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31 August 2018

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RE Official information request CDHB 9913

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

1. Do you have any specific diagnosis data on people living with Long QT syndrome?

There are currently 18 people who are under follow up in the Canterbury DHB Cardiology Service with a diagnosis of primary Long QT Syndrome.

a. Of these people, how many are categorised under different variants of Long QT e.g. LQT-1, LQT-2

We are declining a response to this question under section 18(g) of the Official Information Act i.e. Canterbury DHB does not hold the data to answer this question.

b. How many are male/ female?

There are 11 females and seven males.

c. What is their age?

The ages range from 13 to 63 and the average age is 40.

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?

We are declining a response to these questions under section 18(g) of the Official Information Act i.e. Canterbury DHB does not hold the data to answer these questions.

3. Does the DHB offer free genetic testing for family members of someone living with Long QT?

After counselling and an ECG, if appropriate, genetic testing is offered to family members via the Clinical Genetics Service based in Christchurch 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 Canterbury 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 underline.

Carolyn Gullery
Executive Director
Planning, Funding & Decision Support