**SUDEP studies**

The EpiNet Study group is undertaking two major international studies of sudden unexpected death in epilepsy (SUDEP).

We hope to learn more about risk factors (and factors that reduce the risk), so that we can modify these to keep people with epilepsy alive.

We have set up an international registry to collect information about the circumstances of a person's death. Where possible, we would like to interview relatives to learn more about the living arrangements and what patients were doing when they died. Any physician is welcome to contribute patient data to this registry, if they learn of a patient who has died.

We are using this to determine the incidence of SUDEP in New Zealand. We believe that we can identify every person who dies of SUDEP in New Zealand. This study is a sub-study within the larger SUDEP registry. It would be possible to use this platform to determine the incidence of SUDEP in other countries, too, and to track the incidence over time.

The second study is a Case control study. The study is being performed prospectively. We hope to identify 200 cases of SUDEP. Patients who die from SUDEP need to have been alive at the beginning of the study (Jan 01, 2020). We want to get multiple centres involved. At the outset, each centre will need to identify a cohort from which cases and controls will be identified. The nature of the cohort may vary from centre to centre, but it needs to be defined at the outset, and cases and controls must come from this same cohort. Relatives of cases will be interviewed, and medical records reviewed to learn as much as possible about the circumstances of death, and about the individual's epilepsy and its treatment, and lifestyle issues. How many of them, for instance, were sleeping on their own when they died, and how many were using seizure detection devices.

For each case we will also identify 3 age and sex-matched controls who will also be interviewed. Control subjects will be randomly selected from all potential controls in the same cohort. Finally, we will interview one proxy control, who will be a relative of one of the control subjects with epilepsy.

New people with epilepsy can join the cohort during the course of the study.

If you would like more information about either of these studies, or you would like to enrol patients, please contact us at: Epinetadmin@adhb.govt.nz