Maidstone and Tunbridge Wells NHS Trust

Ref: FOI/GS/ID 7348

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

19 August 2022

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 the treatment of myelofibrosis.

You asked:
Q1. Does your trust treat myelofibrosis? If not, which other trust do you refer these patients to?
Q2.
a) Please provide the total number of patients treated in the last 6 months (or the latest 6 months data you have available) for myelofibrosis (ICD10 code D47.4).
b) How many of these patients were above age 65?
Q3. How many myelofibrosis patients were treated in the past 6 months with Ruxolitinib?
Q4.
a) How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
b) Of these patients, how many were treated in the past 6 months (or the latest 6 months data you have available) with:
I. Hydroxyurea
II. Fedratinib
III. Received No Treatment
Q5. Does your trust participate in any clinical trials for the treatment of myelofibrosis? If so, can you please provide the name of each trial along with the number of patients taking part.

Trust response:
Q1. We do treat very few cases of myelofibrosis at the Trust. We sometimes refer cases onto Kings or Guys but not very many
Q2.
a) Three patients treated between October 2021 and March 2022

b) All three patients were over the age of 65
Q3. The three patients treated were all treated with Ruxolitinib
Q4.
a) This information is not recorded electronically. It may be possible that this information has been entered into a patients record but in order to confirm this each patient record would need to be manually checked by a clinical staff member. The Trust has estimated that it will cost more than the appropriate limit to consider this part of your request. The appropriate limit is specified in regulations and represents the estimated cost of one person spending 3½ working days in determining whether the Trust holds the information, locating, retrieving and extracting the information. Under Section 12 of the Freedom of Information Act 2000 the Trust is not obliged to comply with this part of your request and we will not be processing this part of your request further.
b) This information is not recorded electronically. It may be possible that this information has been entered into a patients record but in order to confirm this each patient record would need to be manually checked by a clinical staff member. The Trust has estimated that it will cost more than the appropriate limit to consider this part of your request. The appropriate limit is specified in regulations and represents the estimated cost of one person spending 3½ working days in determining whether the Trust holds the information, locating, retrieving and extracting the information. Under Section 12 of the Freedom of Information Act 2000 the Trust is not obliged to comply with this part of your request and we will not be processing this part of your request further.
5. The only trial the Trust has is: "A Randomized Open-Label, Phase 3 Study to Evaluate Imetelstat (GRN163L) Versus Best Available Therapy (BAT) in Patients with Intermediate-2 or High-risk Myelofibrosis (MF) Refractory to Janus Kinase (JAK)-Inhibitor" (IRAS 1003434), which will be opening to recruitment shortly.