

This is the second component of a two-part study. The first component was emailed last fall and included brief survey with an optional short educational video. This is the follow-up component, which consists of a short survey, requiring approximately 5 minutes to complete. Please complete this survey if you participated in the first survey sent last fall. If you don't remember if you completed the last survey, please complete this one.

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. To link individual responses from the two components together, at the start of both surveys, you will create a unique participant code. The risk of identification is 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 during either component, 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](mailto: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 survey 6 months ago, 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

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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

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Last 4 digits of your cell phone number:

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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**

What kind of healthcare provider are you?

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

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Please specify what type of physician you are

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Please specify what type of healthcare provider you are

\_\_\_\_\_

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

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

**Please answer the following questions about your practice of talking about risks of epilepsy with epilepsy patients and their families**

Approximately, what proportion of your patients with epilepsy or their families do you talk to about seizure safety?

- 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 seizure safety with epilepsy patients/families?

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Approximately, what proportion of your patients with epilepsy or their families do you talk to about safety when bathing, showering, or swimming?

- 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 water safety with epilepsy patients/families?

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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?

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Do you believe children with a developmental age of 12 years or older should be informed of the risk of SUDEP?

- Yes
- No

In the past 6 months, have you changed your practice of discussing SUDEP with your patients with epilepsy or their families?

- Yes
- No

**Please select the degree to which you agree or disagree with the following:**

**In the past 6 months, I changed my practice of talking to families about SUDEP because...**

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
I know more about SUDEP now	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel more comfortable talking about SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt guilty not talking about SUDEP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What other factors motivated you to change your practice?

- I participated in this study
- I watched the SUDEP education video at the end of the last survey
- I read the AAN practice guidelines on SUDEP
- I attended the 2017 Child Neurology Foundation SUDEP Symposium at the Child Neurology Society meeting
- I lost a patient to SUDEP
- Other

Please describe

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**How have you changed your SUDEP discussion practice?**

	Increased	No change	Decreased
Proportion of epilepsy patients/families I talk to about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Amount of information I share about SUDEP when I talk about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are there other ways you've changed SUDEP discussion practice?

- When I typically talk about it
- How I talk about it
- Whether I include the pediatric patient in the conversation
- Who I select to talk to about SUDEP
- The recommendations I make about SUDEP
- Other
- I have not changed practice in other ways

Please describe

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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

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In the past 6 months, have you sought additional information about SUDEP?

- Yes
- No

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Where have you sought additional information?

- Peer-reviewed journal articles
- Academic conference
- Colleague
- Online resource
- Other

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Which other sources have you consulted?

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**Please answer the following questions**

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

### 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

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

- Yes
- No

Please describe

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**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"/>

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When talking to a patient/family about SUDEP, have you personally noted that the discussion provoked excessive anxiety or worry?

- Yes  
 No

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Please describe

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With patients/families with a history of nonadherence to treatment, have you noted that discussion of SUDEP improved their treatment adherence?

- Yes  
 No  
 Not sure  
 I don't discuss SUDEP with patients/families who have historically been nonadherent  
 I don't have epilepsy patients/families with history of nonadherence

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With patients/families who are resistant to starting therapy, have you noted that discussion of SUDEP improved their likelihood of starting therapy?

- Yes  
 No  
 Not sure  
 I don't discuss SUDEP with patients who are resistant to starting therapy  
 I don't have epilepsy patients/families who are resistant to starting therapy