

## Freedom of Information (Scotland) Act 2002

|                      |   |                    |  |                   |                   |
|----------------------|---|--------------------|--|-------------------|-------------------|
| <b>DATE RECEIVED</b> | <b>02/02/2022</b>                               | <b>SUBJECT</b>     | <b>Neuromuscular Patients and Staffing</b> |                   |                   |
| <b>PASSED TO</b>     | <b>Specialist Nurses<br/>Information<br/>HR</b> | <b>DATE PASSED</b> | <b>03/02/2022</b>                          | <b>RESPOND BY</b> | <b>23/02/2022</b> |
| <b>CATEGORY</b>      | <b>Scottish Parliament</b>                      | <b>FoI NUMBER</b>  | <b>2022-050</b>                            |                   |                   |

Question/s to be Answered

I would be grateful if you could provide me with the following information and that this is treated as a freedom of information request:

- 1) Number of patients with a neuromuscular condition in your area broken down by a) age and b) type of condition

| <b>Condition</b>                                 | <b>Total live patients<br/>resident in Shetland<br/>with Primary Diagnosis<br/>during a Hospital Stay</b> |
|--|---|
| Congenital Myopathies                            | 1   |
| Mitochondrial Myopathy, Not Elsewhere Classified | 2   |
| Muscular Dystrophy                               | 2   |
| Myotonic Disorders                               | 2   |
| Other Primary Disorders Of Muscles               | 1   |
| Primary Disorder Of Muscle, Unspecified          | 1   |
| <b>Total</b>                                     | <b>9</b>  |

- 2) A) average and b) longest waiting time for a patient with a neuromuscular condition to access a specialist muscle clinic appointment, broken down by year since 2017

NHS Shetland patients are seen in NHS Grampian. Our numbers will be included in their response.

- 3) A) Average and b) longest waiting time for a patient with a neuromuscular condition to access a physiotherapy appointment broken down by year since 2017

| <b>Year</b>  | <b>Total New Referrals Seen</b> | <b>Mean Weeks Wait</b> | <b>Max Weeks Wait</b> |
|--------------|---------------------------------|------------------------|-----------------------|
| 2017         | 1                               | 10.6                   | 10.6                  |
| 2018         | 2                               | 1.6                    | 2.6                   |
| 2019         | 1                               | 0.0                    | 0.0                   |
| <b>Total</b> | <b>4</b>                        | <b>3.5</b>             | <b>10.6</b>           |

Please note that above waits were not necessarily referred for treatment to support them with a NM condition, nor does it indicate that they had a NM diagnosis at the time of referral/appointment.

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- 4) Number of patients on the waiting list for a specialist appointment as referred to above, and the a) average and b) longest time they have been waiting, broken down by year since 2017

NHS Shetland patients are seen in NHS Grampian. Our numbers will be included in their response.

- 5) Number of neuromuscular staff, broken down by the different healthcare professionals (i.e. a neuromuscular consultant, neuromuscular physiotherapist) and the hospital they work in

1, Nurse, Gilbert Bain Hospital

- 6) Number of neuromuscular psychologists

0

- 7) What the expected a) weekly and b) monthly allocated time neuromuscular psychologists give to individual patients

0

- 8) Number of vacancies for neuromuscular staff and an average on how long these vacancies have been open, broken down by year since 2017 0

### CLARIFICATION Request to Requester:

I have been asked to seek a clarification request on this freedom of information request on the grounds that neuromuscular condition is very wide. Could you narrow this down please?

### CLARIFICATION Response from Requester

We would consider every condition on this list as a neuromuscular condition:

<https://www.musculardystrophyuk.org/conditions>