



RESPONSE TO PETITION

Prepare in English and French marking 'Original Text' or 'Translation'

PETITION No.: **421-03372**

BY: **Ms. DABRUSIN (TORONTO-DANFORTH)**

DATE: **APRIL 10, 2019**

PRINT NAME OF SIGNATORY: **PAM DAMOFF**

Response by the Minister of Health

SIGNATURE

Minister or Parliamentary Secretary

SUBJECT

Sudden Unexpected Death in Epilepsy

ORIGINAL TEXT

REPLY

The Public Health Agency of Canada, in collaboration with provinces and territories, collects, analyses and reports data on the prevalence, incidence and all-cause mortality associated with epilepsy from the *Canadian Chronic Disease Surveillance System (CCDSS)*. These data are available by sex, age group, province and territory, and over time (currently from 2005–2006 to 2015–2016). Data are collected using a standardized process across jurisdictions. More information on the CCDSS methods to collect epilepsy data is available here: (https://infobase.phac-aspc.gc.ca/ccdss-scsmc/data-tool/publication/CCDSS_Case_Definitions_DataCubes_v2017.xlsx). Guidance on the epilepsy case definition, its implementation, and data interpretation are provided by the *CCDSS Neurological Conditions Working Group*, comprised of provincial government representatives, researchers and clinicians, including Nathalie Jetté – Chair of the International League Against Epilepsy for North America.

According to the most recent CCDSS data (<https://infobase.phac-aspc.gc.ca/ccdss-scsmc/data-tool/>), and as reported in the petition, 0.9% of Canadians aged 1 year and older had diagnosed epilepsy in 2015–2016 (0.6% with active epilepsy). During the same year, there were 56 new cases of epilepsy diagnosed per 100,000 Canadians aged 1 year and older.

PHAC does not capture information on sudden unexpected death in epilepsy (SUDEP). The number of deaths due to epilepsy is low according to the Canadian Vital Statistics Database (CVSD) at Statistics Canada with 249 deaths in 2016

(<https://www150.statcan.gc.ca/t1/tbl1/en/cv.action?pid=1310014501>). This may underestimate the overall mortality burden associated with the disease and its comorbidities as according to CCDSS data (controlling for differences in the age distribution), the risk of dying from any cause in 2015–2016 was 3.5 times higher among Canadians with epilepsy than among Canadians without epilepsy.

The CVSD includes cause of death information as reported on the medical certificates of cause of death received from the provincial and territorial Vital Statistics Offices across Canada. Immediate cause of death as well as antecedent causes, including the underlying cause of death, are included on the death certificate as detailed by the certifier (e.g. physician, coroner, medical examiner, or nurse practitioner). The cause of death information collected and compiled in the CVSD is coded to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10), a classification maintained by the World Health Organization.

SUDEP is not uniquely identified in ICD-10. Furthermore, SUDEP is not consistently reported by provincial and territorial certifiers of medical certificates of cause of death. In order to overcome these limitations, Statistics Canada will be implementing an approach for identifying and extracting SUDEP cases reported within the CVSD. This approach will be used for 2018 deaths and retrospectively applied to reports of SUDEP for the 2016 and 2017 data.