

The SUDC Foundation Launches Postmortem Genetic Testing Initiative in Partnership with GeneDx

FOR IMMEDIATE RELEASE: [Roseland, New Jersey] – The SUDC Foundation is proud to announce the launch of the Postmortem Genetic Testing Program, now available to medical examiner and coroner offices handling active or open investigations. Developed in collaboration with GeneDx, a leading provider of advanced genetic testing services and genomic insights, this program aims to deepen our understanding of Sudden Unexplained Death in Childhood (SUDC). It will also contribute critical genetic data to current and future research efforts, helping to advance our understanding of SUDC and potentially preventing future tragedies.

Recognizing the critical 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 Program. This shift underscores the rapid advancements in genetic testing technology and the increasing acceptance of postmortem testing as an essential investigative tool in achieving comprehensive SUDC investigations.

Sudden Unexplained Death in Childhood (SUDC) is a category of death in children between the ages of 1 and 18 that remains unexplained after a thorough investigation, including an autopsy.

Postmortem genetic testing offers critical insights in cases where the sudden and unexpected loss of a child occurs, helping to identify potential genetic causes of death and assessing whether blood relatives may be at risk for related genetic conditions. By securing a genetic specimen (DNA)—preferably a blood sample collected in a purple top EDTA tube—medical professionals can investigate potential genetic markers linked to sudden death. This testing not only aids in understanding the cause of death but also provides peace of mind to families, particularly when results are negative, as it can rule out hereditary risks.

SUDC Foundation board member, Stephanie Gandomi, MS, MBA, LCGC, states, “We are deeply committed to supporting families who have experienced the unimaginable loss of a child. This new initiative with GeneDx represents a significant step forward in our mission to uncover the genetic factors that may contribute to sudden unexplained deaths in children. By providing these critical insights, we aim to empower families with critical knowledge to prevent additional losses in the future.”

“We understand how impactful a genetic diagnosis can be for a family that is searching for answers and commend SUDC's commitment to helping families find answers during an incredibly difficult time,” said Britt Johnson, PhD, FACMG and Senior Vice President of Medical Affairs at GeneDx. “GeneDx's support of this initiative will not only give peace of mind during this incredibly difficult time but will also help us to better understand gene-disease associations in SUDC and potentially prevent tragic outcomes for future children.”

The SUDC Foundation is committed to assisting medical examiners and coroners by removing financial barriers to accessing complimentary postmortem genetic testing. This ensures that the testing becomes an integral part of autopsy investigations, leading to rigorous and effective outcomes for both professionals and families.

"Post-mortem genetic testing is recognized as a vital component in the thorough death investigation of a child's sudden passing," states Tina Yun Lee, Chief Executive Officer, The SUDC Foundation. "Both the SUDC Foundation and The National Association of Medical Examiners advocate for the importance of this testing."

For more information about the SUDC Foundation's postmortem genetic testing initiative or to inquire about assistance with an active SUDC case, please contact the SUDC Foundation at: <https://sudc.org/post-mortem-genetic-testing/>.

About the SUDC Foundation

The SUDC Foundation is the only organization worldwide whose purpose is to raise awareness, fund research, and serve those affected by Sudden Unexplained Death in Childhood (SUDC). The SUDC Foundation provides all trauma informed services and supports at no cost to the people it serves. www.sudc.org.

About GeneDx

At GeneDx (Nasdaq: WGS), we believe that everyone deserves personalized, targeted medical care—and that it all begins with a genetic diagnosis. Fueled by one of the world's largest, rare disease data sets, our industry-leading exome and genome tests translate complex genomic data into clinical answers that unlock personalized health plans, accelerate drug discovery, and improve health system efficiencies. For more information, please visit genedx.com and connect with us on [LinkedIn](#), [Facebook](#), and [Instagram](#).

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