



Survey

Sudden unexplained death in children with epilepsy

Paediatric sudden unexplained death in epilepsy (SUDEP) refers to the sudden unexpected death in a patient less than 19 years of age:

- with epilepsy (defined as >1 unprovoked seizure)
- with or without evidence of a recent seizure
- without documented status epilepticus
- without structural or toxicological cause being found at autopsy AND
- without trauma.

Children with epilepsy are at an increased risk of SUDEP, and information regarding the frequency in the paediatric population is lacking. One study found that up to 34% of sudden deaths in children under the age of 20 were associated with epilepsy.

The purpose of this one-time survey is to increase awareness of SUDEP among Canadian paediatricians and identify the frequency of SUDEP in children and youth.

Your contribution is greatly appreciated.

1. Were you familiar with the term Sudden Unexplained Death in Epilepsy (SUDEP)? Yes ___ No ___
2. Were you aware that children with epilepsy are at an increased risk of sudden unexplained death (SUDEP) compared to children without epilepsy? Yes ___ No ___
3. Over the past 24 months, have you seen children/youth under the age of 19 years with epilepsy? Yes ___ No ___

If the answer is no, we thank you for participating in this survey.

If yes, how many? <5 ___ 5-10 ___ 11-20 ___ 21-50 ___ 51-100 ___ >100 ___

4. Over the past 24 months, have you been involved with any children who may have met the criteria for SUDEP?
Yes ___ No ___

If the answer is no, we thank you for participating in this survey.

If yes, how many? ___ For each case, please complete this part of the survey (photocopies can be used):

- Were you the treating physician? Yes ___ No ___
- Specify age and sex of patient: _____ (age) M ___ F ___
- Was the event witnessed? Yes ___ No ___ Unknown ___

If yes, describe event: _____

- Was there evidence of a seizure immediately prior to death? Yes ___ No ___ Unknown ___

If yes, specify evidence: Seizure witnessed or heard ___ Tongue bite ___

Vomit at scene of death ___ Other _____

- Was a coroner or medical examiner involved? Yes ___ No ___ Unknown ___

- Was an autopsy performed? Yes ___ No ___ Unknown ___

If yes, specify relevant findings: _____

Please return this survey with your monthly reporting form.

Thank you for your participation.

08/2011