
You are invited to take part in a research study funded by the Child Neurology Foundation and the Ontario Brain Institute about the knowledge and practices of healthcare providers treating children with epilepsy regarding the risk of sudden unexpected death.

If you consent, you will participate in two study components approximately 6 months apart.

- Now : 5 minute survey with an optional educational video at the end.
- 6 months from now: 5 minute survey.

Invitations to participate in this study are disseminated by the Child Neurology Society. Member contact information is not shared with the research team, and no identifying information is collected. At the start of both surveys, you will create a unique participant code. The risk of identification is very low. You will be asked for 4 pieces of information:

- First letter of your last name
- First letter of your mother's maiden name
- Last four digits of your cell phone number
- Day of the month in which you were born

Taking part in this study is voluntary. You do not have to complete both components of this study and you can withdraw at any time. Your responses will be kept strictly confidential. There are no known risks or discomforts associated with this study. Individual benefit includes learning about an important topic related to epilepsy. Benefits to society include greater understanding of the current practices of neurologists regarding epilepsy. If you have questions about this study, please contact Dr. Elizabeth Donner at 416-813-7037 or email elizabeth.donner@sickkids.ca. If you have any questions about your rights as a participant in this study, contact the Hospital for Sick Children Research Ethics Manager at 416-813-5718.

Please feel free to print a copy of this consent page to keep for your records.

Clicking the "Next Page" button below indicates your consent to participate in this study.

No identifying information or contact information is collected as part of this study. To anonymously link your response to this survey with the follow-up survey occurring in about 6 months, please enter the following 4 pieces of information to create a self-generated code.

First letter of your last name (last initial):

- A
- B
- C
- D
- E
- F
- G
- H
- I
- J
- K
- L
- M
- N
- O
- P
- Q
- R
- S
- T
- U
- V
- W
- X
- Y
- Z

First letter of your mother's maiden name:

- A
- B
- C
- D
- E
- F
- G
- H
- I
- J
- K
- L
- M
- N
- O
- P
- Q
- R
- S
- T
- U
- V
- W
- X
- Y
- Z

Last 4 digits of your cell phone number:

Day of the month you were born (e.g. 24):

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- 31

The following 4 questions assess for study eligibility. If you indicate "no" to any of these questions, the survey will end after a message confirming your response.

Are you a healthcare provider?

- Yes
 No

Do you treat patients for epilepsy?

- Yes
 No

Do you devote at least 5% of your time to clinical care?

- Yes
 No

Have you treated at least one patient for epilepsy in the past 6 months?

- Yes
 No

Please answer the following questions

In the past 6 months, approximately how many patients did you treat for epilepsy?

- < 10
 11-25
 26-50
 51-100
 >100

What kind of healthcare provider are you?

- Neurologist
 Pediatrician
 Resident or Fellow
 Advanced Practice Nurse
 Registered Nurse
 Other Physician
 Other

What population do you treat in your practice?

- Pediatric
 Adult
 Both

Please specify what type of physician you are

Please specify what type of healthcare provider you are

Did you complete additional subspecialty training in epilepsy or neurophysiology?

- Yes
 No

How many years have you been in independent, unsupervised practice (e.g. years in practice excluding training)?

- 0 (currently in residency or fellowship)
 < 5
 5-9
 10-14
 15-20
 >20

Do you practice in an academic, university-affiliated institution?

- Yes, Full time
 Yes, Part time
 No

Where do you practice?

- United States
 Canada
 UK
 Elsewhere in Western Europe
 Central and Eastern Europe
 Asia
 Africa
 Middle East
 Mexico, Caribbean, Central America, or South America
 Oceania

Does your income relate to volume of care delivered?

- Yes
 No

Please answer the following questions

Were you aware that patients with epilepsy are at a higher risk of sudden death than those without epilepsy?

- Yes
 No

Prior to today, had you heard of the term "Sudden Unexpected Death in Epilepsy (SUDEP)"?

