

30 April 2021

Auckland DHB
Chief Executive's Office
Level 12
Building 1
Auckland City Hospital
PO Box 92189
Victoria Street West
Auckland 1142
Ph: (09) 630-9943 ext: 22342
Email: ailsac@adhb.govt.nz

Re: Official Information Act request – Data on spinocerebellar ataxia

I refer to your Official Information Act request dated 8 April 2021, and related transfer from Waitemata DHB, requesting the following information:

- 1. Percentage of the population suffering from the medical condition spinocerebellar ataxia**
Response: 4/100,000. This figure is not from actual data collated by Auckland DHB but from a research database.
- 2. Probability of such persons requiring health services costing in excess of \$41000per annum**
- 3. What is the rate of progressive deterioration of health observed in such patients over a 5 year period**
- 4. Percentage of patients who become entirely dependent on health care service provider for their routine care over a 5 year period**
- 5. Mortality rate of such patients- at the age of 60, 70, 80 & 90**

The information related to questions 2-4 does not exist. Neither Waitemata nor Auckland DHB collect the data you are seeking. You may find guidance in the international medical literature, but it is important to understand that this is a highly individual disorder, so each particular patient has their own degree of disability, disease progression and needs.

You are entitled to seek a review of the response by the Ombudsman under section 28(3) of the Official Information Act. Information about how to make a complaint is available at www.ombudsman.parliament.nz or freephone 0800 802 602.

Please note that this response, or an edited version of this response, may be published on the Auckland DHB website.

Yours faithfully



Ailsa Claire, OBE
Chief Executive of Te Toka Tumai (Auckland District Health Board)