

John Morley (Public Health Wales)

From: FOI (Public Health Wales)
Subject: FW: Freedom of Information - MG

I have checked with our public health teams and can now confirm that Public Health Wales does not collect information on Myasthenia Gravis, therefore we do not hold this information. As previously mentioned the information you seek on Volume, Cost and Funding may be held by the individual Health Boards, who can be contacted individually at this website.

<http://www.wales.nhs.uk/ourservices/directory>

There also may be a central collection of information for the Welsh Government via the all Wales Informatics Service who can be contacted here.

<http://www.wales.nhs.uk/ourservices/directory/NationalProgrammesandServices/422>

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of the decision, you should write to the Corporate Complaints Manager, Public Health Wales NHS Trust, Unit 1 Charnwood Court, Heol Billingsley, Parc Nantgarw Cardiff, CF15 7QZ.

If you are not content with the outcome of your complaint or review, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Trust. The Information Commissioner can be contacted at:

Information Commissioner for Wales
2nd Floor
Churchill House
Churchill Way
Cardiff
CF10 2HH
Telephone: 029 2067 8400
Email: wales@ico.org.uk

Kind regards

John

Ivor John Morley

Rheolwr Llyodraethu Gwybodaeth, Iechyd Cyhoeddus Cymru, Teml Heddwch ac Iechyd, Caerdydd CF10 3NW Information Governance Manager, Public Health Wales, Temple of Peace and Health, Cardiff CF10 3NW

WHTN: 1809 5723 (direct line)
Ffôn/Tel: 029 2040 2462 (indirect)
Symudol/Mobile 07794 331580

e-bost/ email i: john.morley@wales.nhs.uk

Rhyngwrwyd/Internet: www.iechydscyhoedduscymru.org / www.publichealthwales.org

Mewnwrwyd/Intranet: nww.publichealth.wales.nhs.uk

Twitter: @IechyddCyhoeddus / @Public Health Wales

Facebook: Iechyd Cyhoeddus Cymru / Public Health Wales

Rydym yn croesawu gohebiaeth yn y Gwmraeg neu'r Saesneg We welcome
correspondance in Welsh or English

-----Original Message-----

From: Elaine [<mailto:elaine.burgess2@googlemail.com>]

Sent: 23 December 2014 14:28

To: FOI (Public Health Wales)

Subject: Freedom of Information - MG

I would like to submit a request under the Freedom of Information Act.

Please could you provide information on the following:

Volume

- number of people in Wales who are recorded as being diagnosed with Myasthenia Gravis [MG] (where possible, please break down by Age, Gender and County location)
- the official estimate, if it exists, of the number of people with undiagnosed MG (where possible, please break down by Age, Gender and County location)
- number of thymectomies per year relating to MG (where possible, please break down by Age, Gender and County location)
- number of individuals prescribed drugs to control the symptoms of MG, including but not limited to Pyridostigmine and Azathioprine
- official rates of MG prevalence, present and historical where available

Cost

- cost of MG to the NHS each year.
- cost of a typical Thymectomy procedure, including after care (if this information does not exist, please provide as much relevant information as you have available including but not limited to details of average length of stay after a Thymectomy in both intensive care and ward based care and the average cost per night of care in each)
- cost of prescriptions to treat symptoms of MG (if this information is not available, please provide all details available, including but not limited to amount the NHS Wales spends per year on Pyridostigmine and Azathioprine [for MG purposes] and the number of individuals who are prescribed these drugs to control MG)

Funding

- amount of Government funding dedicated to MG research per year
- amount of Government funding dedicated to Motor Neurone Disease research per year
- amount of Government funding dedicated to Muscular Dystrophy research per year

Where possible, please return the information in excel where there is information to be broken down. Otherwise, standard email text will suffice where information is simply one figure with no data attached.

Happy to discuss any of the above if you require further clarity or you have any questions about my request.

Thanks

Elaine Burgess

Sent from my iPad