

Ref: FOI/GS/ID 7933

Please reply to:
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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 Epilepsy Treatment.

You asked: All questions are shown as received by the Trust.

In the last 12 months of available data:

1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.

1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

2a. How many patients have been treated with Epidyolex in a paediatric environment?

3a. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

Trust response:

Please note the following information: The Trust codes used do not exactly match what was requested. The codes used are referenced below.

Lennox-Gastaut syndrome: G40.4 Other generalized epilepsy and epileptic syndromes (this code is not specific for this syndrome but could encompass other epileptic syndromes as well) Dravet Syndrome: G40.3 Generalized idiopathic epilepsy and epileptic syndromes (this code is not specific for this syndrome but could also encompass other generalised idiopathic epileptic syndromes) Tuberous sclerosis complex: Q85.1 Tuberous sclerosis

Q3 – Patients are referred to the Trust from their GP. A list of these GP surgeries can be found below.

This data is for inpatients only as outpatients do not have a diagnosis code.

1a.

Requested Diagnosis	ICD-10 Code Description	Total Patients
Lennox-Gastaut syndrome	G404 Other generalized epilepsy and epileptic syndromes	6
Dravet Syndrome	G403 Generalized idiopathic epilepsy and epileptic syndromes	50
Tuberous Sclerosis Complex	Q851 Tuberous sclerosis	0

1b.

Requested Diagnosis	ICD-10 Code Description	Treated in Paediatrics
Lennox-Gastaut syndrome	G404 Other generalized epilepsy and epileptic syndromes	6
Dravet Syndrome	G403 Generalized idiopathic epilepsy and epileptic syndromes	17
Tuberous Sclerosis Complex	Q851 Tuberous sclerosis	0

2a. The Trust does not use Epidyolex.

3a.

Referral Organisation Name
ADUR HEALTH PARTNERSHIP
ALBION PLACE MEDICAL PRACTICE
AMHERST MEDICAL PRACTICE
BEACON SURGERY
BEARSTED
BEECHWOOD SURGERY
BLACKTHORN
BOROUGH GREEN MEDICAL PRACTICE
BREWER STREET
BUXTED MEDICAL CENTRE
EDENBRIDGE MED PRACTICE
GREENSANDS
GROSVENOR & ST JAMES MEDICAL CENTRE
HEATHFIELD SURGERY
HILDENBOROUGH MEDICAL GROUP
HOWELL SURGERY
IVY COURT SURGERY
KINGSWOOD SURGERY
LAMBTON ROAD MEDICAL PRACTICE
LAUNCESTON MEDICAL CENTRE
LINGFIELD SURGERY
LONSDALE MEDICAL CENTRE
MALLING HEALTH FOUR
MARDEN MEDICAL CENTRE
MATRIX MEDICAL PRACTICE
NULL

OLD SCHOOL SURGERY
ORCHARD END
QUEENHILL MEDICAL PRACTICE
SAXONBURY HOUSE SURGERY
SNODLAND MEDICAL PRACTICE
SPECTRUM HEALTH
SPELDHURST & GREGGSWOOD MEDICAL GROUP
ST JOHN'S MEDICAL PRACTICE
ST. JAMES'S MEDICAL CENTRE
THE ALBION SURGERY
THE COLLEGE PRACTICE
THE MEDICAL CENTRE GROUP
THE VINE MEDICAL CENTRE
THE WELLS MEDICAL PRACTICE
THORNHILLS MEDICAL PRACTICE
TONBRIDGE MEDICAL GROUP
WALLIS AVENUE
WARDERS MEDICAL CENTRE
WATERFIELD HOUSE SURGERY
WATERINGBURY
WEST MALLING GROUP PRACTICE
YALDING