Dravet Syndrome Foundation Announces 4 New Grant Awards

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CHERRY HILL, NJ, UNITED STATES, September 24, 2025 /EINPresswire.com/ -- Dravet Syndrome Foundation (DSF) is proud to support four grant awards that advance our strategic priorities to meaningfully advance our research roadmap toward a cure. These awards are distinct from our traditional annual grant cycle and were supported to address emerging opportunities that align closely with our strategic priorities.

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> *Mary Anne Meskis, CEO, Dravet Syndrome Foundation*

With these latest awards, DSF has now invested more than $12.4M in Dravet-specific research since 2009. Mary Anne Meskis, DSF CEO, shared, "Our community remains deeply committed to advancing research. Together, we are driving progress by increasing funding that enables more comprehensive and impactful studies. These awards bring us closer to new insights, better treatment options, and ultimately improved outcomes for everyone affected by Dravet syndrome."

The first grant of $662,231 was awarded to Kelly Knupp, MD, of Children's Hospital Colorado to launch a Longitudinal Dravet Syndrome Natural History Study. By following patients across their lifespan, the study will build a robust database of clinical, neuropsychological, and caregiver-reported information. This includes tracking behavior, development, sleep, appetite, autonomic symptoms, and motor function to better examine how Dravet syndrome changes across the lifespan. Said Dr. Knupp, "A contemporary Natural History Study is essential for the continued development of effective treatments. While significant progress is being made in Europe, similar efforts are lacking in the United States. This study presents a unique opportunity to collaborate with European colleagues and integrate data, creating the most comprehensive understanding of Dravet syndrome to date. By leveraging the Dravet Lifespan Clinic at Children's Hospital Colorado for participant recruitment, we aim to gain unparalleled insights into the full spectrum of the disorder."

The next grant of $338,750 for the Identification of Behavioral Biomarkers in Children with DS: A Pilot Study was awarded to Ivan Soltesz, PhD (Stanford) and Jack Parent, MD (University of Michigan), with collaborators Tilo Gschwind, PhD, and Julie Ziobro, MD, PhD. Their project uses AI-driven behavioral phenotyping to detect subtle movement patterns unseen by traditional observation, providing a fast, non-invasive way to measure treatment response. Preclinical work shows this method can identify epileptic traits and distinguish medication types and doses—even without seizures—highlighting strong potential for patient care. Dr. Parent commented, “These are high risk/high reward pilot studies to adapt to human epilepsy a key AI technology that showed powerful results in preclinical epilepsy mouse models. DSF support is critical at this early stage of research to allow us to begin moving this powerful technology into clinical applications for Dravet syndrome.”

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The third grant award of $750,000 went to Lori Isom, PhD, University of Michigan for her project, “Understanding phenotypes and biomarkers leading to SUDEP in a transgenic rabbit model of Dravet syndrome.” This novel model is allowing new insights into the leading cause of mortality in Dravet syndrome, Sudden Unexpected Death in Epilepsy (SUDEP). Dr. Isom described, “We developed a transgenic rabbit model of Dravet syndrome because rabbits more closely replicate human heart and respiratory physiology than mice and, unlike our previous iPSC work, provide a complete organism to translate to the clinical setting. Our experimental strategy will allow us to record SUDEP in real time in freely moving animals that mimic human disease so that we can more completely understand the details of SUDEP mechanisms.” Understanding and preventing SUDEP remains an urgent priority for DSF. Dr. Isom stated “We are deeply grateful to the Dravet Syndrome Foundation for funding this important, high-risk but high-reward work. We hope that our results will provide critical new insights on the combined contributions of seizures and cardiac arrhythmias to the mechanism of SUDEP.”

The fourth grant of $100,000 provides supplemental funding to continue the work of David Auerbach, PhD, The Research Foundation for SUNY/Upstate Medical University, that was previously supported by DSF. This, Award Supplement for Genetic Substrates and Physiological Triggers for Autonomic and Cardiac Abnormalities in Dravet Syndrome, will continue his work on SUDEP in Dravet syndrome, building on the previous findings from this initial 2022 Clinical Research Award and incorporating new datasets and deeper analyses. Dr. Auerbach shared, “People with Dravet syndrome (DS) are at a high risk of SUDEP. Using cellular and animal models, I demonstrated that DS mutations result in electrical disturbances in the heart, and cardiac

arrhythmias preceded SUDEP. While our cellular results identified a DS patient with electrocardiographic (ECG) abnormalities, the translational relevance of these results remains unknown. Prolongation of the cardiac electrical activation-recovery interval (QTc interval) is a substrate and marker for an increased risk of arrhythmias. We showed that the QTc interval is significantly longer and there is a higher prevalence of clinically defined QTc prolongation in people with DS, compared to healthy controls and two other severe forms of epilepsy. In this study we are looking deeper into the substrates (clinical characteristics & medications) and triggers (physiological state and seizures) for cardiac ECG abnormalities. Additionally, we are performing more detailed analysis of ECG dynamics, which are markers of heart disease and arrhythmias."

Said DSF Chief Scientific Officer, Dr. Veronica Hood, "These special funding awards are allowing DSF to forward crucial research efforts that closely align with our strategic priorities and patient-community needs. Funding a prospective natural history study will further our collective knowledge of the full course and progression of Dravet syndrome, aligning with other similar initiatives to create cohesive datasets that can piece together an even broader picture of Dravet syndrome, improve clinical care, and even positively impact therapeutic development. Investment in two projects that are specifically focused on understanding the mechanistic underpinnings of SUDEP risk in Dravet syndrome highlights the importance of this topic to the patient-family community. Both of these lines of study are led by expert researchers employing innovative and collaborative approaches that are beginning to uncover meaningful insights that could move the needle on SUDEP. Lastly, funding for the investigation of behavioral biomarkers using cutting-edge technology not only positions Dravet syndrome at the forefront of novel discovery but also represents investment in a tool that could address many of the outstanding questions in the field."

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