

Date: 21 January 2020

Our reference: FOIRQ5416

Dear Sir/Madam,

Thank you for your request for information processed under the Freedom of Information Act 2000. Please see our response to your requests for information below:

Your Request and Our Response (in bold)

Request for Meeting Minutes:

I would like to request the following information:

Great Ormond Street Hospital for Children NHS Foundation Trust has responded to your request for information below:

1) Please provide the minutes of the meeting between Great Ormond Street Hospital CEO Peter Steer, duty CEO, clinical staff and families of children diagnosed with type 1 spinal muscular atrophy on 11th May 2017.

The Trust can confirm that searches have been undertaken, however, no minutes of the meeting have not identified. The Trust believes no minutes were taken at the meeting on 11 May 2017.

2) Please provide the agenda for this meeting

There was no formal agenda circulated prior to the meeting; it was covered verbally at the meeting

3) Please provide the emails or other communication which arranged this meeting and details of the commencement of the expanded access program by Great Ormond Street Hospital.

Firstly, Great Ormond Street Hospital organised the SMA meeting on 11 May 2017. Please see attached copies of emails relating to the arrangements of attendance at the SMA meeting; which has been necessary to make redactions to the information relating to third party data, which cannot be disclosed into the public domain. Please see note below**

Please note: **Great Ormond Street Hospital for Children NHS Foundation Trust (the “Trust”) is withholding information relating to

third party individuals under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000. The Trust is of the view that disclosing information relating to third party individuals would contravene the first data protection principles under the Data Protection Act (DPA) 2018. Disclosure of this information could also lead to emotional distress of the individuals concerned with the expectation that their personal data would not be disclosed to FOI applicants.

In order to reduce the risk of identifying third party information, we believe that disclosure would significantly increase the risk of individuals being identified. The Trust also has a duty of confidentiality to protect the disclosure of personal data individuals. Section 41(1) (Information provided in confidence) of the FOIA is also applicable where information was obtained by the Trust, which has the necessary quality of confidence (being neither generally accessible nor trivial); and disclosure of this information to an FOI applicant would therefore give rise to an actionable breach of confidence. The information we have redacted is therefore exempt from disclosure under Section 40(2) and Section 41(1) of the FOIA.

Secondly, The Nusinersen Expanded Access Program (EAP) was implemented for treatment and intrathecal administration at the end of April 2017 for inpatients. The program then began for outpatients from June 2017.

Please note:

The information you have been provided under the Freedom of Information Act 2000 is the information held on the date of the Trust receiving your request for information.

We trust the information provided is sufficient and helpful in answering your questions and any issues or concerns. Should you have any queries in relation to this request for information, please do not hesitate to contact the FOI Team and quote the above reference number on any correspondence relating to this request for information.

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Yours sincerely

Freedom of Information team

Great Ormond Street Hospital for Children NHS Foundation Trust

Email: foiteam@gosh.nhs.uk

[Enclosed – Your Rights – See next page]

Your Rights

If you are dissatisfied with the response you have received to your request for information, please contact the FOI team and quote your reference number on all correspondence relating to your request.

You can also write to the Head of Quality & Safety at the following address:

Quality & Safety Team
Great Ormond Street Hospital
LONDON
WC1N 3JH

If, however, you remain dissatisfied with your response, you have the right to appeal the Information Commissioner as the final stage of the process. You can contact the Information Commissioner's Office at the following address:

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