



West Coast District Health Board

Te Poari Hauora a Rohe o Tai Poutini

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31 August 2018

Jessica Gibson

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[REDACTED]

[REDACTED] [REDACTED]

[REDACTED]

RE Official information request WCDHB 9183

We refer to your email dated 7 August 2018 requesting the following information under the Official Information Act from West Coast DHB regarding Long QT Syndrome. Specifically:

- 1. Do you have any specific diagnosis data on people living with Long QT syndrome? If so:**
 - a. Of these people, how many are categorised under different variants of Long QT e.g. LQT-1, LQT-2**
 - b. How many are male/ female?**
 - c. What is their age?**
- 2. How many people have died from sudden cardiac arrests over the last year?**
 - a. Of these deaths, how many were under the age of 40?**
 - b. How many of these deaths were unexplained?**
 - c. How many had been diagnosed with Long QT syndrome?**
- 3. Does the DHB offer free genetic testing for family members of someone living with Long QT?**

Response:

West Coast DHB does not hold any central record of the number of people who may be living within the West Coast community who may have Long QT syndrome; nor how many deaths there have been in the community of people who have died from sudden cardiac arrest - either with or without having Long QT syndrome. In regards to causes of deaths of people in the community, the Department of Internal Affairs may possibly hold this information if it is recorded on the register of death certificates that come under their auspices.

We are able to supply you with information about people who have come into our hospital services over the past year, however.

During the year 1 July 2017 to 30 June 2018, there was just one person (female) aged over 40 who was admitted to our hospitals who was noted as having Long QT syndrome – but this was a comorbidity to an admission for an unrelated diagnosis, rather than being a principle reason for admission in itself.

There were nine people who died in our hospital wards and Emergency Department during the year 1 July 2017 to 30 June 2018 after having had a sudden cardiac arrest. None of these people was aged under the age of 40, and none of them were noted as having had Long QT syndrome. Three of these cases were referred to the coroner for review.

West Coast patients who are referred for genetic testing are referred to the Clinical Genetics Service based in Christchurch. After counselling and an ECG, if appropriate, genetic testing is offered to family members via the Clinical Genetics Service free of charge.

I trust that this satisfies your interest in this matter.

Please note that this response, or an edited version of this response, may be published on the West Coast DHB website ten working days after your receipt of this response.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Carolyn Gullery', with a long, sweeping horizontal stroke extending to the right.

Carolyn Gullery
Executive Director
Planning, Funding & Decision Support