



FOI REF: 22/591

Tel: 0300 131 4500

Website: www.esht.nhs.uk

31st October 2022

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

I am writing to ask you for information about patients with C3 glomerulopathy (complement component 3 glomerulopathy; C3G).. This encompasses patients with dense deposit disease (DDD) and C3 glomerulonephritis (C3GN). Some of these patients could also be coded under the term membranoproliferative glomerulonephritis (MPGN), specifically MPGN type II.

East Sussex Healthcare NHS Trust do not provide renal services and so are unable to answer your questions. This service is delivered under University Hospitals Sussex NHS Foundation Trust.

You can contact them by email: UHSussex.foi@nhs.net or by post at:

Freedom of Information Office, C/O Company Secretary
University Hospitals Sussex NHS Foundation Trust
Worthing Hospital
Lyndhurst Rd,
Worthing BN11 2DH

I would be grateful if you could answer the questions in the table below:

Question	Response
I. How many adult patients (aged 18 or over) are currently under the care of your Trust/Service with C3 Glomerulopathy?	Not Applicable.
II. How many paediatric patients (aged 18 or under) are currently under the care of your Trust/Service with C3 Glomerulopathy?	Not Applicable.
III. How many patients are currently under the care of your Trust/Service whose C3 Glomerulopathy has recurred following a kidney transplantation?	Not Applicable.
IV. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have had a biopsy confirmation of disease?	Not Applicable.
V. In the last 3 years, how many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have been diagnosed with support from another Trust/service/pathologist for biopsy interpretation, but otherwise not been referred for their care?	Not Applicable.
VI. In the last 3 years, how many of the total patients with C3 Glomerulopathy have been referred from your Trust/Service to another Trust or Service and therefore are no longer within your care?	Not Applicable.
VII. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have proteinuria of >1g/day despite use of an ACE inhibitor or ARB?	Not Applicable.
VIII. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have eGFR =30 mL/min/1.73 m ² ?	Not Applicable.
IX. How many of the total patients currently under the care of your Trust/Service with C3 Glomerulopathy have been entered into The National Registry of Rare Kidney Diseases (RaDaR)?	Not Applicable.

Cont.../

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Linda Thornhill (Mrs)
Corporate Governance Manager
esh-tr.foi@nhs.net