

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:46
To: [REDACTED]
Subject: FW: SMA Families Meeting - 11 May 2017

Categories: SMA

From: [REDACTED]@gosh.nhs.uk>
Sent: 09 May 2017 16:57
To: [REDACTED]@gosh.nhs.uk>
Subject: RE: SMA Families Meeting - 11 May 2017

Hi [REDACTED]
I will be attending the meeting, thank you for the invite
Where is the Charles west room? Sorry I haven't been there before

Thanks

[REDACTED]
[REDACTED]
Great Ormond Street Hospital
[REDACTED]

From: [REDACTED]
Sent: 09 May 2017 15:35
To: [REDACTED]
Subject: SMA Families Meeting - 11 May 2017
Importance: High

Dear all,

Nicola Grinstead has organised a meeting with parent/carer's of a number of SMA patients to discuss SMA medication and to provide an update. The meeting will take place on Thursday 11 May, 10.00 – 12.00pm in the Charles West Room. Attendees are from across the Trust, clinical, non-clinical staff, communications team and external SMA advocacy group representatives. Nicola has asked me to invite you to this meeting. I will shortly forward the meeting appointment.

Please could you confirm if you are available to attend.

Regards
[REDACTED]

[REDACTED]
[REDACTED] to Nicola Grinstead, Deputy Chief Executive
[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH
[REDACTED]

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:47
To: [REDACTED]
Subject: FW: SMA Families Meeting - 11 May 2017

Importance: High

Categories: SMA

From: [REDACTED]
Sent: 10 May 2017 09:25
To: [REDACTED]@gosh.nhs.uk>
Subject: FW: SMA Families Meeting - 11 May 2017
Importance: High

[REDACTED]

I have been asked to extend the invitation to you. Please could you confirm if you are available to attend.

Regards
[REDACTED]

From: [REDACTED]
Sent: 09 May 2017 15:35
To: [REDACTED]
Subject: SMA Families Meeting - 11 May 2017
Importance: High

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Please could you confirm if you are available to attend.

Regards
[REDACTED]

[REDACTED]
[REDACTED] to Nicola Grinstead, Deputy Chief Executive

[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH
[REDACTED]

[REDACTED]

From: [REDACTED]
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To: [REDACTED]
Subject: FW: SMA Families Meeting - 11 May 2017

Categories: SMA

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To: [REDACTED]@gosh.nhs.uk>
Subject: RE: SMA Families Meeting - 11 May 2017

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Thanks

[REDACTED]
[REDACTED]
Great Ormond Street Hospital
[REDACTED]

From: [REDACTED]
Sent: 09 May 2017 15:35
To: [REDACTED]
Subject: SMA Families Meeting - 11 May 2017
Importance: High

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Please could you confirm if you are available to attend.

Regards
[REDACTED]

[REDACTED]
[REDACTED] to Nicola Grinstead, Deputy Chief Executive

[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH
[REDACTED]

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:47
To: [REDACTED]
Subject: FW: URGENT - SMA Meeting - 11 May 2017

Importance: High

Categories: SMA

From: [REDACTED]
Sent: 10 May 2017 10:07
To: [REDACTED]
Subject: URGENT - SMA Meeting - 11 May 2017
Importance: High

Dear [REDACTED]

I would like to inform you that Nicola Grinstead, Deputy Chief Executive at Great Ormond Street Hospital has organised a meeting with parent/carer's of a number of SMA patients to discuss SMA medication and to provide an update. The meeting will take place on Thursday 11 May, 10.00 – 12.00pm in the Charles West Room at Great Ormond Street Hospital. The meeting attendees are from across the Trust, clinical, non-clinical staff, communications team and external SMA advocacy group representatives. I appreciate this invitation has been sent to you at short notice. If you are available to attend, please could you let me know.

Kind regards

[REDACTED]

[REDACTED] Nicola Grinstead, Deputy Chief Executive

[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH

Great Ormond Street 
Hospital for Children
NHS Foundation Trust

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:47
To: [REDACTED]
Subject: FW: URGENT - SMA Meeting at Great Ormond Street Hospital, 11 May 2017
Importance: High
Categories: SMA

From: [REDACTED]
Sent: 10 May 2017 10:09
To: [REDACTED]@live.com
Subject: URGENT - SMA Meeting at Great Ormond Street Hospital, 11 May 2017
Importance: High

Dear [REDACTED]

I would like to inform you that Nicola Grinstead, Deputy Chief Executive at Great Ormond Street Hospital has organised a meeting with parent/carer's of a number of SMA patients to discuss SMA medication and to provide an update. The meeting will take place on Thursday 11 May, 10.00 – 12.00pm in the Charles West Room at Great Ormond Street Hospital. The meeting attendees are from across the Trust, clinical, non-clinical staff, communications team and external SMA advocacy group representatives. I appreciate this invitation has been sent to you at short notice. If you are available to attend, please could you let me know.