- Yes
 No

Approximately, what proportion of your patients with epilepsy or their families do you talk to about the increased risk of sudden death (SUDEP)?

- All or almost all (>90%)
 Most (50-90%)
 Some (10-49%)
 Few (1-9%)
 None (0%)

What are the main reasons you never talk about SUDEP with patients/families?

Do you discuss the risk of SUDEP with your pediatric patients?

- Always
 Sometimes
 Never

From approximately what developmental age in years do you include them in the conversation?

What other factors do you consider when choosing to discuss SUDEP with your pediatric patient?

- Parental preference
 Level of risk
 History of adherence
 Patient's mental well-being
 Parent well-being
 Other

Please describe

To your knowledge, have you ever lost a patient to SUDEP?

- Yes
 No
 Not sure

How many patients have you lost to SUDEP in the past 24 months?

What is the approximate annual incidence of SUDEP in children with epilepsy?

- 1 in 100
 1 in 1000
 1 in 5000
 1 in 10,000
 1 in 15,000
 1 in 50,000
 Not Sure

What is the approximate annual incidence of SUDEP in adults with epilepsy?

- 1 in 100
- 1 in 1000
- 1 in 5000
- 1 in 10,000
- 1 in 15,000
- 1 in 50,000
- Not Sure

What is the most common seizure/epilepsy-related cause of death?

- Status Epilepticus
- Aspiration
- SUDEP
- Trauma or drowning
- Not sure

Which of the following are associated with risk of SUDEP?

Please check all that apply

- History of generalized tonic-clonic seizure
- Specific anticonvulsant drugs
- Frequency of generalized tonic-clonic seizures
- History of nocturnal seizures
- History of Status Epilepticus
- Sleep environment
- Adult onset epilepsy
- Not sure

On April 23, 2017, the American Academy of Neurology and American Epilepsy Society released clinical practice guidelines on SUDEP. Have you read these guidelines?

- Yes
- No

How do the following patient and family characteristics affect your likelihood of talking about SUDEP?

	Decrease likelihood	No effect	Increase likelihood
I consider the patient to be at high risk of SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of poor compliance with AED therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient has intractable seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient or family are generally anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient has generalized tonic-clonic seizures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient is a surgical candidate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient has symptomatic epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient or family have difficulty coping with epilepsy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there a routine time at which you are most likely to talk about SUDEP?
Please check all that apply

- Time of diagnosis
- First follow-up appointment after diagnosis
- When seizures become difficult to treat
- Spontaneously during a routine visit
- If the patient or family asks
- There is no general pattern
- Other

Please describe

Are there other factors you consider when deciding whether or not to talk about SUDEP?

- Yes
- No

Please describe

Please indicate the degree to which you agree or disagree with the following

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
SUDEP can be prevented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking about SUDEP can improve the doctor-patient relationship	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talking about SUDEP with the patient/family can provoke excessive anxiety or worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generally the benefits of talking about SUDEP with a patient/family outweigh potential harms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthcare providers have an ethical obligation to talk about SUDEP with patients/families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For many patients, there are opportunities to reduce the risk of SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are no significant consequences to withholding information about SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There isn't enough time to talk about SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My patients want to know about SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know enough about SUDEP to talk about it with patients/families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you attend the Child Neurology Foundation Symposium on SUDEP at the Child Neurology Society meeting on October 7, 2017?

- Yes
 No

Are you interested in watching a short educational video about SUDEP?

- Yes, I have time to watch it now
 Yes, but not right now
 No

To watch the video at a more convenient time, click the "Save & Return Later" button at the bottom of this page.



To watch the SUDEP video, please visit https://youtu.be/CC4YU_Oi_gU

Did you watch the video to completion?

- Yes
- No

Please indicate the degree to which you agree or disagree with the following

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
I learned something new	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am going to discuss this topic with my colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This video will change my clinical practice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
