

**STUDY: SUDDEN UNEXPECTED DEATH IN EPILEPSY (SUDEP): IS THERE AN OPTIMAL WAY TO INFORM PATIENTS? [HHS REB PROJECT #:12-230]**

Neurologist Dr Rajesh RamachandranNair and his team at Hamilton Health Sciences have received a grant from the Hamilton Academic Health Science Organization to investigate whether there is an optimal way to inform patients about SUDEP.

**Aims:** are to

- Obtain an understanding of the range of patients' views with regards to whether, and how, to approach the issue of SUDEP with patients;
- Clarify the optimal timing and manner/method for information delivery;
- Learn, from the patients, effective counselling strategies capable of minimising emotional burden.

**Method:**

- 1) to conduct interviews with patients who are diagnosed to have epilepsy by a neurologist;
- 2) to conduct interviews with older (>16 years) close relatives (spouse, parent, sibling or child) of a person aged >16 years who died due to presumed SUDEP.

**How you can help:**

If you are a (>16 years old) patient with epilepsy or an individual who lost a close relative (spouse, sibling, parent, child) >16 years old due to presumed SUDEP, the investigators would very much value your participation in this study.

**What you need to know:**

For patients: we offer focus group interviews, which are in groups of 5-10 patients with epilepsy, with an experienced interviewer, for at least two hours.

For relatives: we offer one-to-one interviews, with an experienced interviewer, for one hour.

All interviews (focus group and one-to-one) will be:

- conducted in English;
- recorded;
- **in HAMILTON, Ontario** (at McMaster). Or, if you prefer, one-to-one interviews can be done over the telephone.

As a token of appreciation, interviewees will be reimbursed their gas expense and parking fee. Also, \$50 per participant towards child care (if required) and a \$25 gift card. If you do not have driving privilege due to epilepsy, the person accompanying you will be given a gift card worth \$25.

**For further information, and study recruitment, please contact:**

Tamzin Jeffs at SUDEP Aware

Suite 350, 283 Danforth Avenue, Toronto, Ontario M4K 1N2

Tel: (416) 556-8770

Email: [tcjeffs@sudepaware.org](mailto:tcjeffs@sudepaware.org)

Web: [www.sudepaware.org](http://www.sudepaware.org)