

Ref: FOI/GS/ID 5442

Please reply to:
FOI Administrator
Trust Management
Maidstone Hospital
Hermitage Lane
Maidstone
Kent
ME16 9QQ
Email: mtw-tr.foiadmin@nhs.net

16 May 2019

Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Worster Drought Syndrome.

You asked:

Worster Drought Syndrome is a rare/ultra-rare disease that in 2019, Orphanet estimates to have a European prevalence of 3.7 cases per 100,000 population¹.

There is not a specific ICD 10 code available to attribute to a WDS diagnosis, as a form of cerebral palsy (ICD10 G80). WDS is then included in the sub categories C80.8 (Other Cerebral Palsy) or C80.9 (Cerebral Palsy Unspecified)

- 1. A primary diagnosis of Worster Drought over the last 3 years*
- 2. Worster Drought prevalence (all ages) under your care*
- 3. No of patients diagnosed with Congenital suprabulbar palsy/paresis*
- 4. No of patients diagnosed with Congenital pseudobulbar palsy/paresis*
- 5. No of patients diagnosed with bilateral perisylvian polymicrogyria*
- 6. No of patients diagnosed with foix-chavany-marie syndrome*
- 7. How many patients have had a diagnosis of WDS which has been re coded: to what disease/ICD10 code?*
- 8. How many patients have been re coded to WDS*
- 9. Any specific specialities/services/pathways/recommendations provided for WDS patients*

Trust response:

After wide consultation with all paediatric consultants and Coding staff, we do not, to the best of our knowledge, have any children with this condition.