

STUDY: SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP): LIVING WITH THE KNOWLEDGE [HHS REB PROJECT #15-401]

Neurologist Dr Rajesh RamachandranNair and his team at Hamilton Health Sciences are working with SUDEP Aware to understand the range of patients' and their caregivers' views on how SUDEP awareness has impacted various areas of their lives, including health, career, finances, social life, etc.

Aims:

- To understand the impact of SUDEP awareness on adult patients with epilepsy;
- To understand the impact of SUDEP awareness on primary caregivers of patients with epilepsy;
- To understand the emotional burden of participants, for contribution to the development of effective support systems.

Method:

- 1) To interview participants diagnosed with epilepsy by a neurologist who have known about SUDEP for at least 12 months;
- 2) To interview primary caregivers of patients with epilepsy who have known about SUDEP for at least 12 months.

How YOU can help:

If you were diagnosed with epilepsy or are a caregiver/close relative (spouse, sibling, parent, child) of someone with epilepsy, and have known about SUDEP for at least 12 months, your participation in this study would be very valuable and appreciated.

What YOU need to know:

All interviews will be:

- 45-60 minutes long, one-on-one with an experienced interviewer;
- conducted in English, over the telephone;
- recorded.

Participants will be rewarded with a \$25 gift card, as a token of appreciation for their time commitment.

For more information, or to enroll, please contact:

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