Kind regards
[REDACTED]

[REDACTED]
[REDACTED] to Nicola Grinstead, Deputy Chief Executive

[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH
[REDACTED]

Great Ormond Street 
Hospital for Children
NHS Foundation Trust

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 10:07
To: [REDACTED]
Subject: FW: SMA Meeting at Great Ormond Street Hospital - 11 May
Categories: SMA

From: [REDACTED]@smasupportuk.org.uk>
Sent: 09 May 2017 09:00
To: [REDACTED]@gosh.nhs.uk>
Cc: [REDACTED]@smasupportuk.org.uk>
Subject: RE: SMA Meeting at Great Ormond Street Hospital - 11 May

Thank you very much for the invitation [REDACTED] Both [REDACTED] and I will attend from SMA Support UK.

Kind regards

[REDACTED]

[REDACTED]



Follow us on Twitter: @SMASupportUK // Facebook: SMASupportUK

www.smasupportuk.org.uk // [REDACTED]

Data Protection Act

If this email is in response to an information or support enquiry, please note that your contact information and brief details of your request have been stored and processed using our computerised database. We will use this information to assist you. Your information will not be used for any other purposes. For further information please see our privacy notice: <http://www.smasupportuk.org.uk/privacy-notice>

From: [REDACTED]@gosh.nhs.uk]
Sent: 08 May 2017 16:43
To: [REDACTED]@matrust.org; [REDACTED]@smasupportuk.org.uk>; [REDACTED]@treatsma.uk;
[REDACTED]@muscular dystrophyuk.org; [REDACTED]@biogen.com; [REDACTED]@smasupportuk.org.uk>
Subject: SMA Meeting at Great Ormond Street Hospital - 11 May
Importance: High

Dear all,

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:48
To: [REDACTED]
Subject: FW: URGENT SMA Meeting at Great Ormond Street Hospital, 11 May 2017

Importance: High

Categories: SMA

From: [REDACTED]
Sent: 10 May 2017 10:10
To: [REDACTED]@yahoo.com
Subject: URGENT SMA Meeting at Great Ormond Street Hospital, 11 May 2017
Importance: High

Parents of [REDACTED]

I would like to inform you that Nicola Grinstead, Deputy Chief Executive at Great Ormond Street Hospital has organised a meeting with parent/carer's of a number of SMA patients to discuss SMA medication and to provide an update. The meeting will take place on Thursday 11 May, 10.00 – 12.00pm in the Charles West Room at Great Ormond Street Hospital. The meeting attendees are from across the Trust, clinical, non-clinical staff, communications team and external SMA advocacy group representatives. I appreciate this invitation has been sent to you at short notice. If you are available to attend, please could you let me know.

Kind regards

[REDACTED]

[REDACTED] to Nicola Grinstead, Deputy Chief Executive

[REDACTED] Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH

[REDACTED]

Great Ormond Street **NHS**
Hospital for Children
NHS Foundation Trust

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:41
To: [REDACTED]
Subject: FW: SMA Meeting at Great Ormond Street Hospital - 11 May

From: [REDACTED]@treatsma.uk>
Sent: 08 May 2017 17:31
To: [REDACTED]@gosh.nhs.uk>
Subject: Re: SMA Meeting at Great Ormond Street Hospital - 11 May

Dear [REDACTED]

Thank you for invitation. I am confirming my availability.

I wonder whether [REDACTED] and [REDACTED] both parents of SMA-affected children, could also be invited to the meeting. They are active members of our TreatSMA patient group and will be able to offer valuable contribution to the meeting.

Kind regards,
[REDACTED]

On 8 May 2017 at 16:43, [REDACTED]@gosh.nhs.uk> wrote:

Dear all,

Nicola Grinstead, Deputy Chief Executive would like to invite you to a meeting with carer's and parents of SMA patients at Great Ormond Street Hospital on Thursday 11 May at 10.00 – 12.00pm, Charles West Room, Level 2, Paul O'Gorman Building.

I am aware this meeting is taking place at short notice. Please could you confirm if you are available to attend this meeting.

