

6 November 2023

Rett Syndrome

Under the *Freedom of Information Act*, I would like to request the information as detailed below.

For educational purposes:

1. Do you have any person on your records with Rett Syndrome, either living or deceased? Yes/No
2. If yes, how many living/deceased?
3. How many are over 18 years of age, how many under 18 years of age?
4. How many are in state schools/maintained schools/residential schools?
5. Which schools do they attend?

For Children's/Adult services, inc. Early Years/Disabilities team:

1. Do you have any person on your records with Rett Syndrome, either living or deceased? Yes/No
2. If yes, how many living/deceased?
3. How many are over 18 years of age, how many under 18 years of age?
4. How many are in residential care?
5. How many are under the care of the local authority?
6. Which care providers are involved?

Neurology

The Trust's Specialist Nurse for Neuromuscular Services has confirmed that they do not have any patients in Adult Neurology with Rett syndrome as it is a condition associated with Paediatrics.

Paediatrics / RBHSC

Paediatrics do not have any children on a waiting list for Rett syndrome.

Psychology Service

Information not held in any way that could be accessed without a review of individual patient files, which would take more than 18 hours.

6 November 2023

Belfast Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

Children with Disability/Regional Integrated Support for Education NI (RISE)

To provide this information would require a trawl through over 800 patient records to identify this specific diagnosis. The information requested is not recorded centrally and does not form part of any return made by Belfast Trust. Therefore, the service are not able to answer any part of this FOI request, as to do so would take more than 18 hours.

Early Years & Early Intervention Services

The Early Years and Early Intervention Services Team do not hold any cases and so cannot provide any information. The Sponsored Daycare Team have no recollection of ever having placed a child and the three Trust Sure Starts have not received a referral regarding a child with this syndrome.

Children's Gateway Team

The Gateway Team do not have any service users with this diagnosis.

Family Support and Safeguarding Services

This service has no service users with this diagnosis.

Adult Community & Older Peoples Services / Physical & Sensory Disability

The service does not have systems in place to identify condition specific cases and so to retrieve current service users who may be living with the condition or those who are deceased would take longer than 18 hours to retrieve.

Again, Belfast Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12.

Intellectual Disability

The service is not aware of anyone with this diagnosis, nor do they capture information concerning this.

6 November 2023

Genetics

On the clinical system, with some data cleansing, Genetics can find 46 patients coded with Rett Syndrome with dates of birth ranging from 1977 to 2020 (some younger ones will not have been diagnosed yet). Therefore, that equates to just over 1 per year and, accounting for incomplete diagnosis and possible non-coding, seems consistent with a real incidence of 1/10K girls.

The Genetics cases identified 46 patients:

Of the patients we had info for:

32 patients are living and 13 are deceased
15 patients are less than 18 years old, 29 patients aged 18 and over (as at 09/10/2023 or age at death)

There were 3 patients with no Health & Care Number information, including one from outside Northern Ireland, so Belfast Trust cannot provide information concerning these.

This data is almost certain to be incomplete; there may be patients with a positive diagnosis who have not been coded.