

## CANADIAN PAEDIATRIC SURVEILLANCE PROGRAM

# Study examines sudden unexpected death in epilepsy

Sudden unexpected death in epilepsy, or SUDEP, is a potentially avoidable cause of death in children that has not been adequately explored through research. A new Canadian Paediatric Surveillance Program (CPSP) study aims to better understand children at risk of SUDEP so that they can be better identified and protected.

Many of these deaths may be a result of seizures or co-morbid conditions, but some deaths in children with epilepsy remain unexplained.

For this study, SUDEP is defined as the sudden, unexpected death in someone younger than 18 years of age: with epilepsy (defined as >1 unprovoked seizure); with or without evidence of a recent seizure; without documented status epilepticus; and without trauma.

Ideally to meet strict criteria for SUDEP, a post mortem examination must be completed and demonstrate no anatomical or toxicological cause of death. However, given the low rates of autopsy, researchers use the term 'probable SUDEP' when all criteria are met but when an autopsy has not been performed.

In adults, the annual incidence of SUDEP is estimated to be 1 per 1,000 people with epilepsy; for children, limited literature suggests 0.2-0.4 per 1,000 cases per year

but researchers worry this may be an underestimate.

"Recognition of SUDEP is a significant barrier to accurate statistics. Not infrequently, a child with epilepsy will die and an autopsy will not be performed resulting in the death being attributed to

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Dr. Elizabeth Donner

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another cause without sufficient supporting evidence. These cases may meet criteria for SUDEP, but are not recognized as such," said principal investigator Dr. Elizabeth Donner, Associate Professor of Paediatrics (Neurology), at the Hospital for Sick Children.

Lack of research on childhood SUDEP has contributed to a lack of understanding in the medical community, and may even keep at risk patients from accessing appropriate care.

For example, said Dr. Donner, her research group conducted a previous one-time survey of all CPSP participants in August 2011, to evaluate knowledge of SUDEP. Among paediatricians who reported caring for children with epilepsy, only 56% had prior knowledge that children with epilepsy are at increased risk of sudden unexplained death; only 33% were aware of the term SUDEP.

"We know that many children receive their epilepsy care from paediatricians. It is important that these front-line physicians know about SUDEP and understand how to reduce the risk," said Dr. Donner.

Through this study, investigators hope to establish an updated estimate of the number of Canadian cases as well as the number of autopsies conducted in deaths of children with epilepsy. They also hope their research will help to identify characteristics of children who are most at risk for SUDEP.

"We are so grateful to the CPSP for the opportunity to identify SUDEP deaths in children. SUDEP is a potentially avoidable cause of death in children. By learning more, I believe we will be able to develop targeted preventative strategies aimed at saving lives." said Dr. Donner.

*This study runs from January 2014 to December 2015. For more information on this or other CPSP studies, visit [www.cpsp.cps.ca](http://www.cpsp.cps.ca).* 🌟