

SUDEP Data Alliance Founded to Develop Life-Saving Interventions for SUDEP

SAN FRANCISCO, CA, USA, December 2, 2022 /EINPresswire.com/ -- The SUDEP Data Alliance announces its creation of the world's first open data network with a mission to accelerate the development of new life-saving interventions to prevent Sudden Unexpected Death in Epilepsy (SUDEP). Cofounded by [Neureka®](#) (Neureka AI) and [Briya](#), the SUDEP Data Alliance provides



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John Stern, MD

unprecedented real-world data that unites a global community of researchers, nonprofits, mission-driven companies, and people impacted by epilepsy.

SUDEP is the leading cause of death in people with drug-resistant epilepsy, claiming the lives of up to 1 in 150 people with uncontrolled seizures each year.[1] While its cause is unknown, SUDEP typically occurs unexpectedly during sleep in otherwise healthy individuals.[2]

Neureka is the creator of Neureka Sleep, an AI-powered sleep monitor that brings safety to people with epilepsy who are at risk of SUDEP. Neureka generates data insights for users' healthcare providers, enabling earlier treatment interventions that improve safety and outcomes.

"Exponential technologies have the potential to eradicate SUDEP from human civilization before 2030," says Ray Iskander, CEO of Neureka. "The SUDEP Data Alliance members pledge to work together to make this happen faster."

Briya — founded by cybersecurity specialists with U.S. headquarters in Nashville — is an end-to-end data-retrieval platform that enables longitudinal health data to be securely retrieved in real time. Briya leverages privacy-preserving decentralized architecture to seamlessly provide researchers and clinicians with better data, shortening the time to develop new medicines and treatments.

"Radical partnerships change the world, and it is why Briya is honored to help develop the SUDEP Data Alliance. This partnership will drive the innovation to solve SUDEP and save lives," says Pam Holt, U.S. general manager for Briya.

Using the highest security standards, the SUDEP Data Alliance uses a citizen science approach to

crowdsource data from people and families with epilepsy worldwide. The SUDEP Data Alliance shares anonymized epilepsy data with network members. Members can also find and publish deidentified data sets, while collaborating with other researchers to accelerate the development of new interventions to prevent SUDEP.

“Future success in preventing SUDEP depends on better understanding patterns in epilepsy we can’t see with today’s limited data,” says John Stern, MD, director of the epilepsy clinical program at UCLA, and chair of the scientific advisory board at Neureka. “By crowdsourcing and analyzing large epilepsy data sets, the global research community can unite to help end the tragedy of SUDEP.”

Inaugural members of the SUDEP Data Alliance include: Academy Medical; Dr. Aiman Abdel-Malek, ThirdWayv Inc.; EEG to Go; Health Engine, UC Berkeley's healthcare startup accelerator; Dr. Isa Conradsen, previously with IctalCare A/S; Dr. John Stern, UCLA; Dr. Jörg Hölzing, mySugr GmbH; Dr. Jose Cavazos, UT Health San Antonio; Medicinia; Miles Levin, director of Under the Lights; Dr. Pavel Klein, Mid-Atlantic Epilepsy and Sleep Center; Dr. Robert T. Wechsler, Consultants in Epilepsy & Neurology, PLLC; Dr. Selim Benbadis, University of South Florida; Sofie’s Journey; The Chelsea Hutchison Foundation; Dr. Vikram Rao; and What the EF podcast.

The SUDEP Data Alliance invites applicants worldwide to support its mission.

[1] <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4673971/>

[2] <https://www.epilepsy.com/complications-risks/early-death-sudep/sudep-faq>

About SUDEP Data Alliance

The SUDEP Data Alliance’s mission is to create an open data network to solve the mystery of SUDEP, in the hope of developing new life-saving interventions. The SUDEP Data Alliance provides real-world data that unites a global community of researchers, nonprofits, mission-driven companies, and people impacted by epilepsy. Learn more at www.sudepdata.org.

About Neureka® (Neureka AI)

Neureka is a digital health platform that enables continuous, personalized remote care for epilepsy and other chronic neurological conditions. Neureka offers comfortable wearables to empower people with epilepsy on a safer, faster journey to seizure freedom. Neureka provides peace of mind with caregiver alerts, easy medication management, and at-home monitoring during sleep, when Sudden Unexpected Death in Epilepsy (SUDEP) can strike. Neureka brings users the independent lifestyle they seek, and gives their medical providers actionable data for faster treatment interventions. For more information, visit www.neureka.ai.

About Briya

Briya is a data curation and retrieval platform that allows medical data to be shared seamlessly, with unprecedented ease and speed. The platform handles all technical, regulatory, and logistical aspects of the data transfer, and uses groundbreaking technology to flawlessly match same-patient records across data sources. With Briya, clinicians and researchers are empowered with high quality, up-to-date and longitudinal data that have been unified across the globe and standardized in FHIR to fuel significant insights and clinical action. For more information, please visit www.briya.com.

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