert's Program on Sudden Unexpected Death in Pediatrics, under the leadership of Dr. Richard Goldstein, have been awarded a prestigious National Institute of Neurological Disorders and Stroke (NINDS) R01 grant for a groundbreaking study entitled *Multiomic Investigation of Sudden Unexplained Pediatric Deaths.*

The award will support a five-year research initiative and represents one of the most significant federal investments to date in advancing the understanding of sudden unexplained pediatric deaths. This funding marks an important milestone for families, clinicians, researchers, and advocates who have worked to bring attention to sudden unexplained deaths in infancy, childhood, and adolescence.

The grant supports major research that includes Sudden Unexplained Death in Childhood (SUDC) within the broader study of Sudden Unexpected Pediatric Deaths (SUDP). Spanning infancy through age 20, the project reflects growing national recognition of the urgent need to understand the underlying mechanisms of sudden unexplained deaths across childhood and adolescence.

R01 grants are among the most competitive and respected funding mechanisms awarded by the National Institutes of Health (NIH). Designed to support multi-year scientific investigations with the potential to advance medical knowledge and improve health outcomes, these awards undergo rigorous peer review and represent the highest level of competitive NIH support for independent, investigator-led research programs. For a field that has historically received limited attention and funding, this award validates both the scientific merit and public health significance of research focused on sudden unexplained pediatric deaths.

Led by Dr. Goldstein and colleagues Dr. Ingrid Holm and Dr. Monica Wojcik, the multidisciplinary team will investigate the biological mechanisms underlying sudden unexpected pediatric deaths through comprehensive genetic analysis, detailed clinical phenotyping, innovative metabolomic approaches, and advanced methods for assessing risk across multiple genes and biological pathways.

The study will leverage one of the largest collections of extensively studied sudden unexplained pediatric death cases ever assembled. This effort is strengthened by the partnership among the Robert's Program, the NIH/CDC Sudden Death in the Young (SDY) Registry, and the SUDC Foundation community. Researchers anticipate studying more than 1,400 cases, including approximately 520 newly enrolled children and adolescents.

The research includes three scientific aims, each serving as a critical step toward earlier detection of underlying vulnerabilities and the identification of biomarkers that may one day help identify infants and children at risk before a tragedy occurs.

The first aim focuses on identifying single-gene causes of sudden unexplained death through genome sequencing and advanced long-read sequencing technologies. The second aim will

examine how multiple genetic variants may work together to increase risk for conditions associated with sudden death, including epilepsy and cardiac disorders. The third aim will utilize metabolomic testing to identify biochemical signatures that may reveal previously unrecognized metabolic disorders and other biological pathways associated with sudden unexplained death.

By integrating clinical data, genomic analysis, and metabolomic technologies, researchers hope to uncover new insights into the complex biological factors that contribute to sudden unexplained pediatric deaths. The findings are expected to inform future research aimed at earlier detection, improved risk assessment, targeted interventions, and ultimately prevention.

"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 the Robert's Program on Sudden Unexpected Death in Pediatrics at Boston Children's Hospital and Principal Investigator of the study. "This award will allow us to apply powerful genomic and metabolomic technologies to better understand the biological mechanisms underlying these deaths."

The award also reflects the longstanding leadership of Robert's Program in advancing research and care for families affected by sudden unexplained pediatric deaths. Through decades of clinical investigation, family engagement, and scientific discovery, Dr. Goldstein and his colleagues have helped build the infrastructure necessary to pursue large-scale studies such as this one.

"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 that includes Sudden Unexplained Death in Childhood to date, this investment strengthens the scientific foundation needed to advance discovery, improve risk assessment, and inform future prevention efforts."

The SUDC Foundation is proud to partner with Robert's Program and invest in the specialized neuropathology expertise that has been instrumental in advancing the field's understanding of sudden unexplained pediatric deaths. Meaningful progress depends on collaboration among families, clinicians, medical examiners, coroners, death investigators, neuropathologists, geneticists, and researchers. Together, these partnerships strengthen the scientific foundation needed to advance discovery and inform future prevention efforts.

This NIH-funded award complements the SUDC Foundation's longstanding investment in research through its partnership with Robert's Program, including support for the *Supporting Neuropathological Assessment in Robert's Program* study, which seeks to further advance understanding of SUDC.

Learn more: https://sudc.org/wp-content/uploads/2026/02/2026-SUDCF-Roberts-Program-Grant-Announcement-Press-Release.pdf

Families First. Research Always.

About the Robert's Program on Sudden Unexpected Death in Pediatrics

The Robert's Program on Sudden Unexpected Death in Pediatrics at Boston Children's Hospital is dedicated to improving understanding, investigation, and prevention of sudden unexpected deaths in infants, children, and adolescents. Through multidisciplinary research, clinical consultation, family support, and education, the program advances scientific discovery while supporting families affected by sudden unexplained pediatric deaths.

To learn more about the Robert's Program, visit:
https://www.childrenshospital.org/services/roberts-program

About the SUDC Foundation

The SUDC Foundation is a 501(c)(3) nonprofit organization whose mission is to raise awareness, fund research, and serve those affected by Sudden Unexplained Death in Childhood (SUDC). Through family support, education, research partnerships, and professional outreach, the Foundation works to ensure that no family navigates SUDC alone while advancing efforts to better understand and prevent these deaths.

The Foundation supports more than 2,500 family members across 25 countries and collaborates with researchers, clinicians, medical examiners, and community partners around the world.

Learn more about the SUDC Foundation, please visit: sudc.org

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