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**Sudden Unexplained Death in Epilepsy More Common in Younger Ages Than Thought
*Black and Multiracial Infants and Children 1½ Times More Likely to Die, Study Finds***

CHICAGO - Sudden unexpected death in epilepsy (SUDEP) is significantly more common in infants and children than previously reported, and those who are Black or multiracial are at higher risk, according to findings of a large national registry being presented virtually at [American Epilepsy Society AES2020](#).

The population-based study - the first of its kind in the U.S. - found that the mortality rate from SUDEP was 0.26 per 100,000 live births in infants and children, a 63% higher rate than previously reported. Researchers also determined the SUDEP mortality rate is 1½ times higher in non-white infants and children than in whites. SUDEP - when a person with epilepsy who is otherwise healthy dies suddenly and unexpectedly - most often occurs during sleep or resting.

“While SUDEP is traditionally considered a more significant issue in adults, these findings add to the growing research that it is more common in infants and children than we believed, particularly for certain groups,” said Vicky Whittemore, Ph.D., lead author and program director at the National Institute of Neurological Disorders and Stroke (NINDS), Bethesda, Md. “Physicians often don’t discuss SUDEP with parents because they consider it rare and don’t want to frighten them. But it’s important physicians who have young patients discuss the risk with parents.”

The findings are based on data from the National Institutes of Health/Centers for Disease Control and Prevention Sudden Death in the Young (SDY) Case Registry, which includes infants and children who died suddenly and unexpectedly of natural causes such as sudden cardiac death, SUDEP and sudden infant death syndrome (SIDS), among others. It excludes those who died due to homicide, suicide, intentional overdose, trauma or terminal illness.

Using data from the registry, researchers analyzed 1,769 infants and children (ages 0 to 17 years) who died in nine U.S. states between 2015 and 2017. They categorized 55 (3%) as SUDEP and 13 (1%) as possible cardiac death/SUDEP. Of the SUDEP cases, 40 (73%) occurred in those younger than 14. SUDEP occurred in 32 white infants and children and in 16 Black or multiracial infants and children. Six infants and children who died from SUDEP were Hispanic/Latino.

Past studies have suggested the mortality rate from SUDEP is 0.16 per 100,000 infants and children, which is significantly lower than the findings of the new population-based research (0.26 per 100,000 infants and children).

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Researchers also determined the SUDEP mortality rate to be 0.22 per 100,000 in white infants and children and 0.32 per 100,000 in Black and multiracial infants and children, meaning the death rate is 1½ times higher in non-white infants and children than in whites in the geographic regions included in the SDY Case Registry.

Previous SUDEP studies have reported limited data drawn from death records or referral cases. One of the strengths of this study is the involvement of neurologists and epileptologists in the review and categorization of cases at the state and local level, said Dr. Whittemore. This helps lead to increased awareness of SUDEP in the community and among those involved with investigating and reviewing deaths in infants and children.

“This ongoing research is focused on understanding the underlying causes of SUDEP, the risk factors involved and how the brain changes over time in people with chronic epilepsy, which can contribute to SUDEP,” she said. “Based on this information, prevention strategies can be developed and disseminated.”

About the American Epilepsy Society

Founded in 1946, the American Epilepsy Society (AES) is a medical and scientific society whose members are dedicated to advancing research and education for preventing, treating and curing epilepsy. AES is an inclusive global forum where professionals from academia, private practice, not-for-profit, government and industry can learn, share and grow to eradicate epilepsy and its consequences.

For more information, visit the American Epilepsy Society online at aesnet.org. Join the AES social conversation today by following @AmEpilepsySoc on Twitter and use the hashtag #AES2020.

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