Kind regards
[REDACTED]

[REDACTED]
[REDACTED] to Nicola Grinstead, Deputy Chief Executive

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 09:42
To: [REDACTED]
Subject: FW: Thursday: 10/05/17 10-12 meeting for [REDACTED]
Importance: High

From: [REDACTED]
Sent: 09 May 2017 15:42
To: [REDACTED]@gosh.nhs.uk>
Subject: FW: Thursday: 10/05/17 10-12 meeting fo [REDACTED]
Importance: High

[REDACTED]

Nicola has asked me to invite you to the SMA families meeting on Thursday at 10.00am in the Charles West Room.

Regards
[REDACTED]

From: [REDACTED]
Sent: 09 May 2017 15:39
To: [REDACTED]
Subject: FW: Thursday: 10/05/17 10-12 meeting for [REDACTED]
Importance: High

Can you pls invite [REDACTED] to the meeting too? Explain to him it is to provide a formal update to all SMA Type1 pts on next steps.

thanks

From: [REDACTED]
Sent: 09 May 2017 13:39
To: [REDACTED]
Cc: [REDACTED]
Subject: Thursday: 10/05/17 10-12 meeting for [REDACTED]
Importance: High

Dear [REDACTED]

RE: [REDACTED]

The father of this patient has called to say you have called to offer a meeting tomorrow. He has a couple of questions.

He wants to know who will be attending the meeting and he said you mentioned that there would be external support but he can't remember who that was. Would you either let me know to convey to father or, would you be willing to update him. He said another family are also coming to be met. I'm happy to talk if easier.

[REDACTED]

From: [REDACTED]
Sent: 12 September 2019 12:54
To: [REDACTED]
Subject: FW: SMA Families, advocacy groups and Biogen - contacts
Importance: High

From: [REDACTED]@gosh.nhs.uk>
Sent: 12 September 2019 11:06
To: [REDACTED]@gosh.nhs.uk>
Subject: FW: SMA Families, advocacy groups and Biogen - contacts
Importance: High

From: [REDACTED]
Sent: 08 May 2017 11:52
To: [REDACTED]@gosh.nhs.uk>; [REDACTED]@gosh.nhs.uk>; [REDACTED]
[REDACTED]@gosh.nhs.uk>
Subject: RE: SMA Families, advocacy groups and Biogen - contacts
Importance: High

Dear all,

I have just had chat up with Nicola.

I would like to confirm the meeting with the parents and teams will take place on Thursday 11 May at 10.00 – 12.00pm in the Charles West Room. Please could you ensure your clinical and operational team are available.

Regards
[REDACTED]

From: [REDACTED]
Sent: 08 May 2017 09:37
To: [REDACTED]
Subject: RE: SMA Families, advocacy groups and Biogen - contacts

Hi,

Please see below:

[REDACTED]

Many thanks,

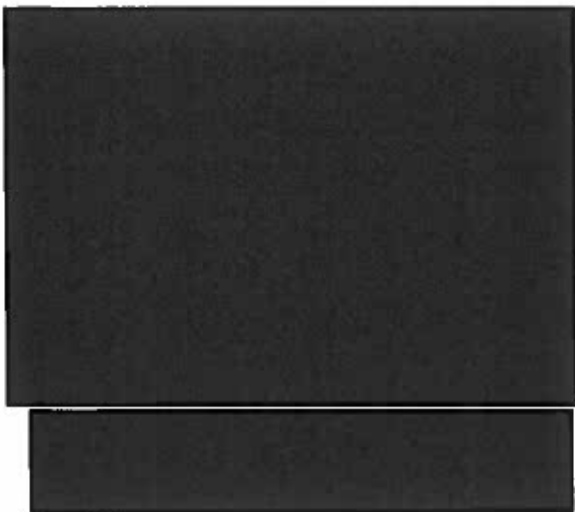
Great Ormond Street Hospital for Children NHS Foundation Trust
London WC1N 3BH

[@gosh.nhs.uk](mailto:info@gosh.nhs.uk)



From: [REDACTED]
Sent: 08 May 2017 08:59
To: [REDACTED]
Cc: [REDACTED]
Subject: RE: SMA Families, advocacy groups and Biogen - contacts

Dear all,



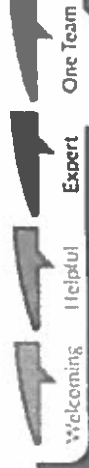


Great Ormond Street
Hospital for Children
NHS Foundation Trust

Nusinersen EAP Update

10 May 2017

The child first and always



Key Contacts

- Clinical Nurse Specialist
[Redacted]
- Admissions Team
[Redacted]
- Service Manager
[Redacted]
- Assistant Service Manager*
[Redacted]